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To the Graduate Council:

I am submitting herewith a dissertation written by Jeffrey Robert Miller entitled "The Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Education.

Gregory C. Petty, Major Professor

We have read this dissertation and recommend its acceptance:

Paul C. Erwin, Charles B. Hamilton, Ernest W. Brewer

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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The Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease

A Dissertation Presented for the Doctor of Philosophy Degree

The University of Tennessee, Knoxville

Jeffrey Robert Miller

December 2012

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DEDICATION

To my grandmothers

Floy Kinser Chapman

Stella Johnson Miller

My parents

John Robert Miller

Hazel Chapman Miller

The Beryllium Support Group of Oak Ridge

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ACKNOWLEDGEMENTS

I would like to express my deep appreciation to those that have helped me complete this important milestone. Dr. Gregory Petty has provided wise advice and important guidance throughout my doctoral program. My committee members Drs. Paul Erwin, Charles Hamilton, Ernest Brewer, and Donna Cragle provide helpful reviews and comments on the study methods and resulting manuscripts. Several individuals provided important insight as I formulated my research topic and developed the conceptual model including Drs. Clea McNeely, Denise Bates, Allison Anders, Laura Miller, Russ Reynolds, Mary Benton, and Otis Cosby. I am especially indebted to the leaders of the Beryllium Support Group of Oak Ridge, Jerry Hall and Doug Holman, for their advice and support. I am grateful to Dr. Lisa Maier and National Jewish Health for providing timely and critical support in reaching study participants outside of the Oak Ridge area. I would like to thank Tom Ford, Gary Hagan, Pete Calkin, Richard Baylor, and the administration at the Y-12 National Security Complex for their support and cooperation throughout my research project. Thank you to Dr. Charles Phillips, CIH, CSP for advice and modeling the way. I would like to express my appreciation to the University of Tennessee, Department of Public Health and Dr. Paul Erwin for financial support of this research. Your collective support and encouragement was of great value to me.

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ABSTRACT

The purpose of this study was to develop and validate a theoretical model that explains the psychosocial effects of beryllium sensitization (BeS) and chronic beryllium disease (CBD). Sequential, mixed research methods were used. The study population was current and former workers from Department of Energy laboratories and manufacturing facilities who have either BeS or CBD. A theoretical model based on uncertainty in illness and psychosocial adjustment to illness theories was developed. It was hypothesized that uncertainty had a negative effect on health quality of life unless mediated by the ability to make psychosocial adjustments to illness. Qualitative study results supported the proposed model; results from interviews with current and former workers with BeS or CBD indicated that they experienced psychosocial effects consistent with uncertainty in illness and psychosocial adjustment to illness theories. Quantitative study results confirmed the strength and direction of the relationships between the variables adding further validation to the model. Statistical analyses confirmed that uncertainty is an independent variable, health quality of life is a dependent variable, and psychosocial adjustment is an intermediate variable. As uncertainty increases, health quality of life decreases unless the effects are mediated by the ability to make psychosocial adjustments to the illness. A multiple regression model indicated that the domains of psychological distress, social environment and domestic environment were the best predictors of the mental component summary score for the study participants. The results also suggested that BeS may have as much, and possibly more, impact on one’s mental health than CBD. It was concluded that the theoretical model explaining the psychosocial effects of BeS and CBD has validity. This

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adds an important new component to the spectrum of CBD – a component that has implications for treatment as well as workers compensation. Healthcare providers and support groups should develop programs focused on helping patients develop coping skills to manage the psychological and social stress of BeS and CBD.

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LIST OF ACRONYMS AND ABBREVIATIONS

Be	beryllium
BeLPT	Beryllium-induced Lymphocyte Proliferation Test
BeS	beryllium sensitization
BSGOR	Beryllium Support Group of Oak Ridge
CBD	chronic beryllium disease
CBDPP	Chronic Beryllium Disease Prevention Program
DOE	Department of Energy
DOL	Department of Labor
EEOICPA	Energy Employees Occupational Illness Compensation Act of 2000
HRP	Human Reliability Program
IH	industrial hygiene
LPT	lymphocyte proliferation test
MMI	maximum medical improvement
MCS	mental component summary
MUIS-C	Mishel Uncertainty in Illness Scale, Community Form
OSHA	Occupational Safety and Health Administration
PPE	personal protective equipment
PAPR	powered air purifying respirator
PAIS-SR	Psychosocial Adjustment to Illness Scale, Self Report
PCS	physical component summary
SC	socially constructed
SOMD	Site Occupational Medical Director

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Workers Comp	Workers Compensation Insurance
Y-12	Y-12 National Security Complex

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INTRODUCTION

Over the past 35 years, a substantial amount of research has been published in the medical literature about chronic beryllium disease (CBD), a rare and incurable occupational lung disease. As a result, we now have a much better understanding of the spectrum of this disease. However, a review of the literature reveals a knowledge gap in one aspect of CBD that is only occasionally discussed among healthcare providers but is a prominent topic among people with the disease: the psychological and sociological effects of CBD. This is a report of a research project that was designed to shed light on this largely unstudied issue.

The purpose of this study was to develop and validate a theoretical model that explains the psychosocial effects of beryllium sensitization (BeS) and CBD. To accomplish that, a sequential, mixed-methods research study design was used. There were three phases to the research project. The first phase was to create a theoretical model. A plausible model was developed by obtaining anecdotal information from healthcare providers, researchers, occupational health specialists, and people with the disease and comparing that information with selected theories described in the medical and psychology literature. A diagram was developed suggesting the relationships between controlling, independent, dependent and mediating variables. The model was socialized among healthcare providers and people with CBD and their feedback incorporated.

The second phase was to conduct a qualitative study to determine if the theoretical model could be corroborated by empirical data from in-depth interviews with a sample of volunteers with either BeS or CBD. Semi-structured interviews were

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conducted with thirteen current and former workers in various stages of the disease. The interviews were focused on learning how BeS or CBD had affected their relationships with family, friends, and co-workers and how it had impacted their mental health. The data was analyzed to determine if the emergent patterns and themes were consistent with the constructs of the model.

The third phase was to conduct a quantitative study to measure the psychosocial effects of BeS and CBD in a larger sample of current and former workers from DOE laboratories and manufacturing facilities with BeS or CBD. Three valid and reliable instruments that had been widely used in studying disease in other populations were used. The survey was mailed to potential participants. One hundred twenty six respondents completed the questionnaires and returned them to the researcher. The self-reported questionnaire data were scored and analyzed. The results were compared to the theoretical model to determine if they were consistent with the hypothesized relationships between the variables in the model and to identify those variables that best predicted psychosocial effects.

The results of the study were written into three manuscripts to be submitted for publication; one paper describing each phase of the study. Each manuscript is complete and complements they others. They focus on determining whether the proposed model has validity. They are capable of standing alone but are most informative when read in sequence. Additional manuscripts are in progress to discuss related topics discovered during the project (e.g., the psychosocial impact of DOE policies on workers with BeS or CBD).

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The study design, model development, qualitative and quantitative research were all performed by the lead author with guidance from his major professor and committee. The manuscripts were written entirely by the researcher with review comments provided by the co-authors.

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CONCLUSION

Based on the results of this study, it was concluded that the proposed model of the psychosocial effects of BeS and CBD has validity. The qualitative and quantitative data affirm the premises and logic of the model; uncertainty is an independent variable, health quality of life is the dependent variable, and psychosocial adjustment is an intermediate variable. As uncertainty increases, health quality of life decreases unless uncertainty is mediated by the ability to make psychosocial adjustments to the illness. It is concluded that BeS and CBD have a significant psychosocial component that can have a negative effect on the health quality of life of affected individuals.

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PART 1 – A CONCEPTUAL MODEL OF THE PSYCHOSOCIAL EFFECTS OF BERYLLIUM SENSITIZATION AND CHRONIC BERYLLIUM DISEASE

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A Conceptual Model of the Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease

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Authors Declaration:

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Abstract

Objectives

The objective of this research was to develop a theoretical model that describes the psychosocial effects of beryllium sensitization (BeS) and chronic beryllium disease (CBD).

Materials and Methods

The medical, nursing, health education, and psychological literature was reviewed to identify theories that might support the development of a psychosocial model of BeS and CBD. A proposed model was synthesized based upon elements from multiple academic disciplines.

Results

The conceptual model was based on three prominent psychological theories: 1) health, stress, and coping, 2) uncertainty and illness, and 3) psychosocial adjustment to illness. The model hypothesizes that workers who are diagnosed with BeS or CBD experience a great deal of uncertainty that has a detrimental effect on their health quality of life. The focal relationship in this model is between the independent variable *uncertainty* and the dependent variable *health quality of life*. It is further hypothesized that the relationship between these two variables is effected by an intermediate variable; the ability to make *psychosocial adjustments to disease*.

Conclusions

Creating this model is a step toward filling a void in our understanding of the natural history of CBD. Once validated it will establish a foundation for future research,

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interventions and program evaluations and may lead to changes in the psychological, social, financial, and disease management support provided to this population.

Key Words

Beryllium; berylliosis, uncertainty in illness; psychosocial adjustment; stress and coping

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Introduction

A research gap exists in the development and testing of theoretical models which might explain the psychosocial aspects of beryllium sensitization (BeS) and chronic beryllium disease (CBD). Such research would help clinicians understand the total experience of their patients and might suggest changes in the types of psychological, social, financial, and disease management support provided to workers with BeS or CBD. The purpose of this research was to develop such a model.

Beryllium is a strong, lightweight metal that is toxic when inhaled into the lungs. People who work in factories where beryllium is processed are sometimes exposed to beryllium particles and may develop an allergic reaction to the metal. In some, this reaction, called BeS, leads to a severe, incurable occupational lung disease known as CBD.

Beryllium is widely used in the aerospace, electronics, biomedical, defense, telecommunications and other industries [Jaskula 2010, National Research Council 2007, Rossman, et al. 1991, Kolanz 2001]. The 2010 estimated consumption of beryllium in the U.S. was 320 metric tons and was valued at about $160 million [Jaskula 2011]. Beryllium consumption is currently dominated by electronics applications [Kelly and Matos 2011]. The estimate for the number of U.S. workers ever exposed to beryllium ranges from 800,000 to 1,000,000 [Cullen, et al. 1986, Infante and Newman 2004, Samuel and Maier 2008].

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Most people who are exposed to beryllium will not experience health effects because there is a strong genetic susceptibility component to sensitization and subsequent disease. However, some develop BeS and some of them go on to develop CBD. Epidemiologic studies have shown that on average, 1-6 percent of exposed workers develop BeS, although the rates can be as high as 19 percent among workers with the highest exposures, such as beryllium machinists [Kreiss, et al. 1993, Kreiss, et al. 1989, Kreiss, et al. 1997, Kreiss, et al. 1996, Maier 2002]. Most workers who are going to develop BeS tend to do so early on, but follow-up testing over the years continues to identify workers with BeS—up to 30 percent in one group of workers [Schuler, et al. 2008].

The percentage of people with BeS who go on to develop CBD is highly variable, ranging from 10-100 percent in different worker populations [Kreiss, et al. 2007]. Individuals exposed to the highest levels of airborne beryllium dust are at greatest risk of sensitization, although skin exposure may also be important [Day, et al. 2006]. Recent research suggests that each year, 6-8 percent of people with BeS will develop CBD [Newman, et al. 2005a]. The latency for converting from BeS to CBD is highly variable, ranging from 1-12 years in one longitudinal study [Newman, et al. 2005b]. Factors such as particle size, type of beryllium used, amount and duration of exposure to beryllium, occupation, industry, and genetics all play a role in determining why some people develop CBD and others do not [Maier 2002, Kreiss, et al. 2007]. Once a person is exposed to beryllium, they carry a lifelong risk of developing beryllium

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sensitization or CBD, even if the exposure amount was small or their exposure ceases. [Kreiss, et al. 2007].

The National Research Council (NRC) [National Research Council 2007] recognized that the diagnosis of BeS or CBD may be associated with psychosocial stress and/or loss of income and that there was an absence of published data on those phenomena. The NRC further suggested that implementation of a comprehensive beryllium-exposure and disease management program that includes appropriate worker education and counseling, medical-removal, and protection against lost wages can minimize such potential adverse consequences [National Research Council 2008].

Materials and Methods

The medical, nursing, health education, and psychological literature was reviewed to identify theories that might support the development of a psychosocial model of BeS and CBD. Online searches were conducted to identify publications in the scientific literature and library searches were conducted to identify and obtain other scholarly works. Government publications were obtained from agency websites or through personal requests to contacts in the agencies.

The search was conducted in a sequential manner starting with the medical and epidemiologic literature related to chronic beryllium disease. This was followed by an analysis of the nursing literature related to the psychosocial effects of illness. The psychological literature related to health, stress, and coping was then evaluated.

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Models from the health education literature were then reviewed to determine how they might be applied to this project.

The literature was synthesized and a figure of the model was developed. Draft versions of the model were shared with subject matter experts from various academic and medical disciplines. Through repeated discussions with experts from multiple disciplines, the proposed model was further refined. The model was shared with key informants who had either BeS or CBD to get their feedback. A research plan was developed to identify how future qualitative and quantitative research projects might be used to validate the proposed model.

Results

The Natural History of CBD

Beryllium induced lung disease can usually be categorized as either an acute or chronic disease process [Middleton 1998]. Acute beryllium disease is of historical significance and was identified in the U.S. in the 1940s [Van Orsdstrand, et al. 1945, Hardy and Tabershaw 1946] and is considered an irritative chemical phenomenon related to high exposure levels [Cummings, et al. 2009]. With advances in industrial hygiene, acute beryllium disease has been virtually eliminated in the U.S. [Middleton 1998]. Despite these historical improvements in workplace exposure conditions, cases of CBD continue to occur [Newman, et al. 1996].

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According to Newman, Lloyd, and Daniloff [1996] CBD is a systemic disorder that occurs when a sensitized (i.e., allergic) person's lungs react with beryllium that has been inhaled, producing inflammation in the lungs which leads to the formation of lung granulomas and scarring. They described CBD as a beryllium-specific, cell-mediated immune response gone awry. Based on their review of historical studies Newman, Lloyd & Daniloff [1996] concluded that: 1) the disease varies in its clinical presentation, 2) the disease varies in its rate of progression, 3) while removal from exposure may be medically prudent, it is not known to what extent such restrictions will change the natural history for more than a minority of patients, and 4) earlier studies did not systematically review the risk factors for disease progression [Newman, et al. 1996].

The symptoms that cause the patient to seek medical evaluation can include arthralgia, chest pain, cough, or most commonly dyspnea with relatively mild exertion [Middleton 1998]. While some persons with CBD die within a few years of diagnosis in respiratory failure and cor pulmonale, others experience a more insidious downhill course extending over decades [Newman, et al. 1996]. Workers exposed to persistent (i.e., non-soluble) beryllium antigen are at lifelong risk of CBD [Kreiss, et al. 2007, Eisenbud and Lisson 1983].

The diagnosis of CBD is usually preceded by identification of BeS and those workers that become sensitized are at high risk for developing CBD [Kreiss, et al. 2007]. Conversion from BeS to CBD is highly variable, ranging from 1-12 years in one

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longitudinal study [Newman, et al. 2005a]. The current diagnostic criteria for CBD include all of the following [Müller-Quernheim, et al. 2006, Maier, et al. 1999]:

1. History of or evidence of beryllium exposure
2. Evidence of an immune response to beryllium, that is, positive response in blood or bronchoalveolar lavage lymphocytes exposed to differing levels of beryllium in *in vitro* cultures (i.e., the beryllium lymphocyte proliferation test or BeLPT) in two independent tests
3. Symptomatic disease with histological demonstration of noncaseating granulomas on lung biopsy

Current medical management of CBD involves cessation of beryllium exposure and use of immunosuppressive drugs [Sood 2009, Sood, et al. 2004] but there is limited literature regarding the effect of these interventions on the natural history of CBD. Published mortality rates range from 5.8 to 38% [Newman 1996].

Beryllium Sensitization

The development of the BeLPT [Kreiss, et al. 1989] created a fundamental change in our knowledge of CBD. According to Maier [2001], it revolutionized our approach to the diagnosis, screening, and surveillance of beryllium health effects. BeS is not a disease in its own right and has no symptoms, but it is important because it identifies a subgroup of exposed workers who are at risk for developing CBD [Council 2007]. A positive BeLPT result differentiates CBD from other lung diseases such as

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sarcoidosis, chronic obstructive pulmonary disease, and hypersensitivity pneumonitis [Council 2007, Müller-Quernheim, et al. 2006, Newman 1995].

BeLPT results are not always consistent or stable, creating clinical uncertainty [Deubner, et al. 2001, Stange, et al. 2004, Mroz, et al. 1991, Middleton, et al. 2011, Middleton, et al. 2006]. Because the test is difficult to perform and results are not always consistent, most physicians and researchers like to require two independent abnormal tests in order to categorize a worker as BeS. Greene and Smith [2008] argued that the empirical uncertainty arising from the probabilistic nature of BeLPT screening can be highly unsettling for workers who might expect clear guidance from medical testing. Despite its limitations in test consistency and repeatability, the BeLPT has been an invaluable tool in the identification of workplace risks in population studies and intervention effectiveness [Kreiss, et al. 2007] and has led to the identification of clinically milder cases [National Research Council 2007].

Lung Cancer

In addition to CBD, workers exposed to beryllium also have significantly elevated risks of lung cancer [Ward, et al. 1992, Steenland and Ward 1991, Sanderson, et al. 2001, Schubauer-Berigan, et al. 2010]. The National Toxicology Program [2009] listed beryllium as a known carcinogen, as did the International Agency for Research on Cancer [1993]. However, beryllium exposure is more commonly associated with CBD than lung cancer and according to the National Institute for Occupational Safety and Health [2011] controlling beryllium exposure to prevent CBD should also reduce the risk

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for lung cancer. The reader is referred to the Agency for Toxic Substances and Disease Registry, Toxicological Profile of Beryllium [2002] and Groth [1980] for comprehensive reviews of the carcinogenic properties of beryllium.

The Epidemiology of CBD

For the most comprehensive description of the epidemiology of CBD, the reader is referred to the literature review completed by the National Research Council, Committee on Toxicology [2007]. This work, along with its companion report [National ResearchCouncil 2008], were completed for the U.S. Air Force and represent the most current and complete compilation of the beryllium literature.

The population at risk for CBD is workers in industries where beryllium is processed in a manner that creates multiple pathways for inhalation and skin contact with beryllium particles [Day, et al. 2006]. The range of estimates for the number of U.S. workers exposed to beryllium is 20,000 to 1,000,000 [Cullen, et al. 1986, Infante and Newman 2004, Samuel and Maier 2008]. Henneberger and others [2004] relied on sampling data from the Occupational Safety and Health Administration (OSHA) to estimate that 134,000 U.S. workers were potentially exposed to beryllium. Kreiss, Day, and Schuler [2007] believed that the number is far higher because OSHA had not sampled for beryllium in military and nuclear weapons complex workplaces. Other workplaces, such as those recycling electronics equipment, may also be a source of previously unsuspected exposure [National Research Council 2007].

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The prevalence of BeS and CBD in exposed workers ranges from 1 - 19% and from 0.1 - 7.8%, respectively [Maier 2002, Kreiss, et al. 2007]. Table 1.1 provides prevalence data of BeS and CBD from recent cross-sectional and longitudinal studies conducted in U.S. industry.

Table 1.1. Prevalence of beryllium sensitization and chronic beryllium disease from selected epidemiologic studies

Industry	n	BeS %	CBD %
Nuclear Workers [Kreiss, et al. 1993]	895	2.0%	1.7%
Nuclear Workers [Stange, et al. 2001]	5,173	4.5%	1.6%
Beryllium Production Workers [Kreiss, et al. 1997]	627	9.4%	4.6%
Beryllium Machinists [Newman, et al. 2001]	235	9.4%	5.5%
Beryllium Ceramics Production [Henneberger, et al. 2001]	151	9.9%	5.3%

BeS=beryllium sensitization; CBD=chronic beryllium disease; %=percent; n=sample size

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CBD is typically considered only when occupational exposure to beryllium is a certainty; however, CBD has occurred in occupational and environmental settings where exposure was unexpected [Middleton 1998]. Individuals who live near plants that process beryllium may be at greater risk than the general population [Maier, et al. 2008, Eisenbud, et al. 1949]. The general population is exposed to beryllium through inhalation of air and consumption of food and drinking water but people who work in beryllium manufacturing, fabricating, and reclaiming industries are exposed to much higher levels of beryllium than the general population [Agency for Toxic Substances and Disease Registry 2002].

The nuclear weapons industry has received substantial attention because of worker exposure to beryllium. In fact, beryllium disease was recognized among workers involved in the early development of atomic energy in the World War II era [Van Orsdstrand, et al. 1945, Hardy 1955]. As nuclear weapons proliferated during the Cold War, the number of workers in the U.S. Department of Energy (DOE) nuclear complex grew and the number of workers exposed to beryllium grew proportionately. Beginning in the late 1980s, clusters of CBD were recognized in workers from nuclear weapons plants across the U.S. [Kreiss, et al. 1989]. A number of additional epidemiologic studies of nuclear workers have been completed over the past two decades helping us to understand the risk of CBD in this population [Kreiss, et al. 1993, Stange, et al. 2001, Stange, et al. 1996a, Stange, et al. 1996b, Sackett, et al. 2004, Welch, et al. 2004, Rodrigues, et al. 2008, Arjomandi, et al. 2010, Mikulski, et al. 2011]. These studies and

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others were chronicled in the DOE regulation (i.e., the Chronic Beryllium Disease Prevention Program) that was established to prevent the continued occurrence of CBD [Department of Energy 1999].

