Asian/Pacific Island Nursing Journal

Contents

Editorial

Advancing the Health and Nursing Knowledge of Asian and Pacific Islander People Through the Asian/Pacific Island Nursing Journal

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As the editor-in-chief, I am happy to announce the launch of a new member of JMIR Publications' open access family of journals, the *Asian/Pacific Island Nursing Journal* (APINJ). Created to fill the gap between nursing science and behavioral/social sciences, APINJ offers a forum for empirical, theoretical, and methodological issues related to Asian American and Pacific Islander ethnic and cultural values and beliefs as well as the biological and physiological phenomena that can affect nursing care. APINJ serves as a voice for nursing and other health care providers for research, education, and practice. APINJ is included in PubMed, PubMed Central, the Directory of Open Access Journals, and Scopus. As an open access journal, APINJ follows a continuous publication model, and articles are published as soon as they have been peer-reviewed and copyedited.

Nursing in Asia and the Pacific Islands comprises a rapidly growing group of professionals, and the region represents the fastest growing minority group in the United States. According to the 2020 United States census [1], there are 20.6 million people who identify as Asian, Native Hawaiian, or Other Pacific Islander alone (not in combination with another race), making up 6.2% of the US population. The 2020 United States census shows that 19.9 million people identified as Asian alone and 4.1 million people identified as Asian in combination with another race; approximately 690,000 people identified as Native Hawaiian or Other Pacific Islander alone, but almost 900,000 identified as Native Hawaiian or Other Pacific Islander in combination with another race. Asian people in the United States include more than 20 distinct ethnic groups with different languages, cultures, customs, and histories. Despite these substantial numbers, information about these groups is sorely lacking in publications that examine their health disparities, immigration and acculturation challenges, health education

needs, policy implications, and responses to varied interventions in acute care and community settings [2,3].

As the official journal of the Asian American / Pacific Islander Nurses Association, APINJ supports researchers, educators, and practitioners in addressing these critical information deficits by providing a quality, peer-reviewed, international forum for the exchange of knowledge in relation to Asian and Pacific Islander health and nursing care. APINJ features research papers; empirical, theoretical, and clinical articles; editorials; abstracts of recent dissertations; and conference summaries that relate to Asian American and Pacific Islander health and nursing written by those in the nursing and social sciences disciplines, such as clinical and developmental psychology, sociology, anthropology, social work, public health, education, genetics, pharmacology, infectious disease, oncology, cardiovascular disease, pulmonary function and disease, dermatology, wound healing, immunology, anesthesiology, endocrinology, gastroenterology, hematology, neonatology, nephrology, pathology, physiology, nutrition, pain management, sleep disturbances, dental health, and mental health.

Building on the JMIR foundation, the scope of APINJ includes, but is not limited to, methods, interventions, instrumentation, and educational techniques; theoretical foundations that increase the understanding of underlying mechanisms for changes in health and illness; biopsychosocial, spiritual, and ecological impacts on practice, education, and research; and policy issues as a result of rigorous research outcomes.

APINJ offers authors a rapid and thorough peer-review, professional copyediting, and professional production of PDF, XHTML, and XML proofs. This journal adheres to the same quality standards as our flagship journal, the *Journal of Medical Internet Research*.

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Conflicts of Interest

HA is the Editor-in-Chief, Asian/Pacific Island Nursing Journal.

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Abbreviations

APINJ: *Asian/Pacific Island Nursing Journal*

<u>Viewpoint</u>

Methodology Considerations in Studying Mental Health, Sleep Quality, and Biopsychosocial Determinants Among Chinese and Korean Americans During the COVID-19 Pandemic

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Abstract

Asians are one of the fastest-growing racial groups in the United States. The mental health of Asian Americans, particularly regarding depression and anxiety, needs significant attention. Various biopsychosocial factors interact to influence the risks of depression, anxiety, and sleep quality among Asian Americans. Currently, multiple methodological issues exist in the research of Asian Americans, such as limited data collection using Asian languages and inconsistent reporting of race and ethnicity data, which may be lacking entirely. All these methodological issues in research may account for the seemingly low prevalence rates of mental health problems among Asian Americans. In our study on mental health and sleep quality among Chinese and Korean Americans, we adopted multiple data collection strategies during the COVID-19 pandemic, including using culturally adaptive and validated measures as well as operating culture-sensitive procedures in the recruitment and data collection. The successful use of these strategies could promote early detection and personalized treatment of depression, anxiety, and sleep disturbance among Asian Americans. These strategies would further improve health care service use in this population.

International Registered Report Identifier (IRRID): RR2-10.1136/bmjopen-2020-047281

KEYWORDS

Introduction

The racial and ethnic inequalities in mental illnesses and mental health care service use are a significant public health problem in the United States. During the COVID-19 pandemic, the prevalence of depression, suicidal thoughts or ideation, and increased or newly initiated substance use was higher among Black and Hispanic adults compared with their White peers [1]. The Healthy People 2030 goals focus on the prevention, screening, assessment, and treatment of mental disorders and behavioral conditions. One of their objectives is to increase the proportion of primary care visits where adolescents and adults are screened for depression [2].

Asian Americans are frequently underrepresented from data on mental health; thus, they remain vulnerable to inequalities in the use of mental health care services and often bear a high burden of mental disorders by tolerating them in silence. Consequently, the existing data examining their mental health and access to health care for prevention and treatment of mental health issues are limited or of poor quality [3]. When we searched on PubMed using search terms and Boolean operators such as "(depression OR anxiety) AND Asian Americans," we retrieved only 781 articles published in the past 10 years compared with 3543 for African Americans and 4003 for Hispanics. This underrepresentation of Asian Americans in mental health research is concerning because Asian Americans are one of the fastest-growing racial groups in the United States,

with a record of 23 million Asian Americans from more than 20 Asian countries [4]. Chinese and Koreans combined represent about one-third of Asians in the United States [4].

Albeit limited, the existing literature has documented widespread depression and anxiety in Asian Americans communities [5,6]. Depression is the most frequently diagnosed mental disorder in Asian American adults [6]. However, there is a huge gap between the statistics on mental health depending on the data source (whether collected nationally or locally). According to the 2019 National Survey on Drug Use and Health, Asians had the lowest prevalence of MDE in comparison to other racial and ethnic groups: 8.5% for non-Hispanic White groups, 6.3% for non-Hispanic Black groups, 6.8% for Hispanics, and 4.7% for Asians [7]. By contrast, a recent systematic review of studies among Asian Americans reported a much higher prevalence of depression than the national statistics, ranging from 26.9% to 35.6% [6]. Moreover, 10.2% of Asian Americans were reported to experience anxiety disorder [8]. Similarly, Koh [3] reported that approximately 33% and 36.9% of the Korean Americans living in Washington DC were at risk for depression and anxiety, respectively; the prevalence of anxiety was even higher compared with findings from previous studies [8]. Despite the inconsistent reporting of depression and anxiety rates among Asian Americans, they tend to manifest more prevalent, persistent, and ongoing depressive symptoms compared with their White peers [6,8]. Additionally, Asian Americans with depression or anxiety likely experience sleep disturbance [9]. As reported, Asian Americans are more likely to report interrupted sleep patterns compared with non-Hispanic White groups (33% vs 28%) [10]. These changes in sleep patterns or sleep disturbance [9] may coincide with symptoms of depression or anxiety, but they may also be caused or exacerbated by the cumulative stress related to the negative experiences of being members of a racial and ethnic minority group. For example, experiencing the effects of daily racial microaggressions is often associated with poorer sleep quality and shorter sleep duration the following day among Asian Americans [11].

Importantly, the proportion of individuals receiving treatment for mental disorders was lower among Asian Americans compared with other racial and ethnic groups. In 2019, it was reported that 51.7% of Asian adults with major depressive episode (MDE) received treatment for depression in the previous year, while 70.2% of non-Hispanic White, 59.6% of non-Hispanic Black, and 58.0% of Hispanic adults with MDE received treatment [7]. Due to the stigma attached to mental disorders and lack of culturally competent mental health services, Asian Americans are less likely than their peers to seek treatment for depression and anxiety [6,12].

Risk Factors of Mental Health and Sleep Disturbance Among Asian Americans

The risks of depression, anxiety, and sleep disturbance among Asian Americans are determined by the interactions among various psychosocial factors, including racial discrimination, lifetime stress, nativity (foreign-born vs US born), immigration status (eg, citizen, permanent resident, or undocumented immigrant), and level of acculturation [6,13,14]. Biological factors also contribute to the risk of mental disorders. To date, various biological markers have been studied to predict mental disorders (eg, anxiety and depression), such as inflammatory markers, oxidative stress, energy balance hormones, genetic, and epigenetic factors [15]. Emerging evidence suggests that the gut microbiome (ie, the gut microbes and their genomes in the gastrointestinal tract) plays a critical role in human mental health and sleep disturbance via the microbiome-gut-brain axis [16,17]. The gut microbiome is heavily influenced by an individual's changes in lifestyle (eg, diet), stress, and geographic environment, which represent significant risk factors for depression, anxiety, and sleep disturbance during the immigration process [18]. The gut microbiome was also found to be associated with sleep disturbance [19]. Thus, studying the changes in the gut microbiome during and after migration could provide a unique opportunity to ascertain how external stimuli (eg, immigration status and lifetime stressors), psychological factors, and biological factors contribute to mental health disorders and poor sleep quality among Asian Americans during the immigration process (Figure 1). We conducted a parent study [20] to examine the relationships of psychosocial factors and the gut microbiome with anxiety, depression, and sleep disturbance among Asian Americans during the COVID-19 pandemic.

Figure 1. Risk factors of mental health and sleep disturbance for Asian Americans.
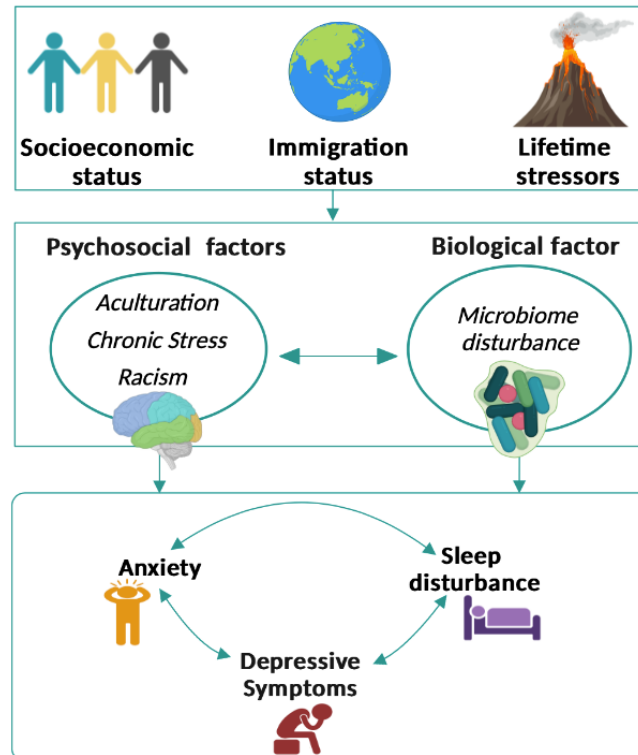
Current Challenges to Address Mental Health and Sleep Disturbance Among Asian Americans

The fact that Asian Americans make up the lowest proportions of reported mental disorders and mental health care use in the national statistics can be viewed through the health inequity lens [21,22]. When addressing mental health among Asian Americans, we should be mindful of existing systemic barriers to accessing mental health services (eg, unavailability of culturally competent health care) [23,24] and, importantly, collecting health data from Asian Americans.

Asian Americans are viewed as a "model minority" who are better off than other racial and ethnic groups in terms of various health outcomes, including mental disorders. This entrenched stereotype contributes to the underestimated rates of depression and anxiety in this community, which may develop or be exacerbated through migration and acculturation [5] and, in turn, depression and anxiety can negatively impact their lives. Moreover, the existing literature has documented various methodological issues in collecting and analyzing data about Asian Americans. For example, the stigma toward mental health [23], linguistic mismatches between the languages of the study and study participants [25,26], and subsequently, unfamiliarity with the research process [26] may jeopardize the integrity of the research process from participant enrollment to data collection, analysis, and reporting [27]. Other methodological issues include misrepresentation and underrepresentation in research; limited data collection using Asian languages (eg, Chinese and Korean); a lack of or inconsistent reporting of race and ethnicity data in disease registries, health plans, and hospitals [27,28]; and insufficient degrees of disaggregation by subethnic group in the data [24]. Most studies categorized all Asian subethnic groups into one group, "Asians," and

generalized one subethnic group's experience to all others due to the small sample sizes [29]. These identified issues result in a lack of high-quality data to ascertain the mental health and care use landscape, and their risk and protective factors among Asian Americans. Moreover, it is unknown to what extent the current criteria for mental disorders are valid and reliable for Asian Americans, considering that current diagnostic and assessment practices are mainly based on European or North American populations [3].

Other nonsystemic barriers encompass unique Asian cultures and experiences in the United States and diversity within the Asian population. Specifically, many Asian cultures embrace Confucianism, which discourages the open discussion of mental illness and the use of professional services [3]; they also view the body and mind as unitary rather than separate entities. Thus, the Asian population is known to express their mental distress in somatic, not psychological, symptoms, making the diagnosis and treatment of mental disorders more difficult [3]. Furthermore, because the Asian American population comprises diverse subethnic groups, such as Chinese (24%), South Indians (21%), Filipinos (19%), Vietnamese (10%), Koreans (9%), and Japanese (7%) [4], it is challenging to generalize findings on Asian Americans in general or on a particular subethnic group compared to other subethnic groups [3], particularly considering the different distributions of chronic health conditions [29].

