

Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease

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Abstract 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 U.S. Department of Energy facilities in Oak Ridge, TN. 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. 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 Derogatis' Psychosocial Adjustment to Illness theory. 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.

Keywords: *Beryllium, berylliosis, uncertainty in illness, psychosocial adjustment, stress and coping*

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1. 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 [1]. 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) [2]. Examination of lung tissue under the microscope may show granulomas. CBD may be confused

with other lung diseases, especially sarcoidosis [3,4]. In advanced cases, there may be manifestations of right-sided heart failure, including cor pulmonale [2].

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 [1,5,6,7,8,9]. 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 [9].

The percentage of people with BeS who go on to develop CBD is highly variable, ranging from 10-100 percent in different worker populations [10]. Individuals exposed to the highest levels of airborne beryllium dust are at greatest risk, although skin exposure may play a role in sensitization [11]. In each population, a certain percentage of people with BeS will not have CBD at the time the BeS is discovered. However, recent research suggests that each year, 6-8 percent of non-diseased people with BeS will develop CBD [12]. The latency for converting from BeS to CBD is highly variable, ranging from 1-12 years in one longitudinal study [13]. 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 [1,10]. 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 [10].

Beryllium is widely used in the aerospace, electronics, biomedical, defense, telecommunications and other industries [14]. Beryllium consumption is currently dominated by electronics applications [15]. The 2010 estimated consumption of beryllium in the U.S. was 320 metric tons and was valued at about \$160 million [14]. The estimated number of U.S. workers currently exposed to beryllium is 134,000 [16] and the total number ever exposed is 800,000 [4] however, these are likely underestimates [2].

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 [17,18]. 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.[6]. 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 [5,19-26]. 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 [27].

The National Research Council [28] 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 [29].

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 [30,31]. 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.

2. 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 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 have 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 feedback and knowledge.

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 are 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 proposed theoretical model of the psychosocial effects of CBD [32].

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 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 1](#).

