

Southern California CSU DNP Consortium

California State University, Fullerton
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BARRIERS TO WEIGHT LOSS IN PATIENTS WITH PRIMARY
IMMUNODEFICIENCY DISEASE

A DOCTORAL PROJECT

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DOCTOR OF NURSING PRACTICE

By

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ABSTRACT

Overweight and obesity are leading risk factors of hypertension, cardiovascular diseases, type-2 diabetes, and certain types of cancer. In patients with primary immune deficiency (PID), obesity-related diseases impose clinical complications beyond that observed in the general population; thus, maintaining a healthy weight should be a clinical goal for patients with PID. The purpose of this study was to explore perceived barriers and facilitators to maintaining healthy weight and weight loss in patients with PID.

This was a cross-sectional study of 128 adult participants with PID who received immunoglobulin treatments at a large, teaching hospital in Southern California. An adapted version of Champion's Health Belief Model survey, consisting of 39 items, was used to measure barriers and other health belief model constructs. Patients were invited to participate and could complete the survey either in hard copy or online. Demographic data was collected from medical records. Descriptive analysis and multiple regression were used for data analysis. A $p < .05$ was considered as statistically significant.

Results indicated that most participants were overweight or obese (64%). Participants who received infusions at home (vs. in the clinic) had increased odds of obesity. Perceived barriers to weight loss were identified as follows: being too tired to exercise, being too embarrassed to ask for help to lose weight, and not having time to prepare a healthy meal. Perceived facilitators to weight loss were the ability to identify

healthy from unhealthy foods, commitment to search for new information to improve health, and belief that losing weight reduced cholesterol, blood pressure and blood sugar.

In conclusion, the prevalence of overweight and obesity was higher in this group than that found at national levels. Significant barriers and facilitators associated with weight loss were identified. Any intervention aiming at weight loss for PID patients needs to take into considerations barriers that are unique to this population. Further research is needed to identify specific associations between PID, its clinical sequelae, and weight loss in groups with more demographic diversity and to confirm the high prevalence of overweight and obesity in the overall PID population.

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DEDICATION

This project is dedicated to my husband and my son for their love and support during my educational endeavor. They are the inspiration and the anchor of my life. It is also dedicated to my parents who love me unconditionally, and from whom I learned how to love and sacrifice for my own family, and to my brother who has also been a friend and a good listener.

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Lastly, I thank God for all the abundant blessings in my life. It was through Nursing that I learned how fragile life can be, but it was through God that I learned how to care with love, compassion, and empathy.

BACKGROUND

Primary Immune Deficiency (PID) diseases are hereditary disorders in which the body lacks the ability to produce adequate and functional antibodies (Immune Deficiency Foundation [IDF], 2013; Hampson et al., 2011). PID differs from secondary immune deficiency which can be the result of aging, side effects of medications, and infections (IDF, 2013; Verma, Thaventhiran, Gathmann, Thventhiran, & Grambacher, 2013). Since the primary function of the immune system is to fight infection and abnormal cells, PID patients are more susceptible to infections, malignancies, and autoimmune disorders (IDF, 2013; Wasserman, 2014).

While immunoglobulin G (IgG) replacement therapy is the cornerstone treatment for PID to prevent recurrent infections, reduce the severity of infections, avoid irreversible organ damage, and restore immune-homeostasis (Wasserman, 2014), one non-pharmacologic intervention that can also benefit PID patients greatly is maintaining an optimal body weight. In addition to lower risk of obesity-related diseases, a healthy body weight reduces the risk of infusion-related side effects, treatment time, and treatment-related expenses. With optimal body weight, patients may feel healthier, and would be more motivated to engage in physical activities and healthy lifestyle behaviors (Sinfield, Baker, Pollard & Tang, 2014).

Problem Statement

Overweight and obesity is a growing public health concern in the United States and around the world (Centers for Disease Control [CDC, 2012]). According to the Centers for Disease Control (2012), 35% of adults and 17% of young Americans are overweight or obese. Overweight and obesity impose an enormous impact to the

healthcare system and the economy (CDC, 2014). It is the leading risk factor of hypertension, cardiovascular diseases, diabetes mellitus, osteoarthritis, and certain types of cancer (CDC, 2012).

The clinical consequences of overweight and obesity in individuals with PID are exponential (Burton, Murphy, & Riley, 2010). Obesity increases risk for infections due to the chronic, low-grade inflammation resulting from adipose tissue metabolism, which in turn responsible for poor antibody response (Parratte, Pesenti & Argenson, 2014). The destruction of the mucosal lining of the gastrointestinal tract and sinus cavities due to acid reflux, secondary to obesity, also contributes to an increased risk of infection.

The risk for esophagus, gallbladder, pancreas, and colon cancer is higher in overweight or obese individuals, and in patients with PID, this risk is greater since the defective immune system cannot detect cancerous cells at an early stage (National Cancer Institute, 2012; Verma et al., 2013). Recurrent infection of the gastrointestinal tract leads to mal-absorption of Vitamin D, placing PID patients at higher risk for osteoporosis and bone fracture (IDF, 2013; Li et al., 2014; Suibhne, Cox, Healy, O'Marain, & O'Sullivan, 2012; Tavakkoli, DiGiacomo, Green, & Lebwohl, 2013), and the extra weight will worsen this predisposition. Overweight and obesity also associate with knee osteoarthritis (Murphy et al., 2008), which often requires surgery. Unfortunately, PID patients are not inherently good candidates for surgical operations due to the risk of post-operative complications such as infections. Therefore, maintaining an optimal weight can avert osteoarthritis and degenerative joint diseases, which in turn avoid the need for surgery.

Other comorbidities associated with obesity are chronic pain (Hitt, McMillen, Tornton-Neaves, Koch, & Cosby, 2007), fibromyalgia, sleep disorders (Okifuji, Donaldson, Barck, & Fine, 2010), chronic fatigue syndrome (Flores, Brown, Adeoye, Jason, & Evans, 2013), and depression (Berkowitz & Fabricatore, 2011). These chronic conditions are also clinical complications of PID diseases (Verma et al., 2013).

PID patients who are overweight or obese will have more clinical challenges beyond obesity-related sequelae. Since IgG dosing is body-weight dependent, the obese PID patient requires higher IgG dose. For intravenous IgG (IVIG) administration, an increased dose, which also means an increased volume, imposes a challenge for patients with hypertension, heart failure, and renal dysfunction, and yet these are clinical conditions frequently observed in patients with obesity (CDC, 2012). A large treatment volume also increases the risk of infusion-related side effects such as headache, fever, sinus tenderness, cough, myalgia, and malaise (Wasserman, 2012) and lengthens infusion time (Fadeyi & Tran, 2013).

Overweight and obesity present a challenge in obtaining venous access for intravenous administration of IgG therapy. While subcutaneous infusion (SCIG) is a better alternative to this problem as it bypasses the need for venous access, nonetheless, SCIG requires higher dosing to account for increased distribution into extra body fluids (Shapiro, 2013). SCIG could be a more favorable therapy choice for overweight or obese patients, but the higher cost associated with higher dosing proposes another kind of challenge.

