American Journal of Public Health Research, 2018, Vol. 6, No. 2, 99-105
Available online at http://pubs.sciepub.com/ajphr/6/2/12

DOI:10.12691/ajphr-6-2-12

Measuring the Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease in Current and Retired Workers

Jeffrey R. Miller[1,*], Gregory C. Petty[2], Paul C. Erwin[2], Donna L. Cragle[1]

[1]Oak Ridge Associated Universities, P.O. Box 117, Oak Ridge, TN 37831-0117
[2]The University of Tennessee, Department of Public Health, 1914 Andy Holt Ave., 369 HPER, Knoxville, TN 37996-3430
*Corresponding author: jeff.miller@orau.org

Abstract Current and former workers from the U.S. Department of Energy complex were surveyed to measure the psychosocial effects of beryllium sensitization (BeS) and chronic beryllium disease (CBD). Questionnaires were administered to measure uncertainty in illness, psychosocial adjustment to illness, and health quality of life. Hypotheses were tested and relationships between variables determined. 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 similar. Psychosocial adjustment scores were also significantly different. Uncertainty scores were approximately equal. Moderate to strong correlations were found between the three variables. As uncertainty increased, health quality of life decreased unless the effects were mediated by psychosocial adjustments to the illness. It was concluded that BeS may have as much impact on mental health as CBD. If true, this adds an important new component to the spectrum of CBD that has implications for treatment and workers compensation.

Keywords: *Beryllium, berylliosis, uncertainty in illness, psychosocial adjustment, health quality of life*

Cite This Article: Jeffrey R. Miller, Gregory C. Petty, Paul C. Erwin, and Donna L. Cragle, "Measuring the Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease in Current and Retired Workers." *American Journal of Public Health Research*, vol. 6, no. 2 (2018): 99-105. doi: 10.12691/ajphr-6-2-12.

1. 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 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. Some that become BeS 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 [1]. 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. 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].

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 also be important [11]. Recent research suggests that each year, 6-8 percent of 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 people develop CBD and others do not [1,10]. Once you are exposed to beryllium, you carry a lifelong risk of developing beryllium sensitization or CBD, even if the exposure amount was small or you are no longer exposed [10].

Beryllium is widely used in the aerospace, electronics, biomedical, defense, telecommunications and other industries [14]. The estimated number of U.S. workers currently exposed to beryllium is 134,000 [15] and the total number ever exposed is approximately 800,000 [4] however, these are likely underestimates [2].

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 [16,17]. 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 epidemiology studies of nuclear workers have been completed over the past two decades helping define the risk of CBD in this population [5,18-25].

The National Research Council [26] 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 [27]. If this is 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.

2. Methods

The study population was current and former workers from the U.S. DOE Complex who had been diagnosed as having either BeS or CBD. The precise number of people in this population was unknown but was estimated at 1167. This is likely an underestimate because there is no comprehensive, nationwide system for reporting cases of BeS or CBD. Table 1 provides an estimate that was based on the best published information from the DOE.

Table 1. Estimated study population

Category	DOE Current Workers	DOE Former Workers
Estimated Total	110,000	600,000
Beryllium-Associated Worker 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: [28,29].
[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 (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. 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 100 people were contacted via the BSGOR.

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 were also some individuals in the database that were interested parties but who did not have BeS or CBD. The precise number of people in the database without BeS or CBD is unknown but was estimated at 20 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 339 potential participants were contacted via the BSGOR and the SOMD direct mailing. Some of these participants consented to in-depth interviews as part of the study. Questionnaires were completed by these participants before they were interviewed.

Third, a similar confidential mailing was made by National Jewish Health to patients that 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 20 for response rate calculations. Recipients were instructed in the cover letter to ignore the mailing if they had already elected to participate. The number of potential participants reached by this method was 354.

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 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 their 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 has been previously demonstrated. [for example: 30] 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. [31] The scoring algorithms and T scores were 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 ($\alpha = 0.74$ to 0.92).[32] The MUIS-C had six primary domains: 1) ambiguity, 2) inconsistency, 3) vagueness, 4) unpredictability, 5) lack of information, and 6) unfamiliarity and was a 23 item Likert-format scale that provided a single total score. The possible scores ranged 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: 33] There were seven principal domains of the PAIS, all of which had been shown to have a high relevancy for adjustment to medical illness. The domains included: 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. [34]

Several measures were taken to help assure data quality. Returned questionnaires were reviewed for completeness. When possible, follow-up inquiries were made with participants to collect missing data. The principal researcher verified the accuracy of data entry prior to analysis. 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 was missing data that influenced the score. If that was the case, that score was removed from the data set. Statistical analysis was performed using IBM® SPSS® Statistics 19.