Although different methodologies have been recommended to guide research among Asian Americans [27,28], few guidelines exist to inform the best practices to design and conduct research on mental health and sleep disturbance in this population. Therefore, the purpose of this study was to suggest methodological considerations in recruiting Asian Americans in the community during the COVID-19 pandemic and to collect

more reliable data on their mental health and sleep quality, as well as their biopsychosocial risk and protective factors. These suggestions were formulated based on our experience in carrying out a parent study [20] to examine the associations of psychosocial determinants and the gut microbiome with mental health and sleep quality among Chinese and Korean immigrants. Here, a summary of our parent study is presented. Subsequently, we will discuss some best practices to design a study, recruit participants, and collect and manage biopsychosocial data from subethnic Asian American groups.

Methodology

Summary of the Parent Study

This was a 1-year pilot project adopting an observational, cross-sectional study design. The study aimed to examine how psychosocial factors (eg, lifetime stress, racial discrimination, acculturation, and the gut microbiome) contribute to anxiety, depression, and sleep quality among Asian Americans [20]. Our study population was those aged 18 years or older, self-identified as Chinese or Korean, reading and speaking in English, Chinese, or Korean, and residing in Atlanta, Georgia. The participants were recruited in web-based and offline settings. The data were collected between November 2020 and May 2021, at the height of the current COVID-19 pandemic. Initially, we aimed to enroll 60 participants (n=30, 50% Chinese and n=30, 50% Korean), but we ultimately recruited 37 participants (n=17, 46% Chinese and n=20, 54% Korean). Our data collection methods included multilingual web-based surveys and biospecimen (fecal sample) collection for the gut microbiome. Specifically, we selected culturally appropriate measures with high reliability and validity for the variables of interest. We translated some of the instruments into Chinese and Korean. Subsequently, a battery

of measures (Table 1) was pilot tested and delivered via web-based survey platforms, including REDCap [30] and LimeSurvey. Moreover, we shipped a stool sample collection kit to the participants' addresses, with which they could easily collect and ship the obtained fecal samples back to the research team. All steps of this process (Figure 2) ensure a rigorous approach to studying mental health, sleep quality, and underlying biopsychosocial factors among Chinese and Korean Americans in Atlanta, Georgia, particularly during the COVID-19 pandemic.

Of importance, our study attempted to address the methodological issues mentioned earlier. First, our target populations were Chinese and Korean adults. Acknowledging potential subethnic differences in many characteristics, we analyzed both aggregated and disaggregated data to examine the associations between biopsychosocial factors and mental health and sleep quality. Second, we made recruitment materials, web-based surveys, and study instructions available to participants in 3 languages (English, Chinese, and Korean). Third, when choosing the survey instruments, we tried to select those designed to reflect Asian American experiences. Lastly, our research team comprised Chinese and Korean bilingual investigators fluent in English and Chinese or Korean. We also strategically employed a coprincipal investigator system, with one principal investigator being Chinese and the other being Korean, to equally represent both subethnic groups' perspectives and lived experiences from the study design to the data analysis stage. The Chinese investigators communicated with Chinese-speaking participants, and the Korean investigators did the same with Korean-speaking participants. We believe these collective efforts increased the accuracy of the measured characteristics among Chinese and Korean Americans.

Table 1. Study measures.

| Variable, measure, and instrument	Linguistic version		
	English	Chinese	Korean
Sociodemographic and clinical factors			
Demographics Short Form (eg, sociodemographic characteristics, health behaviors, and medical history)	X[a]	T[b]	T
Psychosocial factors			
Acculturation			
Nativity (foreign-born vs US born, duration of US residence)	X	T	T
Suinn-Lew Self Identity Acculturation Scale	X	T	T
Stress			
Adult STRAIN[c]	X	T	T
Acculturative Stress Scale	X	X	X
Subtle and Blatant Racism Scale for Asian Americans	X	T	T
Diet			
PrimeScreen Survey	X	T	T
Biological factor			
Gut microbiome			
Fecal specimen	X	T	T
Outcomes			
Depression			
PROMIS[d] Short Form–Depression	X	X	X
Anxiety			
PROMIS Short Form–Anxiety	X	X	X
Sleep disturbance			
Pittsburgh Sleep Quality Index	X	X	X

[a]X: available versions of the measures.

[b]T: translated versions if needed.

[c]STRAIN: Stress and Adversity Inventory.

[d]PROMIS: Patient-Reported Outcomes Measurement Information System.

Figure 2. Flowchart of methodology considerations in research among Asian Americans.

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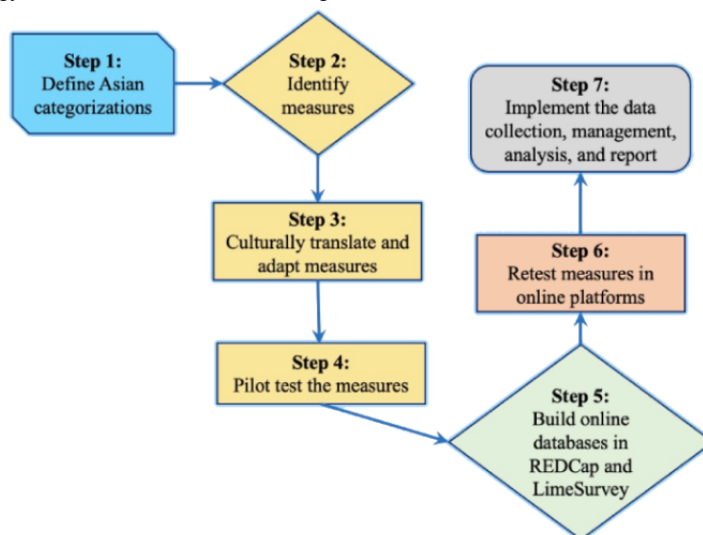
Ethics Approval

All participants provided written informed consent. Ethics approval was provided by the Emory University Institutional Review Board (IRB #: STUDY00000935).

Methodology Considerations in Studying Mental Health and Sleep Disturbance for Asian Americans

Figure 2 describes the flowchart of a 7-step procedure in studying mental health and sleep disturbance among Asian Americans. Details included how we defined a target population of Asian Americans; identified appropriate survey measures; translated, culturally adapted, and pilot tested the selected survey measures; built a web-based database for multilingual surveys; retested the survey measures on web-based platforms; and finally collected, managed, and analyzed the data.

Step 1: Defining a Target Asian Americans Population

Currently, most surveys lack or have limited subgroup categorizations for Asian Americans in terms of nativity, subethnicity, and geolocation [27]. In our study, we defined Asian Americans as those self-identified as Chinese or Korean, including the first- and second-generation Chinese and Korean immigrants, and residing in the Greater Atlanta area, Georgia, US. First-generation immigrants are foreign-born and living in the United States, regardless of the duration and purpose of residence in the United States. Second-generation immigrants are native-born and currently living in the United States. Recent studies using large-scale national epidemiological surveys have demonstrated that the prevalence of depressive symptoms varies in different subgroups based on immigration-related characteristics [31]. The diversity loss and composition changes

in the gut microbiome are determined by changes in the geographic living environment [32], diet acculturation [32,33], risk factors (eg, chronic stress [34] and racial discrimination [35]), and protective factors (eg, stress resilience [36] and social support [37]). Thus, it is important to recruit specific subethnic Asian American groups with different immigrant generations due to their distinct identities and lived experiences that may shape their risks of mental health and sleep disturbance.

Step 2: Identifying Appropriate Measures

Validated measures are essential tools to ensure reliable and accurate assessment and study results [38]. After finalizing the research questions and the study population, the next step is identifying appropriate measures that promote cultural competency by taking Asian Americans' language proficiency into account. Specifically, these are appropriate measures taken for languages available in mother tongues (eg, Chinese and Korean) of the target populations. Choosing the right instruments for studies can be challenging when various measures are available to assess depression, anxiety, and sleep quality, while all measures have their own unique pros and cons. To overcome these difficulties, we used the instrument selection and evaluation criteria (ie, reliability, validity, standardization, and practicality [39]; Table 2) and selected the 6-item Patient-Reported Outcomes Measurement Information System (PROMIS) Short Form–Depression [40], the 6-item PROMIS Short Form–Anxiety [41], and the 10-item Pittsburgh Sleep Quality Index [42] for our outcome variables (depression, anxiety, and sleep disturbance). Using the existing guideline made the instrument selection process less daunting and more systematic.

Table 2. Instrument assessment and evaluation criteria.

Criteria	Definition
Reliability	The degree to which "...scores for people who have not changed are the same for repeated measurements, under several situations," including test-retest reliability, intrarater and interrater reliability, and internal consistency [43].
Validity	The degree to which an instrument truly measures the constructs it purports to measure, including content and face validity, criterion validity, and construct validity [44].
Standardization	The degree to which it can be used across persons so that the administration instructions, content format, and scoring procedures are predetermined and identical no matter who administers and undertakes the scoring.
Practicality	To assess whether the measure is lengthy to complete or complex to score.

Subsequently, we asked the original developers for approval to use those instruments. These 3 measures are available in English, Chinese, and Korean, with excellent reliability and validity among various populations, including Asian Americans [40-42]. We paid a relevant copyright fee to use the Chinese and Korean versions of PROMIS measures and secured corresponding scoring sheets for each measure. Notably, despite the availability of alternative measures, which were free of charge, we selected the PROMIS measures for depression and anxiety to produce data comparable with existing data since the PROMIS, funded by the National Institutes of Health, successfully addressed the lack of standardization in patient-reported outcomes, among which little comparability exists [45].

Similar instrument selection and evaluation criteria [20] were used to select measures for the psychosocial determinants, as

with as the outcome variables (Table 1). These measures included the Suinn-Lew Self Identity Acculturation Scale (to measure acculturation), Acculturative Stress Scale (to measure acculturative stress), Subtle and Blatant Racism Scale for Asian Americans (to assess interpersonal racial discrimination), and Adult STRAIN (Stress and Adversity Inventory; to assess lifetime stress). Confounding factors such as sociodemographic, medical, and behavioral characteristics, as well as diet, were measured by the demographic short form and the PrimeScreen (a brief dietary screening tool), respectively. These instruments have been previously validated, and the English versions are widely used. Some of these measures required translation or adaptation for use in Asian Americans, as discussed below. Lastly, biological data of the gut microbiome were collected using fecal specimens. The sample collection was performed following the Human Microbiome Project protocol [46]. The

adapted version of the gut microbiome data collection has been tested among adults [47] and children with chronic illnesses [48].

Step 3: Translating and Culturally Adapting the Selected Measures

Due to the limited use of Asian languages in data collection [27], our study provided participants with the aforementioned self-report measures in 3 languages (English, Chinese, and Korean) to decrease sampling bias from the high rates of limited English proficiency and linguistic isolation (defined as living in a household in which all members aged 14 years and older speak a non-English language and also having difficulty with English [49]) in Asian Americans [50].

For measures that had not yet been translated into Chinese or Korean, we contacted the instrument developers to obtain permission to use and translate them. Following the instrument translation and cross-cultural adaption guideline from the World Health Organization [51], the Subtle and Blatant Racism Scale for Asian Americans, Adult STRAIN, and PrimeScreen were translated into Chinese and Korean versions. The instrument translation process included forward translation, expert panel back translation, pretesting, and finalizing the measures [51].

We formed a bilingual instrument translation team, which included 3 research team members and 1 external member with extensive research expertise in sociology, Asian immigrants, stress, and mental health. All these members were fluent in English and Chinese or Korean. After one team member translated all the instruments into Chinese or Korean versions (forward translation), another member translated them back into English versions (backward translation). Subsequently, both members compared the original English and back-translated English versions to evaluate the semantic equivalence of the translation. Consensus discussions between these 2 members resolved discrepancies in the translation and meanings to ensure conceptual equivalence across the translations. This instrument translation process ensures the accuracy and validity of instruments across diverse populations [52]. Regarding collecting fecal specimens for the gut microbiome, all the instructions for participants, standard operating procedures, as well as home-based sample collection and return shipping instructions were prepared in English initially and then translated into Chinese and Korean. The Chinese and Korean versions of the documents were reviewed and tested by bilingual research team members before initiating the data collection.

Step 4: Pilot Testing the Measures

Multiple procedures can be used during the instrument translation process to test the final translated instrument for clarity, comprehensiveness, appropriateness, or cultural relevance, such as a monolingual test (ie, examination of the target language version among monolingual subjects) and a bilingual test (ie, examination of both source and target language versions among bilingual subjects) [52]. Current approaches to the instrument test vary. Our study tested the translated instruments among bilingual subjects speaking English and Chinese or English and Korean. Three first-generation Asian immigrants in the research team tested each language version

of the same instrument to identify potential issues in administration. Lastly, our protocol for collecting fecal specimens did not need pilot testing since it has already been demonstrated to work well in our previous studies [47]. In short, we used pictorial and written step-by-step instructions to coach participants to obtain their fecal samples using the home-based stool specimen collection kit.

Step 5: Building a Web-Based Database for Multilingual Surveys

The COVID-19 pandemic has led to a global shift in clinical research methodologies. Many remote data collection approaches (eg, web-based survey platforms, group conference calls, and phone calls) have been widely adopted by researchers to mitigate the impact of restrictions in research activities [53]. As a result of working collaboratively with various partners at our institution such as the IT department, Office of Nursing Research, and Institutional Review Board, the consent form, data collection measures (both original and translated versions), and data management were seamlessly connected between 2 different web-based survey platforms (REDCap and LimeSurvey). This enabled all participants to provide their consent and complete the web-based surveys easily. Importantly, our bilingual team members assisted the participants in their preferred languages throughout recruitment and data collection.

