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Abstract

Factors that underlie the disparity in quality of life among Asian Americans with chronic pruritus

By Kevin M. Luk

INTRODUCTION: Chronic pruritus significantly impacts quality of life (QoL) and differentially impacts individuals by race. In a veterans population, our previous research study found that non-whites have greater pruritus-specific QoL impact. Current literature suggests that Asian or Pacific Islanders (API) have a higher prevalence and burden of disease from chronic pruritus, but the etiology of this disparity remains unclear. API are traditionally grouped into one population or grouped as “Other”, but are in reality a heterogeneous group.

METHODS: We investigated potential factors mediating this disparity in an API population of 47 pruritic and 30 non-pruritic subjects compared to a previously studied veterans population. Surveys assessing QoL (ItchyQoL) and itch severity were given to pruritic subjects, and demographics and medical distrust to all subjects.

RESULTS: The API group had a similar ($p=0.27$) mean itch severity score of 4.8 (SD=2.9) to that of the veterans (5.2, SD 2.3). As in the veteran group, higher itch severity and younger age were significantly associated with higher scores in the total and all three subdomains of the ItchyQoL in the API population ($p<0.05$). However, in the API group, female sex was significantly associated with QoL impact as well. As in the veterans group, itch had disproportionately higher emotional rather than functional or symptomatic impact on QoL among API. However, statistically significant differences in individual ItchyQoL item means

between pruritic API and veterans of different races were also found among all three subscales, especially under the emotional domain. With relation to mean scores, we found certain ItchyQoL items to be drivers under each subscale. In the symptomatic domain, APIs are significantly concerned for residual scarring and seasonal aggravation. In the functional domain, economic costs of managing their itch and disturbances with sleep and concentration were noted, and they also endorsed feelings of frustration or concern that their pruritic skin condition will last forever under the emotional subdomain. Finally, we found differences in medical provider trust between pruritic and non-pruritic subjects; compared to non-pruritic API, pruritic subjects felt less comfortable telling their physicians “anything” (T = -2.07, p=0.04). However, pruritic API more strongly disagreed that “their physicians pretended to know something he or she did not know” (T=-2.60, p=0.011).

CONCLUSIONS: Dissimilarities in the impact of chronic pruritus among different racial groups in specific emotional, functional, and symptomatic factors from their chronic pruritus are highlighted with our larger sample of API. Further exploration of potential sociocultural differences between API ethnicities that may mediate these disparities in pruritus are needed.

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CHAPTER 1: Introduction

1.1 Introduction and rationale

Pruritus, more colloquially known as itch, is defined by the International Forum for the Study of Itch (IFSI) as the unpleasant, cutaneous sensation that causes the sufferer to scratch the area. It is classified as chronic if the patient experiences the symptom for greater than six weeks.[1] Pruritus is a commonly reported symptom in the ambulatory healthcare setting. A study performed by Shive et al. using the 1999-2009 United States (US) National Ambulatory Medical Care Survey (NAMCS) data found that approximately 7 million outpatients annually, or 1% of all outpatient visits involved the management of itch. Approximately one-third of these visits involved chronic pruritus.[2] In a dermatology practice specific study, the point prevalence of pruritus among patient visits was 36.2%, of which 87.6% had chronic pruritus.[3] Similarly, in a previous study conducted by our research team which utilized the US Veterans Affairs (VA) National Patient Care Database to sample over 6000 veterans found that among the 1075 who agreed to participate, 405 or 37% of this sample population reported experiencing chronic pruritus.[4]

Pruritus is not only common, it also is highly relevant to patients’ overall health. Irrespective of the underlying etiology, this debilitating symptom has been found to have a significant impact on quality of life (QoL), with up to 73.6% of patients with chronic itch reporting inhibition of their everyday life.[3] Even more striking is that the burden of disease for pruritus has been found to be comparable to the quality of life impact seen in chronic pain.[5, 6] Using a mean health utility score, the same study also found that patients with chronic pruritus on average were willing to forfeit 13 years of their remaining life expectancy, if they could live the remainder of their life without pruritus.[5] The suffering caused by patients' chronic pruritus has also been associated with a higher propensity towards experiencing sleep impairment, depression, mental distress, eating disorders, and even suicidal ideation.[7-9]

