A Survey of Eating Attitudes and Behaviors in Adolescents and Adults With Phenylalanine Hydroxylase Deficiency

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ABSTRACT

Introduction: Phenylalanine hydroxylase deficiency, commonly known as phenylketonuria (PKU), is an inborn error of metabolism that manifests in severe neurological damage when left untreated. Routine newborn screening has made early identification and treatment of affected individuals possible, changing the prognosis of PKU from devastating to excellent. The most effective treatment for PKU involves lifelong dietary restriction of protein, nutrition supplementation via medical foods, and frequent monitoring of amino acid levels in the blood. However, it has been observed that imposing strict medical control over daily dietary habits can lead to destructive attitudes towards eating and body image. This study investigated whether people with PKU are at increased risk of disordered eating behaviors and attitudes.

Methods: Fifteen patients with PKU between the ages of 12 and 35 from the University of Wisconsin (UW) Biochemical Genetics Clinic were surveyed about their metabolic management and eating attitudes and behaviors.

Results: While this study was too small to make conclusions of clinical significance, our findings did suggest that patients with poor metabolic control exhibited symptoms of disordered eating at a higher frequency than those with good metabolic control.

Conclusions: There is currently no validated screening tool to evaluate for disordered eating behaviors in individuals with PKU, which makes identifying and treating disordered eating and related conditions difficult. The development of this project emphasized the importance of tailored screening and provider awareness for disordered eating for populations with chronic illnesses.

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BACKGROUND

Phenylalanine hydroxylase deficiency, often known as phenylketonuria (PKU), is an inborn error of metabolism caused by a deficiency of phenylalanine hydroxylase (PAH), a hepatic enzyme that metabolizes phenylalanine (Phe) into tyrosine (Tyr).[1] Left untreated, PKU leads to systemically high levels of Phe and low levels of Tyr, leading to neurotoxicity and impaired brain development.[2] The typical presentation of untreated PKU includes irreversible severe to profound cognitive impairment, seizures, autistic behavior, psychiatric disturbances, eczema, decreased pigmentation, and a musty body odor. Advent of the newborn screening program in the 1960s made it possible to detect and initiate treatment for PKU from the neonatal period, thereby preventing the devastating neurotoxic sequelae of the condition.[3,4]

PKU is typically treated through a diet that is low in Phe.[5] Patients are limited to natural foods that are very low in protein, such as vegetables, fruits, and low-protein variants of pantry staples like bread and pasta.[2] This diet alone is nutritionally deficient, so patients also must ingest artificial low-Phe medical foods often referred to as "formula" in the forms of powders, tablets, pills, and shakes. Formula contains micronutrients to promote normal growth and development.[5] and sometimes carbohydrates and fats to help satiety.[2] Over time, PKU medical foods have become more diverse, convenient, and palatable,[6] but most patients are still unable to eat a "standard American diet."

Metabolic clinics also request regular blood samples from their

patients with PKU to monitor Phe levels at least once a month. The American College of Medical Genetics and Genomics (ACMG) recommends that all patients maintain Phe levels in a "goal" range between 2 mg/dL (120 µmol/L) and 6 mg/dL (360 µmol/L), though these recommendations vary slightly from clinic to clinic.[7]

Pharmaceuticals can also help with PKU treatment, the most accessible of which is sapropterin dihydrochloride salt, a synthetic version of tetrahydrobiopterin (BH4) that acts as an essential cofactor for PAH.[2] Phenylalanine ammonia lyase[8] is a new drug that is also being used to treat PKU, though it comes with significant side effects. Pharmaceuticals can help some individuals manage their condition better, but diet remains the primary and most effective treatment.

Eating Disorders and Disordered Eating in Individuals With Chronic Illness

Eating disorders are defined as disturbances of eating or eating-related behavior that result in an altered consumption or absorption of food significant enough to impair the individual's physical health or psychosocial functioning.[9] Disordered eating refers to abnormal behaviors focused around eating or feeding but that do not fit the pattern of a specific eating disorder. These can manifest in behaviors such as restrictive eating, emotional eating, or uncontrolled eating. Maladaptive thoughts or behaviors surrounding food and body image can be triggered by many external factors including, but not limited to, socioeconomic status, familial influences, and differences between individual personalities and social experiences.[10]