Among other things, this rule created the DOE Beryllium-Associated Worker Registry for current workers who are exposed to beryllium in their current job, or may have been exposed to beryllium in the past from work conducted at a DOE site [Department of Energy 2011a]. The goal of the registry is to determine the incidence and prevalence of BeS and CBD. The data are analyzed to better understand CBD and to identify those at risk. Another goal is to monitor and evaluate the effectiveness of the Chronic Beryllium Disease Prevention Program. Coupled with the DOE Former Worker Medical Screening Program [Department of Energy 2011b], these surveillance programs provide a mechanism for collecting data about those at risk for BeS and CBD.

The Psychosocial Aspects of CBD

The National Research Council (NRC) recognized that the diagnosis of CBD or BeS may be associated with psychosocial stress and/or loss of income and that there was an absence of published data on those phenomena [National Research Council 2007, National Research Council 2008]. The NRC further suggested [2008] that implementation of a comprehensive beryllium-exposure and disease management program that includes appropriate worker education and counseling, medical-removal, and protection against lost wages can minimize such potential adverse consequences.

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At the 3rd Annual International Conference on Beryllium Disease, Newman [2007] made a presentation identifying unanswered questions related to CBD. He argued that there was still much to be learned about the neuro-psychological and social effects of CBD on BeS and CBD patients. He reported that his patients asked how beryllium will affect their employment, finances, insurability, workers compensation, personal well-being, and social lives. Later at the same conference, Cragle [2007] encouraged researchers to consider the sensitized/CBD patient as a whole human being and asked, “Where are the social scientists?”

In 1999, at the Conference on Beryllium Effects on Worker Health, Henneberger suggested that it was important to survey former employees to estimate the full extent of the problem and to understand the natural history of CBD [Henneberger and Kreiss 1999]. In 2008, at the Third International Conference on Beryllium Particulates and Their Detection, McCawley [2008] presented the results of a survey of members of the Beryllium Health and Safety Committee to identify the most important topics for future research. In the area of health effects, McCawley reported the second highest priority was to “identify opportunities for therapeutic interventions (pre-CBD) or specific therapies for CBD” and suggested that a research plan needed to be developed to help people with BeS and CBD.

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Current Theoretical Perspectives and Relevant Studies

Stress and Coping Theory

Stress is a term that originated in the disciplines of physics and engineering. Early research on human stress was conducted by scientists in the fields of biology, physiology, and psychology. It was Cannon [1929] who coined the enduring term “fight or flight” to describe the human response to stress. Endocrinologist Hans Selye [1936] was the father of modern stress research and was the first to publish a paper on the biological syndrome of stress. Over the next twenty years he further explored the concept as it related to disease in man, eventually publishing *Stress and Life* [Selye 1956]. In this seminal work, he defined three stages of stress: alarm reaction, stage of resistance, and stage of exhaustion. He described the alarm stage as a generalized call to arms of the defensive forces in the organism. Following this was a stage of biological adaptation of the organs to the stress. After prolonged exposure, the adaptation was eventually lost and the animal entered the stage of exhaustion. At the end of a life under stress, there was a premature aging due to wear and tear. To describe this progression, he used the term *general adaptation syndrome* [Selye 1956]. Thus began the study of stress and illness.

While Selye initially focused on biological stress, others turned their attention to the concept of psychological stress. Lazarus [1966] considered the field of stress a collective term that included physiological, sociological, and psychological phenomena and their respective concepts. He argued that these diverse terms could be combined

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in the same study. Lazarus extended the *general adaptation syndrome* [1966] by incorporating the concepts of stress appraisal and coping. He suggested that for a psychosocial situation to be stressful, it must be appraised as such. That is, one must determine whether a situation is potentially threatening, constitutes a harm/loss, is challenging, or is benign. He theorized that this assessment occurred during primary and secondary appraisals. The primary appraisal includes the perception of how stressful the stimulus is and the secondary appraisal estimates whether one has adequate resources to deal with the problem. He defined coping as the strategies one employs for dealing with stress and that when the individual discovers some important motive or value is being threatened, coping activity is mobilized by this threat, by virtue of the cognition that "my life, health, wealth, or cherished social relationships are in danger." Lazarus [1966] referred to these coping modes as direct action, vigilance, and avoidance.

Selye later published a new model [1975] that divided stress into eustress and distress. This differentiated stress that enhanced physical or mental functioning (i.e., eustress) and persistent stress that was not resolved through coping and adaptation (i.e., distress). Eustress is positive adaptation to stress and is typified by activities such as exercise to build strength and cardiovascular capacity. Distress results in negative functioning and may lead to anxiety, depression and/or physical ailment. This model more accurately represented both the positive and negative potential associated with stress.

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Holroyd and Lazarus [1982] explored the linkage between stress, coping, and illness, describing three ways that stress might lead to somatic illness. The first was by the disruption of tissue function from neural and hormonal outpourings (e.g., pounding heart, sweating, trembling, etc.). The second was by engaging in coping activities that were damaging to health (e.g., tobacco use, alcohol consumption, poor diet). The third way that stress might lead to disease is by psychological and/or sociological factors which lead the person to minimize the significance of symptoms or to fail to comply with treatment programs (e.g., avoidance of doctors). They concluded that whether stress led to somatic illness via one of these mechanisms was influenced by a person's coping methods and skills.

Lazarus and Folkman [1991] recognized that people exhibited different coping styles when confronted with stress. They suggested that coping styles are broad, pervasive, encompassing ways of relating to particular types of situations such as ambiguous or clear, imminent or distant, temporary or chronic, evaluative or nonevaluative. They also recognized that coping styles are dynamic and subject to the personality of the individual. These dynamic properties make for a diversity of strategies for those coping with illness. Stress can also have a distinct physiologic effect.

O'Leary [1990] reviewed the empirical evidence linking emotional stress to immune function in humans. She reported that chronic stress has been associated with suppression of immune function, and that there is evidence that the immune system may not adapt over time [O'Leary 1990]. There is evidence that psychosocial stress

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influences a variety of immune functions and on several disease processes. This presents some provocative questions about the interaction between psychosocial and physiological stress associated with immune mediated diseases, like CBD.

As the theory of stress and coping evolved and matured, key concepts became more defined. Folkman [2011] recognized that the scope of coping had been broadened to include regulation of positive well-being in the face of stress. In addition, research is now being conducted on future-oriented coping, interpersonal coping, and religious and spiritual coping. Models have been developed to explain the concept of stress and coping in society. One such model that explains how stress and coping theory applies to health and well-being is the Transactional Model of Stress and Coping.

Transactional Model of Stress and Coping

Understanding stress and coping is essential to health education, health promotion, and disease prevention [Glanz, et al. 2008] and the Transactional Model of Stress and Coping is a framework for evaluating processes of coping with stressful events. Glanz and Schwartz articulated the constructs of the model which is rooted in the cognitive theory of psychological stress and coping developed by Lazarus and Folkman [1984]. The theory is transactional in that the person and the environment are viewed as being in a dynamic, mutually reciprocal, bi-directional relationship. Stress is conceptualized as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering well-being [Glanz, et al. 2008]. The theory identifies two processes -

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cognitive appraisal (primary and secondary) and coping strategies (problem, emotion, and meaning-based) as critical mediators of stressful person-environment relationships and their immediate and long-term outcomes including emotional well-being, functional status, and health behaviors [Glanz, et al. 2008]. Because stress effects people differently, the ability to cope with stress influences decisions about seeking medical care and social support and whether one believes the advice of professionals. This model serves as the theoretical basis for many health education and disease prevention programs.

Psychosocial Adjustment to Illness Theory

The ability of humans to adjust to threatening events is a derivative of stress and coping theory. Taylor [1983] observed that one of the most impressive qualities of the human psyche is its ability to successfully withstand severe personal tragedy. Based on her experience with cancer patients, cardiac patients, rape victims, and other individuals facing life-threatening events [Taylor 1983], she argued that when an individual has experienced a life-threatening event, the readjustment process focused around three themes: 1) a search for meaning in the experience, 2) an attempt to regain mastery over the event in particular and over one's life more generally, and 3) an effort to enhance one's self-esteem, to feel good about oneself again despite the personal setback.

How one adjusts to illness has been the subject of much research over the past thirty years [Kalman, et al. 1983, Zyzanski, et al. 1981]. Mechanic [1978] noted that

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what interested behavioral scientists was the tremendous variability in response to what was presumably the same illness condition. While one person hardly acknowledged a condition and refused to allow it to alter his/her life, another with a milder form of the same condition would display profound social and psychological disabilities.

Psychosocial adaptation to chronic illness and disability has been the subject of more research as the prevalence of chronic disease increases in our society. Livneh and Antonak [1997] suggested that the prolonged course of treatment, the uncertain prognosis, the constant and intense psychological stress, the gradually increasing interference with the performance of daily activities and life roles, and the associated impact on family and friends all combine to create a profound effect on the lives of persons with chronic illness and disabilities. Cassileth and others [1984] compared the psychosocial status of five groups of patients with chronic illness (i.e., arthritis, diabetes, cancer, renal disease, and dermatologic disorders) and found them remarkably adaptive in comparison to patients with depression. They concluded that psychological status was independent of the specific diagnosis for these chronic diseases.

Derogatis was one of the early pioneers in this field and he, along with Abeloff and Melisaratos [1979], reported on the psychological coping mechanisms in patients with metastatic breast cancer. They found that, in general, the long-term survivors had higher psychological distress levels than the short-term survivors. They also established that cancer patients whose coping styles facilitated external, conscious expression of negative emotions and psychological distress appeared to survive longer

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while patients whose coping styles involved suppression or denial of affect or psychological distress had a shorter length of survival. They [Derogatis, et al. 1979] suggested that psychological interventions could be redesigned to put patients more in touch with their emotions and possibly promote a more successful psychological outcome. This early research led Derogatis to explore the development of psychometric scales that could be used to measure the ability to adjust to illness.

The Global Adjustment to Illness Scale (GAIS) was developed as an instrument to measure the prevalence of psychiatric disorders among cancer patients [Derogatis, et al. 1983]. In this study the GAIS, along with two other instruments, were administered to a sample of 215 cancer patients. The results of the survey indicated that 47% had a psychiatric diagnosis and that approximately 68% of those diagnoses consisted of adjustment disorders. The authors further suggested that pervasive emotional distress and dysphoria often associated with cancer may not be an inherent part of the neoplastic disease, but rather a separate and potentially treatable condition. This study provided an epidemiologic benchmark for the prevalence of psychiatric disorders among cancer patients and has had far-reaching implications for treatment and therapy. It also motivated Derogatis to further refine his psychometric instrument.

In 1986, Derogatis introduced the interview-based Psychosocial Adjustment to Illness Scale (PAIS®) and a self-reporting version (PAIS-SR®) to assess the psychological and social adjustment of medical patients, or members of their immediate families, to the patient’s illness. The PAIS® and PAIS-SR® were developed to reflect

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seven principal domains [Derogatis 1986], all of which had been shown to have a high relevancy for adjustment to medical illness. The seven domains include:

1. health care orientation
2. vocational empowerment
3. domestic environment
4. sexual relationships
5. extended family relationships
6. social environment
7. psychological distress

The instruments were tested for factor structure, reliability, and validity and a library of six normative groups was developed (lung cancer patients, renal dialysis patients, acute burn patients, hypertensive patients, cardiac bypass patients, and heterogeneous cancer patients). Later, other researchers [Merluzzi and Martinez-Sanchez 1997, Rodrigue, et al. 2000] conducted additional factor structure analyses on the PAIS-SR®.

While Derogatis [1986] noted that there were more than two dozen instruments available to assess psychiatric patients, he developed this instrument because there was a dearth of tools for measuring the psychosocial status of non-psychiatric patients. Others [Cain, et al. 1986, Jenkins, et al. 1991, Northouse, et al. 2000, Greer, et al. 1992] began using the instrument to describe the psychosocial illness experience for patients with cancer and occasionally for other conditions like kidney disease [Soskolne

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and De-Nour 1989, De-Nour 1982] chronic lung disease [Stubbing, et al. 1998], burns [Browne, et al. 1985], and multiple sclerosis [Pakenham 1999]. The PAIS® and PAIS-SR® were tools that helped fill the void in this field of research.

Folkman and Greer [2000] provided an appraisal and coping framework that has helped tie adjustment to illness theory to the empirical data generated by research tools like the PAIS®. They suggested a model therapeutic program aimed at improving the psychological well-being of patients facing serious illness. Since the 1990s, psychosocial interventions have become increasingly more relevant as evidenced by the meta analysis that Rehse and Pukrop [2003] conducted on 37 controlled outcome studies. It is now widely recognized [Sharpe and Curran 2006] that understanding the process by which most individuals adjust to illness offers important insights to enhance the efficacy of interventions that facilitate psychological adjustment. Helping individuals adjust to their illness has become a priority, especially for those with chronic diseases.

Uncertainty and Illness Theory

The uncertainty and illness theory is another attempt to explain the human illness experience. Spawned from stress and coping theory, uncertainty and illness has been of particular interest to clinicians and researchers trying to understand the challenges of patients coping with chronic illness.

According to Brashers [2001] uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state

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of knowledge in general. Babrow, Hines, and Kasch [2000] further postulated that because uncertainty is multilayered, interconnected, and temporal, people experience multiple sources of uncertainty at once, that manipulating one type of uncertainty can impact (e.g., increase or decrease) uncertainties of other types, and that experiences of uncertainty are ongoing and changing features of life.

After an exhaustive search of the psychological literature, Norton [1975] concluded that no matter the source, when an event is judged to be uncertain, it will contain one or more of the following eight dimensions: 1) multiple meanings; 2) vagueness; 3) probability; 4) unstructured; 5) lack of information; 6) ambiguity; 7) inconsistencies and contradictions; and 8) unclear. This provided a framework for the concept of uncertainty that has been used in research across multiple disciplines.

Babrow, Kasch, and Ford [1998] identified uncertainty as a central part of the experience of illness. They described multiple sources of variation within the concept of uncertainty including, complexity, qualities of information, probability, structure of information and lay epistemology. For example, clarity (e.g., the use of medical jargon), accuracy (e.g., laboratory analytical methods), and ambiguity (e.g., different interpretations of results) are all qualities of information that can vary greatly. They attempted to reconcile sources of variation in conceptions of uncertainty and synthesize more specific conceptions of uncertainty in illness. Recognizing what contributes to uncertainty in illness and how it can be managed remains a daunting assignment. One of the pioneers in this effort was Dr. Merle Mishel.

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Mishel [1981] investigated the role of uncertainty as a significant variable influencing patients' experiences in illness, treatment, and hospitalization. She proposed a model of perceived uncertainty in illness and developed an instrument (i.e., the Mishel Uncertainty in Illness Scale – MUIS) for measuring uncertainty in symptomatology, diagnosis, treatment, relationship with caregivers, and planning for the future. She continued to refine the structure of the model [Mishel 1983, Mishel 1984, Mishel and Braden 1988] and the MUIS was applied to a variety of populations [Mishel, et al. 1984, Mishel and Murdaugh 1987]. In 1988 she published a seminal paper [Mishel 1988] on uncertainty in illness. In this paper she defined uncertainty as the inability to determine the meaning of illness-related events and stated the fundamental belief that uncertainty concerning what will happen, what the consequences of an event are, and what the event means, are important to a person with any illness. Furthermore, she argued that managing the uncertainty associated with an illness and its treatment may be an essential task in adaptation. She encouraged further research applying the model and MUIS in different patient populations and varied settings.

While the model had been previously applied to acute illnesses or those in a downward illness trajectory, little had been done to understand uncertainty in chronic diseases. Mishel [1988] reconceptualized the uncertainty in illness theory to address the experience of living with continual, constant uncertainty in either a chronic illness or in an illness with a treatable acute phase and possible eventual recurrence. This was based in part on the qualitative observation that the longer chronically ill subjects lived

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with continual uncertainty, the more positively they evaluated the uncertainty. This supported the argument that uncertainty can be a positive experience but was contrary to the cultural value that uncertainty is an aversive experience and, except in an extreme situation, is definitely not preferable to certainty.

Drawing on chaos theory, Michel [1990] postulated that uncertainty surrounding a chronic illness or life-threatening condition qualified as a sufficient fluctuation to threaten the preexisting organization of the person. Michel viewed uncertainty in illness as:

> “A fluctuation that begins in only one part of the human system and, according to chaos theory, can either regress and cause no particular disruption or spread to the whole system. As uncertain disease related factors, like severity of the illness, success of treatment, impact of illness on one’s life, and ability to pursue life’s dreams and ambitions, are introduced into the person’s life the uncertainty competes with the person’s previous mode of functioning. As the concentration of the uncertainty expands, it can exceed the person’s level of tolerance, causing the personal system to become unstable. The uncertainty that early in the illness was the source of fluctuation, later in the illness becomes the foundation on which the person constructs a new sense of order.” [Michel 1990, p. 259]

Thus, she postulated [Mishel 1990] that uncertainty is used by individuals to reformulate their view of life and that this new view of life allows one to view uncertainty as an opportunity rather than a danger or threat. Mishel [1990] encouraged health care providers to adopt a probabilistic rather than a mechanistic paradigm. That is, accept

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uncertainty as a natural, inherent part of reality that is not determinable with precision and abandon the view that uncertainty is the enemy and must be eliminated.

Uncertainty and illness theory has matured over thirty years and become a cornerstone for understanding the psychosocial effects of chronic disease. In studies examining the adjustment to uncertainty in illness [Mishel 1990], the most common conclusion is that high uncertainty is related to high emotional distress, anxiety, depression, and fatigue. This progression has been supported by the work of others beside Mishel who have conducted research to clarify the concepts within the theory [Mishel 1981, Christman, et al. 1988, Mishel 1997, Mishel, et al. 1991, Webster, et al. 1988, White and Frasure-Smith 1995, Johnson, et al. 2006, Bailey, et al. 2010, Sammarco and Konecny 2008], understand how nursing interventions can be used to manage uncertainty [McCormick 2002], to illuminate processes of coping with uncertainty [Neville 2003, Cohen 1993], and to conceptualize how adaptation to uncertainty effects health-related quality of life [Babrow and Kline 2000]. One chronic disease to which uncertainty and illness theory has been successfully applied is prostate cancer.

Psychosocial Effects of Prostate Cancer

According to the American Cancer Society [2010], prostate cancer is the second most commonly diagnosed cancer among men in the U.S. and the second most common cause of cancer death among men. In 2010, an estimated 217,730 new cases of prostate cancer were diagnosed in the U.S. [American Cancer Society 2010].

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Changes in the incidence of prostate cancer over the past 20 years reflect the widespread use of the prostate specific antigen (PSA) screening tool [American Cancer Society 2010]. According to Tombal [2006], the PSA has led to a dramatic increase in the number of patients diagnosed with prostate cancer, a significant number of them being non-clinically significant. The diagnosis of prostate cancer has well-described psychosocial difficulties [Eton and Lepore 2002] that vary across stages of disease and types of treatment. Some men, who are asymptomatic and have low-risk, early stage cancer, are eligible for active surveillance which offers a means to monitor the cancer while delaying treatment [Eton and Lepore 2002, Warlick, et al. 2006]. This is in contrast to watchful waiting which is a conservative management strategy for men who are more likely to die from co-morbidities [Warlick, et al. 2006, Oliffe, et al. 2009]. The result of this phenomenon is that there are now a large number of men living with localized prostate cancer and the uncertainty that it bestows.

Germino, Mishel and others [Germino, et al. 1998] began applying uncertainty of illness theory to prostate cancer soon after the PSA-stimulated diagnosis boom. Since then, studies [Shaha, et al. 2008] have shown that prostate cancer is a disease fraught with uncertainty that often makes adjustment to the illness difficult. To gain a richer understanding of uncertainty in men undergoing watchful waiting or active surveillance, qualitative and quantitative studies [Oliffe, et al. 2009, Wallace 2003, Bailey, et al. 2007, Kazer, et al. 2011, Bailey Jr, et al. 2011] were conducted by a number of researchers. Collectively, this body of knowledge has established a foundation from which

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researchers [Mishel, et al. 2002, Steginga, et al. 2008, Mishel, et al. 2009] can design and conduct randomized clinical trials to evaluate the efficacy of psychosocial interventions. Those experiments and a number of others were recently summarized [Chambers, et al. 2011] in the literature. With evidence on the efficacy of interventions in hand, researchers [Kershaw, et al. 2008, Song, et al. 2010] are now reporting the results of longitudinal studies to measure the change in quality of life among prostate cancer patients and their partners.

Discussion

The example of prostate cancer suggests a possible path forward for the study of the psychosocial effects of CBD. In this example, researchers recognized that prostate cancer was unique from other types of cancers and studied both the physical and psychological aspects of the natural history of the disease. They conducted qualitative studies to gain an initial understanding of the psychosocial problems confronting patients and their partners. Then they developed a theory base (i.e., uncertainty of illness) and conducted quantitative studies to refine a model that accurately described the psychosocial component of prostate cancer. Following this, theory-based interventions were developed, implemented, and evaluated. Finally, longitudinal studies were conducted to determine the long-term effect of the intervention in the study population. Executing a similar systematic approach should be the goal for researchers and clinicians studying the psychosocial effects of BeS and CBD.

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There are psychological theories described in the literature that help us understand stress, coping, and chronic illness.   We know that the stress of chronic diseases, like CBD, affects people differently. Fortunately, humans have a remarkable ability to adapt to stress when faced with chronic disease. The Transactional Model of Stress and Coping was developed to help us understand the inter-relatedness of stress and coping concepts to health and well-being. This model is commonly used by health professionals who are developing interventions to help people cope with stress. There are valid and reliable instruments, like the MUIS and PAIS®, which help us measure the psychosocial effects of stress and chronic disease. These instruments have been used in a variety of studies of chronic illnesses, like prostate cancer, but never to study individuals with CBD.

The Model

The conceptual model is based on three prominent psychological theories: 1) health, stress, and coping, 2) uncertainty and illness, and 3) psychosocial adjustment to illness. The model supports the hypothesis that workers who are diagnosed with BeS or CBD experience a great deal of uncertainty and that has a detrimental effect on their health status. The focal relationship in this model is between the independent variable *uncertainty* (i.e., the characteristic being observed) and the dependent variable *health quality of life* (i.e., the outcome of interest). It is suspected that the relationship between these two variables may be partially mediated by an intermediate variable, the ability to make *psychosocial adjustments to disease*. Figure 1.1 illustrates the conceptual model.