Chronic pruritus also imparts a significant cost burden both from a societal perspective as well as a health payer perspective due to a high rate of management failure and expensive therapeutic costs.[10] Previous studies have analyzed the economic impact of individual pruritic skin conditions. A systematic review done on the economic burden of psoriasis found that the annual cost for US patients with psoriasis amounted to approximately $112 billion.[11] In addition to psoriasis, other studies have found significant financial losses resulting from other commonly pruritic skin conditions. US healthcare insurers, for example, found that more than one-quarter of their costs paid were attributable to atopic dermatitis associated care.[12] A 2008 systematic review estimating the national costs of management for atopic dermatitis in US adults and children ranged widely from $364 million to $3.8 billion per year.[13] Cost analyses for chronic idiopathic urticaria have estimated a disease specific annual healthcare cost of $2000. The mean number of medical visits per year for urticaria was found to be 3.4 visits. Thus, chronic itch not only imparts a high financial burden, but also leads to a significant opportunity costs for afflicted patients utilizing their time to seek medical care.[14, 15]

There is a growing literature surrounding the impact of pruritus on diverse international populations, which suggests that all populations are not equally affected by pruritus. Specifically, Asian and Pacific Islanders appear to have higher rates of itch and greater degrees of itch-related impairment. The NAMCS study found that Asian and Pacific Islanders (API) were over three times more likely than African American or Caucasian to be seen in clinic for itch as they age.[2] In our Veterans Administration (VA) study, nonwhites were found to experience significantly (p=0.05) greater impact on quality of life (QoL) than Whites from their pruritus, even after adjusting for itch severity.[2, 4] Of note, however, API were significantly underrepresented in this study. Therefore, there is an increasing amount of evidence to suggests a disparity in incidence and prevalence pruritic skin conditions and chronic pruritus itself exists among API both in the US and internationally, which possibly place them at a greatest risk of the related financial, medical, and psychological impact associated with chronic pruritus.

1.2 Problem statement

The United States Census Bureau projects that by the year 2044, more than half of the US population will be minorities – defined as any racial group aside from non-Hispanic White. By the year 2060, one in five Americans will have been foreign born.[16] Health disparities among minority groups are tremendous and multifactorial in origin. Structural, organizational, and clinical barriers all play important roles in health disparities. Specifically, clinical barriers encompass social and cultural differences between patients and providers that may lead to patient dissatisfaction, poor preventive measure adherence, and poorer health outcomes.[17] As the current minority populations within the US continue to grow, healthcare providers both within and outside the field of dermatology should become increasingly educated and trained to provide competent care to a diverse patient population. With the increasing recognition of disparities in dermatologic disease incidence and prevalence, especially pruritic skin conditions, and the resultant financial and QoL losses among API, healthcare providers should be trained to provide more culturally competent care to this patient population. These previous population projections and the increasing literature recognizing disparities in chronically pruritic diseases among API underscore the need for further research into the potential factors that underlie this disparity. By recognizing these factors, a concentrated effort in public health, clinical, or pharmaceutical arenas can be made to address this disparity.

1.3 Purpose statement

Chronic pruritus is a medical complaint in over 7 million outpatient visits annually. This symptom also has a significant impact on QoL. The literature and our research among a Veterans population with chronic pruritus suggest that a racial disparity exists in the incidence and burden of pruritus. The overall purpose of this work is to contribute to the reduction of suffering caused by chronic pruritus of which racial and ethnic minority populations – specifically Asian and Pacific Islanders – bear a disproportionate burden by investigating various factors that influence disease experience.

1.4 Research Aims

To inform the public health efforts to better understand the factors that influence the disparity in QoL impact from chronic pruritus, this quantitative research study seeks to achieve the following aims:

- Conduct an in-depth comparison of the factors that impact QoL associated with chronic pruritus between various API subpopulations (Chinese, Korean, Taiwanese, Indian, etc.) living in Atlanta, Georgia and a previously studied veterans population with chronic pruritus through validated survey instruments.
- Explore the social science construct of healthcare provider trust as a potential factor impacted by chronic pruritus among API through survey administration.

