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ORIGINAL ARTICLE

Perceived Sleep Quality in Individuals with Inborn Errors of Immunity

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Abstract

Purpose Chronic sleep issues can lead to poor quality of life and increased mortality and patients with chronic health conditions often report impaired sleep quality. Higher levels of fatigue have been identified in patients diagnosed with inborn errors of immunity (or primary immunodeficiency diseases). This research sought to better understand perceived sleep quality in individuals diagnosed with IEI.

Methods A survey, which included the validated Sleep Quality Scale, was shared across multiple social media groups for individuals with a diagnosis of IEI.

Results Most of the participants were White/Caucasian females, between the ages of 30 and 74 years. The results of the Sleep Quality Scale suggest that this sample of individuals has moderate impairment of their sleep quality (71.8%), with a mean score of 43.0 (SD = 13.1). When comparing the results of the SQS to other patient populations and healthy control groups, the participants in this study had a poorer sleep quality score. Associations were identified between sleep quality and age, hours of sleep per night, time awake at night, times awake to urinate, attempted daytime naps, chronic pain, and mental health diagnoses.

Conclusion This survey suggests that individuals with inborn errors of immunity have a moderate degree of perceived impairment in sleep quality. Healthcare providers are strongly encouraged to incorporate sleep quality screening in their routine assessments of patients with a diagnosis of Inborn Error of Immunity. Patients who are identified as having impaired sleep quality should be referred for further testing and interventions.

Keywords Sleep quality · impaired sleep · fatigue · Sleep Quality Scale · inborn errors of immunity · primary immunodeficiency disease · common variable immune deficiency

Introduction

Inborn errors of immunity (IEI), which are also referred to in the literature as primary immunodeficiency diseases (PID), are rare genetic disorders that affect innate and adaptive immunity. Clinically, IEI will present as an increased susceptibility to infections, autoimmunity, inflammation, allergies, bone marrow failure, and/or malignancy. As of 2022, the International Union of Immunological Societies (IUIS) Expert Committee has identified 485 known genetic defects, with 55 of them discovered in just the past year [1]. Inheritance may be recessive, autosomal dominant, or X-linked and there may be complete and incomplete penetrance of the clinical phenotype [2]. Based on a 2014 report published by Kobrynski et al. [3], an estimated 6 million people worldwide live with IEI, affecting 29.1–50.5 per 100,000 individuals. Common variable immunodeficiency (CVID) is a group of genetic disorders under the IEI umbrella which share a similar phenotype and is considered to be the most common symptomatic antibody deficiency diagnosed in adults with an estimated prevalence between 1:100,000 and 1:10,000 [4], There has been an expanding catalog of research into health-related quality of life for individuals with IEI. Individuals with an IEI diagnosis have been found to have challenges with physical function, anxiety, depression, fatigue, sleep disturbance, social participation, and pain as compared to the general population [5]. Recently,

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the association between fatigue and IEI was explored using a patient registry database. In a 2017 study, Hajjar et al. [6] found a significantly higher incidence of fatigue in patients with IEI (25.9%, CI 23.7–28.3) as compared to non-IEI individuals (6.4%, 95% CI 4.9–8.2). Individuals with a diagnosis of CVID had the highest prevalence of fatigue as compared to other IEI types [6]. Hajjar et al. also found that female sex, higher BMI, depression, bronchiectasis, and autoimmunity were factors associated with a higher degree of fatigue [6]. A 2020 study by Zhang et al. found significant differences between the CVID and non-CVID cohorts in the domains of anxiety, fatigue, and social participation as scored with the Patient-Reported Outcomes Measurement Information System (PROMIS-29) [5]. A study of pediatric IEI patients found that fatigue negatively impacts quality of life and daily functioning, but was not associated with disease activity or comorbidity [7]. Given these more recent findings that substantiate fatigue as an issue in the IEI patient population, further investigation into sleep and sleep quality are necessary.