After pilot testing the instruments, we built web-based surveys in 3 languages (English, Chinese, and Korean) on REDCap [30], a web-based software and workflow methodology for designing, collecting, and managing clinical and translational research databases. Then, we consulted a data manager at the Office of Nursing Research to help build the different versions of the web-based surveys in a coordinated manner, with all 3 language versions of the questionnaires being contained in one REDCap project. Our structure of the web-based surveys—multiple language versions on a single platform—caused many challenges. First, we needed to link the participant's screening survey with the main survey in the language the participant initially selected to use. It was problematic because we had 1 screening survey shared by all participants speaking different languages and 3 language versions of the main surveys. The screening survey asked the participant to click on the preferred language: "English," "한국어," and "中文." Thus, we had to create a branching logic to connect, for example, an answer saying "한국어" with the main survey in Korean. Second, because all 3 versions of the questionnaires were built one after another (English questionnaires appeared first, followed by Korean and Chinese questionnaires), we needed an algorithm for each language survey to stop before it automatically moves to the next questionnaire in a different language. Lastly, although our main survey platform was REDCap, the Adult STRAIN was built by a developer on LimeSurvey. We had to link REDCap and LimeSurvey, which was crucial since lifetime stress exposure assessed by the Adult STRAIN was one of our study's key variables of interest. We were concerned about possible dropouts if 2 survey platforms were sent to the participants, as they might be willing to complete one survey but not the other. As a solution, we embedded the Adult STRAIN's URL at the end of the REDCap survey so that the participants were seamlessly

led to the Adult STRAIN survey. Since we had to link the data from REDCap and LimeSurvey through a unique survey ID assigned to each participant, we created a field in REDCap before the transition to LimeSurvey to inform the participant of their unique REDCap survey ID by using the piping function. The Adult STRAIN asked the participants to enter the study ID. By entering the REDCap survey ID in that field, we could link both surveys for each participant.

Step 6: Retesting the Measures on Web-Based Platforms

The final step was to retest our measures in the form of web-based surveys before moving them from the testing stage to production stage and to identify and resolve any issues regarding transitions of questionnaires, transitions between 2 web-based platforms (REDCap and LimeSurvey), and mismatches between the participant's selected language and the language of the survey. The same 3 bilingual research team members independently tested the 3 language versions of the web-based surveys. This process validated the web-based surveys' feasibility, integrity, and usability from the participant's perspective. All the issues identified during the retesting process were addressed by making the necessary modifications to the surveys, and the process was tested repeatedly until we were confident to launch the web-based surveys.

Step 7: Collecting, Managing, and Analyzing Data

During the implementation stage, several strategies were suggested to improve research engagement with potential participants and reduce mistrust that Asian immigrants might have toward research. First, a multilingual research team was built to promote participant accrual and data analysis. Our team included members with a Chinese or Korean cultural background who could fluently speak English and either Chinese or Korean. In addition, our team members had extensive research experience working with the Asian populations of interest. Second, we established an advisory board comprising academics with expertise in immigrant populations and mental health, as well as community members from churches and clinics, such as a Korean pastor and a Chinese clinician (nurse practitioner). All the community members were Chinese or Korean and served Chinese or Koreans in the Greater Atlanta area. The goal of the advisory board was to improve the research team's engagement with and accessibility to the target Asian populations. Third, our data collectors or points of contact were matched with participants by the subethnic identity and language, which enabled the team to answer the participants' questions or address concerns in a culturally sensitive fashion.

Lastly, a detailed standard operating procedure was created to collect and manage the web-based surveys and biological data. When potentially eligible participants contacted the research team, our bilingual team members emailed them to make an appointment for a brief screening call. During the screening call, if participants met the inclusion criteria and remained interested, the researchers obtained their verbal consent to take part in the study. Due to the COVID-19 pandemic, there were no in-person interactions with participants. Upon obtaining participants' informed consent, the bilingual team members emailed them a link to the REDCap web-based survey. The participants completed the web-based survey in their preferred language. They provided their contact information (eg, name, mailing address, phone number, and email address) in the screening survey, where we specified why this information was requested. For example, participants' names and mailing addresses were used to ship the microbiome data collection kits, including pictorial and written instructions in English, Chinese, or Korean. Participants' phone numbers were used to receive their verbal consent, and email addresses were used to send the study compensation upon the subjects' completion of the study procedures. Our research staff also sent weekly reminders prompting the participants to return their stool samples to the research team.

All self-reported subject data were stored on REDCap and LimeSurvey (Adult STRAIN only). Before statistical analysis, all the data were reviewed for quality, distributions, and missing data bias. Descriptive analyses, including count, percentage, mean, and standard deviation, were used to describe the participants' characteristics and outcome variables including anxiety, depression, and sleep disturbance. When the data were not normally distributed, we used nonparametric statistics, including the Mann-Whitney U and Spearman correlation tests. Spearman correlation was used to examine the associations among anxiety, depression, and sleep problems. For the biological data, the stool samples were placed in −80 °C freezers until DNA extraction. Based on the Human Microbiome Project protocol, the microbial DNA was extracted from fecal specimens using the Power Soil isolation kit (MO BIO Laboratories, Carlsbad, CA, US). The 16S rRNA V3-V4 gene regions [54,55] were extracted and sequenced by Emory University's Integrated Genomics Core. All analyses were conducted using Quantitative Insights into Microbial Ecology 2 [56-58] and R 3.3.3 (R Foundation for Statistical Computing).

Discussion and Conclusion

In our study, the data collection methods—multilingual web-based survey (English, Chinese, and Korean) and biospecimen collection (gut microbiome)—were well accepted by Chinese and Koreans, and no specific concerns or inconveniences were reported by the participants. Within 5 months, 37 Chinese and Korean immigrants were recruited and finished the self-reported data collection, and 21 (57%) of them provided the gut microbiome data.

While recruiting Asian Americans was somewhat challenging, it was still feasible to study their mental health and sleep quality during the COVID-19 pandemic. During the pandemic, Asian Americans have been a target of racial discrimination, including aggression (eg, verbal threat) and physical violence. Those residing in the Greater Atlanta area were especially impacted, either directly or indirectly, by the Atlanta spa shooting by an armed White male who killed 8 women of Asian descent in March 2021. These racially targeted incidents and the social justice movement across the United States might encourage Asian Americans to pay more attention to their mental health and sleep problems, thus convincing Asian Americans to be more willing to participate in this study or other similar studies. Moreover, we found it acceptable to examine both the biological (ie, gut microbiome) and psychosocial (eg, lifetime stress,

racism, and acculturation) determinants through noncontact measures in the Chinese and Korean communities.

This paper discussed the current methodological issues in researching Asian Americans' mental health and sleep quality and suggested multiple solutions, based on our parent study, to mitigate such research problems at the design stage. Islam et al [27] have summarized methodological issues for collection, analysis, and reports of large data sets in Asian Americans, such as US Census, American Community Survey, and the National Health and Nutrition Examination Survey. Poor sampling and low representation of the Asian American population were critically addressed in national-level data sets. Additionally, very limited existing data combined both biological and psychosocial determinants together to contribute to mental health outcomes among Asian Americans [20]. To address these methodological issues, we specifically proposed narrowly defining Asian Americans as a study's target population; selecting culturally adapted and validated measures; translation and reiterative testing; using practical data collection methods (eg, web-based survey, collecting samples at home, and shipping back the samples with prepaid postage); and preparing for culturally appropriate standard operating procedures for recruitment, data collection, and study management. The proposed methods could serve as a guide to other researchers investigating the role of biopsychosocial determinants in mental health and sleep disturbance among Asian Americans.

This study has several limitations to be addressed. Our parent study focused on the mental health and sleep quality in a healthy population. Participants' physical status, such as disease conditions, may present further methodological issues in studying Asian Americans. The 7 steps proposed in this study should be further evaluated among Asian Americans with different care needs. In addition, the best practices of methodology were derived from a pilot study (eg, small sample size and geographic area limitation) among Chinese and Korean Americans. Our study methodology and results may not be generalizable to other Asian American groups, such Vietnamese and Filipino, and this methodology should be carefully evaluated in other Asian subethnic groups. Lastly, the best practices from small-scale studies of Asian Americans should be compared with national-level data sets to confirm the validity of the methodology practices and thereby ensure the rigor of the findings.

In conclusion, this study demonstrated some best practices for design, recruitment, data collection, and analysis among Asian Americans based on an exemplar parent study conducted during the COVID-19 pandemic. Implementing best practices will provide high-quality data that enable us to determine more accurately the landscape of mental health inequities affecting Asian Americans.

Disclaimer

Neither of the funders had a role in the design, implementation, or analysis of this study.

Authors' Contributions

JB, WZ, DC, and SK designed, implemented, and contributed to this manuscript. All authors were involved in measure translations and approved the final manuscript for publication.

Conflicts of Interest

None declared.

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Abbreviations

MDE: major depressive episode
PROMIS: Patient-Reported Outcomes Measurement Information System
STRAIN: Stress and Adversity Inventory

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Original Paper

Online Food Security Discussion Before and During the COVID-19 Pandemic in Native Hawaiian and Pacific Islander Community Groups and Organizations: Content Analysis of Facebook Posts

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Abstract

Background: The Native Hawaiian and Pacific Islander (NHPI) population experiences disproportionately higher rates of food insecurity, which is a risk factor for cardiometabolic diseases such as cardiovascular disease, type 2 diabetes, obesity, and hypertension, when compared to white individuals. Novel and effective approaches that address food insecurity are needed for the NHPI population, particularly in areas of the continental United States, which is a popular migration area for many NHPI families. Social media may serve as an opportune setting to reduce food insecurity and thus the risk factors for cardiometabolic diseases among NHPI people; however, it is unclear if and how food insecurity is discussed in online communities targeting NHPI individuals.

Objective: The objective of this study was to characterize the quantity, nature, and audience engagement of messages related to food insecurity posted online in community groups and organizations that target NHPI audiences.

Methods: Publicly accessible Facebook pages and groups focused on serving NHPI community members living in the states of Washington or Oregon served as the data source. Facebook posts between March and June 2019 (before the COVID-19 pandemic) and from March to June 2020 (during the COVID-19 pandemic) that were related to food security were identified using a set of 36 related keywords. Data on the post and any user engagement (ie, comments, shares, or digital reactions) were extracted for all relevant posts. A content analytical approach was used to identify and quantify the nature of the identified posts and any related comments. The codes resulting from the content analysis were described and compared by year, page type, and engagement.

Results: Of the 1314 nonduplicated posts in the 7 relevant Facebook groups and pages, 88 were related to food security (8 in 2019 and 80 in 2020). The nature of posts was broadly classified into literature-based codes, food assistance (the most common), perspectives of food insecurity, community gratitude and support, and macrolevel contexts. Among the 88 posts, 74% (n=65) had some form of engagement, and posts reflecting community gratitude and support or culture had more engagement than others (mean 19.9, 95% CI 11.2-28.5 vs mean 6.1, 95% CI 1.7-10.4; and mean 26.8, 95% CI 12.7-40.9 vs mean 5.3, 95% CI 3.0-7.7, respectively).

Conclusions: Food security–related posts in publicly accessible Facebook groups targeting NHPI individuals living in Washington and Oregon largely focused on food assistance, although cultural values of gratitude, maintaining NHPI culture, and supporting children were also reflected. Future work should capitalize on social media as a potential avenue to reach a unique cultural group in the United States experiencing inequitably high rates of food insecurity and risk of cardiometabolic diseases.

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Introduction

Background

Food security is defined as "enough food for an active, healthy life" for all members of a household [1]. In contrast, a household is considered to be food insecure when the provisions outlined for food security are limited by money or lack of resources [1]. Food insecurity is associated with poorer outcomes in the prevention and management of chronic cardiometabolic diseases such as diabetes, hypertension, obesity, and cardiovascular disease [2-5]. These disease outcomes are a product of the compensatory behaviors that members of food-insecure households employ to avoid hunger, which can include relying on nutritionally poor, calorie-dense foods [6].

The prevalence of food insecurity in the United States has increased during the COVID-19 pandemic, impacting an estimated 54 million households [7], as many household members experienced periods of under- or unemployment. In attempts to ensure that US households had access to food, many nutrition assistance programs evolved during the COVID-19 pandemic. These evolutions included the rapid expansion of the US Department of Agriculture's pilot program for Supplemental Nutrition Assistance Program (SNAP) benefits to be used online [8]. As internet and social media play a growing role in how individuals access food and nutrition information [9], it is important to consider how the food environment—defined as the interface where people interact with the wider food system—becomes increasingly digital [10]. A scoping review of studies of the digital food environment demonstrated how social networking platforms can be used to shape food culture, drive trends, and also serve as an abundant source of health and nutrition information [9].

Social networking platforms, and the online communities they foster, have been capitalized on in various ways in efforts to address chronic cardiometabolic diseases and food insecurity. Facebook is one of the largest online social networking platforms, which was used by over 2 billion people each month in 2019 and 2020 [11]. Facebook has been used to facilitate emotional and informational support via peer-to-peer and caregiver-to-patient interactions, leading to improved disease self-management among patients with diabetes [12]. However, these approaches to focus on cardiometabolic diseases using social media do not appear to have yet been adapted to address food insecurity. In a scoping review of 39 studies of digital technology use in food assistance programs, only a single study described the use of social media by a food pantry to communicate with clientele [13]. Another single observational study found that consuming information about COVID-19 online was associated with individuals' concerns about food insecurity [14]; however, it remains uncertain how social media may be used to discuss, and ultimately address, food insecurity.

Native Hawaiian and Pacific Islander (NHPI) communities are a priority population for consideration as the digital food environment continues to evolve in the United States. NHPI adults experience a disproportionately higher prevalence of cardiovascular disease, diabetes, hypertension, and obesity compared to other demographic groups [15,16]. Additionally, a recent study showed that NHPI adults experience a higher prevalence of food insecurity (21%) than their non-Hispanic white counterparts (8%) [17]. A population-based survey of primarily NHPI adults (N=637) in low-income households found that very low food security was strongly associated with greater odds of both hypertension and diabetes [18]. Interventions to address these dual burdens of cardiometabolic disease and food insecurity among NHPI adults are needed. NHPI populations have distinct cultural characteristics, including values, history of foreign colonization and exploitation, and emigration to the continental United States, warranting culturally informed interventions [19-21].

