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Exploratory mixed methods study on care-seeking behaviors of Asian Americans with pelvic floor symptoms

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Abstract

Introduction and hypothesis The objective was to evaluate whether younger age was associated with noncare-seeking behavior among Asian Americans with pelvic floor symptoms, and secondarily, to explore multilevel factors that may contribute to noncare-seeking behavior in this population.

Methods We performed a concurrent mixed methods study and heterogeneously sampled Asian Americans with urinary incontinence, urgency-frequency, vaginal bulge, or anal incontinence. We stratified the participants into two groups, care seekers vs noncare seekers. Using Anderson's model as the main framework, we administered validated questionnaires and conducted semi-structured interviews to explore factors associated with care-seeking behaviors.

Results Seventy-eight surveys and 20 interviews were completed and analyzed. Most participants reported urinary leakage (67%), followed by urinary urgency-frequency (50%), anal incontinence (18%), and vaginal bulge (17%). The mean age of the study cohort was 46.1 ± 16.2 years. We found noncare seekers to be younger and with an increased proportion of lifetime spent in the USA, symptom severity, and individual-level resources, both younger age and increased proportion of lifetime spent in USA remained independently associated with noncare-seeking behavior. From qualitative data, we found that noncare seekers often experienced anti-Asian racism across workplace, neighborhoods, and health care settings. Additionally, noncare seekers also reported symptom minimization and decreased self-efficacy when coping with their pelvic floor symptoms.

Conclusions We found that one's age and proportion of lifetime spent in the USA may affect the extent of exposure to anti-Asian racism that is associated with symptom minimization, increased perceived barrier, and noncare-seeking behavior.

Keywords Asian American · Care-seeking behavior · Health disparity · Health equity · Pelvic floor disorders

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Introduction

One in 4 US adults reported at least one pelvic floor disorder (PFD) in their lifetime [1]. Despite PFDs being common, most symptomatic individuals never seek care [2]. Of those with symptomatic PFDs, our recent meta-analysis found that Asian Americans seek pelvic floor care at a lower rate than white individuals [3]. As Asian Americans are projected to be the largest foreign-born population by 2065, addressing PFD care disparity becomes ever more urgent to American public health [4].

There has been an increase in interest in understanding PFD care-seeking disparities over the last decade. Among the many factors examined, several studies have consistently shown that younger age is associated with decreased PFD care utilization [5–7]. However, these studies often did not include Asian Americans [5, 6] or address factors beyond the



individual level [7]. To bridge this knowledge gap, the primary aim of this study is to investigate whether younger age is also associated with decreased PFD care-seeking behavior among Asian Americans. The secondary aim is to explore multilevel factors beyond the individual level that may influence Asian Americans' PFD care-seeking behaviors.

These aims were formulated by two conceptual frameworks: Andersen's Health Service Utilization model and the Asian American Feminist Praxis. Andersen's model is one the most frequently used frameworks when studying careseeking behavior, including PFDs [3]. Andersen's model explains health service utilization using four key domains: need for care, resources, predisposing factors, and macrostructural factors [8]. To understand the health-service utilization patterns of Asian American women, we must consider their unique social positions and experiences in the USA. Therefore, we adapted the Asian American Feminist Praxis, which places emphasis on the lens of multiplicity by highlighting the intersectional identities and common valences of oppression shared among Asian American women [9]. The convergence of these frameworks regards individual health behaviors as the result of environmental and societal influences that also interconnect diverse Asian American communities. Through this minority-centered and coalitional approach, the proposed aims would enable us to examine multilevel factors that mitigate health behaviors shared among the diverse Asian American populations affected by PFDs.