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

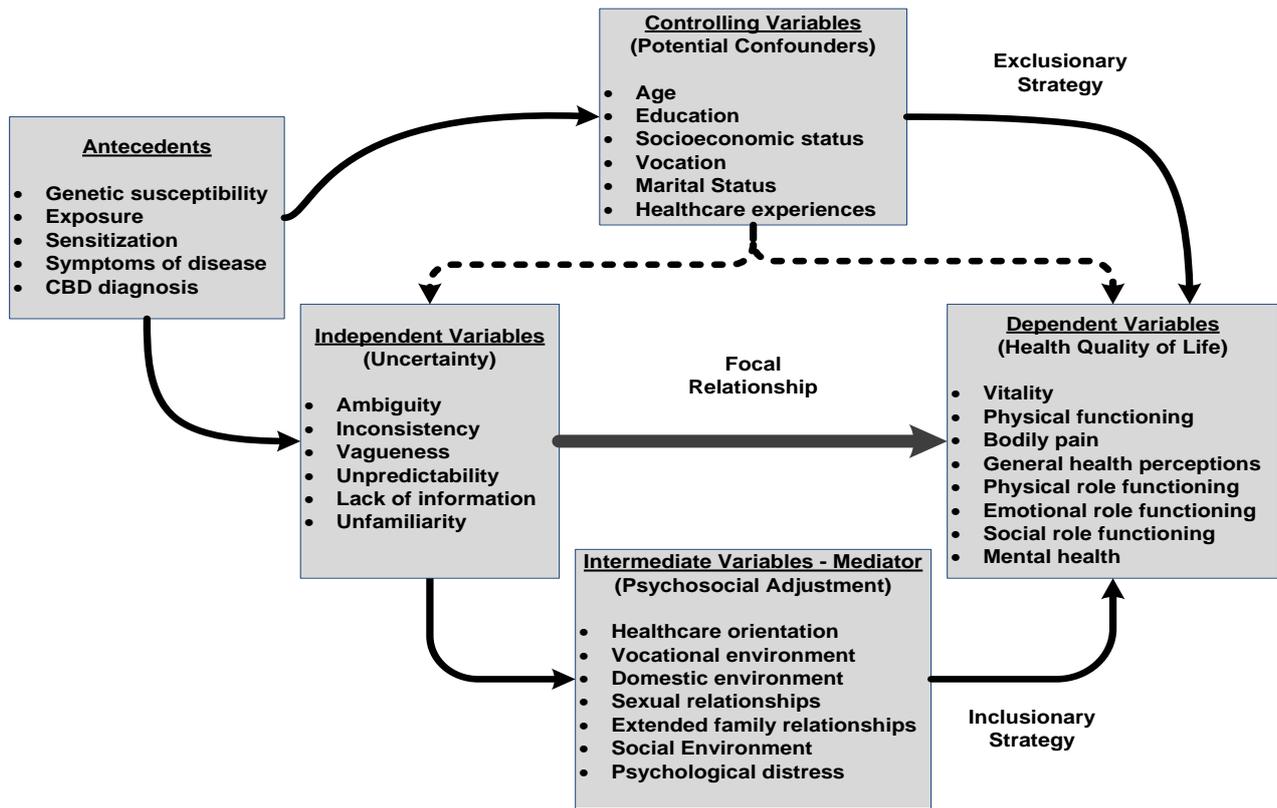


Figure 1. Socially constructed model of the psychosocial effects of chronic beryllium disease

Table 1. Descriptive statistics for the study population

Variable	Description and Frequency
Number of participants	13
Region of residence	East Tennessee, USA
Age	Range = 51-85 years Median = 59 years Mean = 62.4 years
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	\$25-50,000 = 3 \$50-75,000 = 3 \$75-100,000 = 4 >\$100,000 = 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 years Median = 1 year Mean = 2 years
Number of years with CBD	Range = 3-19 years Median = 8 years Mean = 9 years

3. Results

3.1. 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 National Security Complex, Oak Ridge National Laboratory (also known as X-10), 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 1.

3.2. 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 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.