Sleep is behavior that is characterized by changes in body posture and body state [8]; it is also a necessary physiological function to maintain health and well-being [9]. Nelson et al. define sleep quality as an individual's self-satisfaction with all aspects of the sleep experience [10]. Sleep quality can be impacted by diet, physical activity, and genetic and environmental factors [9]. Issues related to sleep and sleep quality are a growing global public health concern due to the association between impaired sleep and poor health outcomes [10]. There is a recognized association between poor sleep and decreased quality of life and increased mortality rates [11]. Sleep quality has been linked to health outcomes; poor sleep quality has been associated with higher incidence of cardiovascular disease, diabetes, depression, anxiety, obesity, stroke, and cancer [10, 12]. Poor sleep quality may lead to increased fatigue, altered mood, decreased motivation, daytime dysfunction, cognitive impairment, irritability, poor concentration, poor dietary choices, increased alcohol or sleep medication use, and increased inflammation [10, 12]. It is critically important that healthcare professionals who treat patients with a chronic disease, such as an IEI, consider the issue of sleep quality as part of a routine health assessment. Sleep disorders have been found to increase the risk of infectious diseases, are linked to the onset and progression of cardiovascular disease and cancer, and increase the incidence of depression [8]. In addition to influencing many body systems and functions, sleep also helps to regulate the adaptive and innate immune response [9]. Chronic sleep disturbance also leads to activation of the hypothalamus-pituitary-adrenal (HPA) axis and the sympathetic nervous system, which will impact the adaptive and innate immune responses [8]. Poor sleep quality is also a risk factor for the development of chronic widespread pain in otherwise healthy populations [13]. This makes the assessment and improvement of sleep quality in patients who are diagnosed with IEI even more important. In theory, improving sleep quality in patients diagnosed with IEI may help reduce inflammation, chronic pain, and infections, and improve their overall immune response. Sleep can be measured objectively and subjectively. There are a wide variety of sleep surveys and questionnaires that allow for valid and reliable measurement of self-reported sleep quality. Technology has also improved the objective measurement of sleep through a variety of wearable devices and apps that measure sleep. This research study sought to better understand perceived sleep quality in individuals diagnosed with IEI.

Methods

This study was Institutional Review Board approved by Stockton University. A survey was created to capture demographic, quality-of-life, and sleep quality information. The survey also contained the entire Sleep Quality Scale (SQS). The survey questions can be found in the supplemented appendix. The first survey question contained the informed consent information; this question also verified the participant eligibility criteria. Participants were eligible to participate if they were 18 years of age or older, were diagnosed with an IEI, and were able to read and understand English. Participants who acknowledged "yes" to the consent and eligibility question were able to advance through the survey. Participants who responded "no" to the consent and eligibility question were exited from the survey. Qualtrics was used as the survey platform to distribute the survey and collect the responses; the survey was available from April to June of 2022. The anonymous survey link was distributed to individuals with a diagnosis of IEI through posting in multiple public and private social media patient support groups. Participants were asked to complete the survey only one time. It was estimated that it would take 20 to 30 minutes to complete the survey. Survey questions were not randomized. Some questions allowed only one response, while others permitted multiple responses. The survey was compatible with any mobile device (such as a tablet or smartphone) or computer. Participants were able to change prior responses and could return to the survey if they were unable to complete it in one sitting. Research students completed the survey to test the survey flow. To improve face validity, the survey was completed by an individual with a diagnosis of IEI prior to sharing the survey with the broader IEI community.