1.5 Significance statement

Much of skin disease across the world does not directly impact mortality but has a tremendous influence over individuals' quality of life, which is why it is of paramount importance to measure and investigate the quality of life impact of dermatologic disease. Dermatology is uniquely affected by cultural views as skin appearance and resultant quality of life living within a community is intimately tied with its cultural beliefs about "normal" skin. Pruritus is currently underappreciated by healthcare professionals, with a paucity of research support and efforts directed towards understanding the pathophysiology of itch but also the burden and risk factors of this symptom. Compounding its significant prevalence as previously described is the perception by patients that providers do not take the symptom of chronic itch seriously.[18] Further elucidating the qualities that might contribute to the racial disparity in QoL impact associated with chronic pruritus for API will not only illuminate the debilitating nature of the symptom but also go on to inform the ability of healthcare providers to provide culturally competent care for this population.

1.6 Definition of terms

Pruritus: The unpleasant cutaneous sensation that leads to the desire to scratch the area.

Chronic pruritus: Pruritus that lasts for 6 or more weeks.

Dermatoses: A disease of the skin.

Health disparities: The variation in rates of disease occurrence and disabilities between socioeconomic and/or geographically defined population groups.

Quality of Life: The subjective perception of the impact of health status, including disease and treatment, on physical psychological and social well being.

Post inflammatory hyperpigmentation: Sequelae of trauma, inflammation, or other insult to the skin that stimulates the release of pigment in the skin.

CHAPTER 2: Review of the Literature

2.1 “Globalization” of the US population

According to the 2010 United States Census, over 17 million Asian and Pacific Islanders (API), including multiracial Americans identifying as Asian, comprise approximately 5.6% of the total United States (US) population. The ethnic groups representing the largest portion of respondents included Chinese, Filipino, Indian, Korean, and Japanese Americans. The US Census Bureau projects that by the year 2044, more than half of the US population will be minorities – defined as any racial group aside from non-Hispanic White. By the year 2060, one in five Americans will have been foreign born.[16] As the current minority populations within the US continue to grow, healthcare providers both within and outside the field of dermatology should become increasingly educated and trained to provide competent care to a diverse patient population.

Health disparities among minority ethnic groups are tremendous and multifactorial in origin. Structural, organizational, and clinical barriers all play important roles in health disparities. Specifically, clinical barriers can magnify social and cultural differences between patients and providers, leading to patient dissatisfaction, poor preventive measure adherence, and poorer health outcomes.[17] While API continue to be the fastest growing minority in the United States, a comprehensive characterization of their dermatoses and resultant quality of life have not been a focus of public health investigation within dermatology to date.

2.2 Quality of life research in dermatology

Estimating the incidence and prevalence of dermatologic disease plays a crucial role in the characterization of population needs. However, measuring and investigating the quality of life impact of dermatologic conditions on populations is also critical, because the overwhelming majority of skin conditions do not impact mortality but have a significant role in individuals' quality of life.[19] According to the 2010 Global Burden of Disease Study, skin disease ranked as the fourth leading cause of nonfatal disease burden. Country specific number of years lived with disability for skin disease ranged from the 2nd to the 11th leading cause.[20] Pointedly, Wolkenstein et al. reported that among the multitude of skin disorders queried about in their cross sectional study, including acne, cold sores, warts, etc., chronic itching was cited as the most burdensome skin disorder.[21] Despite spanning a wide range of systemic diseases, including chronic renal insufficiency, cholestatic liver diseases, anxiety, asthma, obesity as well as primary cutaneous disorders such as cutaneous T-cell lymphoma and atopic dermatitis, and even as a part of the physiologic changes of aging, the impact of this debilitating symptom is frequently underappreciated both within and outside the field of dermatology.[18, 22] Although disease specific and general dermatologic disease quality of life surveys including the VitiQoL, Scalpdex, Skindex, etc., have been created to address this need, pruritus specific QoL instruments that are applicable to the spectrum of associated diseases have only begun to be a concentration of research efforts.[18, 23-25]

Chronic pruritus also imparts a significant economic burden both on the individual and societal level. The American Academy of Dermatology's recent national Burden of Skin Disease report revealed a pruritus-specific total medical cost of $294 million, which notably did not include 33 other cutaneous diseases with significant pruritic components, such as psoriasis and urticaria.[26] Thus, this figure likely underestimated the total cost of managing chronic itch. With regards to individual medical resource utilization, a study conducted by our investigatory team found that approximately one-quarter of a sample of 405 participants utilized one or more primary care provider visits specifically for their itch and spent greater than 15 minutes a day treating their itch (including topical medication application, bathing, etc.). Approximately 13.4% of the participants required additional help from family or friends to carry out activities of daily living and almost 7% missed at least one day of work due to their itch. This was further supported by a study in an atopic dermatitis population, a pruritic skin condition, which found participants lost an average of 8.3 work days per year because of their symptom.[27] In considering the direct and indirect, disease specific economic costs discussed above, chronic pruritus poses a substantial economic concern relevant to public health.