Materials and methods

This was an exploratory-concurrent mixed methods pilot study that took place between March 2020 and February 2022 in Chicago, IL, USA. The Chicago metropolitan area has the highest Asian American population in the Midwest with Indian American, Filipino American, Chinese American, and Korean American being the largest subgroups [10]. We recruited a convenience sample from five primary care and urogynecology outpatient clinics representing three academic and community hospital systems. Additionally, we partnered with eight local Asian American community organizations to recruit individuals who might not have an existing connection to a health care system. To participate in the quantitative portion of the study, participants had to be able to complete a web-based survey in English, selfidentify as Asian American, be at least 18 years of age, and endorse symptoms of urinary incontinence, urinary urgencyfrequency, vaginal bulging, or anal incontinence (as defined by the International Continence Society terminology) in the past 3 months [11]. Symptom-based eligibility was captured by the answer "Yes" to at least one of the selected questions from each subscale of the Pelvic Floor Distress Inventory (PFDI-20) [12, 13]. The participants were then dichotomized as either care seekers or noncare seekers based on the question: "Have you ever asked a doctor, nurse, or other health care professional for help with [respective PFD]? [14]" For the qualitative portion of the study, we recruited both English- and Chinese-speaking care-seeking and noncareseeking participants for in-depth individual interviews. We chose Mandarin Chinese speakers to represent the perspectives of those with limited English proficiency for the interviews because Chinese people constitute the largest Asian ethnic group in the USA and the primary investigator is fluent in this language [15]. The Institutional Review Boards from Northwestern University, University of Illinois, and the Swedish Covenant Hospital approved this study. Informed consent was obtained from all participants in either English or Chinese.

Quantitative methods

To investigate care-seeking behaviors in Asian Americans with PFDs, we adopted and modified Andersen's Health Service Utilization model specifically to our population of interest. Andersen's model is the most commonly used framework in the study of health-service utilization, and it explains care-seeking behaviors by four interacting levels of influence:

- 1. Need for care/perceived needs
- 2. Enabling factors such as community, family, and personal resources
- 3. Predisposition to care-seeking behavior including demographics, social structure, and health beliefs
- 4. Macrostructural or contextual factors affecting the greater population [16, 17]

To compose the survey, we extensively reviewed the literature and selected available validated questionnaires that would address each level of Andersen's model. As the existing validated instruments do not have versions psychometrically evaluated in multiple Asian languages, we decided to limit the survey to English only. For the individual care needs level, we selected both the PFDI-20 and the Pelvic Floor Impact Questionnaire (PFIQ) to assess subjective symptom severity and the impact of PFD on quality of life [11]. For resource-level assessment, we utilized the Barriers to Incontinence Care Seeking Questionnaire (BICS-Q) to evaluate individual-level domains of cost, inconvenience, fear, and relationship with providers, then followed by comparing participants' results with those of historical controls from the original validation study [18]. We also assessed participants' social resources using marital status and the Social Support Survey [19]. Additionally, we inquired about



types of insurance, family history of PFDs, and whether the participant had access to primary care providers.

As for predispositions, we assessed age, ethnicity, Hollingshead Four Factor Index of Social Position validated in a PFD population, and the Prolapse and Incontinence Knowledge Questionnaire (PIKQ) [20]. For the PIKQ, we examined both urinary incontinence (PIKQ UI) and pelvic organ prolapse (PIKU POP), then compared with historical controls from the original validation study [21]. For ethnicities, we included Chinese, Japanese, Asian Indian, Filipino, Korean, Vietnamese, and a space for free-text input by study participants. For the macrostructural assessment, we chose to capture the proportion of lifetime spent in the USA. Previous studies have found that an increased proportion of lifetime spent in the USA has been shown to be associated with a greater health risk among Asian Americans [22, 23]. The proportion of one's lifetime spent in the USA may serve as a proxy for cumulative exposure to systemic racism that impacts health. We used 75% or more lifetime spent in the USA to denote increased exposure to systemic racism based on a previous study on a Asian American population [24]. The survey was tested with the research team, revised, and the final version was then made available on Research Electronic Data Capture software hosted at Northwestern University [25]. Participants received a \$15 gift card and were included in the study if they consistently answered three randomly selected questions from the survey in a subsequent verification email. A total of 98 potential participants were invited and accessed the web-based survey, and 79.6% of them completed the survey. We utilized the Checklist for Reporting Results of Internet e-Surveys when creating and administering this survey (Appendix 1) [26].

Statistical analysis

The primary outcome of the survey study was to determine whether younger age was associated with noncare-seeking behaviors. To determine the sample size needed to adequately power the survey portion of the study, we turned to a large population-based study that demonstrated younger age to be significantly associated with decreased health care utilization and PFD care in a predominately white population [12]. With 39 women in each group (care seekers versus noncare seekers), our study would achieve 80% power with an alpha of 0.05 to show at least a 9-year age difference between care seekers and noncare seekers. We used descriptive analyses to examine group differences. To examine the association between noncare-seeking behaviors and the selected multilevel factors, we carried out multivariate logistic regression models. We included variables that were clinically important or statistically significant from each level of Andersen's model in the regression. All quantitative analyses were conducted using R version 4.2.1.