Theoretically, PID patients, like all patients, can greatly benefit from weight loss. Weight loss requires lifestyle modification such as adopting a healthy diet and engaging

in physical activity. Even a modest weight reduction of 5% can improve blood pressure, blood cholesterol, and blood sugar (CDC, 2011). Persons who have lost weight also reported an increase in energy levels, enhanced physical mobility, happier mood, and greater self-confidence (CDC, 2011). However, losing weight remains a great challenge to many people. While numerous studies have documented barriers, facilitators, and factors affecting weight loss and the dynamics of health behavior and motivation, which is the underpinning force for actions toward a healthy lifestyle (Andajani-Sutjahjo, Ball, Warren, Inglis, & Crawford, 2004; Lee, Arthur & Avis, 2007; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Sinfield et al., 2013; Vann et al., 2011), as of this date no studies have specifically investigated these elements in PID patients; therefore, indicating a knowledge gap that warrants more clinical investigation.

Purpose Statement

The purpose of this study was to explore barriers and facilitators to weight loss in PID patients using the Champion's HBM Scale. Results of this study may be used to design a weight management intervention program for PID patients in the future.

Supporting Framework

The Health Belief Model (HBM) is the theoretical framework chosen for this study to explore determinants of weight loss in PID patients. Originally developed to understand how people utilize health services (Rosenstock, 1974), the HBM has been used widely to explore health behaviors (Carpenter, 2010). The model addresses four major constructs associated with behavior change: (a) perceived susceptibility, (b) perceived seriousness, (c) perceived benefits, and (d) perceived barriers (Rosenstock, 1966). The concept of self-efficacy has been used to assist the understanding of personal

capability (Bandura, 1977) and was incorporated into the HBM by Rosenstock, Strecher, and Becker (1988) to better explain health behaviors.

Perceived Susceptibility

The perceived susceptibility construct refers to the individual's belief of the likelihood of getting an illness or condition (Rosenstock, 1966). Rosenstock (1966) states that the greater the perceived risk by an individual, the greater the chance of engaging in an action to prevent that risk. Perceived susceptibility motivates people to adopt preventive care such as being vaccinated for influenza or using sunscreen for skin protection. Champion (1999) attests that a health threat must be recognized in order for a health-promoting behavior to occur. Therefore, PID patients must realize the extent of the obesity risk factors on their health in order for them to take actions toward weight loss (Daddario, 2007).

Perceived Seriousness

Perceived seriousness refers to an individual's belief about the severity of an illness or condition and its consequences (Rosenstock, 1966). Although this perception is often formed based on medical knowledge, personal experiences can also affect an individual's perception of seriousness of a condition. For instance, knowing the correlation between obesity and diabetes and heart disease, and having a family member with diabetes will increase the perception of seriousness of obesity. This construct is important for understanding health behavior. Studies have found that people may fail to take preventive measures toward an illness because they do not believe in the seriousness of the illness (Champion, 1999; Turner, Hunt, DiBrezza, & Jones, 2004). Similar to the perceived susceptibility construct, when PID patients understand the ramifications of

being overweight or obese to their already compromised health condition, they will be more likely to adopt behavior changes toward a healthy weight.

Perceived Benefits

The perceived benefit is another essential construct of the HBM. Perception of benefit is a person's belief of a beneficial outcome of engaging in a new behavior to decrease the risk of developing the illness or condition (Rosenstock, 1966). This concept is especially important in health behavior in preventive care such as screenings. For example, when people know the benefit of colonoscopy in colon cancer prevention, they are more likely to comply with testing. Similarly, in order for a person to adopt a new action, the individual must believe that the benefits of the new action are worth the efforts to overcome barriers. For PID patients, benefits of losing weight includes feeling healthier, lower IgG treatment dose, less treatment-related side effects, shorter infusion time; hence, less missing time from work or school for treatment, and less treatment expenses.

Perceived Barriers

The perceived barriers construct addresses obstacles perceived by an individual in adopting a new behavior (Rosenstock, 1966). Researchers believe that perceived barriers and perceived benefits are the two most determinants of behavior change (Mohebi et al., 2013). In order for a person to adopt a new action, that individual must believe that the benefits of the new action outweigh the benefits of the current behavior; this enables an individual to overcome barriers and take on new course of action (e.g., healthy eating to promote normal weight status). Applying this construct to a weight management intervention for PID patients, an individual must believe that losing weight will improve

their health (benefit) and/or alleviate the severity of their chronic diseases (benefit) in order for them to adopt new measures for weight loss. They must be willing to overcome barriers (e.g. hunger, going to classes, changes buying habits, etc.) to do this.

Perceived Self-efficacy

Self-efficacy refers to an individual's perception of his/her ability to carry out a particular behavior (Bandura, 1977; Rosenstock, Strecher, & Becker, 1988). Self-efficacy differs from perceived benefits in that an individual may know that losing weight will reduce risks of heart diseases and diabetes, but he/she may not be able to prepare a healthy meal or engage in physical activity. There is growing evidence to support that perceived self-efficacy is the most powerful predictor of behavioral change (Mohebi et al., 2013) and the primary resource for change (Daddario, 2007).

Modifying Variables and Cues to Action

The four major constructs of the HBM may be modified by factors such as educational level, culture, and personal experience (Rosenstock, 1974). Advancement in information technology allows easy access to medical information. When a person is more educated about negative consequences of a certain disease or health condition, there is an increased possibility that the person will be more willing to adopt changes to avoid that certain condition (Mohebi et al., 2013). Sometimes a negative experience in the past can influence a course of action in the future. For example, a person who had post-operative complications after a total knee replacement in the past will be more receptive to behavior change in order to minimize another knee operation.

Cues to action refer to cues or triggers needed to force forward the action necessary for change. These cues to action can be events, people, or things that influence

people to change their behavior (Rosenstock, 1974). Examples of cues to action may be an illness of a family member, media reports, and advice from others (e.g., health care providers). These cues heighten perception of susceptibility and seriousness of a condition, and perception of benefits when adopting new health behaviors. Furthermore, through vicarious experience of observing others successfully performing certain health behaviors (cue), one's perceived self-efficacy can be developed (Bandura, 1977). These cues to action explain why the role of a support group is vital to the success of a weight management intervention program.