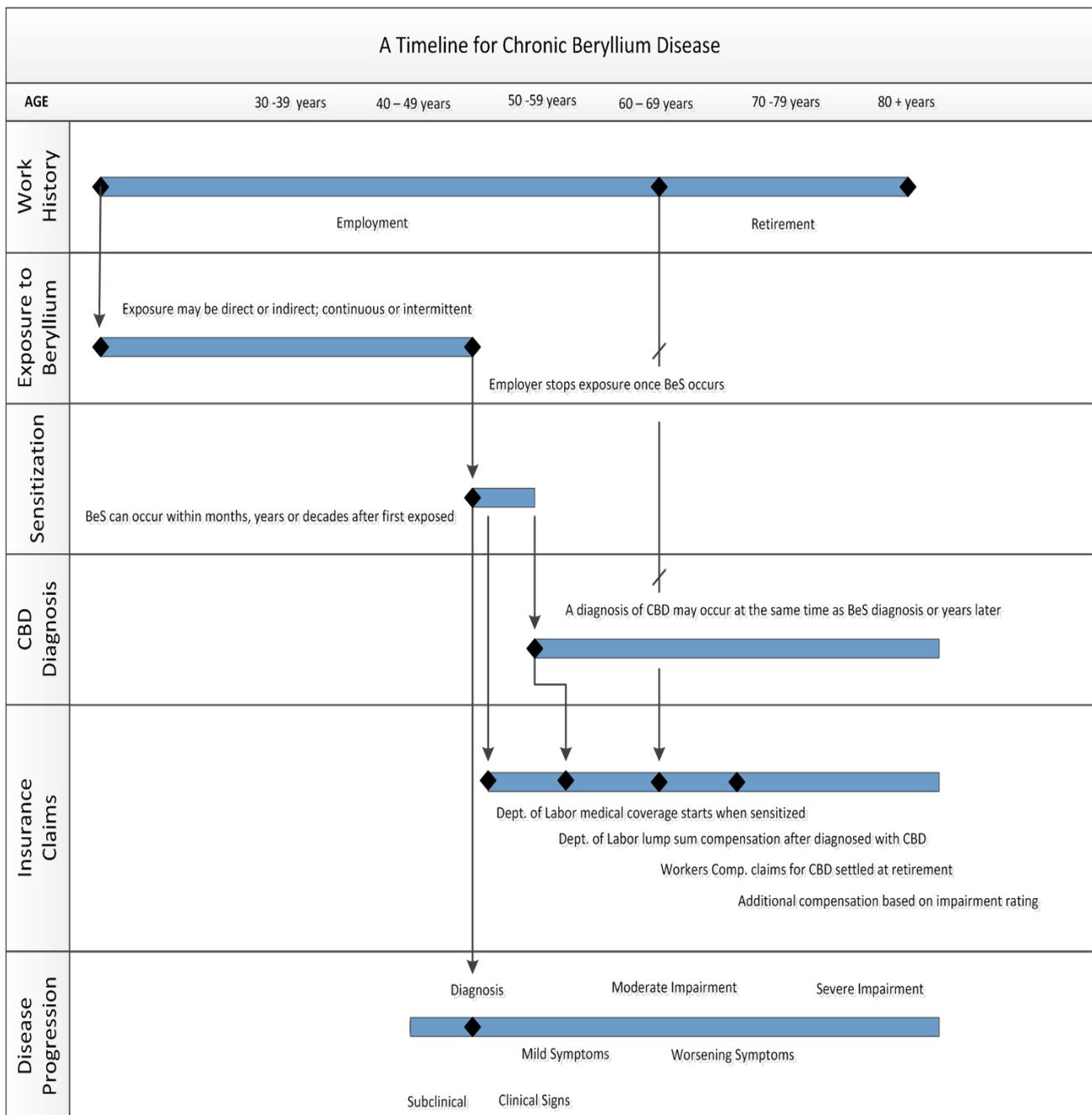


Figure 2. Key medical and sociological events related to chronic beryllium disease

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 varied widely among participants. Once they occurred, they triggered other sociologic events. [Figure 2](#) provides a composite timeline for key medical and sociologic events related to chronic beryllium disease.

3.3. 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 go up on the roof and I would check on the fans, and I didn't know what things were 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 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.

3.4. 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.

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 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?

3.5. 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 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.

3.6. 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 in the U.S. 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 U.S. Department of Labor (DOL), Workers Compensation Insurance (Workers Comp), and the DOE Chronic Beryllium Disease Worker Protection Program (CBDPP). Each domain intersects with the other in a complex web of rules and regulations that involve current workers, retirees, health care providers, employers, insurance carriers, the Federal government, and State government. [Figure 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) [33] and the promulgation of the DOE Chronic Beryllium Disease Prevention Program Final Rule in 1999 [27].

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.

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 [33].

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 [34]. 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.