Context of the Study

Healthy Hearts Among Pacific Islanders (HHAPI) is an educational program created by and for NHPI people. The goal of HHAPI is to utilize culturally grounded evidence-based interventions to mitigate cardiometabolic conditions in the NHPI population via self-management of hypertension and diabetes at the individual, family, and policy levels. At the individual and family levels, HHAPI began in 2016 with in-person hypertension management classes hosted in community organizations in the Pacific Northwest, with one of the largest NHPI populations outside of Hawaii [22], which then shifted online in 2020 due to the COVID-19 pandemic. At the policy level, HHAPI initially intended to influence grocery store labeling of foods as either being low in sodium or high in potassium. Given the unanticipated changes with the COVID-19 pandemic, including the growing importance of social media, the HHAPI project shifted to observing the online food environment and discussions of food insecurity among NHPI people living in the Pacific Northwest, as an opportunity to better understand social media as a potential mechanism to decrease food insecurity and cardiometabolic conditions among NHPI adults.

The purpose of this study was to explore the online presence (static website, social media accounts) of NHPI-serving community groups and cultural or health-focused organizations in Washington state, and to compare the nature (eg, educational, event promotion, resource sharing) and frequency of food insecurity–related messages posted on their social media sites from March through June 2019 and from March through June 2020. We also evaluated the amount and type of engagement (ie, likes, shares, comments) on food insecurity–related messages by the nature of the post.

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Methods

Sample

The sample of online data was extracted from publicly accessible Facebook pages and groups. On Facebook, individuals make posts, comprised of text, image(s), video(s), and/or hyperlink(s) to other webpages, and other individuals can engage with the post. Engagement includes commenting with their own text, image(s), video(s), and/or hyperlink(s), or by clicking the "reaction" button to show one of seven possible reactions (Like, Love, Care, Haha, Wow, Sad, and Angry) as a small, animated symbol listed under the original post [23,24]. Facebook posts can be made on an individual's profile; a page representing a business, organization, or event; or within a group. Pages for businesses, organizations, or events allow for staff or volunteers to make posts to communicate with their target audience. In contrast, Facebook groups are online spaces that allow for any group members to make posts to communicate around shared interests or identities, allowing for a multidirectional conversation. Facebook groups can be public and visible to any Facebook user, or they can be private, restricted to Facebook users who have applied to join the group and have been formally accepted by group administrators.

Facebook business pages and groups focused on serving NHPI community members in the Pacific Northwest region were identified through consultation with three staff members who identified as Native Hawaiian or Pacific Islander and lived in the Pacific Northwest, a region with large communities of NHPI people. Each group's Facebook page or group was reviewed to ascertain corresponding details about each organization's mission or objective. To help maintain confidentiality, the names of the groups and organizations are not included in this manuscript.

Ethics Approval

The study was certified as "Exempt" from approval by the Washington State University Institutional Review Board (IRB) on March 22, 2021 (IRB #18784).

Keywords

The list of keywords used to identify posts related to food security was generated in three steps. First, the keywords were identified through a review of related literature [25-29], which included the terms food desert, food insecurity, food security, food supply, food access, food sufficiency, and food insufficiency. Next, the list was supplemented with plain-language synonyms or related terms to include free food, free lunch, free breakfast, free dinner, free plate, free meal, food pick-up, boxed meals, boxed food, food aid, food kitchen, food distribution, meal center, food donation, hunger, and hungry. Lastly, the list of terms was reviewed by a member of the research team with expertise in food security and experience in conducting systematic literature reviews. Based on their suggestion, the final list of keywords included additional terms referring to food assistance programs (food stamp, food bank, food shelf, food pantry, food drive, soup kitchen, food closet, WIC [Special Supplemental Nutrition Program for Women, Infants, and Children], SNAP, EBT [Electronic Benefits Transfer], SNAP-Ed [SNAP Education], senior meals, and school lunch).

Data Extraction

One research team member searched all identified Facebook pages and groups using each keyword as the search term. The results were restricted to posts made in the months of March through June in the years 2019 and 2020 to compare social media engagement before the COVID-19 pandemic to the same period during the pandemic. The researcher conducting the searches was not a member of any of the Facebook groups or a follower of the Facebook pages searched. All searches were logged and the date of any resulting posts was documented. Each post was then assessed for its relevance to food security. Posts were considered related to food security if they contained information about food assistance opportunities/events or about individual or community needs for food due to income or access constraints. If the post was considered relevant to food security, additional data were documented about the content of the post (ie, text, web links, images, videos) as well as the amount and type of engagement (ie, comments, shares, and reactions). All posts that were not considered relevant were excluded from coding and analysis. These searches were conducted between June and August 2021.

Qualitative Coding Procedures

To identify and quantify the nature of posts identified, a content analytical approach was used to assess patterns of posts and related engagement by their categorical nature [30]. This process began after all searches were completed between September and October 2021. Three members of the research team independently reviewed all of the relevant posts identified, and created memos that reflected possible codes, corresponding definitions, and example posts from the data set. Two members of the research team reviewed the relevant literature to identify possible literature-based codes that have been used in prior research on food security, public health, or online information exchange. These memos and potential literature-based codes were discussed by the three researchers as a group and used to create an initial codebook that was used by all three researchers to independently code the data. The agreement of these independently coded data was evaluated according to the percentage agreement between coders. Differences in interpretation or application of the codebook during the coding process were evaluated and discussed as a group to refine the codebook and maximize clarity and specificity. The final codebook was used by the group to review and finalize codes for all posts and accompanying comments that characterized the nature of information shared and audience engagement.

Analysis

To describe the online presence of the NHPI-serving groups and organizations identified, the purpose or mission of the organization's page or group was broadly categorized. Means and frequencies were used to describe the number of users engaged by each page or group. To assess the nature and engagement of posts, the number of posts identified per page by year and types of engagement (eg, reactions, shares) were enumerated. Codes resulting from the content analysis were

described and compared by year, page type, and engagement. Qualitative coding was organized in a spreadsheet (Excel, Microsoft Office 365) and quantitative descriptive analyses were conducted in STATA/MP 17.0 (StataCorp, LP).

Results

Data Summary

Seven relevant Facebook pages (n=5, 71%) or groups (n=2, 29%) were identified. Broadly, the stated missions or objectives of these organizations and groups created a welcoming online space to build community among Pacific Islanders, share resources, promote events or local businesses, preserve culture, and/or address social or health inequities. All groups or pages had, on average, 4229 (SD 2731) followers or members. Facebook groups had, on average, a greater number of members (mean 6010, SD 2279) than pages had followers (mean 3516, SD 2769).

Across all groups or pages, 1594 posts were identified using all search terms during the selected time periods. Of these, 278 posts were duplicates (ie, different search terms resulted in the same post being identified) and were removed. Of the 1316 nonduplicated posts, 88 (6.69%) were considered relevant to food security. Nonrelevant posts included announcements for surveys and information about hours of local businesses, among other topics. Among the 88 relevant posts, a subset of posts (n=8) were reposted 2-4 times on different dates and/or in different groups with identical text content. These posts were treated as unique and remained in the data set to reflect their greater potential reach. In 2019, there were 8 relevant posts identified in contrast to 80 relevant posts identified in 2020. Across the 7 groups or pages, a range of 0-45 relevant posts were identified with a mean of 12.6 posts (16.2 SD) per group or page. Of the 88 posts, 12 (14%) had comments associated with the posts, which were qualitatively analyzed and are described below.

Codebook

A total of 20 codes for posts and 7 codes for comments were developed and used to characterize the data set. Codes were not mutually exclusive, and each post had a mean number of 3.8 (SD 1.7) codes applied. For the posts in 2019, a total of 15 codes were applied (mean of 1.9 per post), whereas the posts in 2020 had a total of 321 codes applied to them (mean of 4.0 per post). Among posts with comments, a mean of 1.8 (SD 0.8) codes were applied to the comments. After coding was complete, the concepts for posts were broadly organized into 6 categories, with some codes represented in more than one category, to assist with interpretation and presentation of results. Given the small number of comments included in the data set, all 7 codes for comments were interpreted and presented together.

Nature of Posts

Literature-Based Codes

The prevalence of codes based on concepts related to food insecurity or studies of social media–based communication were relatively low (Table 1). Nonfood-related needs of households experiencing food insecurity were referenced in 14 posts (16%), educational resources or information were shared in 4 posts (5%), and promotion of businesses was included in 9 posts (10%). It is possible (and likely) that many posts promoting businesses were not captured in this study given the keywords used. Posts referring to nonfood needs of households experiencing food insecurity made mention of social isolation, employment, and housing issues, among others, reflecting the fact that food insecurity does not occur in isolation without other social risks. All education-coded posts were made in 2020, which shared information about policies and programs, including the 2020 Census, the Fresh Bucks program in King County, and the Pandemic EBT program. Business-promoting posts included advertisements for restaurants and farmer's markets, often referring explicitly to the food(s) being sold and/or incorporating cultural references into the text (Table 1).

Table 1. Literature-based codes, definitions, and example posts.

Codes and subcodes	Definition (post text, hashtags, or images)	Example post
Nonfood social risk factors	Refers to other resources or circumstances that are related to food insecurity but not directly about food availability, such as housing, transportation, health, safety, education, income, isolation, and/or employment	*…We will continue to show up for one another especially for those experiencing elevated social isolation, food - housing - employment insecurity, lack of accessibility, support systems and community connection…*
Education	Provides education (or refers to educational resources) to learn more about the issue of food security, and/or opportunities for individuals or households to acquire education about food preparation and/or nutrition	*Due to COVID-19 school closures, families may be eligible to get help with food benefits. These food benefits are called Pandemic EBT[a] Emergency School Meals Program or P-EBT[b]. Find out more below. No citizenship requirements and is not considered under public charge.*
Paid event or business promotion	Provides information about businesses or events that require payment to support	*[Zanny face emoticon] PLATE SALE WEEK 5 [Zanny face emoticon] PLATE SALE WEEK 5 $ DAY [Victory hand emoticon] [Zanny face emoticon]*
Free meals for kids	Indicating that children are provided meals for free at events (or businesses) that otherwise require payment for food	*School's out! At [Organization name], we are offering FREE kid meals, all day, every day!*
Food item(s)	Identify specific types or examples of foods (not meal occasions) that are being sold or distributed[c]	*Most King County farmers markets are now open! Have SNAP[d]/EBT? You can use it to buy fruits and veggies at farmers markets! Look for Fresh Bucks signs to get a $1 off for every $1 you spend. Fresh Bucks King County #FreshBucks* *More info on how to use Fresh Bucks: [weblink]*
Cultural context	Directed toward AAPI[e] subpopulations through direct mention of population(s), mention of cultural consideration and/or traditional/local foods, inclusion of NHPI[f] language or words, photographs of community members, and/or an AAPI language is mentioned as part of the service/event being described	*When #COVID_19 closed schools, many AAPI students who relied on school lunch & breakfast programs were facing hunger. The Census directs $8.7 BILLION for school meals every year. Get counted to help fight hunger for the next 10 years #AAPI2020 #RootedInCommunity #RisingTogether #APAHM [weblink]*

[a]EBT: Electronic Benefits Transfer.

[b]P-EBT: Pandemic Electronic Benefits Transfer.

[c]Excludes images.

[d]SNAP: Supplemental Nutrition Assistance Program.

[e]AAPI: Asian American and Pacific Islander.

[f]NHPI: Native Hawaiian and Pacific Islander.

Food Assistance

By far, the most common topic (69/88, 78%) of posts was sharing information about food assistance for community members (Table 2). A subset of these posts described foods that would be available, either in broad terms (ie, produce, meat) or listed specifically (ie, katsu chicken, spam, rice). References to NHPI culture, such as through words from NHPI language(s) or pictures of community members, were included in 19% of the 69 posts. Over half of posts about food assistance focused on meeting children's food needs such as through free lunch or breakfast services. Although these services for children were widely discussed in 2020, possibly due to the rapid expansion of services during school closures, they comprised a greater proportion of posts identified in 2019. Food assistance posts were frequently used in both 2019 and 2020 to share logistical information about events or programs, such as dates, addresses, and eligibility criteria. A unique phenomenon to 2020 was the use of posts (n=11) to share time-sensitive information about unanticipated changes to the timing or availability of food assistance. An additional code that was only present in 2020 was the promotion of free meals for children at restaurants or other food retailers (n=4). Although this served as a subcode to business promotion, most of these posts (n=3, 75%) indicated that no purchases were necessary to receive food for children, suggesting that these offers may be an acceptable way to receive food assistance.

Table 2. Food security specific codes, definitions, and example posts.

Codes and subcodes	Definition (post text, hashtags, or images)	Example post
Food assistance		
Food assistance resources	Describe specific events, programs, or other information about food assistance (groceries, meals, and/or lunches) available to individuals and/or children	*!! Stop by today for food boxes. Our food boxes, as usual will be available until supplies last on a first come, first served basis.* *Pick up at our office location in Kent. [Address]*
Child food assistance	Food assistance (lunches, meals, groceries, etc) mentioned is specific to (or primarily targeted toward) providing food for children and/or families with children	*Stop by and pick up a FREE lunch and PBS KIDS educational activity packet during school closure.*
Confidentiality of assistance	Refer to confidentiality or privacy of the food assistance being offered	*If anyone is having a difficult time getting food to feed yourself and your family, please call the Sunshine Pantry in Beaverton, no questions, phone [phone number].*
Logistics of assistance	Provides logistical information about the assistance, such as times/days, location(s), and/or eligibility (or a link or phone number to access this information)[a]	*!! !!Thank you to our volunteers and to everyone that stopped by today for our food distribution. We were able to give away 600 boxes of meat, dairy, and produce. We will continue our food distribution next week Monday up until supplies last. First come first served. So please keep a look out on all our social media platforms for more updates.* *Fa'afetai Tele Lava !!*
Updates to food assistance	Provides time-sensitive information about unanticipated changes to the timing and availability (ie, food is gone or event is over) of food assistance within a time frame of 1 week or less[a]	*THAT's a WRAP!* *Another great big thank you to our community members and committed volunteers for another successful curbside food distribution!* *If you missed us this week, don't worry, stop by the office next week Monday, 2PM* *[Address]*
Food item(s)	Identify specific types or examples of foods (not meal occasions) that are being sold or distributed[b]	*[Location]: Million Pounds of Potatoes giveaway tomorrow (May 14th)* *With the closure of restaurants there is an abundance of potatoes and the [Organization Name] is shifting to help those in need by hosting "On the Road to a Million Pounds of Potatoes" with plans to host their largest potato giveaway to date this Thursday, May 14 at 11am...*
Cultural context	Posts are directed toward AAPI[c] subpopulations through direct mention of population(s), mention of cultural consideration and/or traditional/local foods, inclusion of NHPI[d] language or words, photographs of community members, and/or an AAPI language is mentioned as part of the service/event being described	*…It is 2nd nature for our communities to move into roles of caring for one another with love, compassion, kindness, and tenderness. We will continue to show up for one another...*
Perspectives of food insecurity		
Self-disclosure	Refers to personal experiences of food insecurity or related food hardships experienced by user or user's family members	Not applicable; no relevant content identified
Critical jests about food assistance	Presents information or cues specific to food assistance framed as a critique or joke	*Who selling ebt [e] ??? [4 laughing with tears emoticons]* *let me knoo!!! Hahaha [Name] smdh*
Feedback	Requests that readers provide feedback or provide stories about their experiences with food security or food assistance on surveys or through other structured data collection[a]	*We want to hear from you!* *Share your story about [Organization Name], and we may use it in a future post. #momstrong #[Organization Name]*

[a]Excludes hashtags.