Qualitative methods

An equal number of English- and Mandarin-speaking interviewees were selected, and they purposively represented a diverse range of age, types of PFDs, and ethnicities. A semi-structured interview guide was developed by the study team to include questions and prompts in reference to the impact of each level of the Andersen's model on subjects' lived experiences with PFD and care experiences (Appendix 2). We interviewed 10 care seekers and 10 noncare seekers to reach data saturation based on previous PFD qualitative studies [27, 28]. Each interview lasted between 45 to 60 min and was conducted over the telephone, audio-recorded, transcribed, and translated verbatim by the primary author (TM). The interview transcripts were analyzed using Dedoose software (version 8.0.36) to generate themes using a constant comparison approach. With expertise in urogynecology and qualitative methodology, the two primary coders (TM and OB) independently reviewed transcripts to identify themes and determine meaningful patterns. Emerging themes were analyzed by the coders, who met regularly to discuss, compare, and reach consensus. The third coder (MS) reviewed emerging themes and provided feedback through a similar process to reduce bias. Analysis was repeated until all data were coded, discrepancies were resolved, and thematic saturation was reached.

Results

Seventy-eight surveys along with 20 interviews were completed and analyzed. The most frequently reported symptoms were urinary leakage (67%), followed by urinary urgency-frequency (50%), anal incontinence (18%), and vaginal bulging (17%). The mean age was 46.1 ± 16.2 years, with most subjects reporting being married (60%). The median parity was 2 (IQR 1-2). The predominant ethnic groups were Chinese (38%) and Asian Indian (28%). In this cohort, most had established care with a primary care provider (87%) and almost all were insured (97%). The barriers to care seeking reported via the BICS-Q scores were significantly higher (meaning more barriers) than that of historic controls $(7.6 \pm 7.3 \text{ vs})$ 4.72 ± 6.3 , p < 0.01). As for knowledge regarding PFDs, this cohort had higher scores (meaning more knowledge) for both topics of pelvic organ prolapse and urinary incontinence when compared with historic gynecology controls $(9.9 \pm 1.6 \text{ vs } 5.4 \pm 2.9, p < 0.01 \text{ and } 10.2 \pm 1.6 \text{ vs } 6.6 \pm 3.0,$ p < 0.01 respectively).

We compared the variables from each level of the Andersen's model between care seekers and noncare seekers (Table 1). We did not find statistically significant



Table 1 Quantitative comparisons between care seekers and noncare seekers for Asian Americans with pelvic floor disorders (PFDs)

	Care seekers $(n=39)$	Noncare seekers $(n=39)$	p value
Care needs			
Total PFDI score, median (IQR)	70.8 (49.0–103.7)	57.3 (43.8–93.2)	0.2
Total PFIQ score, median (IQR)	42.9 (19.1–73.8)	33.3 (19.1–54.8)	0.2
Resources, n (%)			
Married	25 (64)	22 (56)	0.5
Positive family history of PFD	17 (44)	13 (33)	0.4
Have established care with a PCP	35 (90)	33 (85)	0.5
Insurance types, n (%)			
Medicaid	4 (10)	2 (5.1)	0.3
Medicare	8 (21)	5 (13)	
Privately insured	25 (64)	32 (82)	
Uninsured	2 (5.1)	0 (0)	
MOS Social Support Score, n (%)			
Low	19 (49)	23 (59)	0.9
High	20 (51)	16 (41)	
BICS-Q, mean (SD)	8.6 (8.2)	6.6 (6.3)	0.2
Predispositions, n (%)			
Age (years), mean (SD)	51.3 (16.1)	40.8 (14.7)	< 0.01
Ethnicity, n (%)			
Asian Indian	15 (38.5)	7 (17.9)	0.11
Cambodian	1 (2.6)	1 (2.6)	
Chinese	10 (25.6)	20 (51.3)	
Filipino	2 (5.1)	4 (10.3)	
Japanese	2 (5.1)	3 (7.7)	
Korean	3 (7.7)	3 (7.7)	
Laotian	1 (2.6)	0 (0)	
Pakistani	1 (2.6)	0 (0)	
Thai	2 (5.1)	0 (0)	
Vietnamese	2 (5.1)	1 (2.6)	
Hollingshead Index of Social Position, mean (SD)	53.1 (10.3)	52.8 (8.0)	0.9
PIKQ % answered correctly (SD)	19.8 (2.5)	20.5 (2.9)	0.2
Macrostructural, n (%)			
>75% lifetime spent in the USA	13 (33)	28 (72)	< 0.01