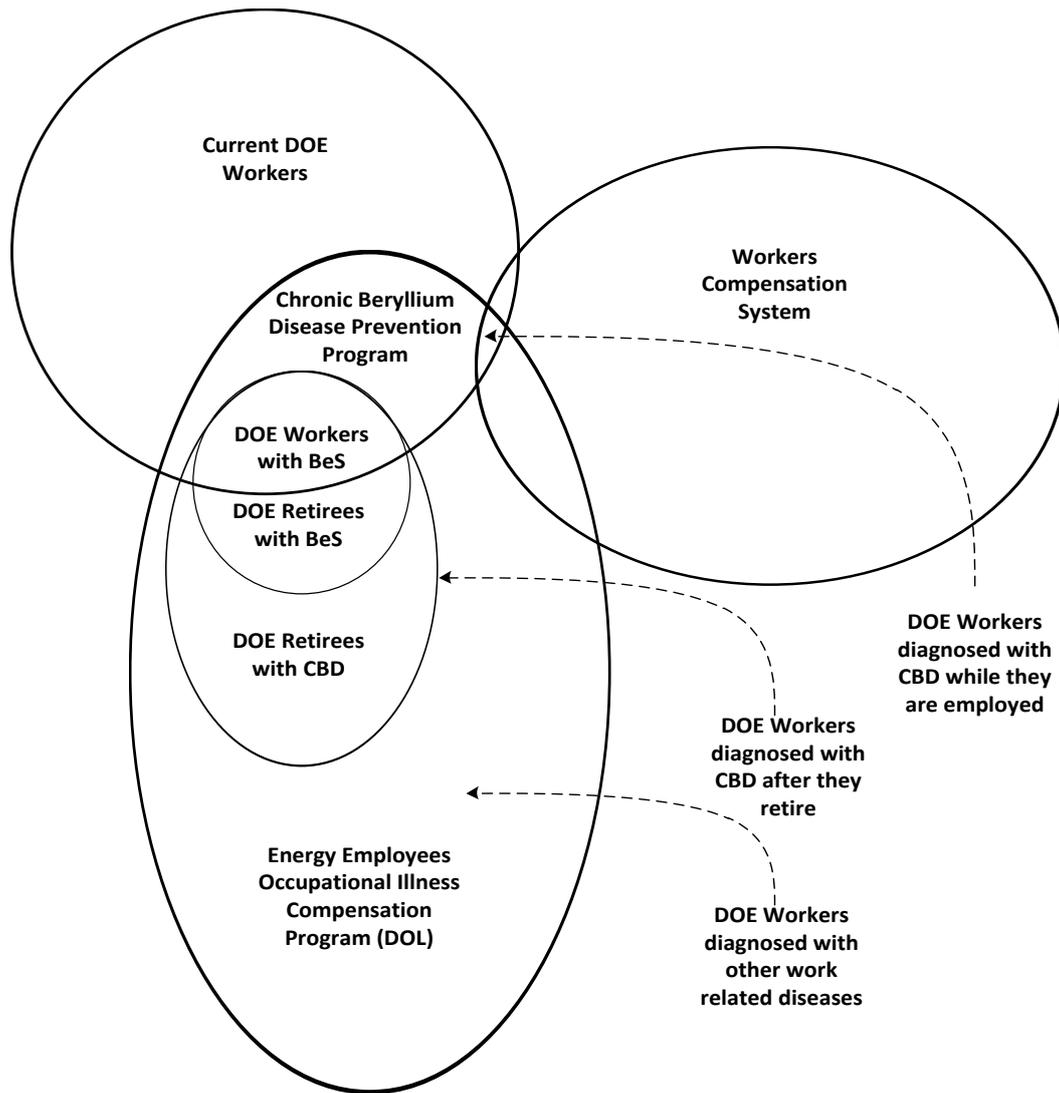


Figure 3. The intersections of the beryllium bureaucracy

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 [27].

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.

3.6.1. 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 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 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.

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.

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.

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.

P1: mean three or four different sets of physicians all agreed I have berylliosis and the Workers Comp doctor said no, 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 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.

3.6.2. 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 got out of their way to help.

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.

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.

3.6.3. 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.

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.

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 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.

3.7. 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%) 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.

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?

3.8. 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.

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.

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.

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 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.

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.

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.

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.

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.

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.

3.9. Psychosocial Adjustment to Disease

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 [35], 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 [36]. 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 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.

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 [36]. The participants reported several work-related circumstances that resulted from their diagnosis of BeS or CBD. 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 possibility 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 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.

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

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.

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 assess problems in adaptation experienced by the participant and their family unit in response to the participant's illness [36]. 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.

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.

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, 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.

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 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 [36]. 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: You know, personally speaking, I've had issues. My wife and me, we don't do anything intimate; we don't do anything physical. In fact that is one of my covered conditions under Department of Labor.

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 [36]. 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.

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 [36]. 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?

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.

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 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.

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 and its sequelae [36]. Participants described a wide range of emotions related to their diagnosis.

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.

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

P1: When you can't breathe there's nothing on your mind except (gasps) you can't breathe. That is so acute, that absolutely you don't think about anything. 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.

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

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.

4. 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 is consistent with Mishel's Uncertainty in Illness Theory [37]. In the model, uncertainty is proposed as an independent variable that influences health status. The Michel Uncertainty in Illness Scale (MUIS) has six primary domains all of which were presented in the results section: 1) ambiguity, 2) inconsistency, 3) vagueness, 4) unpredictability, 5) lack of information, and 6) unfamiliarity. In studies examining the adjustment to uncertainty in illness [38], 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

[35]. 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 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 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.

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. 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 is based on these early experiences. It is called the CBD Pioneers. 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 Pioneers are 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 Pioneers 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 Pioneers fulfilled for many years.

The second theme to emerge from the interviews was termed the CBD rollercoaster. A rollercoaster ride is a metaphor used by one of the participants when he described his experience with CBD, "it's always a rollercoaster." His simple phrase 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 you 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 Pioneers 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 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. 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 for this study that must be considered when interpreting the results. The small sample population may not be representative of the larger population of people 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.

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.

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Authors Declaration

This paper does not breach the copy right of other persons and has not been published or submitted for publication to any other journal or book.

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