2.3 Quality of life impact of chronic pruritus

Chronic pruritus has a significant impact on patients’ quality of life. In order to better appreciate the determinants of quality of life for patients with chronic pruritus, a dermatology research group at Emory expanded on a Biopsychosocial theoretical model first put forth by Verhoeven et al. that sought to describe factors that influence pruritus intensity.[28] The original model focused on how pruritus intensity is affected by various internal, external, mediating, and physiological factors and how their interactions influence experience of pruritus intensity. Factors such as patient psychology and personality traits (internal), life events or stressors (external), and cognitive, behavioral, and social mediating factors all combine with physiology to effect pruritus intensity in the original model. Considering additional factors such as how activities of daily living, quality of life, and their mediating factors such as ethnocultural characteristics, Emory Dermatology's modified Verhoeven biopsychosocial model of itch (Figure 1.) may serve as a comprehensive framework in considering the impact of itch on quality of life and its determinants.

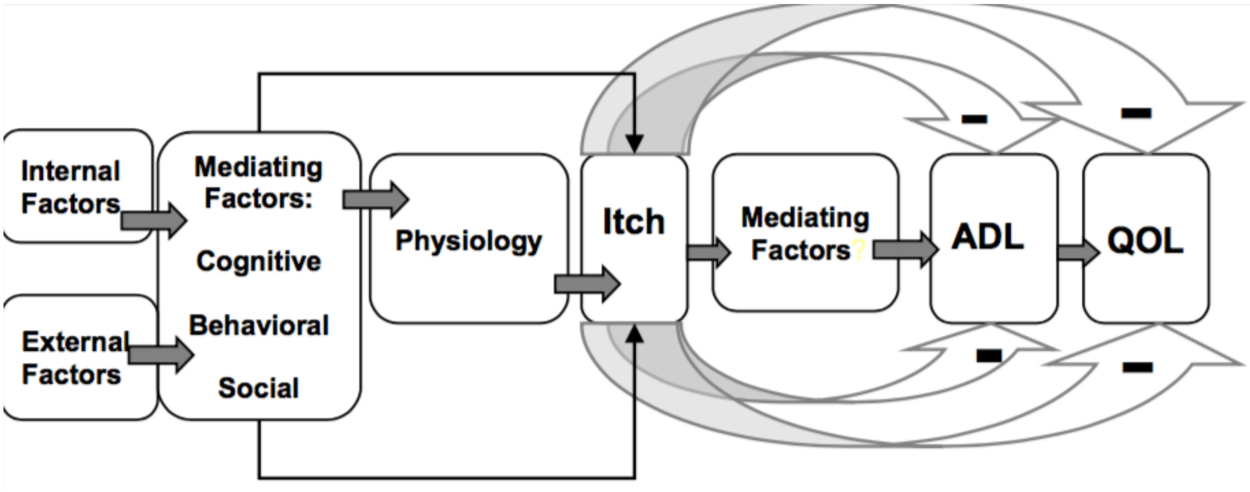

Figure 1. Expanded Verhoeven Biopsychosocial Model of Itch

As previously stated, the severity of impact on quality of life from chronic pruritus has been equated to that of chronic pain as well as sexual dysfunction, constipation, and weight loss.[5, 8] Several pruritic disease-specific quality of life assessments have been conducted. For example, pruritus significantly disturbs patients' ability to sleep; one study found that 58% of 100 chronic idiopathic urticaria patients and 61% of 145 uremic patients surveyed lost sleep due to their chronic itch. A significant percentage of both groups were also found to suffer from depression associated with their symptom.[29] Halvorsen et al. found increased odds for suicidal ideation in adolescents with chronic pruritus compared to those without itch. Again, this was comparable to the odds found in that of those with and without chronic pain (OR: 3.8, CI:2.6 – 5.7).[30] Chronic itch has also been shown to lead to worsening depressed mood, anhedonia, sexual function, and ability to concentrate.[9, 29, 31] Kini et al. highlighted the impact of chronic pruritus by employing time trade-off utilities, a health economic measure of QoL, which found that surveyed patients were willing to trade 13 years of life, on average, to have the remainder of their lives without itch.[5] Quality of life impact from chronic pruritus does not differ based on skin lesion type but has been found to vary depending on other patient characteristics. Female sex, marital status, and higher itch severity were found to be correlated with higher quality of life impact from chronic pruritus. Married subjects in one study were less impacted by their chronic pruritus compared to those who were unmarried. [5, 32]