[b]Excludes images.

[c]AAPI: Asian American and Pacific Islander.

dNHPI: Native Hawaiian and Pacific Islander.

eEBT: Electronic Benefits Transfer.

Perspectives of Food Insecurity

A minority of identified posts demonstrated how Facebook groups could be used by members to communicate their opinions, perceptions, or personal experiences with food insecurity (Table 2). One post was used to make a joke about others in the community using the SNAP benefits with text, emojis, and an accompanying image. This acknowledged the presence of food insecurity and resulting reliance on governmental food assistance, while making the community members' relying on these programs the target of the joke. However, this discourse may not be considered hostile, as one group member posted in 2020 that they participated in the free school meal program; during the COVID-19 pandemic, many schools distributed free meals in Washington state to any children, regardless of income. Thus, use of these programs may not have been as stigmatizing as in prior years. No other individuals created posts disclosing their personal experiences of food insecurity. However, one food assistance organization, a clinic affiliated with the WIC joined the discourse online by creating a post that asked individuals to provide stories about their experiences of food insecurity in an anonymous survey.

Community Gratitude and Support

Positivity and promotion of community were salient sentiments in identified posts (Table 3). This was noted through explicit expressions of gratitude and thankfulness (n=21), which were directed toward individuals, donors, programs, or the community in general, as examples. Posts were also used to advertise opportunities for individuals to volunteer their time or provide donations (n=12) to support programs such as food drives in the community. One post was created by an individual to redistribute food their household had received from a school-based food assistance program.

Table 3. Community- and context-related codes, definitions, and example posts.

Codes and subcodes	Definition (post text, hashtags, or images)	Example post
Community gratitude and support		
Gratitude	Mentions appreciation for support of individuals, organization, or the broader community for support of programs, events, and/organizations	*We are grateful for the opportunity to partner with [Organization Name] and [Organization Name] to provide food meals for our communities in need during the COVID-19 pandemic.*
Support opportunities	Refer to opportunities for community members to provide support to food security through volunteering, food donations, fundraising, or by attending events that support food banks or other charitable organizations	*[Organization Name] - Take what you need, leave what you can.*
		If school closures have you or someone you know worried about access to food, please stop by our front-yard pantry and take what you need.
		If you'd like to help out, please feel free to replenish the pantry as needed. Remember, school is closed until the end of April, so please check in over the next several weeks. We ask that you ONLY restock the shelves that have space. Please do not leave any food outside of the pantry. [Address]
Reallocation of resources received	Indicates the user has excess food or related resources received for food security that they would like to give away[a]	*Anyone in da group in da [city] or [city] area wanna take these off our hands? My neighbors and I have so much from da free lunch program at da school n we not gonna make use of it. We drink almond milk n don't want these to go to waste. Lmk!*
Macrolevel contexts		
COVID-19	Refers to the COVID-19 pandemic explicitly or implicitly and/or ramifications of the pandemic, such as staying healthy, wearing masks, or disruptions to the food system	*We understand that during this time food accessibility can be limited due to vacant grocery stores. Families will be able to pick up a box of Produce, Dairy, or combo of Meat & Produce.*
Federal policies	Refers to federal policy news updates or short-term political activities that may be related to current or future food security	*The Trump administration's proposed rule change to food stamp work requirements could leave hundreds of thousands of the most financially vulnerable Americans without the monthly assistance*
Emoticon use to supplement text	Supplemented with the addition of emoticon(s)[a,b]	*Focus on Pacific Islanders but Open to ALL!!!! Get there EARLY while supplies last [4 man running emoticons, wink face emoticon, thumbs up emoticon] ALL will receive boxes filled with: Produce [emoticons of broccoli, carrot, apple, orange, lemon, pear, banana, avocado] Dairy [emoticons of egg, cheese, glass of milk] Meat [emoticons of meat with bone, poultry leg, steak, and bacon]*

[a]Excludes hashtags.

[b]Excludes images.

Macrolevel Contexts

A subset (34/88, 39%) of identified posts remarked on broader contextual factors beyond the individual- or community-level, which may affect food insecurity (Table 3). Most of these posts (32/34, 94%) were focused on COVID-19 and related hardships or changes that put households at greater risk of food insecurity. The remaining posts provided information or opinions about federal-level decisions or programs such as the 2020 Census and changes to SNAP, as examples.

Supplementary Nontext Content

The text in included posts was often supplemented by additional methods of communication, such as images (72/88, 82%), emoticons (20/88, 23%), and/or videos (2/88, 2%). This supplementary content can serve to draw social media users' attention and/or efficiently provide additional information (Table 3). For example, in the case of food assistance, images included photos of foods being distributed or digital flyers with logistical information about the event or program. Images and videos were also used to share pictures of people in the community who were supporting food security initiatives.

Nature of Comments

There were similarities and differences in the themes of the comments (Table 4) when compared to the larger data set of posts. One key similarity was in the salient gratitude and support reflected by users' comments, mirroring the optimism and community support indicated in the posts. On the one post that included critical jests about food assistance, comments echoed this sentiment. Similar jests were not present in comments on any other included posts. While there were a few posts relevant to literature-based codes (educational and promotion of event or business), there were no comments with relevant content.

Another point of divergence was in self-disclosures of food insecurity experiences. A single disclosure of food insecurity within a comment was explicit about the individual's family having gone hungry in the past.

Table 4. Comment codes, definitions, and example comments from 2019 and 2020.

Comment code	Definition	Example comment
Educational	Refers to educational resources to learn more about the issue of food security and/or opportunities for individuals or households to acquire education about food preparation and/or nutrition	Not applicable; no relevant content identified.
Paid event or business promotion	Provides information about businesses or events that require payment to support	Not applicable; no relevant content identified.
Self-disclosures	Mentions personal experiences of food insecurity or related food hardships experienced by user or user's family members	*My mom said we would go hungry first, sometimes we did. Glad there were farmers in family*
Gratitude	Mentions appreciation for the actions and/or information provided in the post	*Thank you for the boxes today. I feel very blessed!*
Support	Mentions prior, current, desired, or intended financial support for the cause or organization mentioned in the post	*On our way to support local businesses that are helping the community....also, we hungry*
Interest in resources	Mentions the user's interest in receiving the resources mentioned in the post	*This is amazing sister... I'm Gonna share*
Critical jests about food assistance	Presents information or cues specific to food assistance framed as a critique or joke	*I always get jealous when I see someone bust one [EBT [a] card] out [2 laughing with tears emoticons] I say ummmmm excuse me but how can I apply for one lol*

[a]EBT: Electronic Benefits Transfer.

Audience Engagement

Among the analyzed posts, 74% (65/88) had some form of engagement via comments, reactions (Like, Love, Care, Haha, Wow, Sad, and Angry), or shares. Posts coded as reflecting community gratitude or support had descriptively more engagement (mean 19.9, 95% CI 11.2-28.5) in comparison to those that were not (mean 6.1, 95% CI 1.7-10.4). Engagement did not appreciably differ when all other broad code categories were compared. However, posts coded as incorporating culture into their text also had higher amounts of engagement (mean 26.8, 95% CI 12.7-40.9) than those that did not (mean 5.3, 95% CI 3.0-7.7).

Discussion

Understanding and addressing food insecurity is a critical step in reducing the risk of cardiometabolic disease, including hypertension, heart disease, and diabetes, among NHPI cultural groups. The objective of this study was to describe the quantity, nature, and audience engagement of messages related to food insecurity posted online in community groups and organizations that serve NHPI audiences before and during the COVID-19 pandemic. Overall, there was a greater number of food insecurity–related Facebook posts during the pandemic compared to before the pandemic. The majority of identified posts focused on food assistance, including sharing information about resources, time-sensitive updates about services, and opportunities to support these initiatives. Cultural values of children's food security and maintaining NHPI culture were reflected by the quantity of posts and related engagement. Broadly, rhetoric reflected sentiments of gratitude and use of humor to discuss the sensitive, and potentially stigmatizing, topic of food insecurity. This study offers a sample of the discussion on Facebook and provides a unique comparison of food insecurity discussions before and during the COVID-19 pandemic. Future work should capitalize on social media as a potential avenue to reach the unique NHPI cultural group experiencing inequitably high rates of food insecurity and risk of cardiometabolic diseases.

Keeping in mind the heterogeneity of NHPI groups with differing histories, cultural practices, and language, most of these groups faced drastic, detrimental changes after Western contact that impacted physical and mental health, which contributed to an increased risk of cardiometabolic disease and food insecurity [17,19,31,32]. The impacts of colonization continue to affect NHPI communities, with many NHPI people leaving their homelands. For example, of the 1.4 million NHPI people living in the United States, only 355,000 live in Hawai'i [33]. Given the high number of NHPI adults in the United States living away from their ancestral islands, and the elevated rates of food insecurity NHPI communities experience [17], understanding how NHPI people living in the continental United States utilize social networks to address food insecurity and promote health may help to reduce the disparities NHPI communities face. Our findings suggest that social media may be an important source of communication and connection for NHPIs, offering opportunities to share resources and bring the community together with food. For example, kalo (taro) represents the idea of a family with the main stalk representing the parent and the offshoots as the children for Native Hawaiians. There are strong beliefs in connection between food and the 'āina (land that feeds). Additionally, 'ohana (family) and a *kuleana* (responsibility) to the larger community are important values within Hawaiian culture [34]. Our findings indicating the most common posts identified were those that shared information about food assistance and engagement among

other users was higher for culturally relevant posts demonstrate how Hawaiian values and culture among NHPI communities living outside of their homelands are reinforced. With geographic separation, social media may offer NHPI communities' connections to one another to share resources, NHPI culture, and values, and thus present an opportune setting to reduce food insecurity and promote health behaviors.

Communication online related to food security and health is likely influenced by factors established in the broader communication literature. This study demonstrates how cultural values of gratitude and support were reflected in posts online. Posts that reflected these values or incorporated cultural words and references into their text had greater levels of online engagement via comments, shares, and other digital reactions. These results align with broader research in the communications field, which suggests that the way messages are presented, in their framing [35] and inclusion of emotional [36] or cultural [37] elements, can impact the success of communication strategies. Message framing has been employed for smoking cessation [38], COVID-19 vaccination [39], and dietary behavior [40] interventions, and lessons learned from these approaches should be integrated into communication interventions deployed via social media.

With the substantial increases in the use of social media, food insecurity, and the digital food environment since the onset of the COVID-19 pandemic, we explored changes in the nature and frequency of messages during and before the pandemic. Similar to research identifying changes in social media use since the onset of the COVID-19 pandemic [41,42], we identified a 10-fold increase in messages related to food insecurity in March through June of 2020 compared to the same months in 2019. The increase in posts may be related to the significant increase in food insecurity in 2020 compared to 2019 [1]. Considering the high rates of food insecurity among NHPI communities prior to the COVID-19 pandemic, these communities have also been disproportionately impacted by the pandemic; thus, recovery efforts to address the needs of NHPI communities is critical [43]. While we did not assess changes in food insecurity or behavior in this study, social media represents an important aspect of the digital food environment, and could be used to help reduce food insecurity and promote positive health behaviors such as disease management, physical activity, and cooking [12,41,44]. Future research is necessary to better understand how social media groups and pages can assist individuals, reduce food insecurity, and promote chronic disease prevention and management.

Individuals experiencing food insecurity may feel shame about their household's circumstances [45]. Reliance on food assistance programs can be a stigmatizing experience [46] and some individuals experiencing food insecurity hesitate to use food services to avoid these feelings [47]. Thus, individuals in food-insecure households may hesitate to discuss their experiences publicly. In this study, the only public disclosure of food insecurity experiences was identified in a comment on a post, which may be seen by fewer people than the original post. This minimal personal disclosure is likely, in part, a product of the public nature of the pages and groups that were searched. The amount of self-disclosure online is related to

feelings of anonymity [48] and the relationship between the people communicating [49], both of which are not often known in public online spaces. Facebook also hosts private groups, which may be perceived as a more secure online space for individuals to discuss their experiences. However, viewing these data for research would require the consent of the individuals in the groups.