Data are $n\ (\%)$ or median (interquartile range) unless otherwise specified

PFDI Pelvic Floor Distress Inventory, PFIQ Pelvic Floor Impact Questionnaire, IQR interquartile range, PFD Pelvic Floor Disorder, PCP primary care providers, MOS Medical Outcome Study, SD standard deviation, BICS-Q Barrier to Incontinence Care Seeking Questionnaire, PIKQ Prolapse and Incontinence Knowledge Questionnaire

differences in variables on care needs or resources between the two groups. When examining predispositions related to PFD care, noncare seekers were younger than care seekers $(40.8 \pm 14.7 \text{ vs } 51.3 \pm 16.1 \text{ years}, p < 0.01)$. On the macrostructural level, we found noncare seekers were more likely to spend 75% or more of their lifetime in the USA than care seekers (72% vs 33%, p < 0.01). We then performed a multivariate logistic regression model controlling for care needs (PFDI), resources (BICS-Q), predisposition (age), and macrostructure (proportion of lifetime spent in

the USA), both younger age and increased lifetime spent in the USA remained independently associated with noncareseeking behavior (aOR 1.04 95% CI 1.01–1.08 and aOR 4.0 95% CI 1.40–11.79 respectively).

In Table 2, we show the characteristics of the 20 subjects who participated in the interviews, which demonstrated similar distribution of age, language preferences, ethnicities, and PFD types. Table 3 shows themes shared by both care seekers and noncare seekers with quotes. Both groups reported a significant impact from their pelvic floor



Table 2 Characteristics of interview participants

	Care seekers $(n=10)$	Noncare seekers (n = 10)
Age (years), mean (SD)	57.3 (15.2)	55.0 (13.3)
Preferred language, n (%)		
English	5 (50)	5 (50)
Chinese	5 (50)	5 (50)
Ethnicity, n (%)		
Chinese	5 (50)	6 (60)
Asian Indian	1 (10)	2 (20)
Vietnamese	2 (20)	0 (0)
Thai	1 (10)	0 (0
Japanese	1 (10)	1 (10)
Filipino	0 (0)	1 (10)
PFD symptoms, n (%)		
Urinary incontinence	7 (70)	8 (80)
Urinary frequency/urgency	5 (50)	2 (20)
Vaginal bulge	1 (10)	1 (10)
Stool/gas leakage	0 (0)	0 (0)

Data are n (%) unless otherwise specified

PFD pelvic floor disorder, SD standard deviation

symptoms, reported minimal knowledge about PFDs, and had discussed their pelvic floor symptoms in their social circles. However, we noted important thematic differences below.

Systemic anti-Asian racism

Although there is no consensus definition for systemic racism, most articulations emphasize that racism is

pervasive, with intergenerational effects, and driven by white supremacy [29]. In our qualitative analysis, we found that noncare seekers exclusively reported themes of anti-Asian racism manifesting across workplace, neighborhoods, and health care settings. One noncare seeker reported "not being fairly treated [at work and school] ... because I am Asian, and they try to find faults in me ... in class, my professor would say I am slow [but] they always praise white women." Another noncare seeker reported having "bad experiences at work and sometimes I would ask 'Is it because I am not blonde?" Seven out of 10 noncare seekers endorsed experiencing anti-Asian racism at the workplace and school.

Half of the noncare seekers also reported the theme of fear over anti-Asian violence in their neighborhoods. Some said they "felt discriminated against quite severely [because she] hears every day there are crimes in stores, carjacking, physical assault especially in Chinatown." This fear caused many to either "think twice where I am going" or "not want to take subways or train to go around." Some noncare seekers had indirect or direct experiences with anti-Asian violence: "people living close to me who witnessed an old Asian man got hit in head and bleeding" whereas another noncare seeker said, "a woman hit me, and she just fled." The pervasive threat of violence caused noncare seekers to reduce their use of public spaces and resources, including health services.