2.4 Epidemiology of chronic pruritus among different global populations

Pruritus is commonly experienced across the world, but race has also emerged as a significant factor associated with differing symptom prevalence and QoL impact. The European estimated lifetime prevalence of chronic pruritus in adults is 22% and the point prevalence ranges from 8% to 27%.[33-36] In the US, two recent studies have also demonstrated the substantial presence of chronic pruritus. Shive et al. found from the 1999 to 2009 NAMCS that 1% of all outpatient visits, approximately 7 million visits per year, included a code for itch, of which one-third were considered chronic. In a cross sectional study of general internal medicine outpatient clinics, 39.9% of patients were found to have itch as an individual complaint.[2, 8] Similarly, our research team previously utilized the VA National Patient Care Database to randomly select 6,000 veterans who had at least one encounter with the VA hospital system. Of the 1,075 who agreed to participate, 405 (37%) reported pruritus lasting for at least 6 weeks.[4]

Although common worldwide, non-white populations appear to be disproportionately at risk for developing chronic pruritus. In one cross sectional study conducted in Norway, the presence of itch had a significant two-fold increase in prevalence among men from East Asian (18%) or Middle Eastern (13%) descent when compared to Norwegian Caucasian participants (7%).[37] In an analysis of all ambulatory care visits in the US for a complaint of itch, Shive et al. found that patients were 14% more likely to be Asian than Caucasian.[2] The reasons underlying this racial disparity are incompletely understood. Several theories based on biological differences have been proposed. One group hypothesized that Asians experience increased transepidermal water loss from skin, causing increased risk of developing pruritus.[38] Other past studies have attributed this discrepancy to genetic variation in epidermal composition and physiology, including altered serine protease enzyme activity, differences in skin acidity, or polymorphisms in genetic loci, such as that for Interleukin-31 receptors, with no clear consensus in the literature.[38, 39] As described above, “internal” physiologic differences between different ethnic groups may partly underlie this disparity, but sociocultural factors may also play a significant role as well.[39]

2.4.1 Disparities in chronic pruritus among East Asian populations

With regards to susceptibilities, manifestations, and treatment outcomes, it is increasingly recognized that API experience disparities in both non-pruritic dermatoses, such as hyperpigementation and hypertrophic and keloidal scars, as well as pruritic dermatologic disease.[39-41] For instance, a higher incidence of atopic dermatitis – a pruritic skin condition – was reported in Chinese infants as compared to Caucasian infants. This was further corroborated by a 12-month cumulative incidence survey of atopic dermatitis in Chinese (44%) and Vietnamese (17%) infants relative to Caucasian (27%) infants in Melbourne. A majority of Chinese patients with atopic dermatitis (87%) report daily pruritus that is distressing.[31] It was also found that East Asian men are more prone to report itch as their most prevalent skin symptom when compared to Middle East or North African males.[37, 42] A study done in postoperative Hong Kong males compared with Caucasian patients not only revealed higher numeric rating scale pain scores in Chinese patients, but also significantly higher opioid induced incidence of pruritus.[43] In contrast, Reich et al. reported 'severe' and 'very severe' itching significantly more frequently reported by Polish Caucasians relative to their Japanese subjects. However, the study does report that the Polish subjects were significantly older and held a significantly higher burden of psoriasis and lichen planus. The Japanese subjects more frequently had atopic dermatitis.[44] This suggests that there might exist differences in itch experience between different East Asian populations either due to a biologic or sociocultural, or combination, influence.