The SQS was developed to be an all-inclusive self-report to assess sleep quality during the previous month [14]. Yi et al. developed this 28-item, 6 factor scale using item and factor analysis; the 6 factors include daytime dysfunction, restoration after sleep, difficulty falling asleep, difficulty getting up, satisfaction with sleep, and difficulty maintaining

sleep [14]. The SQS uses a 4-point Likert scale (0 = few, 1 = sometimes, 2 = often, and 3 = almost always); factors 2 and 5 are reverse-scored to obtain the global total score [14]. Scores on the SQS can range from 0 to 84, with higher scores representative of poorer sleep quality. The scale was determined to demonstrate reliability and validity. The concurrent validity was established through a significant correlation with the Pittsburgh Sleep Quality Index; the Cronbach's alpha coefficient was 0.92 for internal consistency and the correlation coefficient was 0.81 for test-retest reliability at a 2-week interval [14].

A chi-square test of independence was used to determine if there was any association between demographic or lifestyle factors that were included in the survey and sleep quality (using the SQS ranked as mild, moderate, or severe); the findings are presented in the "Results" section. Additionally, a one sample *t* test was used to compare the results of the SQS for this sample of participants with normative data and with data collected from research done on populations with other diagnoses. These comparative results are detailed in the discussion.

Results

A total of 555 responses were collected; 472 surveys were completed without any missing data. Partial responses were incorporated into the data analysis. Only responses that were complete were utilized to calculate the total SQS score. Participant demographics are presented in Tables 1 and 2.

After the general demographic questions, the survey then focused on questions related to sleep-related diagnoses, symptoms, medications, sleep hygiene, and a variety of other sleep-related issues. Table 3 highlights the survey responses related to sleep quality. These questions explored whether participants had a medical diagnosis related to sleep, symptoms of poor sleep quality, and sleep hygiene practices. For this series of questions, participants could check off multiple responses for each question.

The survey also explored the issues of pain, mental health, smoking, and shift work, given all of these could have a potential impact on sleep quality. Table 4 highlights these responses.

There were 472 participants who completed the SQS; the mean score was 43.0 (SD = 13.1) with a range from 5.0 to 81.0. After converting the SQS to mild, moderate, and severe categories (developed by John et al. in 2022 [15]), 67 (14.2%) had mild impairment, 339 (71.8%) had moderate impairment, and 66 (14.0%) had severe impairment. Table 5 highlights associations identified between demographic or lifestyle factors that were included in the survey and sleep quality (using the SQS ranked as mild, moderate, or severe).

Table 1 Participant demographics

Participants	*n* = 550
Gender % (*n*)	
Male	6.7 (37)
Female	91.8 (505)
Non-binary/non-conforming	0.7 (4)
Transgender	0.4 (2)
Prefer not to identify	0.4 (2)
Age % (*n*)	
18–29 years	7.5 (41)
30–44 years	25.8 (142)
45–54 years	23.3 (128)
55–64 years	24.2 (134)
65–74 years	17.5 (96)
75 years and older	1.6 (9)
Ethnicity % (*n*)	
White/Caucasian	95.5 (525)
Hispanic/Latino	3.3 (18)
Black/African American	0.5 (3)
American Indian/Alaskan Native	1.3 (7)
Asian	0.5 (3)
Native Hawaiian/Pacific Islander	0.4 (2)
Other	1.5 (8)
Prefer not to identify	0.5 (3)

Additionally, the survey sought to quantify the amount of sleep and wake time, prescription (Rx) and non-prescription (OTC) medication usage, and caffeine consumption. These results are shared in the supplementary materials.

Discussion This survey sought to better understand the issue of perceived sleep quality in individuals who have a diagnosis of IEI. The majority of the participants were White/Caucasian females, between the ages of 30 and 74 years, with a diagnosis of CVID. Despite more than half of the participants (51.8%) reporting having no diagnosed sleep disorder, the results of the SQS suggest that this sample of individuals has moderate impairment of their sleep quality (71.8%), with a mean SQS score of 43.0 (SD = 13.1).