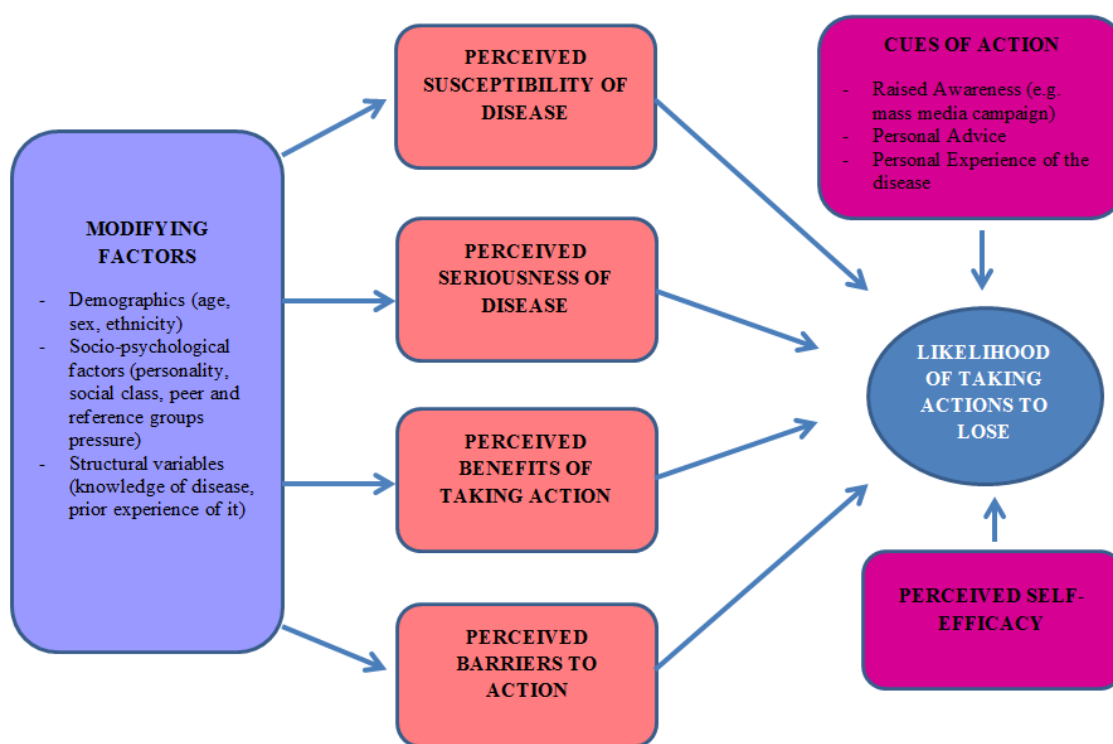


Figure 1. Schematic illustration of the health belief model. Adapted from “Social Learning Theory and the Health Belief Model,” by I. M. Rosenstock, V. J. Strecher, and M. H. Becker, 1988, *Health Education Quarterly*, 15(2), p. 175. Copyright 1988 by SOPHE.

REVIEW OF LITERATURE

Overview

A search of electronic databases PubMed, CINAHL, Cochrane, and PsycINFO was performed using the following key terms: (a) Weight management, (b) obesity, (c) primary immunodeficiency, (d) common variable immune disease (CVID), (e) Health Belief Model, (f) HBM screening scales, and (g) Champion's scale. Search terms used were obesity, overweight, weight loss, "weight management," nutrition, "perceived barriers" to weight loss, obesity intervention, physical activities, physical activity or exercise, barriers, facilitators, quality of life, body mass index (BMI), primary immunodeficiency, hypogammaglobulinemia, CVID, autoimmune diseases, infections, "recurrent infection," "chronic illness and CVID," "obesity and CVID," health belief model, behavior change, "health belief model and obesity," intervention, compliance, adherence, diet, physical activities, self-efficacy, questionnaires, surveys, screening, and scales.

The search was limited to articles published in the English language, peer-reviewed journals including quantitative and qualitative studies, meta-analyses and systematic reviews. To ensure an extensive search, no limitation on publication dates was applied.

Synthesis of Literature

A substantial number of studies examining issues related to weight loss in various populations focused on the health behavior of weight management because behavior change is a fundamental component needed to initiate and sustain the adaptation of a healthy lifestyle. Review of the literature yielded three common themes: (a) barriers to

weight management; (b) HBM as a predictor of health behavior; (c) application of HBM scale to health behavioral change.

Barriers to Weight Management

Lack of motivation, lack of time, and stress are common obstacles to weight management (Andajani-Sutjahjo, Ball, Warren, Inglis, & Crawford, 2004; Ciao, Latner, & Durso, 2012; Ruelaz et al., 2006). In older adults, the lack of knowledge about benefits of moderate physical activity and perceived self-efficacy are additional determinant factors to weight management (Schutzer & Graves, 2004). People with chronic illnesses have blamed poor health as a hindrance to healthy weight (Murphy, Sheane, & Cunnane, 2013). Cultural differences in perceptions of obesity also play a crucial role, either as a barrier or facilitator, to weight management. In many Asian countries, being obese is reflective of wealth rather than unhealthiness (Chang & Yen, 2012). African American women allege that barriers to physical activity are perspiration and appearance while white women complain of lack of support during weight loss (Thomas, Moseley, Stallings, Nichols-English, & Wagner, 2008).

HBM as a Predictor of Health Behavior

Many studies support the appropriateness of HBM for predicting health behavior. When comparing HBM to other behavioral change models, major constructs of the HBM including the recently added self-efficacy, are reliable predictors of behavior change, and perception of benefits, barriers, and self-efficacy as strongest variables (Daddario, 2007; Carpenter, 2010). The importance of HBM in longitudinal studies, in term of temporal relationship of the time of perception to time of behavior change, however, has not been well established.

Champion's HBM Scales for Health Behaviors

Champion's HBM scale is a popular instrument used in many studies to measure HBM variables. Construct validity, internal consistency reliability, and predictive validity of the scales were supported in several studies done for mammography screening maybe included the data for this? (Anagnostopoulos, Dimitrakaki, Niakas, & Tountas, 2013; Champion, 1999), as well as in the adapted version for cervical cancer screening (Guvenc, Akyuz, & Acikel, 2010), prostate cancer screening (Capik & Gozum, 2011), and breast self-examination (Noroozi, Jomand, & Tahmasebi, 2010).

METHODS

Study Design

This was a cross-sectional, self-administered survey study of patients with PID diseases at the Immunology Department in a large, teaching hospital in Southern California.

Human Subjects Protection

Human subject protection approval was obtained from the Institutional Review Boards (IRB) at the University of California Irvine and California State University Fullerton prior to data collection. Written informed consent was not collected from participants because participant response to the survey was used as an implied consent to participate in the study. The survey began with the statement “Thank you for deciding to participate in this study. By completing and submitting this survey, you are agreeing to participate in this research study.” to inform participants about the implied consent.

Participants

There were 128 participants eligible for enrollment based on the following inclusion criteria: (a) diagnosis of PID diseases; (b) are being seen at the Immunology Department at the hospital; (c) are 18 years old or older; (d) are able to understand, read, and write English; and (e) have mailing address available in the Medical Center’s medical database.

Procedure

A survey package was sent to eligible participants using their on-file postal address. Each survey was numerically coded for several reasons: (a) to allow linkage of participant to demographic data; (b) to allow for response monitoring; and (c) to allow for

identification of duplicate responses. We used paper and online surveys to maximize the response rate and sample size.

The survey package included: (a) an invitation page (appendix E) on clinic letterhead explaining the purpose of the study, participant's right to exit the survey at any time, participant's responsibilities to the study, and measures taken by researcher to ensure confidentiality; (b) a self-administered questionnaire (appendix H); (c) a postage-paid return envelope; (d) an instruction sheet (appendix F) on how to complete the survey. Participants could complete the survey by filling out the paper questionnaire and returning it using the return envelope, or by taking the survey online.

For online survey, the SurveyMonkey website address and instructions on how to complete the survey were described in the instruction sheet. This same information was presented to participants on SurveyMonkey prior to accessing the survey. Demographic data of participants (appendix G) was collected from their medical records by the principal investigator. These data included height, weight, BMI, age, gender, health insurance, marital status, and other health issues/diagnoses. Removing demographic questions from the questionnaire allowed for a shorter survey. Shorter surveys increase the chance of participation (Dillman, Smyth, & Christian, 2009).

The principal investigator assembled the survey packages to ensure accuracy of the enclosed materials. Survey packages were sent via United States Postal Services. A thank-you card, also serving as a reminder (Appendix I), was sent to all participants two weeks after the initial survey package shipment to thank them for their participation in the study and to also remind them to complete the survey if they have not done so. A

similar reminder was sent two week after the first reminder. Such reminders have been reported to maximize response rates (Dillman, Smyth, & Christian, 2009).