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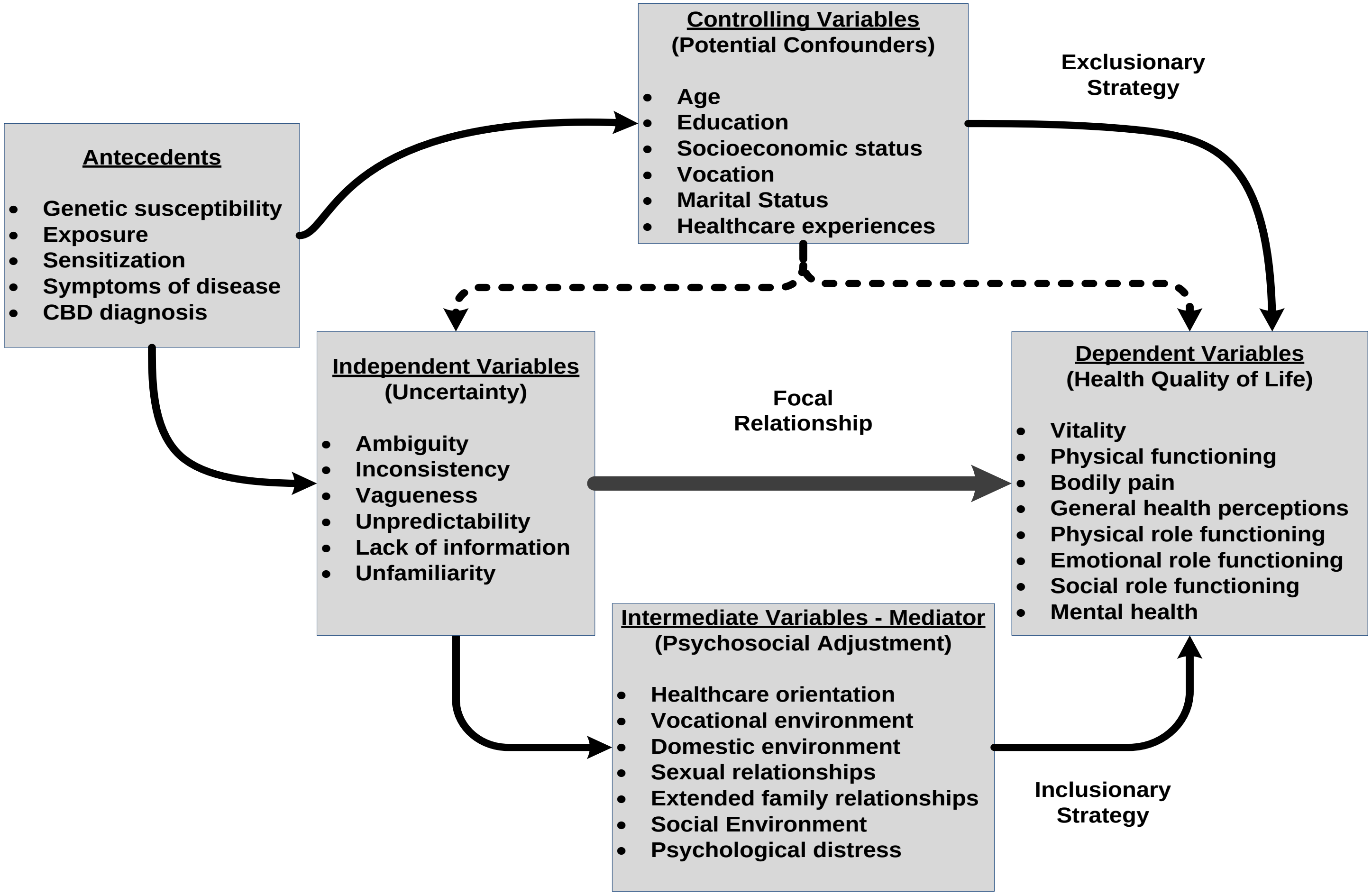

Figure 1.1. Conceptual model of the psychosocial effects of chronic beryllium disease

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As depicted in Figure 1.1 there are five antecedents (i.e., preceding events) that influence the independent variable: 1) host (genetic) susceptibility to beryllium disease, 2) exposure to beryllium in the workplace, 3) sensitization (allergy) to beryllium, 4) symptoms of CBD, and 5) diagnosis of CBD. Exposure to beryllium in the workplace is the most critical antecedent. Exposure is necessary but not sufficient when acting alone (i.e., one cannot get CBD if he/she is never exposed to beryllium, but exposure does not guarantee that disease will occur). Exposure must be combined with host susceptibility, sensitization, symptoms of disease, and/or diagnosis of CBD to create a necessary and sufficient combination of factors to activate the model.

There are at least six potential confounding variables to be considered: 1) age, 2) education level, 3) socioeconomic status, 4) vocation, 5) marital status, and 6) history of involvement with the healthcare system. These variables may distort the truth because they may be associated with both uncertainty and health status. For example, individuals with a higher socioeconomic status may have less uncertainty (e.g., a more predictable life) because they have a stable income, food and shelter. They also may have greater access to healthcare or seek and comply with medical recommendations better, which translates to regular physical exams and screenings that help prevent the development of chronic diseases (i.e., greater physical functioning).

In the model, uncertainty is proposed as an independent variable that influences health quality of life. This proposition is based on the research conducted by Mishel [1981] to determine how uncertainty influences patients' experiences in illness, treatment, and hospitalization. She developed a model of perceived uncertainty in

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illness and developed an instrument (i.e., the Mishel Uncertainty in Illness Scale – MUIS) for measuring uncertainty in symptoms, diagnosis, treatment, relationship with caregivers, and planning for the future. The MUIS has six primary domains: 1) ambiguity, 2) inconsistency, 3) vagueness, 4) unpredictability, 5) lack of information, and 6) unfamiliarity. In studies examining the adjustment to uncertainty in illness [1990], the most common conclusion was that high uncertainty was related to high emotional distress, anxiety, depression, and fatigue.

A proposed intermediate variable is psychosocial adjustment to illness. This proposition is based on the research conducted by Derogatis (1986). He introduced the Psychosocial Adjustment to Illness Scale (PAIS®) to assess the psychological and social adjustment of medical patients, or members of their immediate families, to the patient's illness. The PAIS® was developed to reflect seven principal domains [Derogatis 1986], all of which had been shown to have a high relevancy for adjustment to medical illness: 1) health care orientation, 2) vocational empowerment, 3) domestic environment, 4) sexual relationships, 5) extended family relationships, 6) social environment, and 7) psychological distress. An example of the mediating role this variable may play is illustrated as follows. The lag period between when a person becomes sensitized and develops symptoms of CBD is difficult to predict and may range from months to decades. This period may be tempered by the individual's healthcare orientation (e.g., their general approach to taking care of their health). That is, someone who is very attentive to their health needs and exhibits healthy behaviors,

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such as regular exercising and maintaining a proportional weight, may postpone the onset of CBD symptoms.

In the model, the outcome of interest is health quality of life. This includes both the physical and mental domains. The Rand Corporation developed an instrument (SF-36v2®, Quality Metric Incorporated) that measures eight health concepts: 1) vitality, 2) physical functioning, 3) bodily pain, 4) general health perceptions, 5) physical role functioning, 6) emotional role functioning, 7) social role functioning, and 8) mental health. This is a valid and reliable scale that is widely used to measure health quality of life among sick and well populations. Based on anecdotal reports, a hypothetical test case has been constructed to illustrate how this model functions.

Test Case

A skilled machinist applied for a job at a metal machining and fabrication shop where various aircraft parts were manufactured from beryllium and other metals. Whether he was genetically susceptible to beryllium was unknown. Prior to his employment, he was given a pre-employment physical examination and screened for beryllium sensitization using the BeLPT. The BeLPT was normal, he was declared fit for duty, and hired.

He worked in the factory for 5 years and was promoted to journeyman machinist. Each year he had the BeLPT and the result was normal. Industrial hygiene samples were occasionally collected in the factory and 90% of the results showed that airborne beryllium concentrations were less than the limit of detection of 0.05 micrograms per cubic meter of air (μg/m^3) and all of the results were less than 0.1 μg/m^3. This was 20

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times less than the Occupational Safety and Health Administration (OSHA) standard so management believed the exposure levels were safe. Several breathing zone samples were collected from various machinists but none were ever collected directly from the breathing zone of this Worker.

During the Worker's annual physical at the start of his sixth year, his BeLPT result was abnormal. The plant nurse told him false positives were common with this test and that they needed to repeat the BeLPT to confirm the first result. She drew blood for a second BeLPT and sent it to the laboratory for analysis. The results, received six-weeks later, were reported as "borderline." The plant nurse told the Worker that a third test was needed because a borderline result was neither positive nor negative. They repeated the test and waited six more weeks for results. This result was also abnormal. The Company Doctor told the Worker that he was sensitized to beryllium. The Worker had no symptoms and his pulmonary function tests were normal. The Doctor told him he could not say with certainty if or when he might develop CBD. He said some people never developed symptoms and others developed symptoms within a few months; everyone was different. In the meantime, it was prudent that he no longer work with beryllium.

The Worker's supervisor told him that he would not be able to come back to his machinist position because it was company policy that a sensitized worker could not work around beryllium and they did not have any machinist positions where he would not be potentially exposed to beryllium. He could transfer to the grounds maintenance crew, however, if he chose to do that he would have to work at a 50% pay reduction.

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The Worker went home and told his wife that he would have to take a 50% pay reduction and work on the grounds crew if he wanted to stay at the factory. She was concerned about that but was mostly worried about what would happen if he developed CBD. The Worker wondered if he was going to have to change careers. He had always been a machinist and did not know what else he could do and make an equivalent salary. He wondered if he could make an insurance claim for disability or workers compensation because he was sensitized to beryllium.

In this example, the reader may have recognized two of the antecedents (i.e., exposure and sensitization) along with several sources of uncertainty. Ambiguity was represented by the alternating normal and abnormal BeLPT results. Vagueness was represented by the industrial hygiene sampling results that were reported as less than the limit of detection. Unpredictability was present when the Doctor described the natural history of CBD. Lack of information was present when the Worker wondered about whether he was eligible for a workers compensation or disability insurance claim. Unfamiliarity was present when the Worker wondered about what other trade he could learn.

The effect of this uncertainty may be mediated (i.e., modified) by the Worker's individual situation and life experiences. For example, if his spouse had a job in the healthcare field that paid well that might mediate some of the healthcare and financial uncertainty. If he friends from the factory that also had become sensitized to beryllium and they joined a local CBD support group that might mediate the social functioning. If his brother owned a construction business and he was able to work for him that might

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mediate the vocational uncertainty. This test case is a composite of actual scenarios and demonstrates the potential for uncertainty with BeS and CBD.

Validating the Model

Following the path demonstrated by researchers studying the psychosocial effects of prostate cancer, both qualitative and quantitative research methods should can be used to determine whether empirical data supports this conceptual model. Both inclusionary and exclusionary analytical strategies should be employed.   The exclusionary strategy should seek to demonstrate that there is no relationship between uncertainty, psychosocial adjustment, and health status. The inclusionary strategy should seek to demonstrate that there is a relationship between these variables.

A qualitative study, involve a group of 12-15 current and former workers with either BeS or CBD, will be conducted to help determine if the model has validity. The participants will be interviewed to gain a richer understanding of their disease experience. Semi-structured interviews will identify what effect their disease has had on their mental health and their relationships with family, friends and co-workers. Transcripts of the interviews will be analyzed to determine the degree to which their experience supports the conceptual model.

A quantitative study will be conducted to provide data that can be triangulated with the qualitative data to determine the validity of the conceptual model. A cohort of current and former workers from the U.S. Department of Energy complex who have been diagnosed with BeS or CBD will be surveyed. Each of these workers/former workers will be asked to complete four questionnaires (demographics and work history,

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SF-36v2®, MUIS, and PAIS-SR®) designed to describe their work history/ demographics and to measure health quality of life, uncertainty and illness, and psychosocial adjustment to illness.

Conclusion

Creating this model is a step toward filling a void in our understanding of the natural history of CBD. Once validated, it will establish a foundation for future research and program evaluations and may lead to changes in the psychological, social, financial, and disease management support provided to this population.

Acknowledgements

This research was supported by a grant from University of Tennessee, Department of Public Health.

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PART 2 – A QUALITATIVE STUDY OF THE PSYCHOSOCIAL EFFECTS OF BERYLLIUM SENSITIZATION AND CHRONIC BERYLLIUM DISEASE

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A Qualitative Study of the Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease

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Abstract

Background

The objective of this research was to describe the psychosocial effects of beryllium sensitization (BeS) and chronic beryllium disease (CBD) for a sample of current and former workers from Department of Energy facilities in Oak Ridge, TN.

Methods

Semi-structured interviews were conducted with 13 participants. Interviews were recorded and transcribed. The responses were coded and analyzed to identify patterns and themes and to learn about their experiences. The results were compared to a theoretical model developed by the authors.

Results

Participants described ambiguity, inconsistency, vagueness, unpredictability, lack of information, and unfamiliarity that was consistent with the Michel Uncertainty in Illness Scale. They also described how they adjusted to their illness in a manner aligned with the Derogatis' Psychosocial Adjustment to Illness theory.

Conclusions

Based on the results of this study, it appears appropriate to apply Uncertainty in Illness and Psychosocial Adjustment to Illness theories to BeS and CBD. Uncertainty may be considered an independent variable and psychosocial adjustment an intermediate variable in the study of the psychosocial effects of BeS and CBD.

Key Words

Beryllium; uncertainty in illness; psychosocial adjustment; stress and coping

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Introduction

This is a report of a qualitative study of the psychosocial effects of beryllium sensitization (BeS) and chronic beryllium disease (CBD). The aim of the study was to collect and analyze empirical data to help validate a proposed model of the psychosocial effects of CBD and to aid in the design and evaluation of programs for workers with BeS or CBD and their families.

Beryllium is a strong, lightweight metal that is toxic when inhaled into the lungs. People who work in factories where beryllium is processed are sometimes exposed to beryllium particles and may develop an allergic reaction to the metal. In some, an immune response (BeS) leads to a severe, incurable occupational lung disease known as CBD.

Frequently reported symptoms of CBD include one or more of the following: dyspnea on exertion, cough, fever, night sweats, and chest pain and, less frequently, arthralgia, fatigue, weight loss, or appetite loss [Maier 2002]. On physical examination, a doctor may find signs such as rales, cyanosis, digital clubbing, or lymphadenopathy. A radiograph of the lungs may show many small scars. Patients may also have an abnormal pulmonary function test and peripheral blood beryllium-induced lymphocyte proliferation test (BeLPT) [Samuel and Maier 2008]. Examination of lung tissue under the microscope may show granulomas. CBD may be confused with other lung diseases, especially sarcoidosis [Müller-Quernheim, et al. 2006, Infante and Newman 2004]. In advanced cases, there may be manifestations of right-sided heart failure, including cor pulmonale [Samuel and Maier 2008].

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Most people who are exposed to beryllium will not experience health effects. However, some develop BeS and some of them go on to develop CBD. Epidemiologic studies have shown that a range of 1-6 percent of exposed workers develop BeS, although the rates can be as high as 19 percent among workers with the highest exposures, such as beryllium machinists [Maier 2002, Kreiss, et al. 1993, Kreiss, et al. 1989, Kreiss, et al. 1997, Kreiss, et al. 1996, Schuler, et al. 2008]. Most workers who are going to develop BeS tend to do so early on, but follow-up testing over the years continues to identify workers with BeS—up to 30 percent in one group of workers [Schuler, et al. 2008].

The percentage of people with BeS who go on to develop CBD is highly variable, ranging from 10-100 percent in different worker populations [Kreiss, et al. 2007]. Individuals exposed to the highest levels of airborne beryllium dust are at greatest risk, although skin exposure may play a role in sensitization [Day, et al. 2006]. In each population, a certain percentage of people with BeS will not have CBD at the time the BeS is discovered. Recent research suggests that each year, 6-8 percent of non-diseased people with BeS will develop CBD [Newman, et al. 2005a]. The latency for converting from BeS to CBD is highly variable, ranging from 1-12 years in one longitudinal study [Newman, et al. 2005b]. Factors such as particle size, type of beryllium used, amount and duration of exposure to beryllium, occupation, industry, and genetics all play a role in determining why some BeS people develop CBD and others do not [Maier 2002, Kreiss, et al. 2007]. Once a person is exposed to beryllium, he/she carries a lifelong risk of developing beryllium sensitization or CBD, even if the exposure amount was small or exposure has ended [Kreiss, et al. 2007].

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Beryllium is widely used in the aerospace, electronics, biomedical, defense, telecommunications and other industries [Jaskula 2011]. Beryllium consumption is currently dominated by electronics applications [Kelly and Matos 2011]. The 2010 estimated consumption of beryllium in the U.S. was 320 metric tons and was valued at about $160 million [Jaskula 2011]. The estimated number of U.S. workers currently exposed to beryllium is 134,000 [Henneberger, et al. 2004] and the total number ever exposed is 800,000 [Infante and Newman 2004] however, these are likely underestimates [Samuel and Maier 2008].

The nuclear weapons industry has received substantial attention because of worker exposure to beryllium. In fact, beryllium disease was recognized among workers involved in the early development of atomic energy in the World War II era [Hardy 1955, Van Orsdstrand, et al. 1945]. As nuclear weapons proliferated during the Cold War, the number of workers in the U.S. Department of Energy (DOE) nuclear complex grew and the number of workers exposed to beryllium grew proportionately. Beginning in the late 1980s, clusters of CBD were recognized in workers from nuclear weapons plants across the U.S. [Kreiss, et al. 1989]. Additional epidemiologic studies of nuclear workers have been completed over the past two decades helping us to understand the risk of CBD in this population [Kreiss, et al. 1993, Stange, et al. 1996a, Stange, et al. 1996b, Stange, et al. 2001, Sackett, et al. 2004, Welch, et al. 2004, Rodrigues, et al. 2008, Arjomandi, et al. 2010, Mikulski, et al. 2011]. These studies and others were chronicled in the DOE Chronic Beryllium Disease Prevention Program (CBDPP), a regulation that was promulgated to help prevent CBD in the DOE Complex [Department of Energy 1999].

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The National Research Council [2007] recognized that the diagnosis of BeS or CBD may be associated with psychosocial stress and/or loss of income and that there was an absence of published data on those phenomena. The NRC further suggested that implementation of a comprehensive beryllium-exposure and disease management program that includes appropriate worker education and counseling, medical-removal, and protection against lost wages can minimize such potential adverse consequences [National Research Council 2008].

Since psychosocial stress may be part of the disease experience, it is important to understand the nature and extent of the psychosocial effects so that appropriate interventions can be implemented. Substantial resources are already being invested in educational programs, support groups, counseling, financial compensation, etc. to reduce the impact of CBD on workers and their families [Departmetn of Energy 2011a, Department of Energy 2011b]. These efforts are well-meaning but many do not have a theoretical basis and are not supported by empirical data. That makes it difficult, if not impossible, to evaluate the effectiveness of these programs.

Methods

The study participants were current and retired workers who had been diagnosed with CBD or BeS and work (or worked) at one or more DOE facilities in Oak Ridge, TN. They were recruited through the Beryllium Support Group of Oak Ridge (BSGOR). The BSGOR is an education and advocacy forum for current and retired workers who have either BeS or CBD. The Group is sanctioned and supported by the Y-12 National Security Complex (Y-12). The Group meets twice monthly and provides educational speakers and topical discussions. A presentation was made to approximately 60

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members of the BSGOR and 13 of those volunteered to be interviewed. The interviews were conducted over a four month period.

Two key advisors from the study population provided feedback on the study design. Both were current workers who had been diagnosed with CBD and were active in the BSGOR. They provided feedback on the informed consent statement, the interview protocol, written questionnaires, and recruitment methods. Adjustments were made based on their knowledge and feedback.

Semi-structured interviews were held at either the participant's home or at the New Hope Center, a building at Y-12 with small, private meeting rooms that were available to the public. Interviews lasted from 1-3 hours and were held over 1-2 sessions. An interview script was used to help guide the interviews. The interviews were recorded and the audio files transcribed into text documents. The documents were de-identified to maintain confidentiality and reviewed by an authorized derivative classifier/review officer to ensure no classified information was revealed.

The documents were imported into QDA Miner 4 (Provalis Research Corporation). Each case was assigned a unique identifier and 14 demographic variables were recorded. A two-level coding manual was developed to aid in the analysis of the qualitative data. Socially constructed (SC) codes were created based on a theoretical model of the psychosocial effects of CBD [Miller 2012].

The model is based on three prominent psychological theories: 1) health, stress, and coping, 2) uncertainty and illness, and 3) psychosocial adjustment to illness. The model supports the hypothesis that workers who are diagnosed with BeS or CBD experience a great deal of uncertainty and that has a detrimental effect on their health

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status. The focal relationship in this model is between the independent variable uncertainty (i.e., the characteristic being observed) and the dependent variable health status (i.e., the outcome of interest). It is hypothesized that the relationship between these two variables may be partially mediated by an intermediate variable, the ability to make psychosocial adjustments to disease. The model is illustrated in Figure 2.I.

The SC codes were based on the domains of each of the theories, as listed in the model. Interview questions were structured to probe feelings, thoughts, and experiences about each of these domains as well as to identify key events related to the participants' CBD experience.

The University of Tennessee and DOE Institutional Review Boards approved this study. Participants signed informed consent agreements.