In 2006, Yi et al. validated the SQS using individuals with a diagnosis of insomnia and a control group. [14] Yi et al. found the mean total SQS score for those with insomnia was 31.1 (SD = 13.61, *n* = 191) and for the control group, the mean SQS was 15.8 (SD = 9.06, *n* = 332) [14]. A one sample *t* test was used to compare the mean SQS score (43.0) from this sample of individuals with a IEI diagnosis to the two groups in the validation study. The mean SQS for individuals with IEI (43.0) was compared to the mean SQS for those with insomnia (31.1); there was a significant difference, $t(471) = 19.773$, $p < 0.001$. The mean SQS for individuals with IEI (43.0) was then compared to the mean

Table 2 Health demographics

Participants	$n = 548$
Type of IEI % (*n*)	
CVID	83.8 (459)
SCID	0.5 (3)
SAD	3.6 (20)
IgG subclass deficiency	5.7 (31)
XLA	1.3 (7)
Selective IgA deficiency	0.7 (4)
Complement deficiency	0.2 (1)
CGD	0.4 (2)
Other	2.6 (14)
Unsure	1.3 (7)
Time diagnosed % (*n*)	
< 1 year	7.8 (43)
1–5 years	35.0 (192)
6–10 years	26.1 (143)
11–15 years	16.1 (88)
> 15 years	15.0 (82)
Treatment % (*n*)	
No treatment	6.9 (38)
IVIG	33.4 (183)
SCIG	58.4 (320)
Prophylactic antibiotics	9.3 (51)
Other	2.0 (11)

CVID, common variable immune deficiency; *SCID*, severe combined immune deficiency; *SAD*, specific antibody deficiency; *XLA*, X-linked agammaglobulinemia; *CGD*, chronic granulomatous disease; *IVIG*, intravenous IgG replacement; *SCIG*, subcutaneous IgG replacement

Table 3 Sleep quality demographics

Sleep diagnosis % (*n*)	$n = 548$
None	51.8 (284)
Sleep apnea	28.5 (156)
Insomnia	20.6 (113)
Restless leg syndrome	12.4 (68)
Other [a]	13.3 (73)
Symptoms of poor/disrupted sleep % (*n*)	$n = 548$
Snoring	43.2 (237)
Bruxism	41.4 (227)
Vivid dreams	35.0 (192)
None	17.7 (97)
Nightmares	17.0 (93)
Sleep talking	16.2 (89)
Other [b]	8.2 (45)
Sleep hygiene practices % (*n*)	$n = 548$
Cool/comfortable bedroom temperature	78.6 (431)
Dark and quiet bedroom	67.2 (368)
Avoid large meals/caffeine prior to bed	61.1 (335)
Consistent sleep schedule	52.6 (288)
Relaxing pre-bedtime/bedtime routine	42.5 (233)
Avoid daytime naps	38.5 (211)
Regular physical activity	31.0 (170)
Electronics turned off in the bedroom	30.8 (169)
Avoid electronics 1 hour prior to bedtime	10.2 (56)
No sleep hygiene practices used	4.0 (22)
Hours of sleep per night % (*n*)	$n = 536$
Less than 4 h	3.7 (20)
4–5 h	14.6 (78)
6–7 h	47.6 (255)
8 or more hours	34.1 (183)

Other [a] = hypersomnia, REM sleep behavior disorder, narcolepsy, or sleep hypoventilation, Circadian sleep rhythm disorder. Other [b] = night terrors or sleep walking

SQS for the control group (15.8); again there was a significant difference, $t(471) = 45.150$, $p < 0.001$. In 2009, Yi et al. studied sleep quality in individuals with a diagnosis of obstructive sleep apnea syndrome (OSAS) [16]. In this study, the OSAS group had a mean SQS score of 27.3 (SD = 10.95, $n = 40$) and the control group had a mean SQS of 9.7 (SD = 6.16, $n = 37$). The mean SQS for individuals with IEI (43.0) was compared to the mean SQS for those with OSAS (27.3); there was a significant difference, $t(471) = 26.076$, $p < 0.001$. The mean SQS for individuals with IEI (43.0) was then compared to the mean SQS for the control group (9.7); again there was a significant difference, $t(471) = 55.268$, $p < 0.001$. When comparing the data collected in this survey to the data from Yi et al. [14] and Yi et al. [16], there is poorer sleep quality (based on the SQS) in those diagnosed with IEI as compared to both healthy control groups, those diagnosed with OSAS, and those diagnosed with insomnia. It is of interest that 28.5% ($n = 156$) participants in this study did report a diagnosis of OSAS. It is not clear whether the participants in the Yi et al. (2009) study had co-morbid conditions or other medical diagnoses, so a direct comparison between these two studies is likely to be influenced by other factors.