To ensure confidentiality of participants, participant ID code was used on mailing label for returned mail instead of sender's name. For online version of the survey, the option to collect computer IP addresses was switched to "NO" so that confidentiality can be protected from shared-account holders. Survey data was stored in an access-restrictive location in the infusion clinic for five years. Access to these data and storage location was available only to lead researcher and department manager. After five years, data will be destroyed according to Medical Center's Confidential Data Destruction protocol. Data collection was completed 30 days from the date of survey package shipment. Any conflicts in data interpretations between researchers were resolved by discussion among team members.

Study Instruments

For this study, Champion's (1999) HBM scale was adapted by the principle investigator to focus on weight loss, and was used to explore barriers and facilitators to weight loss in patients with PID diseases. The adapted scale included a total of 40 questions, which were assigned to each construct of the HBM in the context of weight management as follow: (a) 3 questions for perceived susceptibility; (b) 4 questions for perceived seriousness; (c) 8 questions for perceived benefits; (d) 10 questions for perceived barriers; (e) 5 questions for perceived self-efficacy; (f) 6 questions for health motivation. Each item was scored using a 5-point Likert-type scale with a score of 1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = strongly

agree. There were also two open-ended questions about deterrents and facilitators to weight loss included in the questionnaire.

Data Analysis

Descriptive analysis of demographic characteristics that reflect different facets of clinical information of the study participants is presented in Table 1. The subsequent statistical analyses are aimed at determination and estimation of the effects sizes of the best set of predictors of the outcome variables of interest, and the presence or absence of overweight status in study sample. We focused our data analysis on the effects of the ten factors perceived by study sample as barriers to maintaining healthy weight. This was achieved via an implementation of best multivariate logistic model selection. All calculations were performed using the R statistical software package (<http://www.r-project.org>).

RESULTS

Demographic and Clinical Information

One hundred and twenty eight patients with PID diseases were identified as eligible for enrolment in the study by their medical records. Analysis of the age distribution revealed that approximately a 75% of participants aged 65 or older. Analysis of BMI showed that 2.3% of the participants were underweight with BMI between 14.5 and 18.4, 33.6% had normal weight with BMI between 18.5 and 24.9, 37.5% were overweight with BMI between 25 and 29.9, 17% were obese with BMI between 30 and 34.9, 6.2% were clinically obese with BMI between 35 and 39.9 and 3.1% were morbidly obese with BMI over 40. Overall, 64% of the participants were overweight or obese. A little over two thirds of participants were female (69.5%), all (100%) were Caucasian and over half were married (58.6%).

Analysis of the insurance types of the study participants showed that almost half had PPO (46.1%) or Medicare and Supplemental (48.4%) and only 1.6% were on Medicare alone or paid out of pocket, and 2.3% had HMO. Lastly, with respect to the number of health issues, 13.3% of participants having 1 to 2 health issues, 32.8% having between 3 to 4 health issues, 32.8% having between 5 to 8 health issues, and 21.1% having between 9 to 25 medical problems. A detailed demographic and clinical data summary is shown in Table 1.

Table 1

Demographic Information of the Study Participants (N=128)

Variable	n	%
Height (cm)		
147-161	30	23.4
162-167	34	26.6
168-174	32	25.0
175-195	32	25.0
Weight (kg)		
41-63.9	32	25.0
64-73.9	29	22.7
74-89.9	34	26.6
90-136	33	25.8
BMI		
14.5-18.4	3	2.3
18.5-24.9	43	33.6
25-29.9	48	37.5
30-34.9	22	17.2
35-39.9	8	6.2
40-51.2	4	3.1
Age (in years)		
18-48	33	25.8
49-61	33	25.8
62-70	32	25.0
71-89	30	23.4
Gender		
Male	39	30.5
Female	89	69.5
Race		
White	128	100.0
Other	0	0.0
Marital Status		
Married	75	58.6
Other	53	41.4
Insurance Type		
Medicare	2	1.6
PPO	59	46.1
HMO	3	2.3
Medicare + Supplemental	62	48.4
Self-Pay	2	1.6
Number of Health Issues		
1-2	17	13.3
3-4	42	32.8
5-8	42	32.8
9-25	27	21.1

Survey Data Analysis

The selected items distributed as followed: 2 are from the perceived susceptibility items, 1 is from the perceived seriousness items, 4 are from the perceived benefits items, 5 are from the perceived barriers items, 3 are from the perceived self-efficacy items, 2 are from the health motivation items and 2 are dichotomous items denoting the infusion location and the type of questionnaire taken (paper or online survey). Detailed effect size, odds ratios, standard errors and *p*-values from the best model are shown in Table 2. Cronbach Alpha and Factor Analysis were analyzed to determine whether all questions should be aggregated. The result indicated that except for perceived seriousness with Cronbach Alpha of 0.83, the rest of the values were either lower than 0.70 or subsequent factor analysis revealed multiple underlying factors; thus, the authors decided to keep all items as separate variables in the model.

The prevalence of overweight or obesity was 64% ($n = 71$). The odd of overweight and obesity were elevated among participants who receive infusion at home. An odds ratio (OR) of 3.82, ($P = 0.01$) was adjusted for age, gender, ethnicity, marital status, insurance type, and numbers of active health issue. With every-one unit (Exponentiated Beta) increase, there is an increase in the odds of obesity in the following variables: Worrying about weight gain in the next five years (35%), more likely to gain weight than the average person (12%), belief that losing weight prevents osteoarthritis of my knee joint (13%), feeling embarrassed to ask for help to lose weight (21%), being too tired to exercise regularly (29%), I know what to do to lose weight (10%), ability to understand medical statistics (3%), exercise at least 3 times a week (15%).

The following variables are associated with a decrease in the odds ratio of overweight and obesity: Being scared of being overweight (15%), reduced infusion related side-effects with losing weight (9%), eating healthy meals and exercising to lose weight (12%), losing weight reduced cholesterol, blood pressure and blood sugar (18%), I do not exercise because I do not feel well (18%), being too old to worry about weight (14%), do not have time to prepare healthy meal (10%), ability to identify healthy from unhealthy foods (21%), and commitment to search for new information to improve health (20%).