Given the large presence of NHPI members in Pacific Northwest–based Facebook groups and pages, social media may provide useful platforms to provide information and social support related to food insecurity and health conditions in future interventions. Prior research describes how Facebook has been used for diabetes support groups, and particularly in the nutrition management of diabetes [12]. In fact, researchers identified that one of the most frequent topics posted on diabetes-related Facebook groups was related to food, such as preparing meals and nutrition information [12]. Therefore, the provision of nutrition information on social media may be an effective way to reach NHPI people in future initiatives. Although nutrition education was not present in this study, this may be due to the search terms used. Facebook groups and pages could partner with SNAP-Ed implementing staff to provide culturally responsive nutrition education. SNAP-Ed aims to reach and educate low-income households to shop for and prepare healthy foods [50]. Partnerships between SNAP-Ed and existing Facebook groups and pages may be particularly beneficial as SNAP-Ed uses existing frameworks and strategies related to food insecurity, while Facebook serves as a social conduit. The utility of culturally responsive interventions is evidenced by the success of programs that include cultural values and practices to reduce cardiometabolic conditions, such as the Ola Hou i ka Hula program, which saw significant improvement in hypertension management through cultural dance [20]. Culturally responsive toolkits could be efficiently scaled up to reach NHPI communities across the United States through other social media sites that attract individuals with different demographic characteristics in comparison to users of Facebook [51].

Many future research questions could build off this study. Research that seeks to ask similar questions with publicly available social media data may benefit from using community-engaged research approaches, including community members as leaders of research studies. A recent metareview found that community-engaged research can not only support culturally centered interventions but also improve the approach of observational studies [52]. Using community-engaged approaches in studies of social media data may have more comprehensive search terms, culturally informed analyses, and would be poised to inform intervention elements that are highly congruent within the contextual setting. Whenever possible, NHPI researchers should be leading these efforts or serving as crucial collaborators. However, in 2019, only 7.4% of NHPI adults have obtained graduate or professional degrees (vs 14.3% of white adults) [33], and investments to improve the representation of NHPI individuals in graduate programs are necessary to ensure equitable representation on teams investigating NHPI-related research questions. Separately, researchers may consider investigating similar questions within

closed Facebook groups (with IRB approval), on other social media platforms, or in comparison with groups or pages targeting other racial and ethnic groups. Interventions using social media could have a substantial reach, and thus developing and deploying culturally tailored toolkits while studying their effectiveness at improving health-related behaviors and cardiometabolic risk factors among vulnerable groups could have important impact.

This study was not without limitations. First, qualitative research is inherently subjective and individual interpretations of the data vary. For example, had members of the Facebook group been a part of the study team, it would have allowed for insider knowledge to aid coding. However, researchers not belonging to any of the groups studied allowed for greater confidentiality during data extraction. Separately, as this was not an intervention, health data among users were not gathered. Instead, this study serves as a foundation for future research regarding food insecurity among NHPI populations. The study was also limited by the exclusive extraction of data from Facebook. While other social media sites such as Instagram, Twitter, TikTok, and Reddit draw varying demographics, Facebook use is the highest across gender, age, income, education level attainment, and household rurality characteristics [51]. This study was also limited to a subset of groups and pages. Thus, potentially relevant data within private or smaller public groups were missed. Nevertheless, the groups and pages selected had a large collective reach. Additionally, only 4 months of each year were assessed due to the intensive nature of data extraction. However, the time periods corresponded to periods of the most drastic change during the COVID-19 pandemic and the matched period a year prior for comparison. Lastly, results were restricted by the search terms used. To increase comprehensiveness, search terms were identified via the published literature, Medical Subject Headings terms, and consultations with an expert in the field.

Cardiometabolic diseases are prevalent and have pervasive impacts among the NHPI population, with food insecurity as a potential precipitating factor leading to multiple negative health outcomes. Social media and the digital food environment may be an important mechanism to reduce food insecurity and cardiometabolic diseases. Results suggest that Facebook pages and groups provide a setting for NHPI people to virtually gather and share food resources and reinforce NHPI cultural values, which has increased substantially since the onset of the COVID-19 pandemic. Future research will benefit from continued exploration of social media and the digital food environment as a mechanism to reduce food insecurity and reduce cardiometabolic disparities among NHPI adults. Specifically, social media should be further explored as a tool to promote health. Partnerships with nutrition-related organizations such as SNAP-Ed may help NHPI-serving organizations to disseminate culturally tailored messages about food assistance and educational materials to reduce food insecurity and improve health.

Conflicts of Interest

None declared.

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Abbreviations

EBT: Electronic Benefits Transfer
HHAPI: Healthy Hearts Among Pacific Islanders
IRB: Institutional Review Board
NHPI: Native Hawaiian and Pacific Islander
SNAP: Supplemental Nutrition Assistance Program
SNAP-Ed: Supplemental Nutrition Assistance Program Education
WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

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Review

A Transcultural Perspective of Systemic Lupus Erythematosus–Related Fatigue: Systematic Review and Narrative Synthesis

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Abstract

Background: Fatigue is one of the most common symptoms of systemic lupus erythematosus (SLE) worldwide, yet it remains poorly assessed and managed. The lack of universal definition and standard measurement of fatigue may add to the continued limitations in its understanding across cultures.

Objective: The psycho-sociocultural underpinnings of fatigue are understudied; therefore, in this paper, we conducted a systematic review to understand a transcultural perspective of SLE-related fatigue.

Methods: Following PRISMA (Preferred Reporting items for Systematic Reviews and Meta-Analysis) systematic review guidelines, we searched CINAHL Complete, Scopus, and PubMed databases for all published articles covered until the search date. Search was expanded using citation and web search. A 3-step process was used to identify articles meeting the inclusion criteria. The results were analyzed using narrative synthesis.

Results: From a total of 370 (n=364, 98.4% scientific databases; n=6, 1.6% web and citation search) articles searched, 18 (4.9%) studies met the inclusion and exclusion criteria and were included in this review. All (18/18, 100%) studies enrolled primarily female participants, and half (9/18, 50%) had cross-sectional designs. Although race was not reported in all studies, most studies had White racial background as the largest proportion of their samples. A majority (7/18, 39%) of the studies were conducted in the United States. Using a narrative synthesis, the prominent themes drawn based on the domains of the culture care theory (CCT) and the sunrise enabler were as follows: SLE-related fatigue (1) as an integral component of the disease process, (2) as a personal challenge, and (3) as a psychosocial dimension.

Conclusions: CCT and sunrise enabler by Leininger guided this review. There are still gaps on how other domains of the CCT and sunrise enabler might influence SLE-related fatigue experience, assessment, and evaluation. The findings from this review showed that SLE-related fatigue has disease, personal, and psychosocial components. Thus, a purely subjective assessment of fatigue in SLE and even other conditions may limit a more accurate assessment and management. The inclusion of disease, personal, and psychosocial indicators is warranted and essential. A culturally sensitive and congruent assessment as well as evaluation models and measurement tools should be developed to capture fatigue experiences accurately. In addition, since global migration is inevitable, advancement in symptom management strategies should coincide with the understanding that fatigue has subjective and objective indicators present across cultures.

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KEYWORDS

systemic lupus erythematosus; fatigue; transcultural; cross-cultural; multicultural; ethnic; multi-cultural; perspective; perception; attitude; systematic review; narrative synthesis; review; lupus; autoimmune; chronic disease; chronic condition; joint pain; inflammation

Introduction

Due to the increase in global migration, health care organizations are caring for more culturally diverse individuals and families. This culturally diverse setup is likewise expanding in the health care workforce, especially in countries recruiting foreign-educated and trained health professionals. These inevitable changes in the current landscape may influence the accurate assessment of symptoms and provision of culturally congruent care, especially in fatigue, which has robust psycho-sociocultural underpinnings but is currently without universal definition or standard of measurement. Given this situation, a better understanding of fatigue across cultures is needed.

Although there is no universal standard measurement of fatigue [1], it can be defined as an overwhelming, uncommon, extreme tiredness [2]. In patients with systemic lupus erythematosus (SLE), fatigue is the most common and most prevalent symptom. Fatigue is present even with mild and inactive cases of SLE disease [3]. Although numerous studies and reviews highlighted SLE-related fatigue as the most burdensome and often the most reported symptom in SLE, it remains poorly assessed and managed across cultures. Since there is no cure for SLE, quality of life may be improved with accurate assessment, evaluation, and management of SLE-related fatigue. SLE-related fatigue is commonly associated with other symptoms that may compound limitations to individuals with SLE. This article aimed to conduct a systematic review to develop a transcultural perspective of SLE-related fatigue.

A transcultural perspective integrates similarities and differences of certain cultures to provide culturally congruent health care

[4]. Thus, an integrated transcultural perspective of SLE-related fatigue from empirical studies may facilitate a more accurate and culturally congruent symptom assessment, evaluation, and management. Although fatigue severity can be validly and reliably measured in SLE [5,6], a transcultural perspective provides a better understanding because the social and cultural factors (eg, health beliefs) may also determine the threshold for the symptom's normality and pathology [7], especially when caring for individuals across cultures. The social and cultural structures identified in the culture care theory (CCT) and the sunrise enabler influence health patterns and well-being [8].

This article presents a transcultural (nursing) perspective. This perspective aims to provide culturally congruent care and practice based on the domains of the CCT and sunrise enabler, such as "technology, religion, family and kinship, politics, cultural beliefs and practices, economics, physical conditions, and biological factors" [8].

Methods

Search Strategy

A search strategy was developed in consultation with subject matter experts using Medical Subject Headings (MeSH) terms relevant to SLE-associated fatigue and cultural perspectives of fatigue (Textbox 1). We searched for all published articles meeting inclusion criteria in scientific databases such as CINAHL Complete, Scopus, and PubMed until the search date (October 14, 2021). Table 1 presents the search strategy used. We used the same terms in our web search; however, no search terms were used for the citation-based search. Citation-based search means finding articles based on what a related article has referenced.

Textbox 1. Review question and Medical Subject Headings (MeSH) terms. Primary review question: What is the transcultural or cross-cultural perspective of SLE-related fatigue?

MeSH
Systemic lupus erythematosus, lupus erythematosus disseminates, or Lupus AND Fatigue AND Culture, Transcultural, and "Cross-cultural Comparison"
Keywords
"systemic lupus erythematosus" OR "lupus erythematosus disseminatus" OR "libman-sacks disease" OR "libman sacks disease" OR "disease, libman-sacks" OR "lupus" AND fatigue OR exhaust* OR tired* OR lethargy OR "muscle weak*" AND cultur* OR transcultur* OR "cross-cultural comparison"

Table 1. Search strategy and search outcome (N=364).

Databases	Search strategy	No. of records, n (%)
CINAHL Complete	• "systemic lupus erythematosus" OR "lupus erythematosus disseminatus" OR "libman-sacks disease" OR "libman sacks disease" OR "disease, libman-sacks" OR "lupus" AND fatigue OR exhaust* OR tired* OR lethargy OR "muscle weak*" AND cultur* OR transcultur* OR "cross-cultural comparison" OR belief* OR value* OR attitude* • Limiters - Peer Reviewed	59 (16.2)
Scopus	• "systemic lupus erythematosus" OR "lupus erythematosus disseminatus" OR "libman-sacks disease" OR "libman sacks disease" OR "disease, libman-sacks" OR "lupus" AND fatigue OR exhaust* OR tired* OR lethargy OR "muscle weak*" AND cultur* OR transcultur* OR "cross-cultural comparison" OR belief* OR value* OR attitude*	174 (47.8)
PubMed	• "systemic lupus erythematosus" OR "lupus erythematosus disseminatus" OR "libman-sacks disease" OR "libman sacks disease" OR "disease, libman-sacks" OR "lupus" AND fatigue OR exhaust* OR tired* OR lethargy OR "muscle weak*" AND cultur* OR transcultur* OR "cross-cultural comparison" OR belief* OR value* OR attitude*	131 (36)

Inclusion and Exclusion Criteria

Articles were included if (1) they were original peer-reviewed research articles, (2) they were published in English, (3) they focused on patients with SLE, and (4) they mentioned fatigue and its derivative terms in the title or abstract. All research designs were included. Articles were excluded (1) if the articles did not describe a cultural perspective based on the CCT and the sunrise enabler or (2) if the articles were commentary, abstracts, theoretical, quality improvement projects, or literature review articles.

Study Selection

Articles were directly downloaded using the comma-separated values format. The downloaded comma-separated values, which is in Microsoft Excel, assisted the authors with organizing and deduplication. We used a three-step screening process, which is as follows: (1) titles were screened for relevance to the research question; (2) abstracts were then screened to determine further if inclusion criteria were met; and (3) full-text screening was completed on all articles accepted in step 2. Additional articles were also included using web and citation searches. Screenings were conducted independently by JBT and LNS. Disagreements were resolved through discussion. The more senior author (LNS) made the final decision if consensus was not reached. Table 1 presents the search outcome.

Data Abstraction

A data charting form was developed based on PRISMA (Preferred Reporting items for Systematic Reviews and Meta-Analysis) guidelines by JBT and calibrated by both JBT and LNS. JBT extracted the data. LNS performed a quality check on data extraction after data extraction was complete. Based on the extracted information, homogeneity could not be established since the findings were not similar, and therefore meta-analysis or quantitative pooling was not feasible. We did not specify to which domains the findings belong because we maintain that a transcultural perspective is always open to interpretation from various cultures. Thus, by understanding the domains of CCT and the sunrise enabler by Leininger, a transcultural perspective from the findings were extracted.

Quality Appraisal

Quality appraisal was conducted using the Joanna Briggs Institute Critical Appraisal Checklists for Analytical Cross-Sectional Studies [9]. The checklist contains 8 items that assess the risk of bias in studies. The 2 authors independently appraised each article. Disagreements were adjudicated by the more senior author (LNS).

Data Synthesis

We synthesized extracted data using a thematic approach. This type of synthesis is useful when the data are varied and when dealing with abstract findings. Specifically, thematic synthesis involves an iterative review of data to identify patterns or themes. The authors used a narrative approach of thematic type for the following reasons: (1) meta-analysis was not feasible; (2) the main topic dealt with an abstract topic (transcultural perspective); and (3) data extracted from the included studies contained more textual data rather than numerical data.