More recently, a 2022 study by Çakan and Öztürk examined sleep quality in patients with a diagnosis of allergic rhinitis using the SQS [17]. In this study, the allergic rhinitis group had a mean SQS score of 68.68 (SD = 13.15, $n = 65$) and the control group had a mean SQS of 47.72 (SD = 9.3, $n = 65$). The mean SQS for individuals with IEI (43.0) was compared to the mean SQS for those with allergic rhinitis (68.68); there was a significant difference, $t(471) = -42.559$, $p < 0.001$. The mean SQS for individuals with IEI (43.0) was then compared to the mean SQS for the control group (47.72); again there was a significant difference, $t(471) = -7.794$, $p < 0.001$. Interestingly, the participants in this study had better sleep quality (based on the SQS) as compared to both the control group and allergic rhinitis group in

Table 4 Quality of life issues relating to sleep

Chronic pain interferes with sleep % (*n*)	*n* = 531
Yes	58.4 (310)
No	38.4 (204)
Unsure	3.2 (17)
Mental health % (*n*)	*n* = 531
Anxiety	28.1 (149)
Depression	28.5 (151)
Other mental health diagnosis	7.0 (37)
No mental health diagnosis	36.4 (193)
Smoking history % (*n*)	*n* = 529
Never smoked	71.6 (379)
10 years or less	11.7 (62)
More than 10 years	16.6 (88)
Work Shifts % (*n*)	*n* = 530
Not working/working non-shift hours	60.6 (321)
Traditional day shifts	32.6 (173)
Other [c]	6.8 (36)

Other [c] = Late afternoon/early evening shifts, night shifts, rotating shifts, or very early morning shifts

Table 5 Association of demographic and lifestyle factors with sleep quality

	X2	*p*
Age	20.546	0.024*
Gender	14.312	0.074
IEI diagnosis	16.088	0.586
Time IEI diagnosis	7.169	0.519
Rx medication causing fatigue	4.025	0.403
OTC medication causing fatigue	2.449	0.654
Rx medication causing insomnia	5.979	0.201
OTC medication causing insomnia	4.271	0.371
Rx medication for better sleep	3.024	0.554
OTC medication for better sleep	7.934	0.094
Hours of sleep per night	31.257	0.000*
Time awake at night	67.953	0.000*
Times awake to urinate	50.470	0.000*
Daytime naps taken	5.211	0.517
Attempted daytime naps	18.607	0.005*
Caffeinated drinks per day	18.607	0.733
Caffeinated drinks before bed	3.355	0.500
Chronic pain	38.477	0.000*
Mental health diagnoses	17.707	0.007*
Smoking history	8.503	0.580
Work shift	13.533	0.195

* indicates significance at the 0.05 level. *Rx*, prescription; *OTC*, over the counter

a 2022 study by Çakan and Öztürk [17]. However, the study by Çakan and Öztürk was exclusively male participants and this study was nearly all female participants, which may contribute to variations in the SQS scores [17].