Seven out of 10 noncare seekers also reported experiences of anti-Asian racism in health care settings. One noncare seeker said, "maybe because I am Asian American and woman of color, the staff was rude and I felt some doctors don't care enough to give me the right referrals [for PFDs]."

Table 3 Themes shared between care seekers and noncare seekers

	Care seekers	Noncare seekers
Significant impacts by PFDs	"I don't get in the lake anymore. My symptoms got worse and especially when I get out of the house I have to go to bathroom a lot." "I was leaking every time I cough. I would still go out but it is very inconvenient and embarrassing."	"[PFDs] affect me mentally and is a major inconvenience. I had a breakdown one time as I was so worried that I would pee in the lobby." "[PFD] affects me a lot. I have to plan my day around it and find a bathroom that is open."
Minimal PFD knowledge	"I didn't have any idea on treatment options or anything about pelvic floor issues." "Folk tales basically said it is a private matter and com- mon after having kids. But it never goes into details."	"I don't know much about [PFD]. I don't have a deep understanding of this condition. I think there might be medications [for PFD] but I don't know." "I don't know any treatment options for this [PFD] condition I have."
Many shared their PFD symptoms within social circles	"I talked to my friends who had kids and they all had the same problem. It is just a common issue for peo- ple who had kids. Most of them just lived with it." "In my circle of friends, we talk about [PFD] once in a while and some say they have it and some don't have it."	"I told my friends and family, but they didn't say anything about my symptoms or what I need to do." "My sister said to go see a doctor and laughing at me because I have 4 kids. It is just a process of getting older."

Another Chinese-speaking noncare seeker reported witnessing poor treatment of her "dad who also doesn't speak English... and the interpretive service was not professional." The discriminatory care experiences led to breaches in trust, as another Chinese-speaking noncare seeker said: "the white doctor in the Emergency Room made me wait so long... I don't trust him. If I were white, I wouldn't be treated like this."

In contrast, 7 out of 10 care seekers denied experiences of anti-Asian racism. For example, one care seeker said, "I don't think being Asians changes how we access care" whereas another care seeker said similarly "I think no matter what race you are, we all have concerns." Other care seekers reported not being impacted at the height of anti-Asian racism during the COVID-19 pandemic, with one stating "I don't feel affected [by anti-Asian racism] at all, and I am doing pretty well during [the pandemic]."

Contrasting coping responses

Despite both noncare seekers and care seekers experiencing varying levels of bother by their pelvic floor symptoms, noncare seekers were more likely to cope by minimizing the need to seek care, as reported by 6 out of 10 noncare seekers. One noncare seeker said: "I am not seeking care because [my incontinence] is not severe to the point that I need to wear diapers every day," whereas another said "[my incontinence] affects me a lot, I have to plan my day around it... it is denial, I don't want to have another problem." Half of the noncare seekers also reported being burdened by the perceived financial barriers: "finance is a big problem, and it is expensive to see doctors" and "Western medicine is so expensive; it made me scared and not wanting to try it."

In contrast to noncare seekers, all care seekers deemed their pelvic floor symptoms to be serious problems regardless of their degrees of impact. Care seekers described a range of symptoms from "a little inconvenience" to "[PFDs] inhibited me from making certain lifestyle choices." Eight out of 10 care seekers voiced that they perceived the benefits of seeking care to outweigh any barriers.

Similarities between PFD and COVID-19 pandemic coping responses

Although our aim was not to assess Asian Americans' responses to the COVID-19 pandemic, we noted that non-care seekers encountered significant life challenges whereas care seekers demonstrated personal care prioritization during the pandemic. Six of the 10 noncare seekers voiced that they felt "very stressed," "more defeated than I ever felt," or

"stopped seeing [their] family doctors altogether." In contrast, 7 out of 10 care seekers felt that they coped well and thought that "[the pandemic] made me realize I need to take care of myself, and it is important for everyone else that I am healthy." Other care seekers further said that they "have no problems," "started to cook more and make the best of it during COVID," and "do a lot at home, exercise, make something to eat... [with my] whole day very busy."