Results

Study Population

The study population consisted of individuals who were either working at or were retired from one or more of the DOE Facilities in Oak Ridge, TN: Y-12, Oak Ridge National Laboratory and K-25 Gaseous Diffusion Plant/East Tennessee Technology Park. All of the study participants spent the majority of their careers at Y-12. The participants were predominately white, male, craft workers in their late fifties. Most (9/13, 69%) were still working and had been diagnosed with CBD (9/13, 69%). All of the current workers were members of a Labor Union. A description of the study population is provided in Table 2.I.

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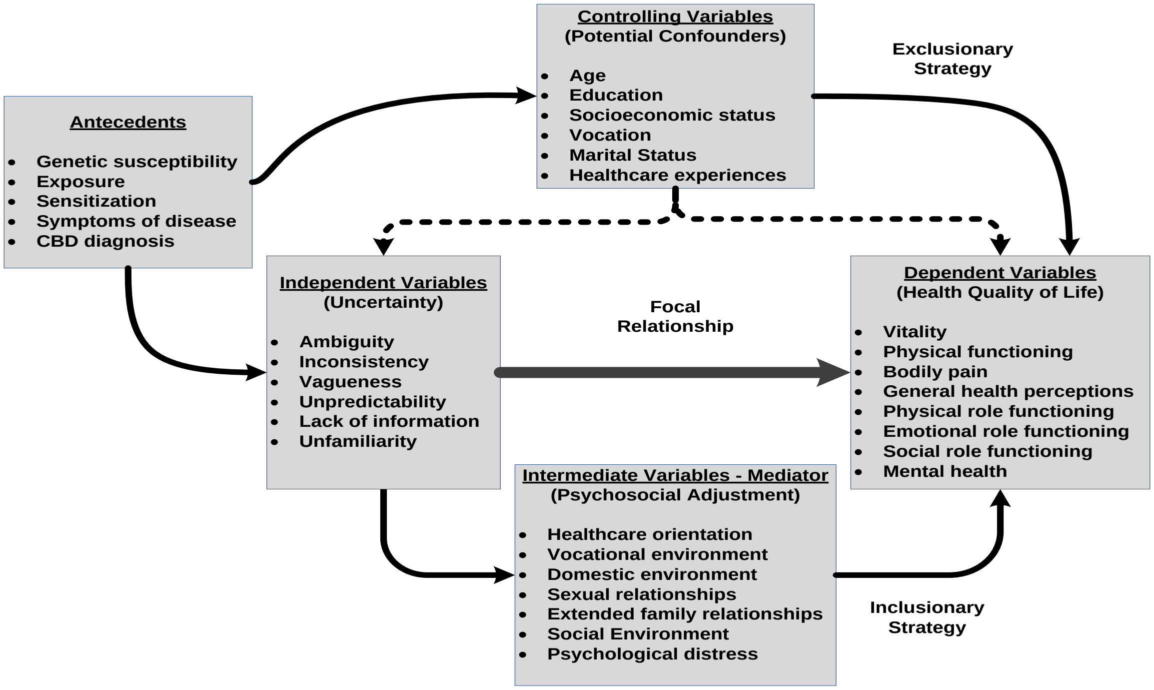

Figure 2.1. Socially constructed model of the psychosocial effects of chronic beryllium disease

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Table 2.1. Descriptive statistics for the study population

Variable	Description
Number of participants	13
Region of residence	East Tennessee
Age	Range = 51-85 Median = 59 Mean = 62.4
Gender	Male = 11 Female = 2
Marital status	Married = 11 Divorced = 2
Race	White = 10 African American = 3
Education	Some college = 12 Associates Degree = 1
Household income	$25-50K = 3 $50-75K = 3 $75-100K = 4 >$100K = 3
Work status	Working = 9 Retired = 4
Place of work	Y-12 = 9 Y-12 and X-10 = 1 Y-12 and K-25 = 1 Y-12 and X-10 and K-25 = 2
Job title	Administration = 1 Chemical operator = 1 Machine maintenance = 1 Machinist = 3 Maintenance craft = 5 Maintenance laborer/janitor = 1 Material control = 1
Disease status	CBD = 9 BeS = 4
Number of years sensitized	Range = 0-7 Median = 1 Mean = 2
Number of years with CBD	Range = 3-19 Median = 8 Mean = 9

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Health Status

The health status of the participants varied widely, as would be expected in a group that had experienced the full spectrum of CBD. Those who were BeS reported a heightened awareness of their respiratory health but were largely asymptomatic.

> Participant 9 (P9): I don't see that I have any significant problems or anything. I can tell maybe that I am getting a little short of breath, but it seems like, being diagnosed as being sensitive, any little thing that I've read on the internet or something that might be a symptom, you're like, well could that be because of that, whereas before I probably wouldn't have thought anything about it.

Others with CBD who were in the early stages of disease reported some mild symptoms but they considered their health to be good overall.

> P4: You know I'm feeling good. The only problem I've had that I've noticed since I was diagnosed is real hot weather. I have a little more problem as far as breathing goes. But you know, in general, I feel good. I don't obsess with it, and so I just keep on going.

Others were in the more advanced stages of CBD and reported more symptoms and limitations related to their health.

> P2: My health is okay. I use two inhalers a day because I do have some shortness of breath, I have like other people, my night sweats, my joint pain, I have insomnia pretty bad and it comes from having some pain that comes into my joints and it makes it hard for me to sleep. Other than using the inhalers just in case you get short winded. I think I'm doing alright. It's

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> about the same from a year ago. It's worse than it was 5 years ago. Where it used to be I didn't have any problem getting out, cutting my yard or going up and down the steps or anything like that to where I may get a little more winded now than I did.

Others reported other chronic conditions in addition to CBD. In general, they indicated that their health was poor and that they had some significant limitations because of their health.

> P7: My health's in pretty bad shape, I have a lot of trouble, it seems like I'm always hurting in my chest, my left lung, especially, And there's been a couple times that, well more than twice, that I'll wake up, my CPAP (continuous positive air pressure – a device used to treat sleep apnea) was torn up, and I didn't have it, and I woke up in the morning and I couldn't breathe, and this has happened several times. I just can't get my breath and it's almost like, well I am, I'm smothering. I can't get my breath.

There were three key events that framed each participant's experience with CBD: occupational exposure to beryllium, diagnosis of BeS, and diagnosis of CBD. The timing of these medically important events carried widely among participants. Once they occurred, they triggered other sociologic events. Figure 2.2 provides a composite timeline for these medical and sociologic events.

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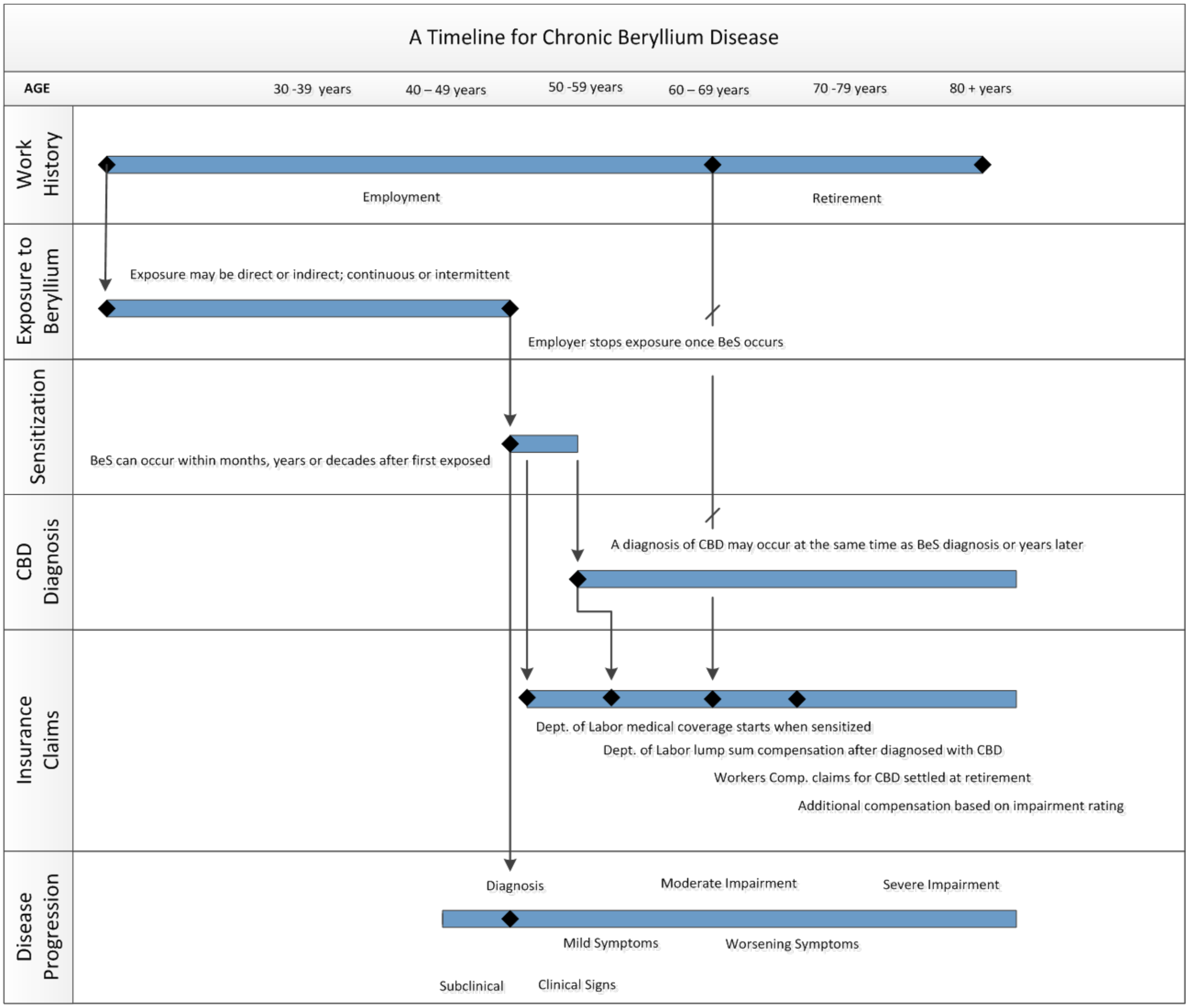

Figure 2.2. Key medical and sociological events related to chronic beryllium disease

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Occupational Exposure to Beryllium

The participants had very different experiences with beryllium exposure and two patterns emerged from the data: some had direct exposure to beryllium as a part of their daily job (e.g., machinist) while others had only indirect, incidental exposure (e.g., electrician). For some, frequent, direct exposure to beryllium occurred from the beginning of their employment.

> P3: The first week at Y-12 I began working in the machine shop; which was the primary production beryllium shop at the time. We also worked with a number of other materials but it was primarily beryllium in several forms.

Others had infrequent, but still direct, contact with beryllium. One participant could recall only a single incident where he had direct contact with beryllium.

> P9: can only remember one time, I had maybe one little brief encounter with some beryllium metal. We were using a grinder to grind some on a lathe but we were flooding it with coolant and we had a vacuum hood over it and everything. And I worked on it maybe one shift so I didn't see really it was a big deal.

Others did not perform any work directly with beryllium but had indirect exposure when performing their job. Those with indirect exposure were often un-informed of the hazards of beryllium and ill-prepared to protect themselves. One electrician described his indirect exposure to beryllium:

> P7: In 1989 I started working on the roof of a building and we had the exhaust fans, and that was one of my jobs, checking the exhaust fans. I'd

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> go up on the roof and I would check on the fans, and I didn't know what things was coming out of each stack. But beryllium was one of them.

Those with indirect exposure also seemed to have been provided with the least information about the hazards of beryllium and methods for personal protection.

> P1: I remember spending the summer in a building inside the plant, working construction, and we were renovating that machine shop to convert it to offices. We worked the whole summer in there. At the end of the summer, I can remember the sprinkler contractor coming in and they were going to put the sprinkler heads in. They were getting ready to do that and they put moon suits on, and I said ‘Whoa-whoa-whoa, what are y’all doing?’ They said ‘This is a beryllium machine shop!’ My response to them was, ‘what's beryllium?’ I had no clue. We had no protection. If we had gloves it was because we bought them ourselves. So I spent the entire summer in there doing that. I have chronic beryllium disease, and I know positively (taps finger vigorously on table for emphasis) that's the building I got it in.

Over the past 15 years, the requirements for personal protective equipment and housekeeping have changed to reduce the potential for exposure. Some participants reported the effects of those regulatory and procedural changes.

> P9: But you know everything is a lot cleaner now than it was back then. I can see that in the shops now, the way they handle whatever it is you're working with,” and “We were always protected, always wore respirators and the right suits and everything by the book,” and “Well, everybody

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> dreads it. It's just different now than it was when I first started wearing a respirator. But I wear one pretty much every day that we've got a job. Most of our jobs are dirty, contaminated areas. As a pipefitter, it goes with the territory. If you're going to work in a nuclear place, it's pretty crappy conditions usually," and finally "Well there was a system set up where you would come into one area you would take your clothes off and leave them and go through a shower and go on home. So we was doing that but yet the supervision and a lot of the secretary type people in the area did not have to do that.

Diagnosis of BeS

There were two BeS patterns among the participants. Some were diagnosed with BeS and CBD at virtually the same time; while others were BeS and had (or are in) the latency period that precedes CBD. All of the participants found out they were BeS by participating in medical screening programs that are part of the DOE current and former worker surveillance programs. One screening program is affiliated with the Atomic Trades Labor Council.

> P1: I decided to come out here and go through the Atomic Trades Labor Council medical screening. Great physical; best physical I've ever had. I went through that and immediately found out I was beryllium sensitive. So I went to see a specialist and he said 'Well, yeah you're beryllium sensitive' and he said 'The only way I can find out if you have the disease is to do a biopsy.' And I said 'Well, then do it, 'cause if I've got something I want to know it.

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Others found out through the routine annual physical provided through the Y-12 Occupational Health Services Department.

> P5: I was a beryllium worker at one point and I went for my physical. Every year we were able to get physicals and I requested to have the LPT test done. That's when I received notice. It came back, and I was called to medical and they informed me that I had been exposed and that I was sensitive.

Three of the participants had virtually no time lag between their BeS diagnosis and their CBD diagnosis. This occurred in older participants who were first screened many years after their first exposure. The majority of workers (9/13, 69%) either had experienced or were in a latency period between BeS and CBD. One participant suspected he had been sensitized for a while and it was only discovered when he started experiencing respiratory symptoms.

> P1: They did a biopsy, and within a month I've got chronic beryllium disease. So I went from sensitive to disease within a couple of months, which kicked my butt. Well see, I probably was beryllium sensitive for 15 years without knowing it. It's only when I finally decided to take the test that I found out I was sensitive, and then I immediately had beryllium disease.

Some (3/12, 23%) experienced the inconsistency that sometimes occurs with the BeLPT. Their results alternated between normal and abnormal.

> P10: So I went down there and took a test, a couple days later they called me and said well I think our machines may have malfunctioned; we didn't

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> get a good reading so we're going to do it again. They always tell you that. So I went and did it again and found out I was sensitive. I didn't know what in the crap they were talking about. I said what does that mean?

Diagnosis of CBD

Most of the participants with CBD (9/13, 69%) reported receiving a medical work-up to establish whether their condition met the case definition for CBD.

> P2: Well I had my first test (BeLPT) in June of '97 then came back in October and said that they needed to do another one and then after that they said that I needed to go to Vanderbilt and had to see a doctor down there and they was going to do a lavage to see exactly what it was. That was in January of '98 and then in February they called me back and told me that I do have the disease. So it was within a 7 month period.

The lack of an abnormal BeLPT was problematic for two of the participants. Both of them reported that they were told that their use of Prednisone was likely interfering with the BeLPT.

> P3: I had very high numbers in the lung lavage. Of course, being symptomatic, they were putting the numbers, the lab work, the symptoms and the history all together, it was pretty much a no brainer and I was diagnosed with CBD right off the bat. But I had one LPT before actually being diagnosed and I wasn't deemed as being sensitized because it was barely below the cutoff. As I learned later, there's a one in four chance of getting a normal when it should be abnormal under the best of, of conditions. I don't remember what medicines I was on at the time, but

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> prednisone will definitely mask a LPT so you know, you've got at least a one in four chance of getting a wrong reading. You know, getting a negative when it should have been a positive to begin with.

One participant had a diagnosis of sarcoidosis for 14 years that was later changed to CBD. Repeated BeLPT tests were normal or borderline before an abnormal result was obtained to help differentiate the diagnoses of CBD from sarcoidosis.

> P6: I actually went through the worst symptoms that people have. I was sick all the time. My pulmonary doctor, he said you know I really don't understand it. And plus we didn't think anything else about it. Because he didn't really know a lot about it, he knew a lot about sarcoid and sarcoidosis but he didn't know anything about CBD. So I'm just thinking that because people don't know, even physicians, it probably really was CBD all along.

The Beryllium Bureaucracy

Every participant described frequent and often frustrating encounters with what was termed the "beryllium bureaucracy." These are the requirements, processes, and systems that have been designed and implemented to provide medical care and compensation for workers in the DOE who develop CBD and to provide preventive measures so that today's beryllium workers have a lower risk of developing disease. Three prominent domains to the bureaucracy were identified by the participants: The Department of Labor (DOL), Workers Compensation Insurance (Workers Comp), and the Chronic Beryllium Disease Worker Protection Program (CBDPP). Each domain intersects with the other in a complex web of rules and regulations that involve current

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workers, retirees, health care providers, employers, insurance carriers, the Federal government, and State government. Figure 2.3 illustrates the interconnections of the beryllium bureaucracy that vary depending on a worker's employment and disease status.

One clear pattern emerged from the data; the experiences of participants changed dramatically with the passage of the Energy Employees Occupational Illness Compensation Act of 2000 (EEOICPA) [2000] and the promulgation of the DOE Chronic Beryllium Disease Prevention Program Final Rule in 1999 [Energy 1999].

The EEOICPA required implementation of a program to provide compensation to employees of DOE, its predecessor Agencies, and its contractors and subcontractors involved in nuclear weapons production and testing programs that develop an occupation-related illness. Adjudication of issues pertaining to all claims for benefits under the EEOICPA is the responsibility of the DOL.

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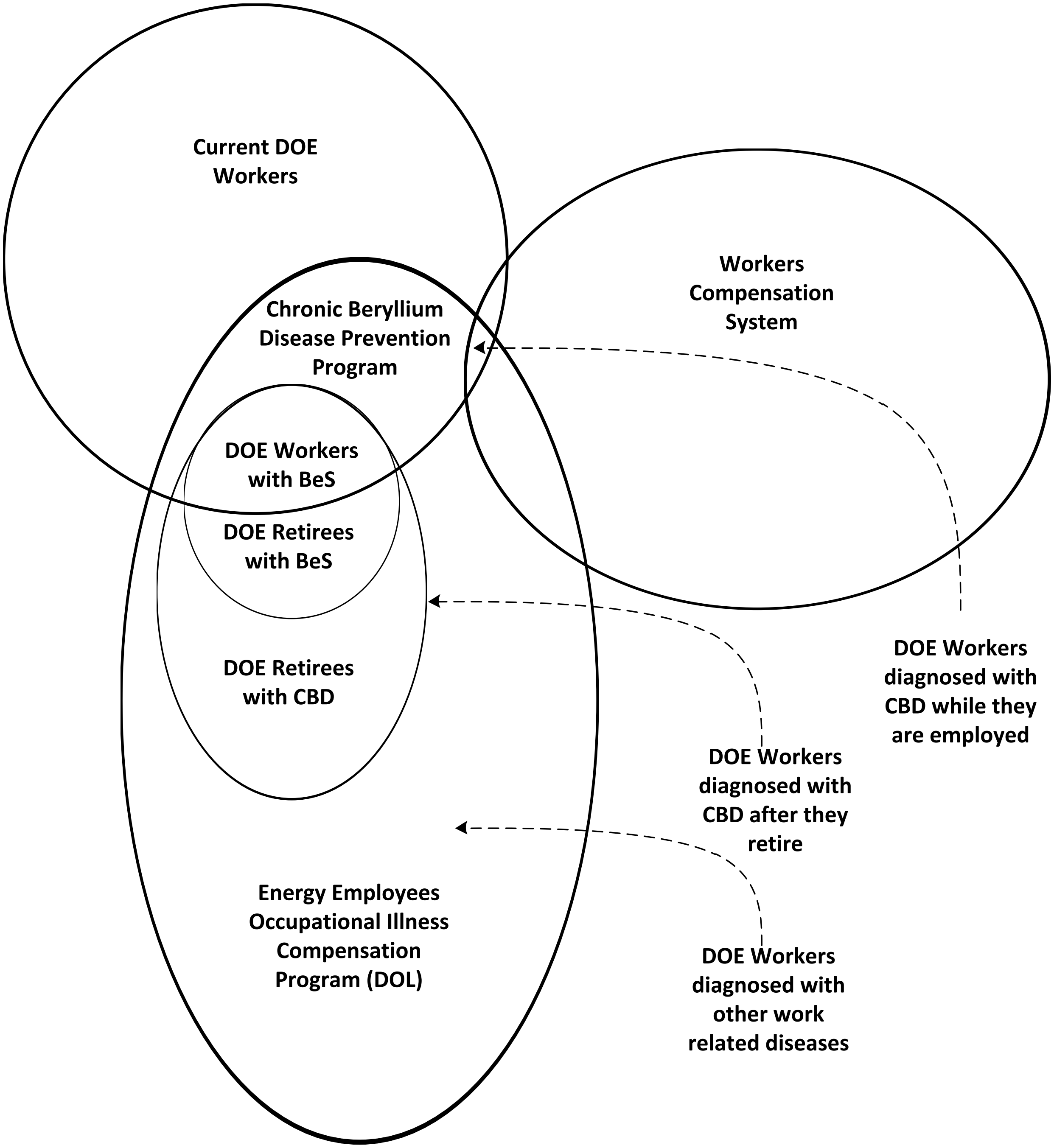

Figure 2.3. Intersections of the beryllium bureaucracy

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Part B of the EEIOCPA was implemented in 2001 to cover current and former workers who have been diagnosed with cancers, beryllium disease, or silicosis and whose illness was caused by exposure to radiation, beryllium, or silica at a covered facility. Individuals or their survivors found eligible under part B may receive a lump-sum compensation payment of $150,000 and medical expenses for their covered condition [EEOICPA 2000].