Individuals with chronic illnesses requiring lifelong dietary management may be at even higher risk of developing disordered eating. For instance, adolescent girls and adult women with type 1 diabetes have demonstrated increased frequency of disordered dieting behaviors, including fasting, dietary restriction, food preoccupation, laxative use, excessive exercising, body image disturbances, and even omitting insulin for weight control.[11,12] Disordered eating behavior has also been observed in individuals with cystic fibrosis, celiac disease, Crohn's disease, ulcerative colitis, inflammatory bowel disease, and irritable bowel syndrome.[11,13,14] For these individuals, the pressure to remain on a special diet to keep symptoms at bay may be a stressor that can trigger disordered eating behaviors or eating disorders.[11] Additionally, some of the drugs used to treat these conditions can dramatically alter body composition, and therefore negatively impact body image.

Exploring Incidence of Disordered Eating in Individuals With PKU

The correlation between disordered eating and PKU has never been established, but like other chronic illnesses, it is likely that individuals with PKU are also at increased risk for disordered eating.[12,15] Lifelong dietary management is recommended; however, compliance in adolescence and adulthood is notoriously poor. Over 70% of adults with PKU have Phe levels elevated above treatment range.[7] This may be due to both social and economic barriers. People with PKU often report feeling isolated due to significant dietary restriction. Formula is expensive and is not always covered by insurance or government-run programs. Patients who cannot bear this financial burden will turn to higher Phe foods to meet their nutritional needs.

While people with PKU who go off-diet in adulthood are not at risk for irreversible neurological damage, they still can develop subtle cognitive deficiencies like anxiety, depression, decreased executive function, and attention deficits,[16] all of which are known risk factors for disordered eating.[10] Additionally, patients with inadequate formula intake can have nutritional deficiencies that can lead to both poor growth[2] and obesity.[17] As a result, they may struggle with body image, another significant risk factor for developing an eating disorder.[10]

Metabolic health care clinicians have expressed concerns that their patients with PKU may be experiencing disordered thinking patterns, but lack of training and resources makes identification of disordered eating in the population difficult and inconsistent (Luu S, Breunig T, Cody P, unpublished data, March 2018). This study aims to investigate the behaviors and attitudes that people with PKU have regarding food and eating. We explored this by reviewing the literature regarding factors that can increase risk for disordered behaviors in populations with chronic illness and by creating a tool that surveyed for disordered eating behaviors specifically in people with PKU.

METHODS

Recruitment

Study participants were recruited from the University of Wisconsin (UW) Biochemical Genetics Clinic in Madison, Wisconsin. Patients were eligible for the study if they were being treated for PKU at the clinic, were born on or between the years of 1983 and 2005, and were brought to clinical attention by newborn screening. The eligible participants were all adolescents or adults at the time of the study and had been prescribed a low-Phe diet and medical formula for life, a protocol that was enacted at the UW Biochemical Genetics Clinic in 1983. Patients were excluded from participation if they had a diagnosis of cognitive impairment, intellectual disability, or a prior eating disorder. Eligibility criteria were determined from UW Health electronic medical records.

Procedure

Recruitment letters were sent to each eligible participant's home address. The recruitment letter introduced the study team, summarized the purpose of the study, and informed the recipient to expect a follow-up package in a week. A week later, eligible participants were mailed a consent form (accompanied by an assent form for minors), a copy of a paper survey, and a postmarked envelope in which to return the survey. Patients also were given a scannable

code if they opted to take the survey online. All recruited individuals were informed that participation in the study was anonymous, completely voluntary, and would not be shared with the metabolic care team at the UW Biochemical Genetics Clinic.

The first part of the survey asked patients to provide demographic information, including sex, age, ethnicity, and race. Participants also were asked to identify the individual who was answering the questions because the survey was only designed for self-reporting.

The second part of the survey asked patients to answer a series of questions designed to identify potential disordered eating attitudes or behaviors. These questions were loosely adapted from the Eating Attitudes Test (EAT-26).[18] The language in the questions was simplified to accommodate for the age of the adolescent participants and any PKU-related neurocognitive deficits caused by being off-diet. Some questions from the EAT-26 were eliminated because they would be answered abnormally by individuals on the PKU diet. Additional qualifying questions were added to elucidate the cause of a behavior that might otherwise be considered "disordered" in the general population (Appendix A). Participants were asked to answer all the behavioral questions using a Likert scale of "Always," "Usually," "Often," "Sometimes," "Rarely," and "Never." Their responses were assigned scores of 1 through 6 respectively.