The participants in this study also had poorer sleep quality (based on the SQS) as compared to those diagnosed with COVID-19 in the study by John et al. [15]. In this study, the participants had a mean SQS score of 28.89 (SD = 12.22, n = 782). The mean SQS for individuals with IEI (43.0) was compared to the mean SQS for those with COVID-19 (28.89); there was a significant difference, $t(471) = 23.439$, $p < 0.001$. Regardless of the comparisons made to other studies, it is evident that most of the participants in this study did have moderate impairment in their perceived sleep quality. A chi-square test of independence was used to determine if there was any association between demographic or lifestyle factors that were included in the survey and sleep quality (using the SQS ranked as mild, moderate, or severe). Associations were identified between sleep quality and age, hours of sleep per night, time awake at night, times awake to urinate, attempted daytime naps, chronic pain, and mental health diagnoses.

Given that a bidirectional relationship between sleep and the immune system has been established [18], the investigation into sleep quality in patients with an IEI diagnosis is even more critical. Healthcare providers should perform a detailed health assessment which incorporates assessment of sleep quality. Medications, pain, and mental health should be evaluated as part of a comprehensive sleep assessment. Validated tools, such as the SQS, Pittsburgh Sleep Quality Index, Sleep Disorders Questionnaire, or Functional Outcomes of Sleep Questionnaire can be used to track sleep quality over time and determine when to implement interventions to improve sleep quality.

Sleep loss, reduced sleep duration, and sleep disturbance are associated with increases in inflammation [13]. Given that patients who are diagnosed with IEI are often at an already increased risk of elevated inflammatory biomarkers and autoinflammatory conditions, it is crucial to identify interventions to address issues that introduce additional inflammation. While pain had not been studied in IEI patient populations, 58.4% of the participants in this survey indicated that chronic pain was interfering with their sleep quality. Long-term poor sleep quality has been associated with increased risk of any chronic musculoskeletal pain and chronic widespread pain [19]. Healthcare providers should assess both acute and chronic pain, if present, and implement appropriate interventions for pain management.

Changes in sleep quality may happen with aging, with many older adults reporting unsatisfactory sleep quality and quantity [20]. Structured moderate to vigorous physical activity is associated with improved sleep quality and lower self-reported fatigue levels in older adults [11]. In

this study, only 31.0% reported that they engaged in regular physical activity. Individuals with an IEI diagnosis should be encouraged to participate in exercise and physical activity, as this may help their sleep quality, general health, and overall quality of life. In this survey, 28.1% participants reported anxiety, 28.5% reported depression, and 7.0% reported another mental health diagnosis. Given that more than half the participants reported a formally diagnosed mental health diagnosis, this is another important aspect that healthcare providers need to explore with their patient. A meta-analysis by Scott et al. [21] found a dose response relationship that greater improvements in sleep quality led to greater improvements in mental health and that improved sleep quality could contribute to reduced depression, anxiety, and stress. There may also be potential for the reverse, that improvements in mental health could lead to improved sleep quality. Addressing mental health issues may have a secondary effect of improving sleep quality for an individual IEI diagnosed patient. Managing a chronic health condition can significantly contribute to mental health challenges, making mental health assessment, referrals, and interventions especially important for patients with a diagnosis of IEI.

Sleep hygiene is a group of behavioral and environmental recommendations to encourage quality sleep [12]. In this survey, the participants did engage in several sleep hygiene practices, but widespread adoption of multiple sleep hygiene practices was not reported. A dark and quiet bedroom was most often used (78.6%), followed by avoiding large meals and caffeine prior to bedtime (61.1%). Only 52.6% reported the use of a consistent sleep schedule and only 10.2% avoided electronic use one hour before bedtime. Increased use of smartphones and other electronic devices has worsened the epidemic of poor sleep [22]. While there has been general support for the implementation of sleep hygiene practices to improve sleep quality, studies have shown better outcomes for individual practices and less conclusive results for global implementation of sleep hygiene education [12]. Healthcare providers should explore the sleep hygiene practices their patient is utilizing and encourage them to expand their use of these methods. Those patients who are utilizing few or no sleep hygiene interventions may find an improvement in sleep quality after implementing these routines. While there are a variety of medications that can be used for those who have poor sleep quality, cognitive behavioral therapy (CBT) has been shown to be more effective than medication for treatment of insomnia [20]. While this has not been explored as an intervention for individuals with a diagnosis of IEI, there is minimal risk posed with the use of CBT. More research is needed on the use of CBT to improve sleep quality in patients with an IEI diagnosis.