Workers Compensation insurance is a mandatory, no-fault system to provide benefits for workers that become sick or injured on the job. It is regulated by state law and covers most employees, not just those in the DOE [Annotated Tennessee Code 2012]. Large employers often are self-insured for Workers Compensation. Participants who were diagnosed prior to 2001 dealt exclusively with the Workers Comp system.

> P3: When I was first diagnosed, I was still working at the time, and since it's a work-related illness, it's covered by worker's comp. But the Plant itself is self-insured, so instead of the paperwork being filed through the state of Tennessee as it is with a lot of companies, the Plant handles its own Workers Comp. But it has to follow Tennessee State law. So, as I said, I was diagnosed before the DOL program came into existence. So I was covered early on by Workers Comp and worker's comp gives you a choice of three doctors. The Company picks the list of doctors and then you pick one from that list. With Workers Comp pretty much everything that is justifiable to be work related is covered a hundred percent. That's the good thing. The bad thing is it's an insurance company and they balk at a lot of things.

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Insurance coverage for participants was a combination of coverage through Workers Comp, the EEOICPA administered by the DOL, individual healthcare insurance, and Medicare. The applicable coverage was determined by their employment status (employed or retired), their age (for Medicare), and the status of their disease (BeS or CBD diagnosis). Participants were in varying stages of the claims process, depending on their disease status. The results of the interviews provided a glimpse into the complexity of the two systems and the conflicts that the participants experienced as they sought compensation for their work-related disease.

The CBPDD was created to: reduce the number of workers currently exposed to beryllium at DOE facilities managed by DOE or its contractors; minimize the levels of and potential for exposure to beryllium; establish medical surveillance requirements to ensure early detection of disease; and improve the state of information regarding CBD and BeS. It prescribed beryllium operation controls, reduced exposure limits, and medical surveillance requirements that are enforced throughout the DOE complex [Energy 1999].

Navigating through the bureaucracies appeared to be more difficult for those participants who were diagnosed in the 1990s, before the passage of the EEOICPA and CBDPP. Participants more recently diagnosed described fewer problems with the Beryllium Bureaucracy. Clearly, individuals in the 1990s blazed the trail and in some instances help establish a system that was simpler to navigate.

Workers Compensation System

One pattern that emerged when interviewing participants about their experience with the Workers Comp System was a conflict between treating physicians. There was

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often a conflict between the DOL and Workers Comp doctors and the participants were forced to choose one over the other. This sometimes put participants in a position of leaving the care of a doctor who they liked and trusted (their DOL doctor) in order to maintain their Workers Comp claim. They could see either their DOL or Workers Comp doctor, but not both.

> P2: I've had some problems. One of the problems that we all have had is the Plant picks the doctors on the (Workers Comp) panel that you go to. Well the doctors on the panel don't agree with them being your doctor and you having one under the Department of Labor also. They don't see why you need two, and one of the reasons that we try to tell them is the Department of Labor is saying that whatever doctor you go to with them has to be your primary doctor. Department of Labor wants them to be the primary doctor that you go to, but Workers Comp is saying that they've got to be the primary doctor. There's a struggle, they both want to be the primary doctor.

> P10: Well see people are getting in trouble. I was going to (DOL Pulmonologist) and then my Workers Comp doctor said look here, this ain't going to happen. He chewed me out three times. He said I'm not going to treat you if you're going to another doctor, getting medicine from him that may counteract some of the medicine that I'm going to give you, and then we're going to have a bad problem. He said either you stop going to him or you stop going to me. So I quit going to (DOL Pulmonologist). I

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> said well you're going to be my Workers Comp doctor, so I really need you more than I need him. Well another guy out here at the Plant had the same situation as me, had the same two doctors. He wouldn't drop his DOL doctor, so he (the Workers Comp Doctor) dropped him. He said you need to find you another Workers Comp doctor because I'm not going to treat you anymore.
>
> P1: I don't really know that I understand, to me it's gotta be a personality thing. They just don't want somebody second guessing 'em. I never had a problem with my heart surgeon and my cardiologist, they're both heart doctors, they worked as a team. I don't know why, these people can't work as a team. The conflict is between them and we're caught in between.

A second pattern that emerged was the sometimes adversarial nature of the Workers Comp claim.

> P3: You know, I understand from a Workers Comp point of view, that their goal is, supposedly, to give the best treatment for the lowest cost. But we don't always see that in action. We have the perception that they don't have our best interests at heart.
>
> P1: Workers Comp makes you feel like you did something stupid and they have to pay for your stupidity. I'm fairly new to this process and I'm already seeing it. Workers Comp gave me an oxygenator for at night at home and when I was going on a trip I asked for a portable one and they

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> said no you can do without. The Department of Labor said no problem; here's a prescription. It’s puzzling to me why they would say you're gonna be gone a week and you don't need oxygen even though it really makes you feel better. That really pissed me off.
>
> P3: We butted heads with Workers Comp people quite a bit. The doctors did, especially.
>
> P2: Okay when you go through the Department of Labor and you've already went to National Jewish or to Cleveland Institute and they diagnosed you with the disease (CBD) and now the Workers Comp doctor is saying you don't have the disease. It’s creating a problem. Does that mean that we don't get the benefits of Workers Comp? My feelings on it is that the Workers Comp doctor needs to work with the Department of Labor doctor instead of putting the stress on the person and telling them that no you don't have the disease even though three other doctors say you do. Don’t be sayin’ I'm the doctor for the company and the company is saying that you don't have it even though the Department of Labor is saying that you do.

Workers Comp benefits also do not cover BeS while the DOL program does. This possibly delays treatment for some people with BeS because it was not covered under Workers Comp.

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> P3: Workers Comp does not cover beryllium sensitization. In my opinion it should, because especially in 10CFR850 it states that even though it's a precursor, it is an occupational illness. But the Company is saying that the state of Tennessee does not recognize it as an illness so you're not covered by Workers Comp until you're diagnosed with CBD. Most coverage is denied under Workers Comp if you're only sensitized. The thing about it is, most people that are sensitized have CBD, it just hasn't been proved yet.

> P2: I think as far as people working in the Plant once a person is diagnosed as sensitized they ought to have the same right that a person that got the disease has as far as going to pulmonary rehab because the people that are sensitized a lot of time it's just that the doctor hasn't been able to identify it yet. They are having the joint pain, the night sweats, that headache, the heart palpitations. Everything that people with the disease are having they are having. So I think that the Plant needs to be more proactive for people that are sensitized and give them the chance to start rehab as soon as they find out.

Some participants questioned the knowledge and experience of the Workers Comp doctors in relation to CBD.

> P2: The rest of them said that they would learn as they go because treating berylliosis was the same as treating COPD, and that's what each one of them would tell us. Now some of the doctors that they are putting

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> on the Workers Comp panel are saying that they don't have time to go to seminars or anything like that but from patients they will learn.
>
> P1: mean three or four different sets of physicians all agreed I have berylliosis and the Workers Comp doctor said naw, gotta be asthma. They don't know what they're talking about. So it's really agitating to the patient to have to fight the Workers Comp doctor when you've got a panel of physicians saying we agree; you are sick.

The Workers Comp System evaluates impairment using a Maximum Medical Improvement (MMI) rating. This process caused consternation for some participants.

> P10: They talk about that MMI crap. My MMI was before I ever got CBD. That's set up for like a broken bone or broken leg or something. You know this is as good as it's going to get. For chronic disease it's pitiful. The best you ever gonna be is before you ever got that crap. Well that's what they use to send you back to work. Like if you get hurt on the job, break your arm or something like that, they say okay he's at MMI he can go back to work. So what are they gonna do for us that's got CBD, we're never going to be at MMI, there is no MMI for us. They're still living in the stone ages.

One participant who was recently diagnosed with CBD reported no problems with the Workers Comp system and in fact saw cooperation between the two systems.

> P6: A lot of people have had problems but I did not. My Workers Comp doctor, he's very good. I see him twice a year. And he said as long as I'm not ill, I have my pulmonary function test, and he does an x-ray, he'll take

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> blood. And same thing with my DOL doctor, they'll both do the same thing. Here I come on board in 2010 and everything's just going along smooth with both (DOL and Workers Comp). Yeah, nobody could believe it. I mean everybody's just agreeing, going together and I'm not having any problems.

Energy Employees Occupational Illness Compensation Act (EEOICPA)

In contrast to the Workers Comp system, the DOL administration of the EEOICPA was viewed very favorably and the claims process was not difficult for most participants. It appeared that today’s DOL process was improved over the process when the Program first started.

> P1: That program has been probably one of the best things that the government has ever done to help the nuke workers. After I was diagnosed with the disease they said, ‘Well you need to go over there to the sick worker's program.’ I walked in. I'm looking around thinking ‘What is this?’ The people over there are so helpful. You know I was upset when I first came in, ‘cause that was like a day or so after I was told that you've got this disease and I don't even know what it is. But you've got a disease and I know I can't breathe, so it's got to be bad. So, they were real helpful. Everybody over there, every single person I've ever met over there, is empathetic, kind, courteous--the lady that runs it has got to be an angel. And they really, they seem like they go out of their way to help.

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P1: It should not be, but Workers Comp is adversarial. The Department of Labor, most of the time, feels like your family doctor trying to help you.

P9: I just called over there one day from work and set up an appointment. Went over there, my time come and she called me back and took about maybe an hour. Filled out some forms and she helped me with all that. She helped me fill out those forms and stuff and then sent it off and it came back and I didn't have a bit of a problem.

P8: It went real smooth. I'd already been through the other part, the cancer part. But it went real good, they went right through, got my card, you know I got the card in my pocket and I carry it everywhere I go. You know so it's real smooth.

P4: The Department of Labor side of it was painless. I mean you know when I was diagnosed with CBD I went down and filed a claim and it was pretty much, just cut and dry. That was really easy.

P5: I just gave them some information that they asked for. And they more or less just took it from there. It's a situation where they get the information, send it to Jacksonville, and they either approve it or not. I want to say it was this side of 6 or 8 weeks (to get approval).

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> P2: I was thinking it was 2000. Once I put my paperwork in it took me 11 months from start to finish. But once it went through there wasn't any problem. I got my card and under the program, started getting seen by the doctors, so I don't have any problem with it. I think it works well.

Chronic Beryllium Disease Prevention Program (CBDPP)

The CBDPP affected those participants who were still in the workforce. All of the current workers in the study population were witness to the changes that occurred in the DOE Complex after the CBDPP regulation was established. There were mixed emotions about the regulations. Some participants expressed disappointment that it took too long for the protective measures to become law.

> P1: They knew beryllium was a problem in 1930, but they didn’t address those issues until they’ve got enough injuries, I call it a body count. Then they address the health issues.

In contrast, others were more circumspect about past practices and the difficulties of establishing new regulations and implementing programs to prevent CBD.

> P4: I've always considered this a safe place to work, you know I really have. And I think that the precautions were all we knew to do. We wore respirators, but we weren't wearing respirators where they're wearing them today. I honestly think that this Plant is doing everything they can to mitigate the hazards of beryllium.

Some of the participants described how the requirements of the CBDPP had directly impacted their work.

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> P6: I had to go to medical and talk to them, and the doctor recommended that anybody who was sensitive that the best thing to do is just not be around it. So they tried to find places that people who are sensitive can go where there's no beryllium," and "I can't go in a beryllium buffer area, anything that's got a beryllium sign on it I'm out. So that's cost me a lot of work and a lot of overtime jobs," and "They have the signs up now, where they didn't exist probably up until 2000. You're more aware of where you're going. Make sure you're wearing the right PPE (personal protective equipment). It makes you more aware of what's going on. Is there anything in this room that could hurt me in any way;" and, "It's just different now than it was when I first started wearing a respirator. But I wear one pretty much every day that we've got a job. It's either a respirator or a PAPR (Powered air purifying respirator) or fresh air (supplied air respirator).

One participant described how senior management had enforced policies that were designed to help those who develop BeS or CBD.

> P8: When we first started these beryllium meetings now, I had a foreman that didn't want me to come over here, we were busy. And I said well whatever and I kind of let it go, and then after a while somebody said well he's got to let you go I even heard one of the big wigs say it. He didn't give me any lip at all after that. I said you heard the man, I think I'm going, He said, well you go on now, if you want to go.

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There were situations where elements of the CBDPP had resulted in confusion and caused some of the participants to worry about their long-term employment prospects. For example, some participants expressed concern about the medical removal protection benefits defined in the CBDPP.

> P8: They start coming out with this stuff that you're on the clock, and they may get rid of you. You know, they don't have to pay you after two years. That's what come out here in the last few years. That puts me on the hot seat, I gotta keep my job, but I also don't want to risk my life going back in there. I even thought about going back in and going to talk to them again about the possibility of getting back in again, because they were talking about all this start your clock, even had their company lawyer out here to talk to us, and the Doctor come out here and he was talking about it, and he said nobody's going to lose anything. But according to the way the rules read that once your clock starts, they only have to keep you going for two years. I'm kind of in the middle of a big dilemma here on what I need to do.

Some of the participants questioned some of the industrial hygiene methods used to fulfill requirements of the CBDPP.

> P9: One thing that I think I've kind of argued a little bit in years past, Y-12 I'm thinking is one of the only places around that does what they call the dry smears. It seems obvious to me that you're going to get more with the wet smear tests. Maybe they don't want to find beryllium over here in this place. Or if you'd done the wet smear, you'd find the trace, you name it or

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> something, where the dry smear's going to find it but it's going to be below the limit or something.
>
> P1: Over the years, two issues become very clear. Number one is the rules change. The standards change. The second thing, which is probably even more troubling, it's not as prevalent now as it used to be, it's the bureaucracy. Well we really don't know that the stuff will hurt you, so go ahead and work. They wipe test stuff; they check all kinds of hazards after we do our work. That's what I call the bureaucracy.
>
> P5: We have IH (Industrial Hygiene Department) come take smears and we find it's there. And sometimes it's been over the limit so we're not sure and that's been the thing that really bothers me. They'll come in and say “well we've cleaned this area and we've cleaned that area and we're gonna take smears so it's okay, we've cleaned them.” But it's not 100 percent because they'll go in it and they'll spot check places. So the areas that you've cleaned, yeah that's fine but I can go in there and say “well what about that area right there?” They go and take a swipe and the next thing you know, it's over the limit.

Financial Stability

The results of these interviews indicated that the majority of participants (10/13, 77%) reported an annual income greater than $50,000 per year and 3/13 (23%)

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reported an annual income greater than $100,000. None of the participants reported significant financial problems, such as bankruptcy due to their medical condition. Several things appeared to positively contribute to the participants' financial health.

The DOL Program provides for a lump sum benefit of $150,000 and up to $250,000 for impairment for DOE workers that develop CBD and assures that they will always have insurance coverage for the medical expenses related to CBD. This contributed to the financial stability of some participants.

> P3: Doctor bills, medicines, the breathing machine, everything has pretty much been paid for. So there hasn't been a big financial loss because of that.

Despite the obvious value of this benefit created by the EEOICPA, the settlement created mixed emotions for the participants.

> P2: Everyone would tell you that we feel there is that monetary gift they give you because you got the disease that we feel our lives are worth a lot more than that, but it's good that the government recognizes we were exposed during the cold war days.

> P4: You know the funniest thing that happens, at least for me, and I laugh about it. You know people will come up and say, 'Hey I heard you had CBD.' Yeah. 'Did you get that money?' I mean it's not that much money, you guys! It's really sad to me that companies or government can buy you for such little money. It's sad.

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> P2: You get $150,000 once a person is diagnosed with the disease and then they have impairment that you get $2,500 dollars per point of impairment that the doctor gives you up to $250,000. The total amount that you can get is $400,000 dollars. So then that person that gets the $250,000 they've got 100% impairment, and if you've got 100% impairment you can't do a lot; total oxygen and everything.

> P8: I mean $150,000 ain't crap. It ain't really. It's enough to keep her (his wife) going for a little while. Softens the blow a bit but it ain't enough to where she can live forever. But I don't want it; don't want no part of it. Because if I get it, it means I'm in trouble.

> P1: I had a union rep tell me one time, 'There would be a lot less people in this valley that had chronic beryllium disease if there was no money attached.' Which, I'm thinking, how could you possibly think that, that paltry amount of money for my lungs is why I have chronic beryllium disease?

Uncertainty in Illness

The participants provided numerous examples of situations where they described uncertainty that aligned with the domains of the MUIS. The MUIS has six primary domains: 1) ambiguity, 2) inconsistency, 3) vagueness, 4) unpredictability, 5) lack of information, and 6) unfamiliarity.

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When something is ambiguous it is open to more than one interpretation. Participants shared several experiences that were ambiguous, the most prominent being the results of the BeLPT. They described what it was like to receive a “borderline” test result.

> P3: I had the beryllium testing started in '92 and in retrospect, if I had known what I was looking at my first blood LPT was borderline. I don't remember the numbers, but it was something like a 2.8 on a 3 cutoff. That may not have been the numbers but it was something along that line. If I had known what I know now, I could look at that and been like, okay, that's like being borderline pregnant.
>
> P4: Well my first test was positive, and then they called me back up and I had another one, and it was borderline. And then when I went to see my doctor he said, “Okay, I want you to have another test.” Well I came back here for another test and they wouldn't give it to me. So I tell him, I said, “They won't give it to me.” And he said, “Okay well I'll give it to you.” So he drew blood and it came back positive.
>
> P5: One question that I've had and I still really don't understand because when you say ‘borderline’ that, to me, that's telling me that you've been exposed. And I don't know how they calculate it or whatever, but I know there's some people where I work at right now that's borderline. They've received three or four borderlines, and they have some of the same

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> symptoms of people who are sensitized and with the disease but they can't get medical benefit from the Department of Labor.

The ambiguity of a having a borderline BeLPT result is different than having two or more test results that lack in agreement. That is, one test result was abnormal, followed by a second test result that was normal, followed by a third test result that was abnormal, etc. This is an example of *inconsistency*, the second domain in Uncertainty in Illness theory. Some participants had experienced the erratic nature of the BeLPT test results. One participant had an abnormal BeLPT that was followed by several normal results.

> P8: Well you had to make a decision if you wanted to stay in it or go out of it, you know? It was your decision what to do. When it comes down to your livelihood, I ain't for sure, you know they had a bunch of false positives, so I didn't know if I had one or not, but I'm not going to take a chance on it. I gotta keep my job, but I also don't want to risk my life going back in there. Was it a false positive? ‘Cause I've had nothing but clean slates ever since then.

Inconsistency was not limited to BeLPT results. There were other examples, such as disagreement between doctors on the diagnosis.

> P2: But what's happening with some of the doctors now is they want to go back and run the lavage. They want to go back and do all the testing and then on a couple of people they are telling them ‘no you don't have the disease.’ Okay, when you go through the Department of Labor and you've

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> already seen that Doctor and they say you’ve got the disease and now the Workers Comp Doctor is saying you don't have the disease.

Some of the situations that the participants perceived to be inconsistent were the result of changes in regulations and policies.

> P4: I was back down in my area yesterday, first time in a long time. It's kind of interesting to discover that a lot of the areas I had worked in with just coveralls and now it's full dress out in respirators.

Vagueness means that something is not clearly understood or is not definitely known. Participants described several situations where they experienced vagueness.

> P6: Well I didn't like that feeling of not knowing, especially in the beginning they were giving me like, ‘no it's not the sarcoid; I think you have an ear-nose-throat infection.’ I didn't like that because I'm sick, and they wanted to blame it on anxiety, or having stress. I said you know my job was fine, my home life was fine. I had no reason to be stressed. I told them they were making me stressed because somebody needed to find out what was wrong with me.

> P1: Working in the Plant most people have the assumption that they're exposed. There are hazards in the Plant. We call it ethyl-methyl-bad stuff.’ I mean when you take a look at the list when you go to the Sick Worker's Program and you see a list of all these materials, they say “Have you been exposed to these materials?” I put on all of them yes because it's very difficult to say you haven't.

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P12: I've noticed it (shortness of breath) for a lot longer than I want to admit. Because I just didn't want to admit that I'm getting older. Probably about 45 actually I started feeling something. I assumed that it was just my age that was doing that. I think that's what most people do that have this problem.

P12: I don't have it, I don't think. I hope I don't. I'm sensitive, and that don't mean jack squat really.

P7: I wake up about four or five times every night. Four minimum, and I just don't know what causes it.

P4: I work with a guy right now that's had a positive LPT but he don't want to know. He said, ‘I don't want to know.’ A lot of people are like that, they don't want to know.

P3: I lived a reasonably healthy lifestyle. Why are these breathing problems developing? My pulmonary doctor and I had a good working relationship and he said we need to get to the bottom of this and find out what caused this.

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> P8: Well see when you hear cancer, it totally got my attention. When she talked about beryllium you know, what, what are you talking about? And you know what do you mean I'm sensitive? What does that involve? You've not got the disease or nothing, with the other one, I knew I had it. Ain't no I may get it, I already had it.

When something is unpredictable it is difficult or impossible to foretell or foresee. The participants reported many instances where they had experienced unpredictability related to their disease.

> P5: Right now, I'm fine, I'm okay. And it could be like that, I mean, it could never turn into CBD. But then there's always a possible chance that I can get it and then that would be another conversation.

> P5: Well, I would say the worst part is not knowing. People react different, you know. I'm the type, I pray about it, and my faith is that everything is going to be alright. So I mean I try not worry about the unexpected. But yeah, you think about it.

> P12: It's not that big of a deal to me right now (sensitization). But like I said, you know things change when they tell you that you've got the full blown berylliosis and then, then it seems like the clock's ticking. Up to that point it's just, hey it ain't nothing ‘til they say you've got it.