The third part of the survey asked patients about their medical compliance. Participants were asked about their height, weight, their recommended treatment, the frequency at which they checked their Phe levels, their last blood Phe concentration, and whether they were pregnant or trying to become pregnant. They also were asked to evaluate how well they thought they managed their PKU. Lastly, participants were asked to disclose any other diagnoses that could possibly require additional dietary management or change their mental status or learning abilities. Disclosure of additional diagnoses was considered in data analysis but did not exclude any participants from the study.

Data Management and Analysis

The study team compiled and deidentified all responses. The data were analyzed by the UW Department of Biostatistics and Medical Informatics and the study team. All descriptive and statistical analyses were performed in Microsoft Excel. Wilcoxon rank sum tests were used to evaluate significance among ranked variables.

This study protocol was reviewed and approved by the UW-Madison Health Sciences Institutional Review Board.

RESULTS

Fifty-eight eligible participants were identified from the UW Biochemical Genetics Clinic medical records. Eight of the recruitment letters were returned to the sender because the documented patient address was no longer current. Fifteen responses were collected, yielding a 30% response rate.

Table 1. Patient Demographics

Demographics	N = 15 (100%)
Sex	
Male	9 (60%)
Female	6 (40%)
Age (years)	
12 - 17	6 (40%)
18 - 35	9 (60%)
Mean: 20.8 ± 7.1	
Median: 20	
Range: 12 - 34	
Ethnicity	
Hispanic or Latino	0 (0%)
Not Hispanic or Latino	15 (100%)
Race	
White	15 (100%)
Body Mass Index	
Underweight (<18.5)	0 (0%)
Normal (18.5 - 24.9)	15 (100%)
Overweight (>24.9)	0 (0%)
Survey Method	
Paper	12 (80%)
Online	3 (20%)

Demographics

Forty percent of participants were adolescents at the time of the study while 60% were adults (18 years and above); 60% of participants were male and 40% were female. All participants identified as white, and all had body mass indexes (BMI) in the average range (Table 1).

Compliance to Treatment

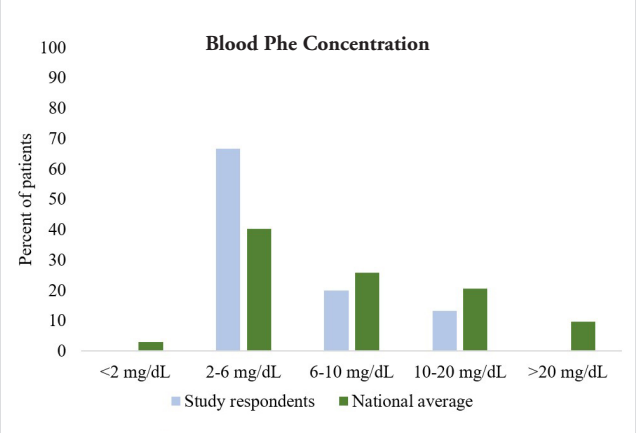
Study participants' compliance to medical recommendations were compared to a nationally representative survey that asked metabolic clinics about their patients' medical compliance. The study participants also were asked to self-evaluate how well they thought they controlled their PKU. Sixty-six percent of participants maintained Phe levels between 2 mg/dL and 6 mg/dL, and 60% of participants checked Phe levels monthly in compliance with ACMG guidelines, compared to a national average of 40% and 24%, respectively.[7] Fifty-three percent of study participants believed that they managed their PKU "very well" (Figure 1). Overall, a participant's self-reported metabolic control was consistent with their Phe levels and frequency of Phe checks.

Eating Behaviors and Attitudes

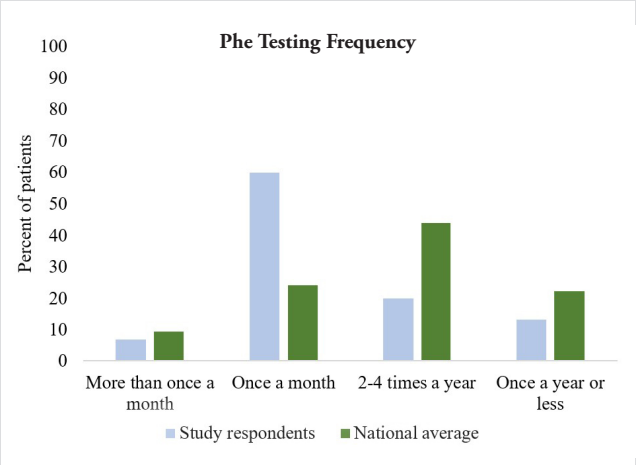
Participants answered 38 behavioral questions on a Likert scale of "Always," "Usually," "Often," "Sometimes," "Rarely," and "Never." Their responses were scored 1 through 6, respectively, except for the question, "Eating is enjoyable for me," for which the numerical scores were reversed. The mean score for each question was calculated. Lower scores for a question indicated that the surveyed sample was more symptomatic for that behavior.