Table 2

Best Logistic Regression Model Results (N = 71)

<i>Questions</i>	<i>B</i>	<i>SE B</i>	<i>Exp(B)</i>	<i>t-value</i>	<i>p-value</i>
Do you receive your infusion in the clinic or at home	0.31	0.10	1.37	3.12	.003
I worry about gaining more weight in the next 5 years	0.30	0.07	1.35	4.39	<.001
I am more likely to gain weight than average person	0.11	0.05	1.12	2.14	.04
The thought of being overweight scares me	-0.16	0.06	0.85	-2.57	.01
If I lose weight my treatment dose will be decreased. This will help improve my infusion related side effects	-0.10	0.05	0.91	-2.16	.04
When I eat well-balanced meals and exercise at least 3 times a week, I do not have to worry as much about my weight	-0.13	0.05	0.88	-2.46	.02
Losing weight can help prevent me from developing osteoarthritis of my knee joints	0.13	0.06	1.13	2.25	.03
Losing weight can help lower my blood pressure, cholesterols, and blood sugar	-0.20	0.07	0.82	-2.81	.007
I am too embarrassed to ask for help to lose weight	0.19	0.05	1.21	3.78	<.001

<i>Questions</i>	<i>B</i>	<i>SE B</i>	<i>Exp(B)</i>	<i>t-value</i>	<i>p-value</i>
I do not exercise because I do not feel well	-0.20	0.06	0.82	-3.35	.002
I am too tired to exercise regularly	0.26	0.07	1.29	3.90	<.001
I am too old to worry about being overweight	-0.15	0.05	0.86	-2.96	.005
I do not have time to prepare a healthy meal	-0.10	0.04	0.90	-2.26	.03
I know what to do to lose weight	0.10	0.04	1.10	2.63	.01
I am able to identify healthy foods from unhealthy foods	-0.23	0.09	0.79	-2.52	.02
I understand medical statistics such as probability, risk, odds, and percentages	0.03	0.01	1.03	3.05	.004
I search new information to improve my health	-0.22	0.04	0.80	-5.58	<.001
I exercise at least 3 times a week	0.14	0.05	1.15	2.54	.01
Type of questionnaire taken	-0.26	0.10	0.77	-2.57	.01

Note. B = beta; Exp (B) = exponentiated B; SE B = Standard of Error Beta.

DISCUSSION

The purpose of this study was to explore barriers to weight loss in PID patients at a large teaching hospital in Southern California. Results of this study reveal several significant findings of the association between the HBM scale and obesity. First, 71 out of 128 participants completed the survey (55%). This high response rate suggests that the PID patients who participated in this study were concerned about their weight management. The study results also indicate a higher obesity rate among PID patients (64%) compared to the general population (35%). This finding is not unexpected in patients with immune disorders. The lack of energy, coupled with medications such as antidepressants, antiepileptics, and steroids, poor food choices, and lack of exercise can contribute to weight gain (Berkowitz & Fabricatore, 2011). Interestingly, patients who receive infusion at home have 37% higher odd of being obese compared to those receiving infusion at the hospital. There are many reasons why patients choose home infusion. These include transportation difficulty, lack of insurance coverage, and busy work schedules. Decreased mobility due to chronic fatigue, neuropathy, and other debilitating diseases, such as fibromyalgia (Okifuju, Donaldson, Barck, & Fine, 2009) is another common reason why patients opt for home care. Decreased mobility is a vicious, self-perpetuating problem to weight loss since immobility reduces activity thus results in less caloric expenditure and more weight gain, and may be a possible explanation for a higher obesity rate observed in this patient population (Andajani-Sutjahjo et al., 2004).

There is an association between the perception of susceptibility and obesity. Patients who believed that they are more likely to gain weight than the average person and those who worried about gaining weight in the next five years have an increased odd

of being overweight, yet there is a reduction in the odd of obesity in patients who scored highly on the perceived seriousness of this problem. Perhaps an explanation for these findings is that when people feels susceptible to obesity, they may already having the weight issue, but when they recognize the seriousness of the problem on their health, they are more motivated to take actions toward resolution. Turner, Hunt, DiBrezza, and Jones (2004) found that the reason people fail to comply with osteoporosis prevention is the lack of knowledge about the seriousness of bone loss. Similarly, Saunders, Frederick, Silverman, and Paphesh (2013) concluded that older adults who did not seek help with hearing loss were those who had the lowest scores on perceived severity. These findings, along with the results of our study, suggest a need for patient education on the severity and seriousness of a particular health problem such as obesity, in able to bring change to a health behavior. Moreover, our study results show a reduction in the odd of obesity when patients recognize the benefits of maintaining a healthy weight on their immune treatment and other chronic diseases related to obesity. However, there is an increase in the odd of being overweigh in patients who perceived that healthy weight could help prevent the development of osteoarthritis of the knee joints. This particular result contradicts with existing clinical evidence illustrating the negative impact of obesity on osteoarthritis (Friedman & Fanning, 2004; Parratte, Pesenti, & Argenson, 2014). Perhaps there was a misinterpretation of the question or that participants felt they were not susceptible to orthopedic ailment, such as in younger adults. A pilot study could have helped clarify if there was a sematic ambiguity in the question.

When examining perceived barriers to weight loss in PID patients, it is reasonable to expect, with clinical evidence supports, that the higher the score in this category, the

higher the odd of obesity. This assumption is observed when asked if patients are too embarrassed to ask for help to loose weight (21% increased odds) and if they are too tired to exercise regularly (29% increased odds). Nonetheless, there is a reverse observation in the correlation between the odd of obesity and perceived barriers to weight loss in items “I do not exercise because I do not feel well,” “I am too old to worry about being overweight,” and “I do not have time to prepare a healthy meal.” Perhaps an explanation for the unexpected observation here is the influence of the modifying factors on patients’ responses to these questions. The word “feeling well” is subjective, and could be a causal effect of depression. Lack of appetite, feeling sad, and lethargy are symptoms that often seen in depressive patients. Moreover, there is a relationship between polypharmacy and weight loss in older adults (Agostini, Han, & Tinetti, 2004), and could be the reason why even though patients stated they are too old to worry about weight, they still have a lower odds of gaining weight. Therefore, more investigation is warranted to determine how modifying factors impact participant’s perception of barriers toward weight loss.

When the person is able to identify healthy foods from unhealthy foods, and he/she is actively searching new information to improve his/her health, the odd of obesity is decreased. Interestingly, when a person exercises at least 3 times a week, the odd of obesity is slightly increased. This may be due to the fact that when an individual is more aware and proactive about exercise and loosing weight, there may be already an existing weight issue.

From the two open-ended questions included in the survey regarding barriers stopping them from weight loss (if participant is overweight) and what factors have

helped them success if they have lost weight in the past, it appears that patients were not deficient in knowledge of how to lose weight. Many participants responded that exercise and less calories intake are the two best ways to achieve weight loss, and illness is almost unanimously identified as the biggest barrier to shedding the extra pounds. This information is essential in the designing of a weight loss program for PID patients because besides focusing on educating patients about the benefits of weight loss, health care providers also need to consider the physiological and psychological challenges of these patients.

This study has some limitations on the generalizations from its findings. Generalization of the study results to other population is limited because participants were predominately Caucasian patients living in Southern California with PID disorders and PPO insurance plans. Thus a larger, more geographically diverse sample study is warranted. Although participants may have responded honestly to the self-reported survey, there was no verification of the reported data. Another constraint was the cross-sectional design of the study, which does not allow for the observation of trends over time. The survey was also conducted during the holiday season when the topic of foods and healthy dieting is more sensitive and ambivalent. Also, a pilot study should have been conducted to help refine the survey questionnaire and strengthen the study validity.

Using BMI as a predictive indicator for obesity also contest to the concern of accuracy. While BMI is a popular index to use as a general measure of obesity, it does not differentiate between body fat and muscle mass, neither does it take into consideration of the person activity level, body type, age, and ethnicity. Furthermore, there is increasing clinical evidence supporting the waist-to-height ratio as a better

screening tool for adult cardiovascular and cardiometabolic risk factors (Ashwell, Gunn, & Gibson, 2012; Lee, Huxley, Wildman, & Woodward, 2008).