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> P3: My symptoms are all over the map, I'm having a good day today, I didn't have a good day yesterday. Well I'm still wheezing some today but that's still a good day. But, you know, we don't know what to expect.

> P4: Of course we've had a lot of concern among people that have beryllium disease or are beryllium sensitized out here that somehow it's going to cost them their jobs.

> P10: We (he and his doctor) ended up talking for about thirty minutes and I was scared to death. I didn't know what was going to happen. I've always heard that this could turn into cancer, and all that stuff.

Several participants described having a lack of information about the hazards of beryllium or about the symptoms of disease. This seemed more prevalent when participants described their experiences in the 1980s and ‘90s.

> P4: You know, when I came here in '82 and we were given some asbestos training but beryllium training didn't come till later. And I couldn't tell you what the year was, but it was later.

> P7: I knew several people that had it. And back then though it was kept quiet, very quiet. I knew what I had, but I never had anybody talk about it. So it was kept very quiet. After I was diagnosed, then they started diagnosing all these other people that had it. Up until then it was kept very quiet. You didn't hear any talk of berylliosis while I was working.

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> P8: Back then I'd never heard of beryllium, didn't even know what it was. You know when they told me I was a beryllium worker I didn't have a clue. What? What are you talking about?

The final domain in Uncertainty in Illness theory is unfamiliarity. This refers to situations that seem strange or that are not within one's knowledge. Participants offered some examples of unfamiliar situations that they had encountered.

> P3: At the time that I received the information that I had CBD we didn't have the network of informing people like we do now. I got my report from the University of Pennsylvania, who did the testing, in a manila plant envelope, at work on shop time and I had to root through it like, three times before I really understood it. I mean, I didn't understand all the tests that were done, I didn't understand what they meant, and it was pretty overwhelming.

> P12: I'm walking in like I just walked into a calculus class. I just got out of general math okay, and y'alls talking calculus here and I don't even got a clue. They're talking way over my head and I just kept coming down there and finally I got to learn what they're talking about. Right at the first it was like I was in a German class and I'm going, what'd they just say?

> P3: I know I told my supervisor and a couple of coworkers. I'm not really one to hold things in but still, I was confused myself and didn't really know what all this meant. I didn't really talk about it to very many people initially.

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> ‘Cause you know who was I going to talk to? Like I said I didn't really know where to go.

> P4: Somebody explained it to me like, depending on where your lymphocytes are in your body, you know lymphocytes go to where they're needed in your body, and in my case it was my lungs. Like I said, I don't understand all that.

Psychosocial Adjustment to Illness

During the interviews, participants described many situations that reflected their ability or inability to adjust to their illness. Their situations were compared to the seven principal domains of the PAIS [Derogatis 1986], all of which had been shown to have a high relevancy for adjustment to medical illness. The domains include: 1) health care orientation, 2) vocational empowerment, 3) domestic environment, 4) sexual relationships, 5) extended family relationships, 6) social environment, and 7) psychological distress.

The domain of healthcare orientation addresses the nature of the participant’s health care posture and whether it will function to promote a positive or negative adjustment to the illness and its treatment [Derogatis 1990]. Some participants were highly engaged in their healthcare while others were less attentive.

> P3: I've learned when I go to a doctor's appointment I take a list of my medications, I do a daily vital signs chart, so I can see myself and show the doctor is there a pattern to this? Is it worse certain times of year? I've learned to take notes to the doctor. I mean if I just go in to the doctor and

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> he says how's it going and I say everything's fine. He goes on to the next patient. But if I've got my notes, say okay two weeks ago I had a really bad attack and I bumped my Prednisone up 40 milligrams for three days, and it's helped me organize better so far as taking care of myself.
>
> P5: Being sensitive there's really not that much I can do right now. They keep me monitored; every six months I go to my pulmonologist and he'll do a CT scan or chest x-ray just to see how I'm doing. I keep up with it.
>
> P8: I had (a doctor) and he passed away, so I just kind of let it slide for about three years and then I went over here again just the other day, and that new doctor, boy he just wants to help you do everything, he's too helpful. This guy was setting me up for another scan you know, and he's really taken a lot of interest in me. And it's like well alright, you know. So I think I'm alright, but you know it makes you wonder.

Sometimes the spouse of the participant helped keep track of medical issues.

> P1: (She) has the persistence to see the paperwork through. She makes sure that I have files; you know a DOL file, a Workers Comp file, a physician file. So she's, she's my paper pusher, my pill pusher, my record keeper. I'm a good carpenter but that part of it I leave to her.

The vocational empowerment domain reflects the impact that a medical disorder may have on vocational adjustment [Derogatis 1990]. The participants reported several work-related circumstances that resulted from their diagnosis of BeS or CBD.

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Sometimes they were treated differently by their supervisor or co-workers because of their disease:

> P1: Some of it may be joking or kidding, but you never know with some of the guys if it's really heartfelt. They just don't have the balls to come out and say, ‘you don't have to do this dirty job because you can't wear a respirator and I have to do it.’ When you can't suit up anymore because of lung issues, you get the cushy jobs and they do the hard work. So yeah, there's discrimination but you either allow it to consume you or you just roll with it and keep going.

Co-workers were often curious and eager to learn more about CBD from the participants. Sometimes their coworkers were concerned about the possibly that they too might get CBD.

> P2: I told them (coworkers). They were surprised because I was the first one in the area where we were that had been diagnosed, and then it was less than 6 months after I was diagnosed that this other fellow was diagnosed with it. So everybody started wondering, am I next?

One participant said that sharing information with his co-workers was therapeutic for him and helped him adjust to his disease

> P10: Best I can remember nobody treated me any differently. A lot of people asked me questions about it. It's kind of weird I guess, but I enjoyed talking with people about it because it made me feel good and hopefully gave them a little bit more education about it. My supervisor at

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> the time talked to me a whole lot about it, because he wanted to learn about it (CBD).

Being diagnosed with BeS or CBD did restrict the job mobility of some of the participants. Once they were diagnosed, they were not allowed to work in areas where beryllium was present. This had a financial impact for some of the participants because it limited their ability to work overtime and/or their participation in the Human Reliability Program (HRP) for which there is a 10 percent wage premium.

> P2: There are different jobs in my classification that pay more money that I can't go to because of the area they are in, I am confined to one area and if they said they didn't have any more jobs in there then I would be put on a two-year clock to either retrain for something else or end up losing my job. So it (CBD) restricts me to one area.
>
> P8: The only thing that's good about working beryllium out here is you get a lot of overtime. I'm missing the extra money that I would make from it, but I decided I could do without it.
>
> P9: I dropped out of HRP. It cost me 10 percent of my pay. Everybody thought I was crazy, and I said well that 10 percent's not going to do me much good if I’m sitting on a bed sucking on an oxygen bottle.

A frequent overtone from the participants was a sense of duty to try and prevent others, especially younger workers, from getting BeS or CBD.

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> P4: I don't guess it (CBD) made me feel any different about my work. You know it just made me think, man we got to fix this, we got to prevent. Then I got to thinking about the areas I worked in, you know I looked at all the characterizations of the buildings and I thought, ‘Man, we're going to have a lot of people, just not me, and the latency period is just catching up with us.

> P6: I think a lot of young people come in here, they don't know, they don't understand. They're young and healthy; they think they're invincible. You know that's how young people think. And I look at these young people and I'll tell them if I see them, you don't know what you're doing to yourself, follow procedure. Don't take a risk. You be careful.

> P6: It's so much better than what it used to be. The problem is getting people to follow the instructions and procedures. Now, they can say oh well I don't need to, yes you do. If that job requires you to have a respirator and a Tyvek™ suit, you need to wear that. But you've still got people trying to cut corners. They're not worried about it because they're not sick; they're not having any problems. And they are penalized I mean it could even cost them their job. The workers have got to get it in their mind. We have got to think safety.

The domain of the domestic environment is oriented toward illness-induced difficulties that arise primarily in the home or family environment. It is designed to

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assess problems in adaptation experienced by the participant and their family unit in response to the participant's illness [Derogatis 1990]. Most of the participants (11/13, 85%) were married and most had adult children. They described how their condition had impacted their spouse.

> P7: It hasn't affected anybody except for my wife and me. It's affected her quite a bit. I lay in bed at night and, it's kinda funny, but she'd reach over and put her hand on me to make sure I'm still breathing.

> P10: My wife's kind of wondering how worse am I gonna get. Am I going to have to take care of you for the rest of your life? Yeah, I know she stresses about that.

> P9: The first one (abnormal BeLPT) I didn't say nothing to anybody. And then the second one I did tell my wife, she's a nurse. And she said, 'what's that?' And I described to her what I thought it was and everything and she was like, oh, okay. Probably about 2 months later, I seen a piece of paper where she's scribbled about 10 or 12 things on it. She said you've been having night sweats and every now and then you have a bump come up, a sore place. She said, you've got slow wound healing. She went down the list of 12 things and said you've got maybe 6 or 7 of them. At first when I told her it was kind of over her head? But then she went on her own and done this extra research.

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> P8: My wife, she just calmed me down right off the bat. She went well listen, you don't know you've got anything yet, it's just one (abnormal BeLPT), we're going to do another one, see how it comes back.

> P10: We've got all these DVD's that we made out here. My wife's never watched them. I took them home and she's never wanted to watch them. She said I just don't want to do that. I mean she's curious about it, she's seen what it's done to me, how it's affected me but I don't think she wants to get that emotionally tore up over it. Some of the scenes are pretty graphic in those DVD's and they have people describing what it's done to them and all it's done, and I don't think she wants to hear all that.

The participants also talked about the adjustments that they had made with their partners. Some reported that their spouse also had severe health issues and this sometimes helped them better appreciate what the other was experiencing.

> P3: We know to cut each other slack because we understand, we understand that there's going to be good days, there's going to be bad days. There's going to be disappointments. We've planned on doing things and had to cancel at the last minute because of me or her. It could be either one.

> P3: Any chronic disease, but CBD in particular, it does affect every relationship you have and this is where I have tried to work on communication skills to help the people that I'm involved with, whether it's

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> children, significant other, friends, whatever. Help them understand the impact that CBD has on me. Communicate back and forth, let them know when I'm on high doses of medication and my moods might be through the ceiling or below the floor. The Prednisone causes bad mood swings so it's crucial that the people you're in contact with know what medications you're on and what affect they can have and that, kind of like the old saying ‘it's the whiskey talking, not me,’ and reserve the right to go back and say I'm sorry. Because you probably will have some conflict because of that and I think the communication is crucial.

> P3: I know personally I have had, in the last 10 or 12 years, I have had two relationships that failed, at least in part, because the other person could not or would not cope with a potentially serious chronic illness. The relationship that I'm in now, I'm involved with a lady that has a fairly severe disability, so we understand each other a lot better than if one of us did not have issues, have health issues.

When the participants told their children about their condition it sometimes created fear and uncertainty for their children.

> P1: You know daughters and fathers; Daddies are supposed to be bullet proof. She's concerned. She's afraid. She's pissed. She's angry that I have something that's wrong with me, that they gave me something. Ultimately, she's the one that takes it the hardest. My son, if he sees me impaired, not able to do something, he usually jumps in and helps. But,

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> he's typical boy. He hides the emotions much better than my daughter. So it's harder on them in a way than it is on me.
>
> P6: I think it's bad for any kid to know that your parent is sick and that you really don't know what's going on. My youngest son especially, well both of them. You know, they were afraid. Is my dad going to die? It's questions like that. I had to go through and explain everything that the doctor told me. Even though he was like 18, he was still kind of afraid of the unknown, not knowing. Since then, I say I've got to go to the doctor, they say, "What's wrong? Is everything okay? Are you okay?"
>
> P11: I have daughters. I've talked to them a little bit about it (BeS), when I first got my diagnosis. (One said) "Well daddy what's that mean? You're okay, aren't you?" and I said "'yeah baby, I'm fine." That was pretty much it. But then there's always a possible chance that I can (get CBD), and then that would be another conversation.

Some of the participants worried about the financial security of their family should they become disabled and unable to work.

> P8: As soon as I got home I told my wife about it. She said well what the heck is that? I said it could affect me sometime down the road, but I'm covered. I said the Department of Labor is going to cover me so if anything happens you know we'll be alright. It comforts her a little bit because I'm her sole source of money. If something happens to me you

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> know she's in trouble. So it's something I really worry about, you know making sure that the family's taken care of.

The domain of sexual relationships is designed to provide a measure of any changes in the quality of sexual functioning or relationship associated with the participant’s illness or sequelae of the illness [Derogatis 1990]. Some participants described both physiological and psychological intimacy issues that they felt were related to their disease and/or the medications they were taking.

> P3: One point that I wanted to make was in the area of relationships because it's really difficult to maintain a relationship when you've got a chronic illness. I've seen several people, maybe it doesn't just apply to CBD, but other chronic illnesses as well, where people just give up on a relationship, I mean they give up on the possibility of a relationship because they think nobody's going to want me because I'm damaged goods, more or less. They deprive themselves of the possibility of a relationship because of that.

> P3: You know, personally speaking, I've had issues, and in fact that is one of my covered conditions under Department of Labor. You know there's treatment.

> P9: My testosterone level was way low. He (his doctor) said it was about nonexistent. And he said, have you noticed any problems, any sexual

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> problems? And I said yeah a little bit, I just thought I was getting old, cholesterol and all that stuff too.

> P3: I know people personally that have opened up and in the support group that say “well we, my wife and I or my significant other and me, we don't do anything intimate we don't do anything physical.” Nothing? You know if you at least touch each other, a back rub beats nothing!

The domain of extended family relationships is devoted to measuring any disruption or derangement in relationships with the extended family that arises with the illness experience [Derogatis 1990]. Most participants described little to no discussion about their condition with extended family members,

> P10: It's hard to talk to people that don't work here. You have to go through the whole deal of explaining what it is. You know my brother, I had told him before that I had a disease, but it just never registered with him. And then when he was down here last year I said something about it and he must have forgot and he said what are you talking about? I said I have an incurable disease that I contracted from work that could end up giving me cancer or kill me or something. So then I guess he didn't know what kind of questions to ask. Yeah, he just, kinda well looked at me real funny and he didn't really know what to say.

> P1: Family, they don't know what it is. They just know that you have a lung issue, that you can't breathe good. But it's not too big of a deal, I've got

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> two brothers on sleep apnea machines so they understand that part." I mean a lot of times they tell me I'm not supposed to do as much as I do, but I'm gonna do what I do until I die.

The domain of social environment reflects the status of the participant's current social and leisure time activities and the degree to which the participant has suffered impairment or constriction of these activities as a result of their illness [Derogatis 1990]. Most of the participants had made adjustments in their leisure activities based on their degree of impairment.

> P12: If you'd have asked me 10 years ago, what are you going to do for retirement? I'd have said hunting and fishing, but that ain't going to happen. I go and stay for three days and I'm good, come back home and I'm glad to be home. Back ten years ago I'm going to hunt the whole season, every day. Things change. Is this (BeS) making things change, or is it just age?

> P10: I went to Alaska last year on a cruise and that was great, the weather up there was super good for me. Went to Seattle spent two days in Seattle. Boy that was awesome. I felt great up there. But when I got back here I could feel that humidity, whew!

> P2: Really nobody outside of my wife really knows I got the disease. So it hasn't created any problems when I go to church socials or anywhere else. Nobody really knows that I'm using my inhaler or I'm struggling or

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> anything like that. So it hasn't created any problems. I don't get out and run with my grandkids the way I used to but I'm older of course. But I don't do all of that and they don't know it's because my breathing has changed. So outside of work, with family and friends they can't tell the difference.

The BSGOR became an important social network for most of the participants. Participants described a variety of reasons why people attend and what keeps the network functional

> P3: The support group is like a lot of other groups, it rises and falls. I mean sometimes there's really good attendance and sometimes there's just a very, sprinkling of people that will attend. You have a few people who will lead and do most of the work, and then you have some followers and then you have people who drift in and out. But I know in my case my involvement in the support group over the years was therapy.

> P4: Well, you know, I mean, look, I've got beryllium disease, there's nothing I can do to change it. Just go in there (to BSGOR meetings) and listen to people go on and on and on. We call them berylliacs because they are so obsessed with the whole thing, and I go come on, live your life. You've got it, here it is. You know I'm a black and white type of person.

One participant described efforts to use social media to help people with BeS or CBD connect and share information.

> P3: It (beryllium group on Facebook®) hasn't had a lot of action, to tell the truth. But the people that have got on there, you know they're just, just like

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> people that come to the support group. They are trying to understand the Department of Labor bill and how it applies to them and how to file claims. It hasn't grown as I expected it to. But it is serving a purpose.

Other participants relied upon their faith and church to help them adjust to their condition.

> P6: Our faith has helped us to get over a lot of our fears. And I think that's what's keeping us going. I mean right now, I don't think about it as much as I did. Like I said when I first found out I had anxiety but it's been years for me so I feel better about it now.

> P9: Well guess it was probably a couple of weeks ago, we were talking at church, me and the preacher and he stepped up to me real somber like and said, ‘now how've you been doing?’ I was like, you talkin’ to me? (laughing) I'm doing okay I think. ‘I mean how's your breathing?’ I was like well I'm still okay I guess.

> P5: Faith never really comes up. I've never heard somebody just come out and say you know my faith in God is what keeps me going, helps me through this. I don't live one day thinking about what can happen or will happen. ‘Cause like I said, whatever's gonna be is gonna be.

The domain of psychological distress is designed to measure dysphoric thoughts or feelings that accompany the participant’s disorder or are a direct result of the illness

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and its sequelae [Derogatis 1990]. Participants described a wide range of emotions related to their diagnosis.

> P1: When I first got it I was enraged. I was really pissed. I've had a lot of stuff to deal with--been married twice, I've been through Vietnam; three tours in Asia. I've had stress. I've had issues. But this kicked my ass, because I would think back and say I know where I got this. There for a while, I think mentally I was worse than I was physically.
>
> P6: Well, when they first diagnosed me it was very terrifying.
>
> P3: Being diagnosed with beryllium disease, that changes your attitude about a lot of things. There were feelings of betrayal, of anger, you know just a wave of depression. Like, okay, what does this mean? That's the big question. I know I have this and I know I already have symptoms, how much worse is it going to get? How long is it going to take? It's all these unanswered questions that kind of, plug you at the same time.
>
> P12: I'm tireder. I can breathe a little less. But hey I'm getting older, and that's what I'm thinking up to this point. And then they tell you, yeah you're sensitive and then you start having these anxiety type things, going this may be for real. I may have what they say I got.

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> P3: You know, in some ways it's almost a relief when you get the diagnosis because at least now you have something. OK, this is the issue and now we can go forward with how can we deal with it.

Some of the participants who were in an advanced state of disease described the stress associated with the physical symptoms of CBD.

> P1: I don't know that even my heart attack was as tunnel vision as the first few times that I could not breathe. That is so acute, that absolutely you don't think about anything. Even during the heart attack, I'd think about something – my kids, my wife, all the work I hadn't done. But when you can't breathe there's nothing on your mind except (gasps) you can't breathe. It's…it's a, well for the lack of a better word, a terror.

> P7: I woke up in the morning and I couldn't breathe, and this has happened several times. I just can't get my breath. And it's almost like, well I am, I'm smothering. I can't get my breath. When I get that, it does a number on me.

> P3: It's never a straight line with me. It's always a roller coaster, up and down. When I have a bad day, when I'm having trouble breathing and aching all over and man, it's not worth it. I have to convince myself that it is. So it's, it's an ongoing battle.

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> P3: You've got to learn your own body and learn that it's OK to backslide sometimes because you're going to have bad days, bad weeks, maybe bad months. And the hardest part is, you know when you do backslide it's to get started back up again.

> P9: A lot of people don't want to look at the end out there, but I don't really have a problem with it. You don't want to leave anytime soon but I realize my own mortality, which a lot of people have a big problem with that. You're gonna leave this world for one reason or another. I could die of prostate cancer or get killed in a car wreck, you know. So my faith I think helps me with life in general, as far as stuff like that.

Others described the ill feelings that resulted from their encounters with the beryllium bureaucracy.

> P1: It's really agitating to the patient to have to fight the worker's comp doctor when you've got a panel of physicians saying you are sick.

> P1: It was a shock to find out that I had a disease that was work related and that probably could have been prevented. And, you know, I… all these emotions come in to play when you find out what caused your condition. We pretty much believed what we were told. We believed that we were working in a safe environment.

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P3: All these little pieces add up. You know the resentment toward the company, the stress of wondering whether you're going to have your job next week or next month, is my significant other going to understand this and how much is this going to take off of my projected lifespan? I mean all of these little pieces add up and it can lead to a major depression.

P4: Early on I went a lot (to Support Group meetings) and I felt like I would go and I would listen and it was, it was kind of a woe is me pity party type thing. And I just, I didn't need that. That didn't do it for me.

P7: I have nightmares about the Plant almost every night. I dream about that place and I'm always trying to get from this place to that place and I can't go because I can't get through the security part of it to get over there. And it's just, like I said it's almost every night. One time I'll be on the back road over there trying to get into another place and I can't go that way because I can't get through the guard gate. And I can't get out and it's just like that almost every night. I can always get in, but I can't get in certain posts.

P11: I have such god-awful dreams you ever wanted to think about. Sometimes they'll run for four or five days, and then I'll go without it. Some of them were just being out there at work. And the people, some of the people I knew. Things like that, especially at Y12, I don't know why at

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> Y12. You know, we had to go through three checkpoints to get to work. I know the people and was talking to them, just like we are talking now. I don't know, it isn't all the time in the same way, it isn't all the time with my night sweats.

> P8: I never thought I'd ever get it, we always wore respirators when we got around it. We always took precautions, so I always thought I was pretty safe. You know, and all the sudden it was kind of a rude awakening when she told me I was sensitized. That kind of shook me up. It did shake me up a little bit.