This study was approved by the University of Tennessee and U.S. Department of Energy (DOE) Institutional Review Boards. Written informed consent was obtained from study participants.

3. 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. The estimated combined response rate was response 18.7%. The sample population was estimated to be 11% (126/1167) of the study population.

Table 2. Demographic characteristics of study participants

Variable	Description
Number of participants	126
Age	Range = 42-85 years Median = 62.5 years Mean = 63.6 years
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	Less than high school diploma = 1 (0.8%) Some high school or GED = 21 (16.7%) College or 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%) Chose not to disclose = 15 (11.9%)
Work status	Working = 52 (41.3%) Retired = 63 (50.0 %) Medical leave = 9 (7.1%) Looking for work = 2 (1.6 %)

Table 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

The participants were predominately married, white, males, with some college or trade school education. Half of the group was retired. The demographics of the sample population are provided in Table 2. Most of the participants work or worked at one of five DOE facilities: Y-12, Rocky Flats, Hanford, Kansas City Plant, or Pantex. This distribution of cases by DOE site is similar to that reported in the Former Worker Medical Screening Program Annual Report [28] and Beryllium Associated Worker Registry Summary [29]. The distribution of participants with CBD and BeS by DOE site is presented in Table 3.

All of the participants 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 that were BeS had been so an average of 9.9 years with a range of 1 to 24 years. Those with CBD had the disease 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 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 significantly less (p=.038) than the mean score for participants with BeS. The null hypothesis was rejected for the PCS. All other mean scores appeared to be equal. Table 4 provides the results of the SF-36v2® Health Survey.

Table 4. Results of the SF-36v2® Health Survey

Survey Component and Domains	Mean Score		
	CBD	BeS	Combined
Physical Component Summary	39.08*	43.20	41.66
Physical Functioning	40.79	43.20	42.29
Role Physical	40.91	43.72	42.67
Bodily Pain	42.41	45.04	44.15
General Health	39.11	41.85	40.96
Mental Component Summary	47.09	46.39	46.82
Vitality	44.58	44.50	44.70
Social Functioning	43.60	44.13	44.08
Role Emotional	42.51	44.08	43.56
Mental Health	48.23	47.30	47.78

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

The MUIS-C Survey results for participants with CBD were compared to 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 mean MUIS-C score for participants with CBD was were approximately equal to the mean score for participants with BeS. The null hypothesis was not rejected. Table 5 provides the results of the MUIS-C Survey.

Table 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 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 6 provides the results of the PAIS-SR® Survey.

Table 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 Coefficient (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. Because higher PCS and MCS indicate poorer health status, this result can be interpreted to mean that for participants with BeS, their mental health became poorer as their physical health declined.

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=-.286) and a moderate, negative correlation for those with BeS (r=-.42, p<0.001). These results suggest that

those that were less effective at making psychosocial adjustments (i.e., higher scores) had poorer health quality of life (i.e., lower scores).

Table 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.

The PAIS-SR® scores had a strong positive relationship with the MUIS-C scores for those with CBD ($r=.62$, $p<.001$) and BeS ($r=.627$, $p<.001$). This 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 MUIS-C scores had a weak, negative correlation with PCS and MCS scores for all participants. Table 7 summarizes the correlational analyses.

4. Discussion and Conclusions

The results of this study support the proposed model of the psychosocial effects of CBD [35]. 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 1 illustrates the model and the correlations between the variables that were measured in this study.

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.