CONCLUSION

To our knowledge, this is the first study that explored barriers to weight management in patients with PID diseases. Overweight and obesity prevalence is higher in this group of patients compared to the national levels. There was strong correlation between being too tired to exercise and being too embarrassed to ask for help in losing weight and obesity. Factors associated with reduction of the odds of obesity were the ability to identify healthy foods and commitment to search for new information to improve health.

There is certainly a need for more research studies for this topic in this patient population. Studies should include both qualitative and quantitative methods to further explore what personal and environmental factors associate with participation or nonparticipation in physical activity and healthy diet in PID patients. Moreover, considering participants in this study are patients with PID, we recommend for longitudinal studies to investigate any causal relations between chronic illness and obesity. Studies should include greater demographic and geographic diversity to support generalization. Due to the complex nature of PID and its comorbidities, any intervention programs should include an interdisciplinary approach to address all physiological and psychological needs of the patients. We also suggest the inclusion of a support network into the weight loss strategies to promote adherence to weight loss intervention should also be investigated.

Maintaining a healthy weight is the cornerstone in the prevention of many chronic diseases, and for PID patients the benefits of weight loss are beyond those observed in other populations. Considering that participants are patients being seen at the hospital,

nurses and other health care providers play a pivotal role in educating and promoting healthy weight maintenance, and providing support and interventions to these patients using factors identified in this study.

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APPENDIX A

TABLES OF EVIDENCE

Quantitative Studies on Weight Management

Purpose (Source)	Study Design & Key Variables	Sample & Setting	Measurements, Operational Definitions of Variables	Results or Findings	Author's Conclusions, Limitations, Notes
To examine the relationship between weight loss and number of medications consumed (Agostini et al., 2004)	Descriptive cross-sectional and longitudinal cohort study. Key variables: Weight loss ≥ 10 lbs, number of medications taken, composite of four balance measures.	885 geriatric patients > 72 yo in urban community.	Self-report of decrease 10 lbs. or more from baseline to telephone f/u interview at 1 yr. Impaired balance was determined with examination of side-by-side balance, sternal nudge, tandem stand, & one-leg standing balance. Multiple logistic regression models used to evaluate associations between numbers of medications and weight loss and impaired balance.	Age mean 81 ± 5.2 Increase in the risk for weight loss and impaired balance with each additional level of medication consumption regardless of the type of medications. Digoxin & diuretic increase risk of weight loss ($OR = 1.6$, $CI + 95\%$). ACE-I & Digoxin increase risk of impaired balance ($OR = 1.3$, $CI = 95\%$).	Strength of study: Data obtained during home visits, exams combined with hospital records. Limitations: It was not clear if the numbers of medications contribute to weight loss or specific medications. Notes: Regardless of either numbers of medications or medications' S/Es is contributing to weight loss and impaired balance, older patients still have these risks.
To study the impact of motivational interviewing-based (MI) health coaching on	Quasi-experimental. Intervention: health coaching via telephone communication.	Participants with one or more chronic illnesses who participated in the intervention. Control group:	Variables measured in this study: a) Self-efficacy for managing chronic illness, b) perceived global health status, c) self-assessment of most important behavior change to achieve best health or quality of life, d) risk	Improved self-efficacy in intervention group ($p = .02$). Increased perceived health status in intervention group ($p = .03$).	Success of intervention attributed to MI technique rather than health coaching program. Limitations: Selection bias exists.

Purpose (Source)	Study Design & Key Variables	Sample & Setting	Measurements, Operational Definitions of Variables	Results or Findings	Author's Conclusions, Limitations, Notes
chronically ill patients (Linden et al., 2010).	Pre & post survey data analysis.	participants with one or more chronic illnesses who do not participate in the intervention program.	factors for readiness to change. Multiple-additive-regression model was used for data analysis to account for non-linear relationship between multiple outcome variables.	Self-assessment of important behavior change for better QOL was increased in intervention group ($p = .01$). Risk status for readiness to change was less in participants ($p < .01$) than non-participants.	Notes: MI more effective for health management. This may be true to weight management as well.
Purpose: To compare the effectiveness and feasibility of in-person and telephone-based intervention using behavioral change & motivational interviewing techniques to encourage an increase in PA and reduction in caloric intake in CA survivors (Harris et al., 2013).	Prospective pilot study over 1 yr. Blinding: assessment staff, testing lab personnel. In-person intervention vs. telephone intervention, increased PA, reduced caloric intake. Phase I (6 mos): One group received in-person interviews and the other received telephone interviews. Phase II (6 mos): All groups received monthly calls via phone.	Overweight/obese women (BMI = 25-45 kg/m ²) with remitted BCA. Exclusion: Fasting TG \geq 500 mg/dL, Urine protein > 100 mg/dL, serum CR > 1.5 mg/dL, H/O CVD, DM, or conditions preventing pts from participating in study.	Outcomes were measured as weight loss in kg. Outcomes measured at baseline, completion of phase I, and completion of phase II.	Phase I: Significant weight loss in both groups. Phase II: Significant difference in weight loss between groups ($p = .056$), weight gained in in-person based group (1.3 kg, $p = .009$) and no change in phone-based group (-1.0 kg, $p = .185$). Within groups: significant weight change in in-person based group between phase I and II ($p = .001$) but not with telephone-based group ($p = .149$). Weight change from baseline to completion: Significant in telephone-based group ($p = .012$) and not in-person based group-based ($p = .119$).	In-person and telephone intervention are equally effective, thus makes telephone-based model more feasible d/t low-cost aspect. Telephone-based approach can also be used to promote weight management. The change seen in in-person based group may d/t difficulty adjusting from in-person to telephone based intervention. Limitation: no randomization threatens internal validity. Lack of assessments for PA and dietary habit at 25 and 50 weeks.

Notes. ACE-I = angiotensin-converting enzyme inhibitor; BCA = breast cancer; BG = blood glucose; BMI = body mass index; CA = cancer; CVA = cerebrovascular accident; CVD = cardiovascular disease; D/T = due to; DM = diabetes mellitus; H/O = history of; MI = motivational interviewing; DZ = disease; f/u = follow up; QOL = quality of life; yr = year; y/n = yes or no; pt = patient; bls = pound; wk = week.

Qualitative Studies on Weight Management

Purpose, Study Questions (Author(s), Year)	Study Design & Theoretical Frameworks,	Sample & Setting	Data Collection & Data Analysis Process, Data Management Process	Results or Findings	Author's Conclusions, Limitations, Notes
Aim: To study the experiences of those who have been successful at weight maintenance (Hindle & Carpenter, 2011).	Qualitative, in-depth, semi-structured interview study. One lengthy interview initially, and second interview scheduled if needed to further explore emergent themes.	10 participants who maintained at least 10% weight loss of their original weight at least 1 yr or more were interviewed. Inclusion: 18yr or older, English speaking. Exclusion: Weight loss by surgery or very low calorie diet, or within 6 mos of giving birth. Interview was approximately 45min at participant's home or workplace.	Phenomenology used. Data analysis done using Colaizzi method.	4 major themes identified: a) motivation to lose weight b) approach taken to lose and maintain weight c) support d) Barriers to weight maintenance. Participants identified components attributing to unsuccessful weight loss: Lack of personal reason to do it, strict approach, and unrealistic expectation.	Primary motivation for weight loss health related. Long-term, realistic goals for weight loss and weight maintenance keys to success. Realistic goals lead to better adherence to weight loss program. Self-motivation leads to nutrition knowledge. Maintenance. Support key to maintaining weight loss. Positive reinforcement during first 2-5 yrs following weight loss crucial.
To study impact of weight-loss expectation on actual outcomes (Crawford & Glover, 2012).	Qualitative, systematic review study. Peer-reviewed, published journals. Databases searched: MEDLINE, PsycINFO, and Web of Science.	Inclusion: Studies assessed & analyzed weight-related expectations on pts 18 yo or older.	Downs and Black's quality checklist (1998) used to assess quality. Studies assessed for validity, measurements used, and participant characteristics.	No relationship between expectation and weight loss found. No association between weight-loss expectation and weight regain. Association between weight-loss expectation and attendance/attrition also unclear	Limitations: by using peer-reviewed and published articles only in paper, there is potential for publication bias.