> P8: Well after I read all the paperwork, and listened to them guys, you know, a few months of going over there I started realizing what it was all about you know. And you see these guys, and you see them over the years deteriorate, you know that's what strikes you, watching them deteriorate.

Discussion and Conclusions

Do the qualitative data provided by the participants support the *a priori* model of the psychosocial effects of CBD? First, is the question of whether the participants reported uncertainty in a manner that was consistent with Mishel's Uncertainty in Illness Theory [1981]. In the model, uncertainty was proposed as an independent variable that influenced health quality of life. The Michel Uncertainty in Illness Scale (MUIS) has six primary domains all of which were presented in the results section: 1) ambiguity, 2)

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inconsistency, 3) vagueness, 4) unpredictability, 5) lack of information, and 6) unfamiliarity. In studies examining the adjustment to uncertainty in illness [1990], the most common conclusion was that high uncertainty was related to high emotional distress, anxiety, depression, and fatigue.

The participants provided multiple examples of uncertainty resulting from their BeS or CBD. These examples provided clear and specific examples that were consistent with the definitions for each of the six domains of the Mishel Uncertainty in Illness Theory. All of the domains were represented but the number of passages that were coded to the unpredictability domain was greater than the other domains. This suggests that for these participants, unpredictability may be the dominant feature of uncertainty.

Second is the question of whether the participants described adjustment to illness that was consistent with DeRogatis' theory of Psychosocial Adjustment to Illness. [Derogatis 1986]. This was proposed as an intermediate variable in the model. The Psychosocial Adjustment to Illness theory reflects seven principal domains all of which had been shown to have a high relevancy for adjustment to medical illness: 1) health care orientation, 2) vocational empowerment, 3) domestic environment, 4) sexual relationships, 5) extended family relationships, 6) social environment, and 7) psychological distress.

The participants provided descriptions of how they and their family members had adjusted to their illness. There were examples that were consistent with each of the seven domains of the Psychosocial Adjustment to Illness theory. All of the domains were represented but the number of passages that were coded to psychological distress

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was greater than the other domains. This suggests that for these participants, methods for coping with psychological distress may have been more important than other mediating factors. One factor that did not clearly fit into the Psychosocial Adjustment to Illness model was financial security. The participants appeared to be in a moderately secure financial position and this may have been an important mediating factor in their adjustment to illness.

Based on the results of this study, it appears appropriate to apply Uncertainty in Illness and Psychosocial Adjustment to Illness theories to beryllium sensitization and chronic beryllium disease. Uncertainty may be considered an independent variable and psychosocial adjustment an intermediate variable in the study of the psychosocial effects of CBD. A quantitative study to measure the relationship between these variables and health quality of life is underway. Those results will be reported in the future.

All of the participants described key events related to their disease. Some of these key events were part of the natural history of CBD (e.g., diagnosis) while other events were sociological phenomena (e.g., filing a Workers Compensation claim). Regardless of their origin, each of these key events was capable of producing a variety of psychosocial effects. The chronology of these key events varied greatly among the participants; some events could occur over a wide range of years (e.g., length of BeS period) and certain events were predecessors for others (BeS diagnosis must precede filing a DOL claim). The medical events (i.e., exposure, sensitization, diagnosis of CBD, and disability) have been well documented in the literature but they have not been reported in context with and linked to the other sociological events.

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While these key events were common to the participants, depending on the progression of their disease, the circumstances surrounding how the events occurred varied widely. For example, the participants who were the first to file Workers Comp claims in the 1990s and DOL claims in the early 2000s reported a much more difficult and frustrating experience than those that had filed claims within the last 2-3 years. The psychosocial effect of these events appeared much greater for those participants that blazed the trail for others behind them.

The first theme to emerge from the qualitative data – the CBD Trailblazers – was based on these early experiences. There are several people that are often thought of as medical pioneers who recognized the association between beryllium exposure and disease. Some went on to conduct groundbreaking epidemiologic studies and discover new diagnostic and testing methods that are used in today's surveillance and treatment protocols. What we have not recognized is that there have also been workers that have had to navigate their way through an untested and often times ill-prepared bureaucracy to receive treatment and just compensation for their incurable occupational illness. These CBD Trailblazers were mostly craftsmen who were diagnosed with CBD and, out of necessity, became vocal advocates for sick workers. They helped shape the laws and regulations that are now in place to prevent CBD and to ease the burden on future workers who are unfortunate enough to develop BeS or CBD. The CBD Trailblazers are now tired and sick as they enter the later stages of CBD. Fortunately, there have been others who have demonstrated a willingness to lead and assume responsibility for the roles that the CBD Trailblazers fulfilled for many years.

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The second theme to emerge from the interviews was termed the CBD rollercoaster. A rollercoaster ride was a metaphor used by one of the participants when he described his experience with CBD, “it's always a rollercoaster.” His metaphor was expanded and applied to the total CBD experience as described by the participants.

Because exposure to beryllium carries with it a lifetime risk of developing CBD, this is a rollercoaster that one can get on but never get off. In years past, many people did not know they were exposed to beryllium while today’s beryllium workers are trained and informed of the risk on a regular basis. At least now, most workers have a choice as to whether they wish to get on the CBD rollercoaster. The CBD Trailblazers did not always have that choice.

At the outset, no one can predict with certainty the nature of the ride. For the vast majority of people, there are no consequences to their exposure to beryllium. They never develop any signs or symptoms of CBD and they go about their lives, the only difference being that they retain some unquantifiable risk of developing CBD, a risk of which they may not be aware. Their rollercoaster ride is tame; some workers may never even know that they are on the ride.

Others, those considered beryllium workers, are in for a much different experience; especially those who are genetically susceptible. Beginning with the BeLPT testing, they may be jerked left and right, up and down, normal and abnormal. Once they have a confirmed abnormal BeLPT, the rollercoaster enters a dark tunnel. The darkness represents BeS and their inability to predict their future. They do not know when the next turn or dip will occur. They are anxious and filled with uncertainty. They don’t know how long they will be in the dark, only knowing that at some point they

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will emerge into the light. They are hyper-alert to changes in their body and when they begin to experience symptoms they fear that they will be diagnosed with CBD. It is only when they are diagnosed with CBD that they emerge from the darkness.

After diagnosis, the twists, turns, peaks and valleys of the CBD rollercoaster become visible but not predictable. Symptoms wax and wane. One does not know how long the climb will be nor how steep the descent. The speed with which symptoms develop and the severity provide added terror. Workers Comp provides a corkscrew in the track. The DOL absorbs some of the shock. The ride goes on forever. They get paid to endure the ride; only wishing they could pay to get off.

It is important that we learn from those that have experienced BeS and CBD. The participants in this study shared rich examples of how BeS and CBD had affected them, their families, friends, and coworkers. Their knowledge can help healthcare providers develop programs focused on the coping skills to manage the psychological and social stress of BeS and CBD.

There are limitations to this study that must be considered when interpreting the results. The small sample population may not be representative of the larger population of individuals with BeS or CBD. Each of the participants attended at least some of the BSGOR meetings. This may have had an effect on their disease experience and influenced their responses. All of the participants were volunteers. Their motives for volunteering may make them different from those who did not volunteer. Due to the limitations of this study, inferences based on these results about the larger DOE population or for beryllium workers in private industry may not be valid.

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Further research to understand the relationships between uncertainty, psychosocial adjustment and health quality of life is needed. This would help validate the proposed model of the psychosocial effects of BeS and CBD. Additional analysis and modeling would be useful for learning which domains of psychosocial adjustment are most important. This would be helpful for healthcare providers and support groups that develop and deliver tertiary prevention programs to this population.

Acknowledgments

This research was supported by a grant from University of Tennessee, Department of Public Health.

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PART 3 – UNCERTAINTY, PSYCHOSOCIAL ADJUSTMENT AND HEALTH QUALITY OF LIFE AMONG CURRENT AND RETIRED WORKERS WTH BERYLLIUM SENSITIZATION OR CHRONIC BERYLLIUM DISEASE

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Uncertainty, Psychosocial Adjustment and Health Quality of Life among Current and Retired Workers with Beryllium Sensitization or Chronic Beryllium Disease

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Abstract

Background

Current and former workers from Department of Energy laboratories and manufacturing facilities were surveyed to measure the psychosocial effects of beryllium sensitization (BeS) and chronic beryllium disease (CBD).

Methods

Questionnaires were administered to measure uncertainty in illness, psychosocial adjustment to illness, and health quality of life. Differences between mean scores were tested, correlations between variables were measured and a multiple regression model was developed. Results were compared to a model describing the psychosocial effects of BeS and CBD.

Results

There were 126 participants; 52 with CBD and 74 with BeS. The health quality of life survey indicated participants with CBD had significantly different physical component summary scores than those with BeS. Mental component summary scores were not significantly different. Psychosocial adjustment scores were significantly different. Uncertainty scores were not significantly different. Moderate to strong correlations were found between the three variables. A multiple regression model indicated that psychological distress, social environment and domestic environment were the best

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predictors of mental component summary scores. As uncertainty increased, health quality of life decreased unless the effects were mediated by psychosocial adjustments to the illness.

Conclusions

The results added validity to the model of the psychosocial effects of BeS and CBD. Uncertainty is an independent variable that influences health quality of life, the dependent variable. Psychosocial adjustment is as an intermediate variable that mediates the effects of uncertainty. BeS may have as much impact on mental health as CBD. Psychosocial effects are an important component to the spectrum of CBD that has implications for treatment and workers compensation.

Key Words

Chronic beryllium disease, berylliosis; beryllium sensitization; uncertainty in illness; psychosocial adjustment; health quality of life

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Introduction

This is a report of a study of the psychosocial effects of beryllium sensitization (BeS) and chronic beryllium disease (CBD). The aim of the study was to collect and analyze empirical data to add validity to a proposed model of the psychosocial effects of BeS and CBD and to aid in the design, implementation and evaluation of support programs for workers with BeS or CBD and their families.

Beryllium is a strong, lightweight metal that is toxic when particles are inhaled into the lungs. People who work in factories where beryllium is processed are potentially exposed to beryllium particles and may develop an allergic reaction to the metal. Some that become sensitized to beryllium go on to develop CBD, a severe and incurable occupational lung disease.

Frequently reported symptoms of CBD include one or more of the following: dyspnea on exertion, cough, fever, night sweats, and chest pain and, less frequently, arthralgia, fatigue, weight loss, or appetite loss [Maier 2002]. On physical examination, a health care provider may find signs such as rales, cyanosis, digital clubbing, or lymphadenopathy. A radiograph of the lungs may show many small scars. Examination of lung tissue under the microscope may show granulomas. Patients also may have an abnormal pulmonary function test and when lymphocytes are cultured in the laboratory in media containing beryllium they will exhibit abnormally rapid proliferation in a specialized test called the peripheral blood beryllium-induced lymphocyte proliferation test (BeLPT) [Samuel and Maier 2008]. CBD may be confused with other lung diseases, especially sarcoidosis [Müller-Quernheim, et al. 2006, Infante and Newman

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2004]. In advanced cases, there may be manifestations of right-sided heart failure, including cor pulmonale [Samuel and Maier 2008].

Epidemiologic studies have shown that a range of 1-6 percent of workers exposed to beryllium develop BeS, although the rates can be as high as 19 percent among workers with the highest exposures to particles or fumes, such as beryllium machinists [Maier 2002, Kreiss, et al. 1993, Kreiss, et al. 1989, Kreiss, et al. 1997, Kreiss, et al. 1996, Schuler, et al. 2008]. Most workers who are going to develop BeS tend to do so early on, but follow-up testing over the years continues to identify workers with BeS—up to 30 percent in one group of workers [Schuler, et al. 2008]. Continued testing can reveal new sensitization many years after a worker stops working with beryllium.

The percentage of people with BeS who go on to develop CBD is highly variable, ranging from 10-100 percent in different worker populations [Kreiss, et al. 2007]. Individuals exposed to the highest levels of airborne beryllium dust are at greatest risk, although skin exposure may also be important in the development of BeS [Day, et al. 2006]. Recent research suggests that each year, 6-8 percent of people with BeS will develop CBD [Newman, et al. 2005a]. The latency for converting from BeS to CBD is highly variable, ranging from 1-12 years in one longitudinal study [Newman, et al. 2005b]. Factors such as particle size, type of beryllium used, amount and duration of exposure to beryllium, occupation, industry, and genetics all play a role in determining why some people develop CBD and others do not [Maier 2002, Kreiss, et al. 2007]. Once a person is exposed to beryllium, he/she carries a lifelong risk of developing BeS

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or CBD, even if the exposure amount was small or exposure has ended [Kreiss, et al. 2007].

Beryllium is widely used in the aerospace, electronics, biomedical, defense, telecommunications and other industries [Jaskula 2011]. The estimated number of U.S. workers currently exposed to beryllium is 134,000 [Henneberger, et al. 2004] and the total number ever exposed is approximately 800,000 [Infante and Newman 2004] however, these are likely underestimates [Samuel and Maier 2008].

The nuclear weapons industry has received substantial attention related to worker exposures to beryllium. Beryllium disease was recognized among workers involved in the early development of atomic energy in the World War II era [Hardy 1955, Van Orsdstrand, et al. 1945]. As nuclear weapons proliferated during the Cold War, the number of workers in the U.S. Department of Energy (DOE) nuclear complex grew and the number of workers exposed to beryllium grew proportionately. Beginning in the late 1980s, clusters of CBD were recognized in workers from nuclear weapons plants across the U.S. [Kreiss, et al. 1989]. Additional epidemiologic studies of nuclear workers have been completed over the past two decades helping define the risk of CBD in this population [Kreiss, et al. 1993, Stange, et al. 1996a, Stange, et al. 1996b, Stange, et al. 2001, Sackett, et al. 2004, Welch, et al. 2004, Rodrigues, et al. 2008, Arjomandi, et al. 2010, Mikulski, et al. 2011].

The National Research Council (NRC) [2007] recognized that the diagnosis of BeS or CBD may be associated with psychosocial stress and/or loss of income and that there was an absence of published data on those phenomena. The NRC further suggested that implementation of a comprehensive beryllium-exposure and disease

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management program that includes appropriate worker education and counseling, medical-removal, and protection against lost wages can minimize such potential adverse consequences [National Research Council 2008]. If psychosocial distress is part of the disease experience, it is important to understand the nature and extent of these effects so that appropriate interventions can be developed and implemented.

Methods

The study population was drawn from current and former workers who had been diagnosed as having either BeS or CBD and worked in the DOE Complex, a collection of more than 20 large government-owned laboratories and manufacturing plants across the U.S. The precise number of people in this population was unknown but was estimated at 1167. This is likely an underestimate because the data from the two nationwide systems for reporting cases of BeS and CBD, one for current workers and one for former workers, are not coordinated and both systems have difficulty identifying new cases of CBD. Table 3.I provides an estimate that was based on the best published information from the DOE.

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Table 3.I. Estimated study population

Category	DOE Current Workers	DOE Former Workers
Estimated Total	110,000	600,000
Beryllium-Associated Worker Registry Participants	22,392	0
Former Work Medical Surveillance Participants	0	76,899
BeS Diagnosis	355	514
CBD Diagnosis	134	164[a]
Subtotal (BeS or CBD)	489	678
Total	1,167	

Sources: [Department of Energy 2011a]; [Department of Energy 2011b]
[a]=Estimated; DOE=Department of Energy; BeS=beryllium sensitization; CBD=chronic beryllium disease

Convenience sampling was used to select participants for the study. Three recruiting methods were used. First, presentations were made to the Beryllium Support Group of Oak Ridge, TN (BSGOR). The BSGOR is an education and advocacy forum for current and retired workers who have either BeS or CBD and their families. The Group is sanctioned and supported by the Y-12 National Security Complex (Y-12), a DOE manufacturing facility. The Group meets twice monthly and provides educational speakers and topical discussions. Attendance ranges from 20-200 people per meeting. Two presentations were made to the BSGOR about this study and informational packets were provided to potential participants. Information packets contained a cover letter, consent form, four different questionnaires, and a return envelope. An estimated 80 people were contacted via the BSGOR. Some of these participants consented to in-depth interviews as part of a related qualitative study. Questionnaires were completed by these participants before they were interviewed.

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Second, a mailing was made to current and former workers who were on the mail distribution list maintained by the Y-12 Site Occupational Medical Director (SOMD). This database consisted primarily of current and former workers who had been diagnosed with BeS or CBD and worked at one or more of the three DOE facilities in Oak Ridge, TN. There also were some individuals in the database that were interested parties but they did not have BeS or CBD (e.g., health care providers). The precise number of people in the database without BeS or CBD is unknown but was estimated at 50 people for response rate calculations. To maintain patient confidentiality, packets of information were provided to the SOMD who distributed them to the people in the database via the U.S. Postal Service or e-mail. Those wishing to participate responded directly to the researcher. The identities of those not choosing to participate remained confidential to the SOMD. There was significant overlap between people attending the BSGOR and the SOMD database. Recipients were instructed in the cover letter to ignore the mailing if they had already elected to participate at a BSGOR meeting. An estimated 209 potential participants were contacted via the SOMD direct mailing.

Third, a similar confidential mailing was made by National Jewish Health to patients who were current or former workers from the DOE Complex with either BeS or CBD. Patient confidentiality was maintained in the same manner as with the Y-12 SOMD. There was some overlap between this database and the other two methods. The precise amount of overlap is unknown, but was estimated at 75 people for response rate calculations. Recipients were instructed in the cover letter to ignore the mailing if they already had elected to participate. Thirteen packets were returned as not deliverable or because the person was deceased. The number of potential participants

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reached by this method was 299. A total of 588 potential participants were contacted via the three methods described.

Four questionnaires were used to collect data for the study. Questionnaires are not reprinted in this manuscript due to copyright restrictions. All instruments were reviewed by beryllium subject matter experts, the University of Tennessee and U.S. Department of Energy Institutional Review Boards (IRB) and key advisors from the BSGOR. Instruments were field tested prior to administration of the survey. A demographic and work history questionnaire was developed for this study. This instrument collected standard demographic information (e.g., age, gender, race, etc.) as well as information about work history (e.g., location, job titles, duration, etc.,) and disease status (e.g., BeS diagnosis, CBD diagnosis, dates, etc.). Results were entered into an Excel® spreadsheet.

The SF-36v2® Health Survey (QualityMetric, Inc.) was used to measure the health-related quality of life of the participants. The validity and reliability of this instrument have been previously demonstrated. [for example: Findler 2001] This instrument collected information on eight domains: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. The data were used to calculate a Physical Component Summary (PCS) and Mental Component Summary (MCS) for each participant. The data were converted to t-scores and compared to a sample from the general U.S. population (Quality Metric 2009 General Population Sample). Each scale had the same mean (50) and standard deviation (10). A scale score below 50 indicated a health status below average relative to the general U.S. population [Ware 2001]. The scoring algorithms and t-scores were

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calculated by QualityMetric Health Outcomes™ Scoring Software 4.5, provided by QualityMetric, Inc.

The Mishel Uncertainty in Illness Scale – Community Form (MUIS-C) was used to measure uncertainty in illness. The reliabilities for the MUIS-C are reported as moderate to high (α = 0.74 to 0.92) [Mishel 1997]. The MUIS-C has six primary domains: 1) ambiguity, 2) inconsistency, 3) vagueness, 4) unpredictability, 5) lack of information, and 6) unfamiliarity. The 23-item Likert-format scale provided a single total score with a possible range from 23 to 115 with a midrange score of 69. The MUIS-C produces scores in the direction of higher uncertainty. Data from completed MUIS-C questionnaires were entered into and scored in Excel®.

The Psychosocial Adjustment to Illness Scale – Self Report (PAIS-SR®) was used to assess the participants' psychosocial adjustment to their medical condition. The validity and reliability of the instrument have been previously reported [for example: Derogatis 1986]. There are seven principal domains of the PAIS®, all of which have been shown to have a high relevancy for adjustment to medical illness. The domains include: 1) health care orientation, 2) vocational empowerment, 3) domestic environment, 4) sexual relationships, 5) extended family relationships, 6) social environment, and 7) psychological distress. Data from completed questionnaires were entered and scored by software provided by the vendor (Clinical Psychometric Research Inc.). Raw scores were used for analysis. Higher scores indicate poorer adjustment [Derogatis 1990].

Several measures were taken to help assure data quality. Returned questionnaires were reviewed for completeness. When possible, follow-up inquiries

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were made with participants to collect missing or incomplete data. The principal researcher verified the accuracy of data entry by comparing each completed questionnaire directly to data entered into the spreadsheet, making corrections as necessary. Scattergrams were produced to identify outlier scores. When extremely high and low scores were identified, the researcher returned to the raw data file to determine if there were missing data that influenced the score. If that was the case, that score was coded as missing. Statistical analysis was performed using IBM® SPSS® Statistics 19.

This study was approved by the University of Tennessee and DOE IRBs. Written informed consent was obtained from study participants.

Results

The sample population consisted of 126 volunteers with either BeS or CBD who were either currently working at or were retired from DOE Facilities. Twenty-five (20%) of the participants were enrolled as a result of presentations to the BSGOR. Nine (7%) of the participants were enrolled via direct mail from the Y-12 SOMD. The remaining 92 participants (73%) were enrolled via direct mail from National Jewish Health. Four packets were returned but were not useable due to incompleteness or they were received after the deadline. The combined response rate was 22% (130/588).

The participants were predominately married, white and male, with some college or trade school education. Half of the group was retired. The demographics of the sample population are provided in Table 3.2. Most of the participants work or worked at one of five DOE facilities: Y-12 (Oak Ridge, TN), Rocky Flats (Golden, CO), Hanford (Richland, WA), Kansas City Plant (Kansas City, MO) or Pantex (Amarillo, TX). This distribution of cases by DOE site is similar to that reported in the Former Worker

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Medical Screening Program Annual Report [Department of Energy 2011b] and the Beryllium Associated Worker Registry Summary [Department of Energy 2011a]. The distribution of participants with CBD and BeS by DOE site is presented in Table 3.3.