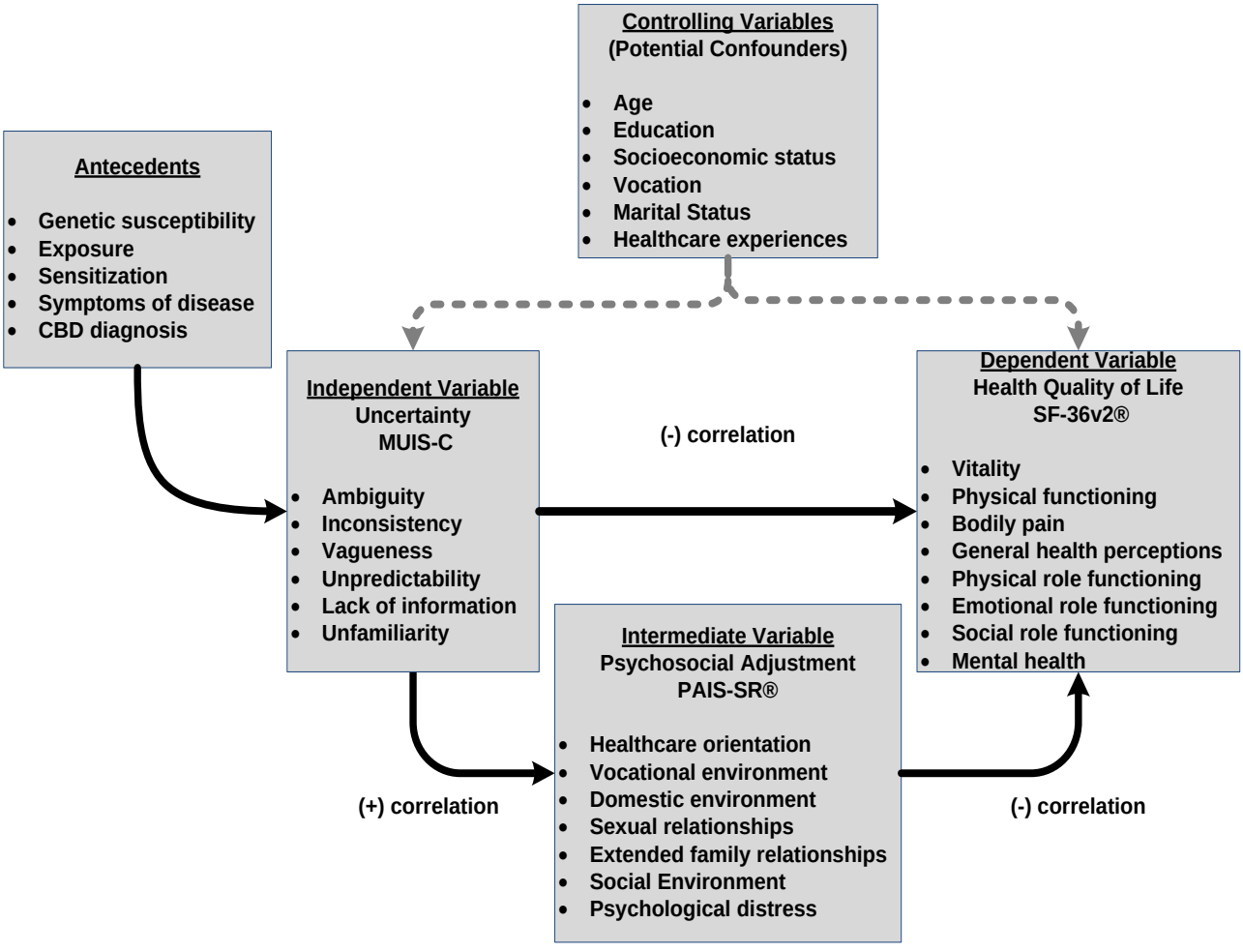

Figure 1. Relationship between variables in the model of the psychosocial effects of beryllium sensitization and chronic beryllium disease

The analysis also provided evidence that as uncertainty in illness increased the inability to make psychosocial adjustments to illness also increased (positive correlation, strong association). This suggests that the uncertainty of BeS or CBD may overwhelm the coping strategies of individuals and further amplifies the need for interventions that reduce uncertainty.

Finally, the relationship between psychosocial adjustment and health quality of life (negative correlation, moderate strength) suggested that those with BeS or CBD could benefit from interventions that help them develop new or varied coping strategies. Interventions through medical providers and/or support groups may best serve their patients/participants by focusing on healthcare orientation and psychological distress coping strategies for those with BeS. Those with CBD would benefit from these as well as coping strategies for the vocational environment, domestic environment, sexual relationships, and social environment.

The results of this study also suggest that BeS may have as much, and possibly more, impact on one's mental health than 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. If true, this adds an important new component to the spectrum of CBD – a component that has implications for treatment as well as workers compensation. Currently, compensation is linked to the physical signs and symptoms of CBD and BeS is not compensable. These results suggest that compensation 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 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. This domain measures dysphoric thoughts and feelings that accompany the individual's disorder and as indicated by anxiety, depression, hostility, reduced self-esteem, body image problems, and inappropriate guilt.[34] The scores were not significantly different for those with CBD compared to those with BeS indicating that those with BeS have dysphoric thoughts and feelings similar to those with 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.

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 for this study that must be considered when interpreting the results. The small 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 that were contacted was also low. These factors contributed to a small sample size. Due to this limitation, 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. Efforts to create a multiple regression model using the data from this study were unsuccessful. The various models that were tested did not adequately explain variability from the regression line. Further data collection and modeling to help understand which domains of the SF-36v2® Health Survey and PAIS-SR® were most important would be helpful when designing interventions.

Acknowledgments

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

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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