Notes. AGFI = Adjusted-Goodness-Of-Fit Index; BCA = Breast Cancer; BSE =Breast Self-Examination; CFI = Comparative Fit Index; HMB = Health Belief Model; FHX = Familial History; MOS = Month; NNFI = Non-Normed Fit Index; RMSEA = Root-Mean-Square Error of Approximation; χ^2 = Chi-Square; YR = Year.

Systematic Reviews on Weight Management

Purpose, Study Questions (Author(s), Year)	Study Design, Methods of Research, Search Strategies	Sample & Setting, Inclusion & Exclusion Criteria	Data Extraction & Data Analysis Process.	Results or Findings	Author's Conclusions, Limitations, Notes
Aim: to examine research literature that addresses PA and nutrition intervention used for weight loss management in low-income women (Moredich, & Kessler, 2013).	Meta-analysis, quantitative-integrative review. Published and unpublished intervention studies measured PA behavior outcomes. Databases searched: Cochrane, JBI COnNECT+, MEDLINE, CINAHL, PsycINFO, ProQuest Nursing, Allied Health Source, Academic Search Premier Nursing.	Inclusion: English, targeted low-income adult women, focused on PA or nutrition behavior as intervention, published after 2005, peer-reviewed studies. Exclusion: Studies targeted postpartum or breastfeeding women, focused on other interventions.	Data extraction and quality appraisal done by 2 independent researchers. CASP appraisal tools used (design's rigor, validity, reliability, applicability to practice). Studies appraised against 10 questions (concise focus, sufficient power, blinded, randomization, validity, consistency, applicability to practice). Seven levels of evidence scale was used to rate studies' qualities.	Effective interventions: a) were structured in a group, b) were peer-educator led, c) included pragmatic nutrition advice, d) encouraged increase in PA, e) culturally congruent.	Absence of studies with low or negative ES to change PA behavior, compared to those focused on multiple health. Using Peer-led leaders eliminates the cost of using health professionals, thus increase sustainability. Limitation: Comorbidities not well reported.

Notes. CASP = critical appraisal skills program; CINAHL= cumulative index to nursing and allied health literature; JBICOnNECT = Joanna Briggs Institute Library of Systematic Reviews; PA = physical activity; PsycINFO = Psychology Information.

Champions HBM Scale

Purpose, Study Questions (Author(s), Year)	Study Design & Theoretical Frameworks,	Background, Sample & Setting	Data Management Process	Results or Findings	Author's Conclusions, Limitations, Notes
Purpose: To review the use of HBM for weight management (Daddario, 2007).	HMB, BC, TPB models used for weight management.	Inclusion criteria: studies with analysis or research using HBM to maintain healthy weight or to lose weight for an overweight or obese person.	Comparing HBM to other theoretical frameworks (Behavioral Change model and Theory of Planned Behavior model) used in addressing behavior change in weight management.	Perceived susceptibility is the primary motivation for behavior change in weight management. Perceived self-efficacy is the primary resource to make change to lose weight or maintain healthy weight.	HBM is an appropriate and effective model for use in successful weight management.
Purpose: To assess the reliability and validity of HBM constructs in mammography screening in Greek women (Anagnostopoulos, Dimitrakaki, Niakas, & Tountas, 2013).	Champion's HBM scale was used in the study to assess Greek women health behavior toward mammography screening.	Sample: 1478 participants recruited randomly from population census data. Setting: urban areas and rural areas of Greece.	Demographic data collected: age, education, social class, health insurance coverage, and familial history of BCA. Spearman's correlation coefficients were used to test inter-correlations among HBM variables. Goodness-of-fit was assessed using RMSEA, CFI, and NNFI. Internal consistency and reliability were measured using Cronbach's alpha.	Age mean: 58.3, <i>SD</i> = 12.3. 73.8% married, 70% lived in urban areas, 34.3% belong to lower social class, 53.7% had last mammogram a year ago or less, and 19.3% had it 2 yr ago. Goodness-of-fit was significant ($X^2/df = 2.77$, NNFI = .97, CFI = .97, RMSEA = .06).	The Champion's scale measuring perceived benefits, perceived barriers, and self-efficacy is a reliable and valid instrument for use in assessing health behavior for mammography screening among women.

Purpose, Study Questions (Author(s), Year)	Study Design & Theoretical Frameworks,	Background, Sample & Setting	Data Management Process	Results or Findings	Author's Conclusions, Limitations, Notes
			Independent samples <i>t</i> -tests were used to analyze scale differences. Predictive validity was analyzed using hierarchical logistic regression.		
Purpose: To study the HBM as a predictor to BSE in Iranian women (Noroozi, Jomand, & Tahmasebi, 2010).	Champion's HBM Scale and a demographic questionnaire were given to participants for self-administered survey.	Sample: 382 women 18 year or older, not pregnant or breast feeding, mentally and physically able, and able to read and write. Setting: participants recruited from public places in a city of Iran.	Path analysis was used to study the effect of HBM to BSE. Chi-square, AGFI and RMSEA were used to study fitness of HBM for BSE.	Path analysis supported fitness of HBM when modifying factors (knowledge of BCA, employment status, contraception use, gravidity, and health insurance coverage) were adjusted ($X^2 = 171.97$, $df = 62$, $p < .001$, $RMSEA = .068$, $AGFI = .87$).	Perceived self-efficacy and perceived benefits were the most predictive constructs related to BSE. HBM is a good framework for examining behavior change in BSE. Among modifying factors, age has significant positive effect on BSE. Limitation: X^2 can be sensitive to large sample size.

Notes: AGFI = Adjusted-Goodness-Of-Fit Index; BC = Behavior Change; BCA = Breast Cancer; BSE =Breast Self-Examination; CFI = Comparative Fit Index; HMB = Health Belief Model; FHX = Familial History; MOS = Month; NNFI = Non-Normed Fit Index; RMSEA = Root-Mean-Square Error of Approximation; x^2 = Chi-Square; YR = Year.; TPB = Theory Of Planned Behavior.

APPENDIX B**INVITATION LETTER TO PARTICIPATE IN RESEARCH STUDY****Study Title: Barriers to Weight Loss in Patients with Primary Immunodeficiency****Participant ID: A0001**

Dear _____,

My name is Thu Michelle Tran. I am a doctoral student at California State University in Fullerton. I am conducting a research study as part of the requirements of my degree in Nursing, and I would like to invite you to participate.

The purpose of this study is to identify barriers to weight loss in patients with Primary Immunodeficiency. If you agree to participate, please follow the survey instruction to complete the questionnaire survey. The survey should take no more than 30 minutes to complete. There is no compensation for your participation in this academic study.