Discussion

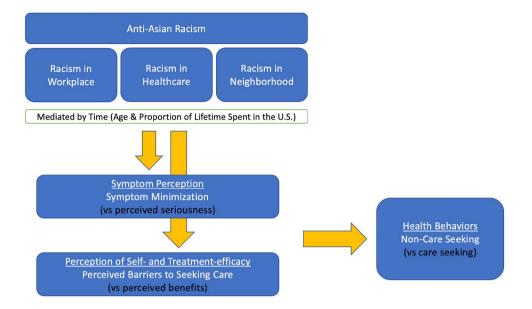
In this pilot study, we examined multilevel variables and synthesized our findings in the context of a race-conscious framework to hypothesize a PFD care-seeking model for symptomatic Asian Americans (see Fig. 1). Among noncare-seeking Asian Americans, we identified possible systemic manifestations of anti-Asian racism across the workplace, health care settings, and neighborhoods. Based on our findings, we hypothesize that one's age and proportion of lifetime spent in USA may affect the extent of exposure to anti-Asian racism that is associated with poorer health behaviors, such as symptom minimization, increased perceived barrier, and ultimately noncare seeking. This finding is most consistent with the Extended Parallel Process Model, where one's perceptions of illness severity, care efficacy, and self-efficacy in obtaining care altogether led to care-seeking or noncare-seeking behavior [30]. In this study, we further found potential evidence to suggest that experiences of anti-Asian racism might be the most proximal factor to exert the overall influence over Asian Americans' social experiences, self-perceptions, and their subsequent health behaviors.

A major strength of this study is the use of mixed research methods. This provided a broader picture of the understudied factors contributing to care-seeking behavior in a minority population. Additionally, we acknowledged that Asian Americans are heterogenous. At the same time, a common theme raised among Asian American communities is the shared experience of discrimination and adjustment to the acculturated environments [31]. This study intentionally sampled a diverse group of Asian Americans to work towards inclusivity and solidarity.

This pilot study has limitations that should be considered. First, it was not possible to calculate a true response rate for the surveys as they were distributed using referrals, email lists, and social media through community-engaged recruitment methods. Although this method of recruitment allowed for a wider reach, those who responded may be more aware and feel less stigmatized about PFDs. Second, there could be a selection bias, as we recruited through clinical or community organizations that may provide key services to study participants, such



Fig. 1 Race-conscious framework to hypothesize a PFD care-seeking model for symptomatic Asian Americans



as assistance in obtaining health insurance, education on health-promoting behaviors, or awareness of anti-Asian racism. This could minimize the influence of health beliefs and resources on care-seeking behavior by inadvertently excluding hard-to-reach populations with less access to important health-promoting services. Third, the findings and experiences reported by a cross-sectional sample of Asian Americans residing in Chicago may not be representative of the diverse Asian American populations in other parts of the country with continuously evolving demographics and experiences. However, by applying the Asian American Feminist Praxis, we worked toward identifying potentially shared struggles across this heterogenous population. Fourth, the interviews were conducted by one cisgender Asian American male urogynecologist. Although the interviewer had extensive experience working with vulnerable populations on sensitive topics, gender identity discordancy could cause discomfort among participants and lead to biased responses. Last, the quantitative portion of the study was not powered to detect differences other than age, and the measures selected were deliberate but not comprehensive, as the measurements were limited to validated instruments in English only. The utilization of validated measurements relies heavily on the existing research norm in gynecology, which is rife with inequities and disciplinary bias, particularly against those with limited English proficiency. Therefore, we hope that our pilot study will lead to better hypotheses and the creation of relevant multilevel measurements to better understand health behaviors of the diverse Asian American population.

In conclusion, this pilot study found that experiences of anti-Asian racism may be associated with noncareseeking behavior for PFDs among Asian Americans. Future efforts to re-examine this finding among a larger Asian American population are warranted. To our knowledge, this is the first study to examine the mechanisms of PFD care disparity by centering on Asian Americans. By centering on minority in health disparity research, we hope to prevent propagation of racist reinforcement and cultural stereotypes that are harmful to Asian Americans.

Supplementary information The online version contains supplementary material available at https://doi.org/10.1007/s00192-023-05574-6.

Authors' contributions T. Mou: project development, data collection, manuscript writing; O. Brown: data analysis, manuscript writing; S. Dong: data analysis, manuscript writing; V. Leung: project development, data collection; S. Abbasy: project development, data collection; M. Simon: project development, data analysis, manuscript writing.

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Data Availability The data that support the findings of this study are not openly available due to reasons of sensitivity and are available from the corresponding author upon reasonable request.

Declarations

Conflicts of interest None.

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