Results

Study Selection

A total of 364 articles were initially identified. After deduplication of these 364 articles, 290 (79.7%) underwent title and abstract screening; of these, 27 (9.3%) were eligible for full-text screening. In step 3, of the 27 eligible articles, 14 (52%) were excluded (Figure 1). Moreover, we identified 6 additional articles during the citation and web search; of these 6 articles, 1 (17%) was excluded (Figure 1), resulting in a final sample of 18 articles.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 flow diagram, which includes search of databases, registers, and other sources. SLE: systemic lupus erythematosus. *Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers). **If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.
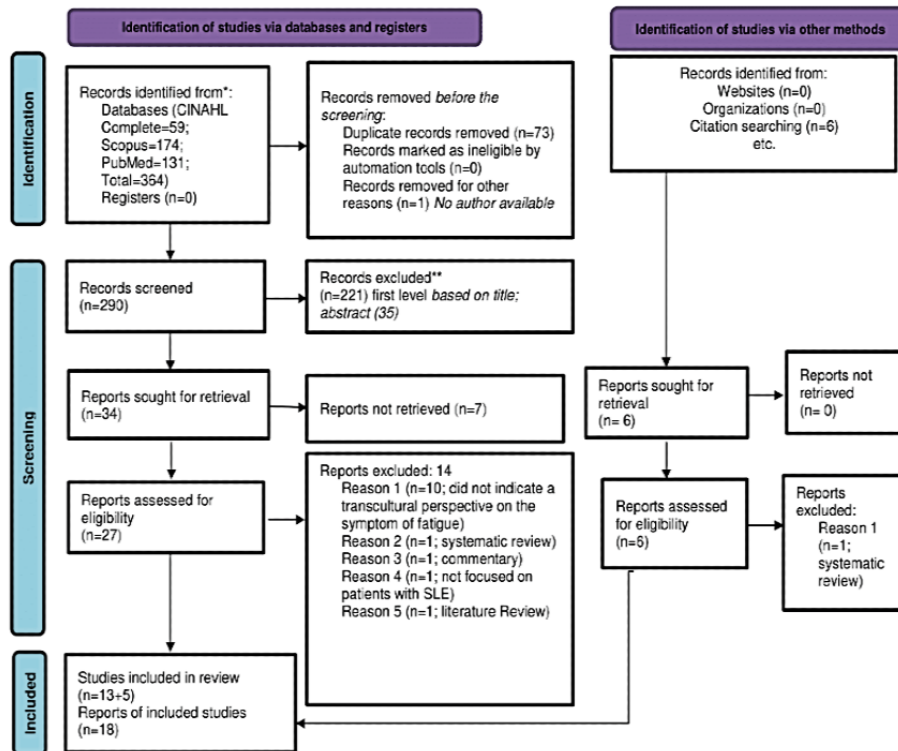
Study Characteristics

The details regarding article characteristics included in this review are in Table 2. Briefly, 9 countries were represented, the United States [10-16], Canada [17,18], Sweden [19,20], Ireland [21,22], the United Kingdom [23], Denmark [24], Puerto Rico [25], Australia [26], and South Africa [27]. The participants in these studies were predominantly female and of White racial backgrounds. Of the 18 studies, 9 (50%) used cross-sectional designs [10-12,15-17,20,23,26], 4 (22%) were qualitative [13,19,24,27], 2 (11%) used mixed-methods [14,21,22], and 2 (11%) were longitudinal studies [18,25].

Table 2. Study characteristics and the related findings of the studies included.

Author, year, and country	Title	Design and objectives	Sample	Transcultural fatigue perspective	Other key findings
Almehed et al [20], 2010, Sweden	Health-related quality of life in systemic lupus erythematosus and its association with disease and work disability	Cross-sectional study: to determine the quality of life and its association with disease variables, employment status, and vertebral fracture among women with SLE[a].	N=163; mean age: 48.5 (SD 13.6) years, sex: 100% female; race or ethnicity: "Predominantly Caucasian"	Patients with SLE scored significantly lower than controls on all SF-36[b] subscales. SF-36 is a tool to assess HRQoL[c] and a frequently cited general tool to measure fatigue.	The physical component score of SF-36 is associated with working ability, low SLEDAI-2K[d], glucocorticosteroid dose, and BMI. Being able to work was also significantly associated with younger age and high scores in PF[e] and RP[f].
Burgos et al [25], 2009, United States and Puerto Rico	Disease Activity and Damage Are Not Associated With Increased Levels of Fatigue in Systemic Lupus Erythematosus Patients From a Multiethnic Cohort: LXVII	Longitudinal multiethnic cohort study: to determine the factors associated with increased levels of fatigue symptom through the disease course among patients with SLE.	N=515; mean age: 37.2 (SD 12.6) years; sex: 90.5% female; race or ethnicity: 32.8% African Americans	Increased fatigue levels were associated with White ethnicity; constitutional symptoms such as fever and chills, higher levels of the pain experience, abnormal illness-related behaviors, and helplessness. At the same time, the exercise showed to be associated with lower fatigue levels. Using SF-36, lower physical component score and mental component score, higher levels of helplessness, and abnormal illness-related behaviors were associated with higher fatigue levels. While higher levels of social support and lower levels of fatigue show association.	Demographics and socioeconomic factors were not significantly associated with fatigue. In addition, clinical characteristics were not associated with the (higher or lower) fatigue levels.
Connolly et al [21], 2014, Ireland	Fatigue in systemic lupus erythematosus: impact on occupational participation and reported management strategies	Exploratory study (descriptive statistics and qualitative descriptive guidelines): to explore how people with SLE describe and cope with fatigue in their everyday lives.	N=12; mean age: 14.3 (SD 10) years; sex: 91.67% (11/12) female; race or ethnicity:100% White	In the study, fatigue was described as an unpredictable and constant characteristic of SLE, which affects work, leisure, and occupation. The most common factors to increase fatigue among the participants were stress, physical activity, and joint pain. Stress is the most commonly expressed concern, along with the experience of fatigue.	Social support from family, friends, and neighbors was valuable and provided practical help. Participation in employment requires routine and environmental modifications and considerable flexibility.
Da Costa et al [17], 2006, Canada	Dimensions of Fatigue in Systemic Lupus Erythematosus: Relationship to Disease Status and Behavioral and Psychosocial Factors	Cross-sectional study: using a multidimensional assessment, the study aimed to characterize the experience of fatigue in patients with SLE. It also determined the contributors to the physical and mental aspects of fatigue.	N=130; mean age: 45.4 (SD 14) years; sex: 100% female; race or ethnicity: "Primarily Caucasian"	In the study, there were significant positive correlations between physical fatigue, disease activity and damage, the presence of fibromyalgia, depression, and impaired sleep quality. There were also significant negative correlations between social support satisfaction and exercise.	Greater disease damage and disease activity; the presence of fibromyalgia, depressed mood, sleep disturbance, and less participation in leisure-time physical activity contributed to higher physical fatigue scores.

Author, year, and country	Title	Design and objectives	Sample	Transcultural fatigue perspective	Other key findings
Dobkin et al [18], 2001, Canada	Living with Lupus: A Prospective Pan-Canadian Study	Prospective study: to portray the life of women with lupus and identify the predictors to the symptom of fatigue.	N=120; mean age: 42.50 (SD 10.83) years; sex: 100% female; race or ethnicity: 84.2% White	Patients experienced less fatigue with decreased depression and stress.	In the final follow-up of the study, even though the majority is faring in terms of distress, there remains a subset who experience distress and may benefit from psychosocial interventions.
Donnelly et al [10], 2018, United States	Fatigue and Depression Predict Reduced Health-Related Quality of Life in Childhood-Onset Lupus	Cross-sectional study: to identify the risk factors that persistently reduced patients' health-related QoL[g] with childhood-onset lupus. It also described a risk profile for persistent reduced health-related QoL.	N=50; mean age: 16.2 (SD 2.5) years; sex: 84% female; race or ethnicity: 23 (46%) African American; 23 (46%) White	At follow-up, poorer HRQoL was significantly predicted by higher fatigue symptoms and depressive symptoms during the initial visit.	A profile of significant anxiety, greater pain, and coping difficulties was seen in the high-risk group.
Jump et al [11], 2005, United States	Fatigue in Systemic Lupus Erythematosus: Contributions of Disease Activity, Pain, Depression, and Perceived Social Support	Cross-sectional study: to investigate the associations between pain, depression, fatigue, and disease activity in patients with SLE.	N=127; mean age: 40.6 (SD 12.2) years; sex: 100% female; race or ethnicity: 62 (48.8%) White	There was an inverse relationship between perceived social support and fatigue. Perceived social support accounted for an additional 4% of the variance in fatigue scores.	Fatigue was the most rated symptom, significantly higher than all other symptoms assessed.
Kent et al [23], 2017, United Kingdom	Burden of illness in systemic lupus erythematosus: results from a UK patient and carer online survey	Cross-sectional web-based survey: to assess the impact of SLE on both patients and carers.	N=121; age: 34% from 41-50 years median age group; sex: 94% female; race or ethnicity: 77% White	The symptom of fatigue and the feeling of being a burden to others greatly influenced the patient's HRQoL. In addition, the patient's social interactions are affected. Patients also reported reduced ability to engage in social activities (N=121, 89%).	Fatigue was the most debilitating symptom experienced daily by 79% (N=121) of patients. Patients with SLE relied heavily for help on their carer with basic daily chores, and 62% (N=121) also required emotional or social support.
Kier et al [24], 2016, Denmark	How do women with lupus manage fatigue? A focus group study	Explorative qualitative study (focus group study): to describe the way patients with SLE manage their experience of fatigue.	N=27; median age: 53 (range 26-72) years; sex: 100% female; race or ethnicity: White	The main themes covered were related to being open, listening to the body, and accepting the experience of fatigue.	Fatigue is considered a controlling factor in everyday life of women with SLE.
Kozora et al [12], 2005, United States	Major life stress, coping styles, and social support in relation to psychological distress in patients with systemic lupus erythematosus	Cross-sectional study: to examine the psychological processes in patients with SLE and rheumatoid arthritis with the measures of life stress, coping styles, social support, and cognitive ability.	N=52 patients with SLE; mean age: 34.6 (range 18-57) years; sex: 90.38% (n=47) female; race or ethnicity: 56.9% White in SLE group; 86%-96% White in the RA[h] and control groups	Patients with SLE had greater distress (which included fatigue) than patients with rheumatoid arthritis and healthy controls on all the subscales and the total score.	Patients with SLE had a significantly higher Social Withdrawal Subscale score from the Coping Style Inventory compared with healthy controls.
Mattsson et al [19], 2012, Sweden	Uncertainty and Opportunities in Patients with Established Systemic Lupus Erythematosus: A Qualitative Study	Qualitative study: to describe the experience in everyday life of patients with established SLE; this included the negative and positive aspects.	N=19; median age: 55 (range 27-80) years; sex: 84.21% (n=16) female; race or ethnicity: not reported	Pain and fatigue influenced the everyday life of patients with SLE.	The experience of patients with SLE reflects uncertainties and opportunities.

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Author, year, and country	Title	Design and objectives	Sample	Transcultural fatigue perspective	Other key findings
Moses et al [26], 2005, Australia	Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus	Cross-sectional descriptive study: to assess the prevalence and associations of perceived unmet needs of people with SLE.	N=386; mean age: 52.5 (SD 14.4) years; sex: 94% (n=363) female; race or ethnicity: not reported	Results showed that the need for help with tiredness had the highest prevalence (81%).	Reported proportions of unmet daily living issues varied from 17% to 61% for everyday living issues and reading difficulties, respectively.
O'Riordan et al [22], 2017, Ireland	Fatigue and Activity Management Education for Individuals with Systemic Lupus Erythematosus	Sequential explanatory mixed methods design: to assess the impact of an occupational participation and fatigue management program called FAME.	N=21; mean age: 48.1 (SD 15.25) years; sex:100% female; race or ethnicity: not reported	Participants expressed a lack of understanding of their experience of fatigue. However, attendance to the fatigue management program validated through others in the group helped them accept their experience of fatigue.	The program provided a statistically significant improvement in depression and categories of "burden to others" and "fatigue" of the LupusQoL.
Phuti et al [27], 2019, South Africa	Living with systemic lupus erythematosus in South Africa: a bitter pill to swallow	Phenomenology: to explore the lived experiences, perceptions, and unmet needs of South African patients with SLE.	N=25; mean age: 30.9 (range 22-45) years; sex: 100% female; race or ethnicity: 72% (n=18) Black African	Most of the participants talk about their challenges living with fatigue. Fatigue is commonly misunderstood, which negatively affects activities of daily living, work, and sexual well-being.	Similarly, pain is considered a common complaint affecting ADLs[i], family, and social life.
Raymond et al [13], 2021, United States	Patient Experience With Fatigue and Qualitative Interview-Based Evidence of Content Validation of The FACIT-Fatigue in Systemic Lupus Erythematosus	Qualitative study: to assess the content validity of the FACIT[j]-Fatigue for patients with SLE and explore the experience of patients with SLE-related fatigue.	N=15; mean age: 52.1 (SD 13.1) years; sex: 86.7% (n=13) female; race or ethnicity: 53.3% non-Hispanic or White	Fatigue impacted the participants' physical functioning (9/15, 60%), emotional impacts (15/15, 100%), social impacts (14/15, 93%), work or school-related roles (12/15, 80%), limited ADLs (15/15, 100%), and unable to do much (14/15, 93%).	The physical difficulties experienced affected their work, while the physical inactivity interfered with their ability to maintain a healthy weight. In addition, being unable to participate in social events was the most frequently reported social functioning limitation.
Robinson et al [14], 2010, United States	Impact of Systemic Lupus Erythematosus on Health, Family, and Work: The Patient Perspective	Phenomenological, mixed-methods approach: to determine the critical health issue of patients with SLE from their perspective.	N=23; mean age: 43 (SD 13) years; sex: 83% (n=19) female; race or ethnicity: 61% (n=14) White	Focus group findings identified the most frequent health issues such as pain (n=19, 83%), fatigue (n=14, 61%), work or school impairment (n=13, 57%). From questionnaire findings, inability to do previous activities (87%), fatigue (87%), pain (87%), and inability to attend work or school (83%).	Arising from the literature review, some of the health issues identified were fatigue, energy, or vitality (n=8); depression (n=7); pain (n=4); helplessness (n=4); and the inability to cope with the disease (n=4). Impaired concentration (n=3), impaired work-life (n=3), anxiety or distress (n=3), and impaired or compromised personal relationships (n=2).
Sterling et al [15], 2014, United States	Patient-reported fatigue and its impact on patients with systemic lupus erythematosus	Cross-sectional qualitative study: to explore the experiences of fatigue among patients with SLE and its impact on their lives.	N=22; mean age: 45.5 (SD 12.52) years; sex: 95% (n=21) female; race or ethnicity: 59% (n=13) African American or Black	Patients reported having variability in nature (frequency and severity). The symptom of fatigue was described to impact emotional, cognitive aspects, ADLs, leisure, as well as social and family activities.	Some participants associated depression with fatigue.