The behavioral question responses were compared between participants who had been recommended a restricted protein

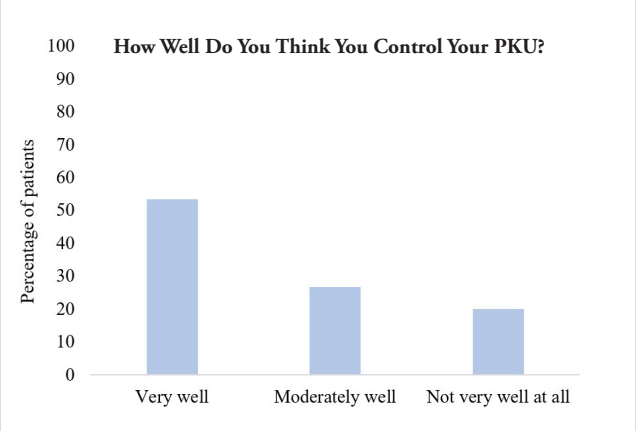
Figure 1. Study Participants' Compliance to Phenylketonuria (PKU) Management vs National Average



A. Blood Phe concentrations of patients with PKU. Study participants self-reported their last Phe concentration (n=15). National average was reported from 44 metabolic clinics, totaling 1,278 actively managed PKU patients between ages 13 and 29 years.



B. Frequency of blood Phe testing. Study participants self-reported their frequency of blood Phe testing (n=15). National average was reported from 44 metabolic clinics, totaling 1,328 actively managed PKU patients between ages 13 and 29 years.



C. Study participants self-evaluated how well they managed their own PKU.

diet with those who had not. Patients who had been prescribed a restricted protein diet reported that they were preoccupied with thoughts of food more often than patients who had not been prescribed a restricted protein diet ($P<0.05$) (Figure 2).

Finally, the behavioral question responses were compared between participants who responded that their PKU was "well controlled" with participants who responded that their PKU was "not very well controlled." Patients who self-reported poor metabolic control had disordered eating thoughts more often on 7 of the 38 items when compared to patients who self-reported good metabolic control ($P<0.05$). Patients who self-reported good metabolic control only had disordered eating thoughts more often than patients who self-reported poor metabolic control on 1 of the 38 items ($P<0.05$) (Figure 3).

DISCUSSION

Prevalence of Disordered Behavior in People With PKU

This study found that the average participant "Sometimes," "Rarely," or "Never," demonstrated maladaptive eating and dieting behaviors or attitudes. It is reasonable to conclude that this sample of individuals with PKU did not exhibit thinking patterns concerning for disordered eating. All study participants also had average BMIs, further evidence to support that none of them were showing disordered behaviors severe enough to affect physical body composition, though it should be noted that some individuals with eating disorders can have normal BMIs.

One exception was that all participants averaged an unusually low or symptomatic score (3.87) for the item, "I take longer than others to eat my meals." It is possible that individuals with PKU may need to take more time to determine the protein content of their meals, but there are no anatomical or physiological differences that would cause patients to take more time to eat.

Eating Behaviors Between Patients On and Off Protein-Restricted Diets

Most patients with PKU need to eat a low-protein diet and medical foods for life to maintain Phe levels within goal range; however, some individuals with more mild disease presentation may be able to eat less restrictive or even normal diets. It was anticipated that patients on restricted diets would think about food much more often than those not on a restricted diet, because they must strictly control their oral intake to meet Phe goals.[19] This hypothesis was supported: patients on a restricted protein diet were statistically preoccupied with food more often, not only before checking their Phe levels, but also at all other times as well (Figure 2).