Table 3.2. Demographic characteristics of study participants

Variable	Description	Frequency	Percent
Participants	Total	126	100
Age	Range (years)	42-85	-
	Median	62.5	-
	Mean	63.6	-
Gender	Male	93	73.8
	Female	33	26.2
Marital status	Married	106	86.2
	Divorced	12	9.8
	Other	5	4.0
Race	White	105	83.3
	White Hispanic	12	9.5
	African American	7	5.6
	Other	2	1.6
Education	<High school diploma	1	0.8
	High school or GED	21	16.7
	Some college/ trade school	59	46.8
	Associates degree	20	15.9
	Bachelor degree	10	7.9
	Graduate degree	15	11.9
Household income	$0-25,000	8	6.3
	$25-50,000	32	25.4
	$50-75,000	31	24.6
	$75-100,000	22	17.5
	>$100,000	18	14.3
	Not disclosed	15	11.9
Work status	Working	52	41.3
	Retired	63	50.0
	Medical leave	9	7.1
	Looking for work	2	1.6

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Table 3.3. Distribution of participants by disease status and Department of Energy site

DOE Site	Current Workers		Former Workers		Total	
	CBD	BeS	CBD	BeS	N	%
Y-12	7	15	7	5	34	27.0
Rocky Flats	3	3	8	8	22	17.5
Hanford	1	6	7	6	20	15.9
Kansas City Plant	3	5	2	10	20	15.9
Pantex	2	7	1	1	11	8.7
Los Alamos Nat Lab	2	0	4	2	8	6.3
Nevada Test Site	0	2	2	0	4	3.1
Idaho Nat Lab	0	0	1	2	3	2.4
Lawrence Livermore Nat Lab	0	0	1	1	2	1.6
Oak Ridge Nat Lab	0	0	1	0	1	0.8
Sandia Nat Labs	0	1	0	0	1	0.8
Total	18	39	34	35	126	100

DOE=Department of Energy; BeS=beryllium sensitization; CBD=chronic beryllium disease; Nat=National; Lab=Laboratory

All of the participants reported that they had been told by a physician that they had BeS or CBD. Fifty two (52, 41.3%) of the participants had been diagnosed with CBD while the remainder (74, 58.7%) were BeS. Participants who were BeS had been sensitized an average of 9.9 years with a range of 1 to 24 years. Those with CBD had the diagnosis an average of 8.8 years with a range of <1 to 24 years.

The results of the SF-36v2® Health Survey indicated that the participants had worse health than the normative population (Quality Metric 2009 General Population Sample). This was true for the Physical Component Summary (PCS), Mental Component Summary (MCS), and all domains (general health, physical functioning, role physical, bodily pain, vitality, social functioning, and role emotional).

SF-36v2® Health Survey results for participants with CBD were compared to results for participants with BeS. The two-independent-sample t-test was used to test

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the null hypothesis that the mean scores of the two groups were equal. The results indicated that the mean PCS score for participants with CBD was not equal to the mean score for participants with BeS (p=.038). The null hypothesis was rejected for the PCS. All other mean scores were not significantly different. Table 3.4 provides the results of the SF-36v2® Health Survey.

Table 3.4. Results of the SF-36v2® Health Survey

Survey Component and Domains	Mean Score	
	CBD	BeS
Physical Component Summary	39.1*	43.2
Physical Functioning	40.8	43.2
Role Physical	40.9	43.7
Bodily Pain	42.4	45.0
General Health	39.1	41.8
Mental Component Summary	47.1	46.4
Vitality	44.6	44.5
Social Functioning	43.6	44.1
Role Emotional	42.5	44.1
Mental Health	48.2	47.3

* p=.038, t-test (2-tailed); BeS=beryllium sensitization; CBD=chronic beryllium disease

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The MUIS-C Survey results for participants with CBD were compared to the results for those with BeS. The two-independent-sample t-test was used to test the null hypothesis that the mean scores of the two groups were equal. The results indicated that the mean MUIS-C score for participants with CBD was not significantly different from the mean score for participants with BeS. The null hypothesis was not rejected. Table 3.5 provides the results of the MUIS-C Survey.

Table 3.5. Results of the Mishel Uncertainty in Illness Scale–Community Form (MUIS-C) Survey

Disease Status	N	Mean Score	Standard Deviation
CBD	50	68.3	12.9
BeS	71	68.1	10.8
Total	121	68.2	11.6

Missing=5; BeS=beryllium sensitization; CBD=chronic beryllium disease

The PAIS-SR® survey results for participants with CBD were compared to results for participants with BeS. The two-independent-sample t-test was used to test the null hypothesis that the mean scores of the two groups were equal. The results indicated that the mean overall PAIS-SR® score for participants with CBD was significantly greater (p=.02) than the mean overall score for participants with BeS. The null hypothesis was rejected for the overall PAIS-SR® score. The mean scores for four of seven PAIS-SR® domains were also significantly different: healthcare orientation (p=.003), vocational environment (p=.003), domestic environment (p=.02), sexual relationships (p=.02), and social environment (p=.04). Table 3.6 provides the results of the PAIS-SR® Survey.

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Table 3.6. Results of the Psychosocial Adjustment to Illness Scale–Self Report (PAIS-SR®) Survey

Domain	Mean Score	
	CBD	BeS
Overall Score	433.7*	411.7
Healthcare Orientation	62.9	63.9
Vocational Environment	63.6**	59.5
Domestic Environment	63.4*	57.8
Sexual Relationships	63.7*	59.1
Extended Family Relationships	62.5	59.6
Social Environment	61.4***	58.3
Psychological Distress	56.3	53.4

* p=.02, t-test (2-tailed), ** p=.003, t-test (2-tailed), ***p=.04, t-test (2-tailed)
BeS=beryllium sensitization; CBD=chronic beryllium disease

Correlational analysis was conducted to evaluate the relationships between the scores for PAIS-SR®, MUIS-C, and SF-36v2® Health Survey. Pearson's Product Moment Correlation Coefficients (2-tailed) were calculated to determine the direction of correlation and strength of association. The data were grouped into CBD and BeS subsets for analyses. Several statistically significant relationships were identified.

The PCS and MCS scores showed a moderate, positive correlation for participants with BeS (r=.33, p=0.01) indicating that mental health scores increased as physical health scores increased.

The PAIS-SR® scores had a moderate, negative correlation with MCS for those with CBD (r=-.31, p<0.05) and BeS (r=-.45, p<0.001). The PAIS-SR® scores had a weak, negative correlation with PCS for those with CBD (r=-.24) and a moderate, negative correlation for those with BeS (r=-.42, p<0.001).

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The PAIS-SR® scores had a strong positive relationship with the MUIS-C scores for those with CBD (r=.62, p<.001) and BeS (r=.59, p<.001). The MUIS-C scores had a weak, negative correlation with PCS and MCS scores for all participants. Table 3.7 summarizes the correlational analyses.

Table 3.7. Correlation matrix for SF-36v2® Health Survey, Psychosocial Adjustment to Illness Scale–Self Report (PAIS-SR®) Survey and Mishel Uncertainty in Illness Scale–Community Form (MUIS-C) Survey scores

Disease Status		MCS	PCS	PAIS-SR®	MUIS-C
CBD	MCS	1			
	PCS	.26	1		
	PAIS-SR®	-.31*	-.24	1	
	MUIS-C	-.21	-.21	.62***	1
BeS	MCS	1			
	PCS	.33**	1		
	PAIS-SR®	-.45**	-.42**	1	
	MUIS-C	-.23	-.23	.59***	1

*significant at the 0.05 level (Pearson Correlation, 2-tailed)
**significant at the 0.01 level (Pearson Correlation, 2-tailed)
***significant at the 0.001 level (Pearson Correlation, 2-tailed)
BeS=beryllium sensitization; CBD=chronic beryllium disease; MCS=mental component summary; PCS=physical component summary

Regression analysis was performed to determine the best predictors of the psychosocial effects of BeS and CBD. MCS was selected as the dependent variable and the domains of the PAIS-SR® were selected as the independent variables. Five outlier MCS values were trimmed from the dataset for the analysis. The null hypothesis was that there was no linear relationship between the variables.

A multiple regression model including psychological distress, social environment and domestic environment as the independent variables best predicted the MCS score.

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for the domain of psychological distress. The domain of psychological distress measures dysphoric thoughts and feelings that accompany the individual's disorder as indicated by anxiety, depression, hostility, reduced self-esteem, body image problems, and inappropriate guilt [Derogatis 1990]. The domain of social environment reflects the status of the participant's current social and leisure time activities and the degree to which the participant has suffered impairment or constriction of these activities as a result of their illness [Derogatis 1990]. The domain of domestic environment is oriented toward illness-induced difficulties that arise primarily in the home or family environment. It is designed to assess problems in adaptation experienced by the participant and their family unit in response to the participant's illness [Derogatis 1990].

Those variables accounted for 30% of the variability in the model (R^2=0.304). Healthcare orientation, vocational environment, sexual relationships and extended family relationships were not statistically significant and were excluded from the model. The null hypothesis was rejected (ANOVA, F=16.3, p<0.001).

Gender and BeS status were selected as control variables and the data was re-analyzed. Females had a higher R^2 than males (0.40 vs. 0.19) and those with BeS had a higher R^2 than those with CBD (0.33 vs. 0.22). Additional analyses were conducted controlling for age, income, and retirement status. None of those variables had a significant effect on the model. Table 3.8 and Figure 3.1 summarize the multiple regression model.

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Table 3.8.Multiple regression model to predict mental component summary scores

Variable	Unstandardized Coefficients		Standardized Coefficients	t	Significance
	B	Standard Error	Beta		
(Constant)	81.7	6.59	-	12.4	<0.001
Psychological distress	-0.48	0.12	-0.44	3.78	<0.001
Social environment	-0.56	0.17	-0.41	3.30	0.001
Domestic environment	0.40	0.14	0.36	2.84	0.005

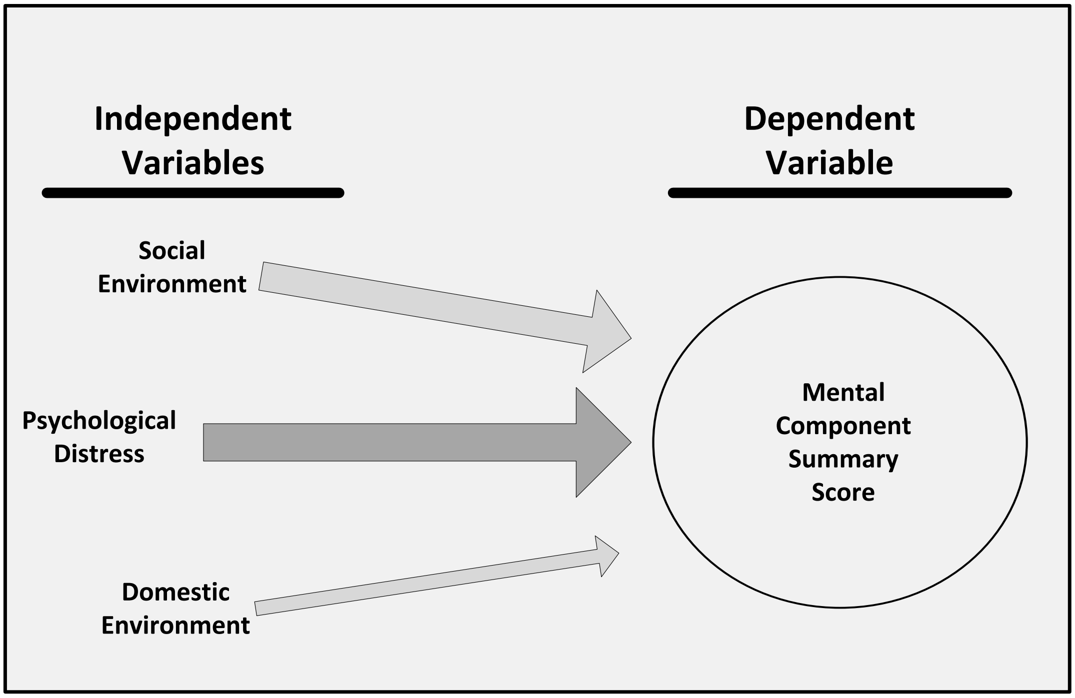

Figure 3.1.Multiple regression model path analysis

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Discussion and Conclusions

The results of this study support the model of the psychosocial effects of CBD [Miller 2012]. In the model, uncertainty was proposed as an independent variable that influenced health quality of life, the dependent variable. Psychosocial adjustment was proposed as an intermediate variable that mediated the effects of uncertainty. This model suggested that as uncertainty increased, health quality of life decreased unless the effects were mediated by the ability to make psychosocial adjustments to the illness. Figure 3.1 illustrates the model and the correlations between the variables that were measured in this study.

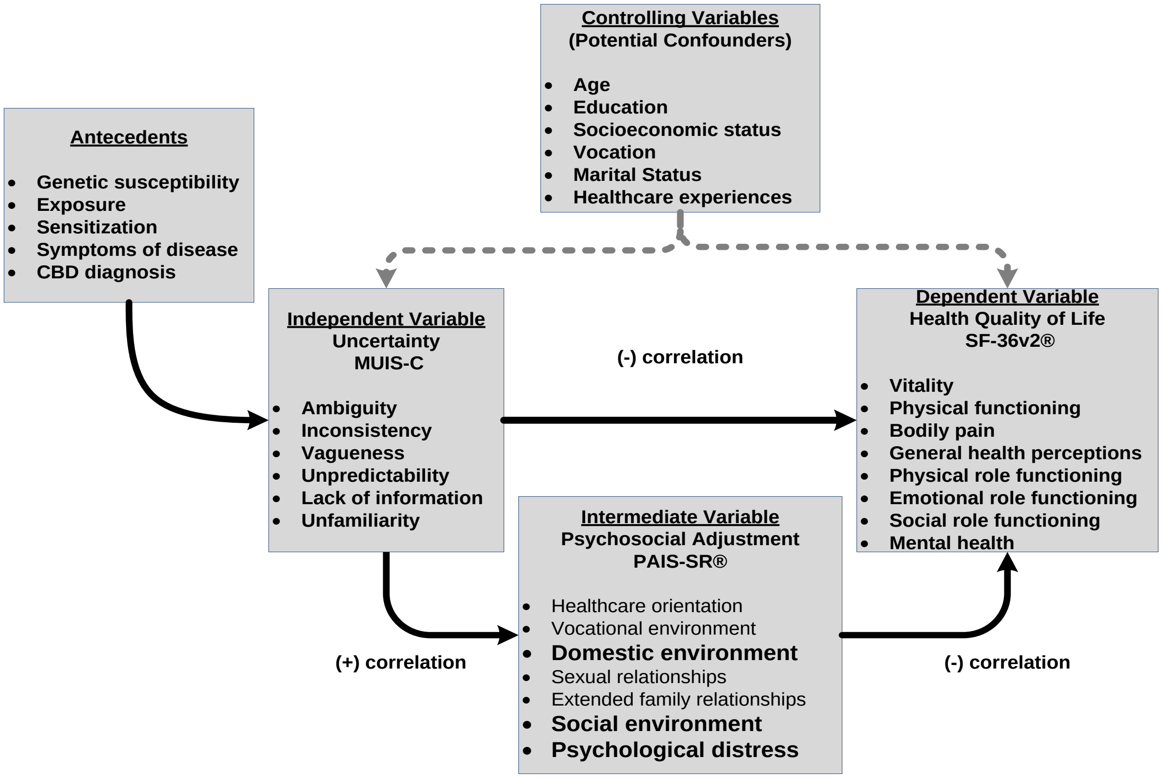

Figure 3.2. Relationships between variables in the model of the psychosocial effects of beryllium sensitization and chronic beryllium disease

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The direction and strength of the correlations between uncertainty and health quality of life (negative correlation, moderate strength) supported the theoretical model. That is, as uncertainty increased the health quality of life decreased. This suggests that efforts to reduce uncertainty (e.g., providing information and education) may help mitigate the negative effect that uncertainty has on health quality of life. It appears this is important for those with BeS as well as those with CBD so interventions to reduce uncertainty are important for both segments of the population.

The strong positive relationship between the PAIS-SR® scores and the MUIS-C scores indicated that greater uncertainty (i.e., high MUIS-C scores) was associated with a poorer ability to adjust to illness (i.e., high PAIS-SR® score). The analysis provides evidence that as uncertainty in illness increases the inability to make psychosocial adjustments to illness also increases. This suggests that the uncertainty of BeS or CBD may overwhelm the coping strategies of individuals and indicate the need for interventions that reduce uncertainty and improve psychosocial adjustment skills.

Finally, the negative correlation between the PAIS-SR® scores and MCS/PCS scores suggest that those who were less effective at making psychosocial adjustments (i.e., mediating uncertainty) had poorer health quality of life (i.e., lower scores). Because of this relationship, it can be hypothesized that those with BeS or CBD could benefit from interventions that help them develop new or varied coping strategies to mediate uncertainty and adjust to their illness.

There are many reasons why a person may have a high MCS score. The multiple regression model indicated that psychological distress, social environment and domestic environment had a linear relationship with MCS score and may therefore be

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important targets for intervention programs. Interventions through medical providers and/or support groups may best serve their patients/participants by focusing on psychological distress, social environment and domestic environment coping strategies for those with BeS and CBD.

These variables accounted for only 30% of the variability in the model so there is important research to be done to explain the remaining variability in the model. With a larger dataset, one could further explore models that differentiate psychosocial effects between men and women and between those with BeS and CBD.

Comparison of the mean scores for all of the mental health scales indicated the same trend; those with BeS had scores similar to those with CBD. This suggests that BeS may have as much, and possibly more, impact on one's mental health than CBD. An alternate explanation is that those with CBD have already progressed through the more psychologically damaging phase of BeS and are more resolved to their status with CBD.

This research describes the psychosocial effects of BeS and CBD and fills a gap in our understanding of the spectrum of the disease. These results have implications for treatment as well as workers compensation. Currently, compensation is linked to the physical signs and symptoms of CBD while BeS is not compensable under most workers compensation insurance programs. These results suggest that insurance coverage/compensation for counseling and treatment for psychological distress and other mental health components may be warranted for those with BeS.

Several findings support the notion that the mental health aspects are an important feature of BeS. The MCS and PCS mean scores from the SF-36v2® Health

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Survey suggest that BeS manifests itself primarily in the mental health domain while the physical aspects are secondary. When CBD develops, the physical aspects increase while the mental health aspects appear to remain an important factor. It was not surprising that the mean PCS score were significantly lower for those with CBD. Many of these participants reported moderate to severe physical disability associated with their disease. This was in contrast to participants with BeS who often reported no physical symptoms.

The mean MCS score was equal for participants with CBD and BeS. Those with BeS actually had higher mean scores on the MCS and three of four mental health domains when compared to those with CBD. While not statistically significant, these data suggest that BeS may have as much impact on mental health as CBD. Supporting this notion was the PAIS-SR® score for the domain of psychological distress (i.e., having dysphoric thoughts and feelings that accompany the individual’s disorder). The scores were not significantly different for those with CBD compared to those with BeS. This may indicate that those with BeS have dysphoric thoughts and feelings similar to those who have CBD.

The mean PAIS-SR® score for the domain of healthcare orientation was actually higher for those with BeS when compared to those with CBD. This result suggests that those participants with BeS have a more negative healthcare posture (i.e., attitude, quality of information, and expectations for treatment) and that may impede their ability to adjust to their medical condition.

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The mean MUIS-C scores were approximately equal for those with CBD and those with BeS. This is consistent with the results for the MCS and the PAIS-SR® psychological distress domain.

There are limitations to this study that must be considered when interpreting the results. The sample population may not be representative of the larger study population. The lack of a central BeS/CBD database, patient confidentiality requirements, the geographic dispersion of cases across the U.S., and limited resources made access to the entire study population difficult. The response rate from those who were contacted was also low. These factors contributed to a small sample size. Information was self-reported by the participants. No attempt was made to medically verify self-reported information. The cross-sectional nature of the study design also has inherent limitations that impact the ability to draw conclusions about cause and effect based on the study results. Due to these limitations, inferences based on these results about the larger DOE population or for beryllium workers in private industry may not be valid.

Future research that demonstrates the reliability of the SF-36v2® Health Survey, PAIS-SR®, and MUIS-C questionnaires for people with BeS or CBD would provide assurance that they were appropriate for this study. Further analysis to describe the specific types of uncertainty in the study population would be a key next step in designing intervention programs.

Acknowledgments

This research was supported by a grant from University of Tennessee, Department of Public Health.

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VITA

Jeffrey Miller was born in Carrollton, IL to J. Robert and Hazel C. Miller. He graduated from Greenfield High School in 1976. He received a B.S. in Health Sciences in 1980 from Western Illinois University where he was advised by Dr. James Neutens. He continued at Western Illinois, taking graduate classes in public health while working at the McDonough County Health Department. In 1981, he accepted a position with the DuPage County Health Department in the Chicago area. He took additional undergraduate and graduate classes in mathematics, chemistry and public health at the College of DuPage and the University of Illinois – Chicago. In 1985, he accepted a position with the Tri-County Health Department in the Denver area and enrolled at the University of Colorado Health Sciences Center. In 1989, he received his M.S.P.H. from the University of Colorado. His advisors were Dr. William Marine and Dr. Cecil Burchfiel. His thesis was a study of Cumulative Trauma Disorders in Colorado Grocery Clerks. He also became a Certified Industrial Hygienist and Certified Safety Professional. He worked for the Colorado Department of Health then transitioned to the private sector working twenty five years with professional services and health care companies. He was President and Chief Executive Officer at three different companies. In 2007, he moved to Knoxville, TN and enrolled in the doctoral program at the University of Tennessee, Department of Public Health. He worked as a technical consultant at the Y-12 National Security Complex while pursuing his doctoral studies. With Dr. Gregory Petty as his advisor, he completed his research project on “The Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease” and received his PhD in December 2012.

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