Author, year, and country	Title	Design and objectives	Sample	Transcultural fatigue perspective	Other key findings
Utset et al [16], 2008, United States	Correlates of Formal Work Disability in an Urban University Systemic Lupus Erythematosus Practice	Cross-sectional study: to determine the demographic, disease-specific, and psychological features associated with work disability among patients with SLE in a medical center.	N=143; mean age: 40.4 (SD 11.6) years; sex: 92% (n=132) female; race or ethnicity: 60.8% African Americans	Fatigue severity scores were significantly worse in formal work disability subjects compared with never-disabled subjects.	Ethnicity was associated with work disability status.

[a]SLE: systemic lupus erythematosus.

[b]SF-36: 36-Item Short Form Survey.

[c]HRQoL: health-related quality of life.

[d]SLEDAI-2K: Systemic Lupus Erythematosus Disease Activity Index 2000.

[e]PF: physical functioning.

[f]RP: role physical.

[g]QoL: quality of life.

[h]RA: rheumatoid arthritis.

[i]ADLs: activities of daily living.

[j]FACIT: Functional Assessment of Chronic Illness Therapy.

Risk of Bias

In the quality appraisal of the studies included, there are apparent differences in the methodological scores of studies. The scores ranged between 2 and 8 points, which is justifiable since the methodologies are incomparable. Thus, we did not set a cut-off score for inclusion in the review. Based on our appraisal, all studies included information on the criteria for sample inclusion. There was an incomplete discussion of the confounding variables and strategies for dealing with them. In the quality appraisal, the authors rated studies that employed qualitative methodology with "Not Applicable (N/A)," which was reasonable because some of the items in the quality appraisal checklist were not applicable for studies that employed a qualitative methodology.

Themes

This section presents the narrative synthesis of themes drawn from the studies included. The themes were extracted based on the patterns from the studies following the domains of the culture care theory.

SLE-Related Fatigue as Integral to the Disease Process

Based on the studies included in this review, SLE-related fatigue showed variation in the nature and severity in the course of the disease [15]. Greater disease damage and disease activity contributed to higher physical fatigue scores [17]. SLE-related fatigue is also considered an unstable yet constant characteristic of SLE. Its impact ranges from work, leisure, occupation [21], emotional and cognitive aspects, activities of daily living, as well as social and family activities [15]. The common factors to increase fatigue were stress, physical activity, joint pain [21], higher levels of helplessness, and abnormal illness-related behaviors, although exercise is associated with lower levels of fatigue [25]. Thus, SLE-related fatigue can be considered integral to the disease process because it is a common and distinct characteristic of the disease affecting daily functioning and activities. The factors influencing SLE-related fatigue as provided in the literature above reflect the biological, kinship, social, and cultural values, as well as belief and lifeway factors in the domains of the CCT and sunrise enabler.

SLE-Related Fatigue as a Personal Challenge

In this review, SLE-related fatigue has been shown to be contributing to the daily challenges of patients with SLE. SLE-related fatigue was considered a controlling factor in the everyday life of women with SLE [24]. It has also been associated with poor Quality of Life (QoL). Patients with SLE had lower 36-Item Short Form Survey (SF-36) scores on all subscales compared with controls [20]. SF-36 is a tool to assess health-related quality of life and is a frequently cited general tool to measure fatigue [28]. In a cross-sectional study, poorer health-related QoL was significantly predicted by higher depressive and fatigue symptoms during the initial visit [10]. SLE-related fatigue, along with pain, influenced the everyday life of patients with SLE [19].

Moreover, SLE-related fatigue is commonly misunderstood, which negatively affects activities of daily living, work, and sexual well-being [27]. Fatigue severity scores were also significantly worse in formal work disability subjects compared with never-disabled subjects [16]. In addition, fatigue and the feeling of being a burden to others had the greatest influence on patients' health-related QoL [23]. Overall, SLE-related fatigue can be considered a personal challenge because it is associated with a reduced health-related quality of life and daily functioning and has contributed to the daily challenges of individuals with SLE. QoL, as the commonly identified findings associated with SLE-related fatigue, may be related to all the domains of the CCT and sunrise enabler since QoL is a holistic aspect that may influence the domains of the CCT and the sunrise enabler.

SLE-Related Fatigue as a Psychosocial Dimension

The psychosocial dimension has influenced SLE-related fatigue's nature and severity levels. Higher levels of social

support were associated with lower fatigue levels [25]. Social support from family, friends, and neighbors of individuals with SLE was considered valuable help while managing their fatigue [21]. There was an inverse relationship between perceived social support and fatigue [11]. Attendance to the fatigue management program of individuals with SLE validated their fatigue experience through others in the group. The program provided a statistically significant improvement in the depression and categories of "burden to others" and "fatigue" using the LupusQoL [22]. Fatigue impacted the participants' physical functioning (9/15, 60%); it had emotional (15/15, 100%) and social impacts (14/15, 93%); it had also influenced their work or school-related roles (12/15, 80%) and limited activities of daily living (15/15, 100%), and most of the participants (14/15, 93%) reported that they were unable to perform many activities. In addition, being unable to participate in social events was the most frequently reported social functioning limitation [13]. Focus group findings identified the most frequent health issues such as pain (83%), fatigue (61%), and work or school impairment (48%). On questionnaire responses, the findings were similar. The most common health issue was the inability to perform previous activities (87%), pain (87%), and fatigue (87%) [14].

Stress as a social construct also influenced fatigue levels. Patients were less fatigued when depression and stress were decreased [18]. Some participants associated depression with fatigue [15]. Patients with SLE reported fatigue as the most debilitating symptom, which was being experienced daily (N=121, 79%). They also reported reliance on help from their caregivers and a reduced ability to engage in social activities (N=121, 89%) [23]. Patients with SLE experienced more distress compared with patients with rheumatoid arthritis and healthy controls on all the subscales and in total scores. Patients with SLE had significantly higher Social Withdrawal Subscale scores compared with healthy controls [12]. Results showed that the need for help in relation to tiredness had the highest prevalence (81%) [26]. Strong social support is a significant driver in reducing the severity of SLE-related fatigue, while, on the contrary, stress worsens SLE-related fatigue. The CCT domains and sunrise enabler, which represent the findings in this theme, may be related to kinship, social factors, and economic factors.

Discussion

Principal Findings

Although SLE-related fatigue is one of the most common symptoms in SLE, there is still an inadequate understanding of it across cultures, which limits providing an accurate assessment, evaluation, and management. Currently, there are no consistent findings on the relationship of SLE-related fatigue and immunologic and inflammatory disease characteristics; however, some psychosocial characteristics are associated with SLE-related fatigue [29]. Following the domains of CCT and the sunrise enabler, this review examined the transcultural perspective of SLE-related fatigue from published empirical studies in identified scientific electronic databases.

The development of the CCT and the sunrise enabler was traced back from Leininger's dissertation in 1970s, which, as she

explained, was derived from anthropology. The theory aims to facilitate and explain the interdependence of culture and care by noting differences and similarities across cultures to achieve a culturally congruent care. Along with the theory is the sunrise enabler, which serves to introduce the different aspects of the theory such as the dimensions, facets, and its components [8]. In the theory, cultural and social structures that influence care expression, patterns and practices, as well as holistic health and well-being are as follows: (1) technological factors; (2) religious, spiritual, and philosophical factors; (3) kinship and social factors; (4) cultural beliefs and lifeways; (5) biological factors; (6) political and legal factor; (6) economic factor; and (7) educational factors [8].

The key findings from this review affirm that SLE-related fatigue has underpinnings rooted in (1) biological factors; (2) kinship and social factors; (3) cultural values, beliefs, and lifeways factors; (4) economic factors; and (5) all factors of the CCT and the sunrise enabler that relate to QoL. Based on the themes of this review, SLE-related fatigue reflects an expanding dimension from a biological point of view to environmental and cultural dimensions.

Often, fatigue is understood from biological factors or from a clinical lens; in this review, the clinical attributes of individual with SLE-related fatigue may represent a biological factor. In the CCT and sunrise enabler, biological factors include hereditary, genetic conditions, including those influencing and being influenced by professional and generic care [8].

Fatigue may be associated with disease activity; however, this is not always the case [30]. In a large international observational study with a systematic review of literature, disease activity showed a weak association with fatigue [31]. Hierarchical multiple regression showed that greater disease damage, disease activity, and other factors contributed to higher physical fatigue scores [17]. Although there are a good number of studies separating fatigue and disease activity, a closer assessment and management of fatigue in all cultures or ethnicities are warranted. In fact, in recent updates of the CCT and sunrise enabler, the biological factors covering culture-bound syndromes as well as the role of genetics and heredity were recognized to affect social and cultural factors [8], which may influence how SLE-related fatigue is expressed and managed. The inclusion of biological factors in understanding fatigue supports the idea that even when mood disorders are absent (common associations of fatigue), fatigue still exists in autoimmune and inflammatory diseases, including SLE [32].

The culture, value, belief, and lifeway factors influencing SLE-related fatigue were the QoL and individual functioning, whereas in terms of kinship and social factors, stress and social support should be taken into consideration. QoL, functioning, social support, and stress are intertwined in a social and cultural setting because they exist in the day-to-day living conditions of individuals with SLE. These findings support those of a prior study that there were significant associations among changes in fatigue scores, SF-36 physical subscale, mood, and some domains of LupusQOL [33], which included pain and burden to others [34]. All LupusQoL domains had low scores with fatigue and being a burden to others as the most affected [35].

A seminal Integrated Fatigue Management Model supports the findings of this review. The dimensions of fatigue, such as subjective, physiological, biochemical and metabolic, and behavioral aspects, are surrounded by social factors such as cultural and ethnic practices, significant life event patterns, environmental patterns, psychological, activity and rest, race, and genetic makeup, among others. The surrounding factors are thought to modulate fatigue [2]. The theory of symptom management also supported the multidimensional aspect of symptoms such as fatigue. The interdependent circles of symptom experience, management strategies, and symptom status outcome interact with the 3 domains of nursing, which include the person domain (demographic, psychological, physiological, sociological, and developmental), environment domain (physical, social, and cultural), and health and illness domain (risk factors, health status and disease, and injury) [36]. Finally, in a concept analysis of fatigue, some of the identified critical attributes of fatigue encompassed physical, cognitive, and emotional dimensions; accordingly, fatigue causes distress and chronic or unrelenting symptoms, and it is dependent on the individual's perception [37]. Recent developments in symptom clusters also pointed out that symptoms occurring in clusters have strong psycho-sociocultural underpinnings. The psycho-sociocultural factors may mediate or modulate fatigue symptom severity or intensity. Fatigue commonly co-occurs with other symptoms such as in SLE. Although fatigue remains challenging to conceptualize across cultures, this review highlighted the expanding multidimensionality of SLE-related fatigue.

Limitations

Some of the limitations of this review should be considered. First, a meta-analysis was not feasible due to the variations in methodologies used. With this variation, a narrative summary was deemed more appropriate, and only 3 databases were considered and expanded to citation and web searches. Since only 3 databases were considered, articles from other countries may have been missed. Third, only 1 author (JBT) conducted the synthesis, and it was ascertained by the second author (LNS), which may pose limitations to the breadth of the review. The review may also be limited to the countries where the studies were conducted. For instance, there was no study conducted in an Asian country in this review. An additional limitation of the review may also be pointed to the predominantly female sample and White ethnicity of the study participants enrolled. The name of the research designs was based on what the authors have indicated in their respective articles. Since this review used a thematic approach in presenting the data, this may limit the presentation in terms of the heterogeneity of the studies included. The conclusion may also be biased since the themes were based on a single theoretical framework. There was also an incomplete discussion of the confounding variables in the studies included. Future research or review should also include more male individuals and participants from other racial and ethnic backgrounds and use other theoretical frameworks to comprehensively assess the transcultural aspect of SLE-related fatigue.

Implications and Conclusions

This systematic review, focusing on SLE-related fatigue, draws evidence that SLE-related fatigue experience has both disease-related, personal, and psychosocial components. Applying culture care theory and sunrise enabler by Leininger, there are still gaps in the literature on how technological advances, individuals' religion and philosophy, political climate, economic and educational factors, and the worldviews of particular geographic locations might influence SLE-related fatigue experience across cultures. More culturally congruent fatigue symptom assessment and treatment may also be derived by applying the findings of this review. The CCT and the sunrise enabler may be used in different conditions to capture the holistic components of different aspects of the disease. Cultural and contextual considerations are also warranted to improve the assessment and evaluation of the outcomes of SLE-related fatigue. Pure symptom assessment based on subjective data may narrow the potential or actual factors contributing to SLE-related fatigue. Adding the disease, personal and psychosocial indicators of fatigue should be considered. Future research should be conducted on the following areas: (1) large-scale cross-cultural study focusing on contributing factors for SLE-related fatigue; (2) employment impact of SLE-related fatigue; (3) increasing male participants in empirical studies conducted; and (4) transcultural perspective of fatigue in other conditions.

Conflicts of Interest

None declared.

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Abbreviations

CCT: culture care theory
MeSH: Medical Subject Headings
PRISMA: Preferred Reporting items for Systematic Reviews and Meta-Analysis
QoL: Quality of Life
SF-36: 36-Item Short Form Survey
SLE: systemic lupus erythematosus

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