While preoccupation with food may be a symptom of disordered eating behavior in the typical population, it may not be a negative attitude in the well-controlled PKU population. Instead, it may be an indicator that patients are motivated to maintain good long-term metabolic control. Study participants on protein-

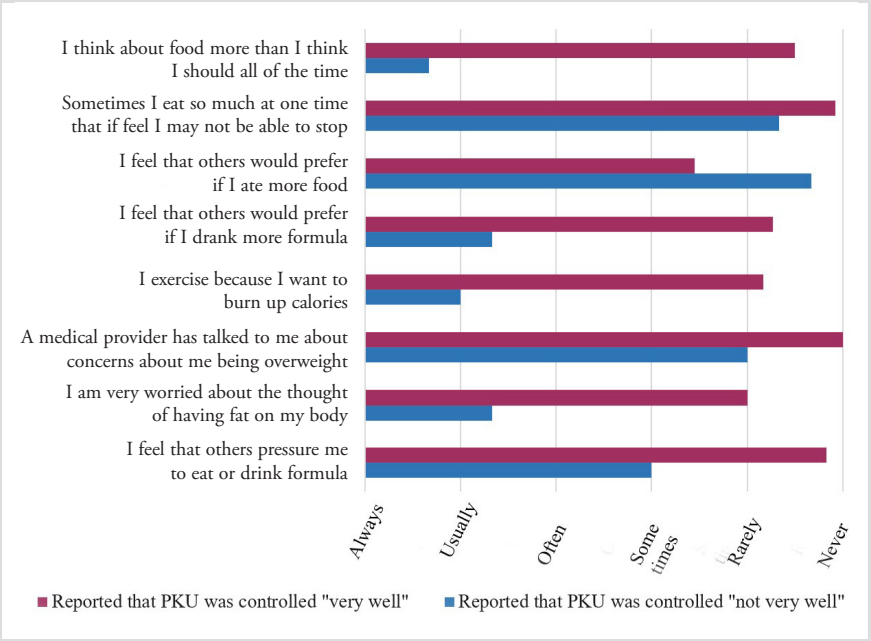
restricted diets did not report feeling like their PKU caused them stress with family or friends, caused them problems at work or school, or that "food controlled [their] lives" more often than their counterparts not on diet – all reassuring attitudes for patients' metabolic control and mental health.

Eating Behaviors Between Patients With Good and Poor Metabolic Control

Patients who self-reported poor metabolic control were preoccupied about food "all of time" much more often than patients who self-reported good metabolic control (Figure 3). However, there was no statistical significance in the frequency at which patients thought about food before Phe checks, regardless of how well they controlled their PKU. In fact, poorly controlled patients were less likely to think about food before checking their Phe than during other points of the day. This suggests that food is a pervasive thought for patients who do not manage their PKU well but, perhaps, they fail to draw the connection between diet and Phe levels.

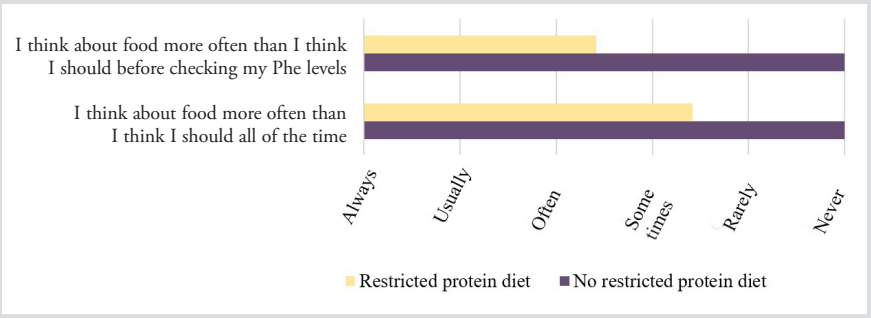
Patients who reported poor metabolic control also reported more disordered behavior in dieting and body image. Patients who felt they did not manage their PKU well were more worried about gaining weight and engaged in activities to lose weight more often. They acknowledged that others seemed concerned about their dietary habits, suggesting that patients with poor metabolic control were more likely to limit their oral intake. In addition to the higher frequency of dieting behavior, these patients also were more likely to report that they had been clinically overweight. There is a strong correlation between dieting and dissatisfaction of body image, often due to frequent and dramatic fluctuations in weight.[20] Lastly, patients with poor metabolic control did report bingeing behavior more often than patients who controlled their PKU well; however, the small deviation between the groups and tiny sample sizes leaves the significance of this item in question (Figure 3). These data are worrisome; results suggest that patients with PKU who are not well-controlled are still thinking about food, but in a way that does not improve their overall health and instead infiltrates into their body image and healthy socialization, when compared to well-controlled patients who seem to think about dieting purely as a way to manage their condition.