This protocol contains no foreseeable risks to your safety or health care. The benefits derived from the results of this study will assist in developing future weight management programs specific to patients with Primary Immunodeficiency.

Confidentiality will be provided to the extent allowed by law. Study information will be kept in a secure location at the University of California in Irvine. The results of the study may be published or presented at professional meetings, but your identity will not be revealed.

Your participation in this study is voluntary and you are free to withdraw your participation from this study at any time. You also do not have to answer any question you are not comfortable answering.

I will be happy to answer any questions you have about the study. You may contact me at (949) 824-8334 and via email at thumt@uci.edu, or my faculty advisor, Dr. Al-Majid, at (657) 278-2368 or via email at sAl-Majid@fullerton.edu if you have study related questions or problems.

Thank you for your consideration. If you would like to participate, please consider responding online. Read the INSTRUCTION sheet carefully and follow the instruction to complete the survey.

PLEASE REMEMBER TO TAKE THE ONLINE SURVEY OR PAPER SURVEY ONLY.

Sincerely,

Thu Michelle Tran
1 Medical Plaza Dr. Room 1618
Irvine, CA 92697
Ph: (949) 824-8334
Email: thumt@uci.edu

APPENDIX C**INSTRUCTION LETTER ON HOW TO COMPLETE THE SURVEY STUDY****Participant ID: A0001**

Thank you for deciding to participate in this study. By completing and submitting this survey, you are agreeing to participate in this research study.

PLEASE CONSIDER RESPONDING ONLINE.

To complete the survey online, please go to the URL below:
<https://www.surveymonkey.com/s/PIDD-SURVEY>. Enter your participant ID number that appears at the top of this letter, and then start taking the survey.

If you do not have access to the Internet, or prefer to answer the questionnaire on paper, please complete the enclosed questionnaire and return it in the provided envelope. Your participant ID is already on the survey and the return envelope.

Confidentiality will be provided to the extent allowed by law. Your participant ID will be used for tracking purposes only. The results of the survey will be reported in a summary format, so there will be no personal information linking you to your responses.

Thank you again for your participation in this important study. If you have any questions about the administration of the survey, please contact me at (949)-824-8334 or via email at thumt@uci.edu.

PLEASE REMEMBER TO TAKE ONLY ONE SURVEY: WEB-BASED SURVEY OR PAPER SURVEY.

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APPENDIX D**DEMOGRAPHIC DATA COLLECTION FORM****Participant ID: A0001**

Height: _____ inches

Weight: _____ Kilograms

BMI: _____

Age: _____

Gender: _____

Race: _____

Marital Status: _____

Health Insurance: Primary _____; Secondary _____

Health Issues: _____

APPENDIX E

CHAMPION'S HBM SCALE ADAPTED FOR WEIGHT LOSS

Barriers to Weight Loss in Patients with PIDD				
Survey Instruction				
<p>Thank you for deciding to participate in this study. By completing and submitting this survey, you are indicating your consent to participate in the study. If you have any questions regarding this survey, please contact Michelle Tran at 949-824-8334 or via email at thumt@uci.edu.</p>				
1. Please enter your participant ID code				
<input type="text"/>				
2. Do you have a caretaker (example: spouse, helper)?				
<input type="checkbox"/> Yes				
<input type="checkbox"/> No				
3. Do you receive your infusion in the clinic or at home?				
<input type="checkbox"/> Infusion Clinic				
<input type="checkbox"/> Home				
4. I worry about my current weight.				
Strongly Disagree	Somewhat Disagree	Neither Disagree Nor Agree	Somewhat Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I worry about gaining more weight in the next 5 years.				
Strongly Disagree	Somewhat Disagree	Neither Disagree Nor Agree	Somewhat Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I am more likely to gain weight than average person.				
Strongly Disagree	Somewhat Disagree	Neither Disagree Nor Agree	Somewhat Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. The thought of being overweight scares me.				
Strongly Disagree	Somewhat Disagree	Neither Disagree Nor Agree	Somewhat Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. My relationship with my spouse or significant other would suffer if I am overweight.				
Strongly Disagree	Somewhat Disagree	Neither Disagree Nor Agree	Somewhat Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Being overweight would affect my whole life in a negative way.				
Strongly Disagree	Somewhat Disagree	Neither Disagree Nor Agree	Somewhat Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Barriers to Weight Loss in Patients with PIDD

10. Being overweight can cause serious health problems such as diabetes, heart diseases, and cancer.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

11. If I lose weight my treatment dose will be decreased. This will help improve my infusion-related side effects.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

12. If I lose weight my treatment dose will be decreased. This will help reduce my treatment cost.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

13. Managing my weight makes me feel healthier.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

14. When I eat well-balanced meals and exercise at least 3 times a week, I do not have to worry as much about my weight.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

15. Losing weight can help prevent me from developing osteoarthritis of my knee joints.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

16. Losing weight can help lower my blood pressure, cholesterols, and blood sugar.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

17. If I maintain a healthy weight, I will decrease my chance of dying from obesity-related conditions.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

18. Losing weight will help decrease my chance of having depression.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

Barriers to Weight Loss in Patients with PIDD

19. I do not know what to do to lose weight.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

20. I am too embarrassed to ask for help to lose weight.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

21. Exercise takes too much time.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

22. Losing weight is too difficult.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

23. I have other problems more important than my weight.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

24. I do not exercise because I do not feel well.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

25. I am too tired to exercise regularly.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

26. I am too old to worry about being overweight.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

27. I do not have time to prepare a healthy meal.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

28. I am not motivated to lose weight.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

29. I know what to do to lose weight.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

Barriers to Weight Loss in Patients with PIDD

30. I am able to prepare well-balanced meals for myself.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

31. In a typical week, how many days do you exercise?

- I don't regularly exercise
- Once a week
- 2 to 4 days a week
- 5 to 7 days a week

32. I am able to identify healthy foods from unhealthy foods.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

33. I understand medical statistics such as probability, risk, odds, and percentages.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

34. Maintaining a healthy weight is extremely important to me.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

35. I want to work on my weight problem as soon as it develops.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

36. I search new information to improve my health.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

37. I weigh myself at least once a month.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

38. I eat well-balanced meals.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

39. I exercise at least 3 times a week.

Strongly Disagree Somewhat Disagree Neither Disagree Nor Agree Somewhat Agree Strongly Agree

40. If you are overweight what deters you from losing weight?

Barriers to Weight Loss in Patients with PIDD

41. If you have lost weight in the past, what had helped you lose weight?

APPENDIX F
THANK YOU/REMINDER CARD

Participant ID: A0001

Dear _____,

Approximately two weeks ago, I have sent you a study package inviting you to participate in an academic study to identify barriers to weight loss in patients with Primary Immunodeficiency.

If you have completed the survey, thank you! If you have not had a chance to take the survey yet, I would appreciate your reading the message below and completing the survey. This survey should take no more than 30 minutes to complete.

To take the web-based survey, please go to this URL address:

<https://www.surveymonkey.com/s/PIDD-SURVEY>. If you prefer to take the paper survey, please complete the questionnaire enclosed in the survey package. If you cannot locate your paper questionnaire, please contact me at (949) 824-8334 or via email at thumt@uci.edu for another copy.

Thank you very much for your participation in this study.

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