This study is limited in its generalizability to all IEI patients, given that 91.8% of participants were female, 83.8% had a diagnosis of CVID, and 95.5% were White/Caucasian. The demographics of the participants in this survey are not representative of the broader IEI patient population. However, given the number of respondents, the survey results are useful if evaluating this subgroup of patients. Future sleep quality assessments should be conducted across a broader patient demographic. This survey was also a sample of convenience, distributed through an online social media platform. Though social media surveys have advantages related to speed, cost, and accessibility, they do have a tendency to overrepresent young, White females, as was seen in this survey [23]. Surveys distributed through social media platforms are limited in accessibility to those who are members of the social media group. While this survey was distributed to multiple public and private IEI patient groups, the survey participants are limited to those who are actively engaging in those social media groups. Online social media surveys do not capture adequate representation of those who lack internet service, the elderly, low income, or those living in remote locations [24]. It would be beneficial to have a broader distribution of the survey that allows participation by those who do not have online access; distribution of the survey could be expanded through trusted healthcare providers to reach a wider demographic of IEI patients. All individuals with a diagnosis of IEI were encouraged to participate in the survey, regardless of their sleep or sleep quality. However, online surveys are at risk for sample bias and overrepresentation of the specific issue being explored [24]. Another significant limitation of this study was the lack of investigation into body weight or obesity as a risk factor. Elevated body weight and obesity are linked to poor quality of sleep; medical conditions, such as OSAS, can also impact sleep and sleep quality [25]. It is important to note that in this survey, 28.5% ($n = 156$) of participants did report a diagnosis of sleep apnea.

This survey, though limited in generalizability, suggests that individuals with IEI have a moderate degree of perceived impairment in sleep quality. This research study serves as justification that sleep quality issues are present in the IEI patient population and validates the need for more comprehensive studies on this topic. The United States Immunodeficiency Network (USIDNET) houses a database of information, which includes surveys and other data from patients with a diagnosis of IEI [26]. This, and other similar databases, contain survey responses to the Patient-Reported Outcomes Measurement Information System (PROMIS-29). The PROMIS-29 measures a variety of physical, mental, and social domains of health and includes four questions related to sleep and sleep quality [27]. It is evident from this research study that in-depth, sleep-specific questionnaires should be included as part of these patient data repositories.

Healthcare providers are strongly encouraged to incorporate sleep quality screening in their routine assessments

of patients with an IEI diagnosis. Valid and reliable tools should be used to track sleep quality over time and can assist in the determination of when to implement interventions to improve sleep quality. For patients with significant impairments in sleep quality, referrals should be made for diagnostic assessments, which may include polysomnogram, multiple sleep latency testing, or a maintenance of wakefulness testing. Referrals can then be made to specialists based on the aspect of sleep that is identified as impaired. Additionally, it is important to assess mental health and chronic pain in this patient population. Further interventions or referrals related to those areas should be made. Sleep and sleep quality are critical aspects of health that can impact quality of life, daily functioning, and long-term health outcomes. Assessing and providing appropriate interventions to improve sleep quality can make a lasting impact on IEI patient health and wellness.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10875-023-01474-y.

Author's Contribution All authors were involved in the development of the study design. Data analysis and the first draft of the manuscript were completed by Dr. Sowers. All authors were involved in the editing of the manuscript and review of the final manuscript.

Data Availability The authors are willing to share the original survey data collected in this study upon request.

Declarations

Ethics Approval This research study was IRB approved through Stockton University.

Consent to Participate Informed consent was obtained from all participants in this research.

Consent for Publication Consent for publication was obtained from all participants in this research.

Conflict of Interest The authors declare no competing interests.

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