Figure 2. Comparison of Eating Behaviors and Attitudes Between Patients Who Had Been Recommended to Follow a Restricted Protein Diet With Those Who Had Not



All behavioral items displayed showed statistical significance between the group that was on a restricted protein diet (n = 12) and the group that was not on a restricted protein diet (n = 3) on a Wilcoxon rank sum test ($P \leq 0.05$).

Figure 3. Comparison of Eating Behaviors and Attitudes Between Patients Who Self-Reported Good and Poor Metabolic Control



All behavioral items displayed showed statistical significance between the group who reported that their PKU was "very well" controlled" (n = 8) and the group who reported that their PKU was "not very well" controlled (n = 3) on a Wilcoxon rank sum test ($P \leq 0.05$).

Limitations

This study did yield statistically significant findings, but the sample size was small (n = 15) and had evidence of selection biases. There are over 7,000 people diagnosed with PKU in the United States, and approximately 40% of those patients are between the ages of 12 and 35.[7] This study only surveyed a very small pro-

portion of patients with PKU and was not representative of the national population. While the study sample included male and female patients, it was racially and ethnically homogeneous (Table 1). PKU is most common in people of European ancestry, but it can affect people of all ethnicities.[20] Therefore, this cohort is not demographically representative.

Additionally, it appears that this study only sampled a subset of the population with exceptional metabolic control. In the United States, roughly half of adult patients with PKU are lost to follow-up.[7] All the participants in this study responded to mail contact and many gave responses to medical management questions that suggested they were seen in their metabolic clinic regularly. On average, participants in this study also reported much better medical compliance (lower Phe concentrations and more frequent Phe checks) than patients with PKU of a nationally representative sample (Figure 1).

It should be noted that PKU care is unique in the state of Wisconsin because every diagnosed individual is eligible to receive medical formula and low-protein foods for life. Most other states have restrictions on the kinds of foods that are covered and the ages of people who can receive them,[21] therefore creating access barriers that are not present for patients in Wisconsin.

Lastly, statistically significant findings in this study should be regarded with caution. Questions in the study survey were changed significantly from the original EAT-26 (Appendix A), and the survey was scored with a different scale. EAT-26 only assigns scores to responses of "Always," "Usually," and "Often;" it considers all other responses nonsymptomatic.[22] This study, however, ranked all responses, therefore imparting varying levels of pathogenicity to any answer.

Future Directions

This small study yielded intriguing results, but these results would be of more consequence in a larger sample. Ideally, the scope of this project would be expanded to encompass a nationally representative sample.

Anecdotal evidence suggests that metabolic dietitians are concerned that PKU patients would be at higher risk for disordered eating, but also feel powerless to improve the situation because they were the ones imposing the dietary restrictions.[17] Formally surveying dieticians may speak for a much wider and representative population of PKU patients, as well as offer a different perspective on this issue.

This research study demonstrates the difficulties in identifying disordered eating behaviors in people with PKU. Disordered eating in this population may be missed because they can be mistaken as behaviors used to maintain their medically recommended diet. Existing validated screening tools for eating disorders often do not work on people with PKU or other diet-managed conditions because these individuals often answer questions differently due to their disease or prescribed treatment, leading to low sensitivity or high false positive rates. The survey used in this study was a screening tool for research purposes. Subsequent iterations could prepare the questionnaire for clinic utilization.

CONCLUSIONS

This nascent study suggested that patients with PKU may be more prone to have certain thoughts regarding eating and body image that could possibly impede social functioning or physical health. Factors such as restricted diet or medical compliance may put certain individuals at greater risk for developing disordered eating.

However, identifying and treating disordered eating in people with PKU is challenging. Protocols to address a suspected eating disorder vary from clinic to clinic; there is no consensus on what should be done if a medical provider suspects an eating disorder in a patient. There is even less certainty when that patient also has a chronic illness such as PKU. Therefore, metabolic health care providers should maintain a low threshold for suspecting disordered eating in their patients with PKU. Developing guidelines to identify and care for this population with eating disorders or maladaptive behaviors and attitudes towards food can lead to more effective and consistent care for patients in all areas of their health.

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