2.5 Factors in chronic pruritus quality of life from a veterans population study

Our previously published work on racial disparities in chronic pruritus quality of life in a US veterans population uncovered more of the underpinnings in the racial disparity in chronic pruritus. Our work revealed that the non-Caucasian subjects, which were subdivided into "African American" (18%) and "Other" (12%) cohorts, were differentially impacted by their chronic pruritus in specific emotional, functional, and symptomatic domains (i.e. concern about scarring, seasonal change, and concern for how others perceive them). A majority of the significant differences fell under the emotional subscale score, with African Americans feeling more angry or irritable and more often reporting a personality change, while the non-Caucasian cohort – encompassing African American and “other” participants – as a whole were more often “driven crazy/nuts” from their itch. Functionally, the African American cohort reported the need to use more specialized soaps, lotions, and detergents for their itch and required special clothing. This population was also found to have a higher number of primary care provider visits for their chronic pruritus but a comparable number of specialty and emergency room visits when compared to the Caucasian or the “other” cohort. Oftentimes the statistical trend of the African American cohort was paralleled by the “other” cohort in this study, but the latter cohort also appeared to differ from both Caucasian and African American groups in some instances, such as stinging or burning associated with their itch. However, this “other” subgroup was small (n= 49) and was composed of a combination of survey responders who identified as Asian, American Indian/Alaskan Native, Pacific Islander, none, and unknown. Given that only a subset identified as API, this heterogeneous population was not adequately represented out of a total sample population of over 400 veterans.

2.6 Healthcare system experiences and their influence on health seeking behaviors of Asian Americans

Based on our previous work investigating racial disparities in chronic pruritus, the highly impacted African American population had a higher rate of primary care versus specialist provider visits for the management of their chronic pruritus. One of our hypotheses regarding this discrepancy was that it might be related to healthcare provider comfort or perceived healthcare racism amongst African Americans. Unfortunately, given the history of healthcare system mistreatment in this population, the hypothesis that this population might choose to remain in the direct care of primary care providers who they have established a rapport with was highly probable for this finding.[45-47] From this finding, we became interested in the potential association between health provider trust amongst API with and without chronic pruritus. Part of our hypothesis originates from the literature currently available surrounding healthcare system experience in ethnic minority populations. Minorities were reported to be less likely to have a general practitioner, be admitted to hospital, tested for prostate-specific antigen, receive a mammogram, or given a Pap test, especially amongst the older Chinese immigrant population in one study.[48] The range of reasoning for underutilization of Western healthcare included: language barriers, transportation concerns, cost, time, cultural norms related to thresholds for need of care, preference for self over professional care, and distrust of Western biomedicine.[48, 49] Studies have reported pervasive distrust of medicine amongst the Chinese patient population, as poor experiences in their home country's healthcare system created a general distrust of medical systems for prioritizing profits over patient health outcomes.[50] Related to this, API more broadly are reported to have lower rates of visiting dermatology clinics compared with other ethnic groups.[51] Compounding the language barrier issue specifically for chronic pruritus may be a reported difficulty by patients in describing their symptoms to providers even in their native tongue, causing frustration in the clinical encounter.[52]

CHAPTER 3: Manuscript

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Title: Factors that underlie the disparity in quality of life among Asian Americans with chronic pruritus

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Key words: chronic pruritus, health disparities, Asian Americans, veterans

Abstract

INTRODUCTION: Chronic pruritus significantly impacts quality of life (QoL) and differentially impacts individuals by race. Asian or Pacific Islanders (API) have a higher prevalence and burden of disease from chronic pruritus, and a more significant impact of pruritus on their QoL; however, the etiology of these disparities remains unclear.

OBJECTIVE: To compare a community-recruited sample of API with a previously studied veterans population, in terms of QoL associated with chronic pruritus.

METHODS: We investigated potential factors mediating this disparity in an API population of 47 pruritic and 30 non-pruritic subjects. Surveys assessing QoL (ItchyQoL) and itch severity were given to pruritic subjects, and demographic items and a scale measuring medical distrust to all subjects (including those with and without chronic pruritus).

RESULTS: The API group had a similar ($p=0.27$) mean itch severity score of 4.8 (SD=2.9) to that of the veterans (5.2, SD 2.3). As in the veteran group, higher itch severity and younger age were significantly associated with higher scores in the total and all three subdomains of the ItchyQoL in the API population ($p<0.05$), corresponding to a worse QoL. However, in the API group, female sex was significantly associated with higher QoL impact as well. As in the veterans group, itch had disproportionately higher emotional rather than functional or symptomatic impact on QoL among API. However, statistically significant differences in individual ItchyQoL item means between pruritic API and veterans of different races were also found among all three subscales, especially under the emotional domain. With relation to mean

scores, we found certain ItchyQoL items to be drivers under each subscale. APIs are significantly concerned for residual scarring and seasonal aggravation under symptomatic, economic costs of managing their itch and problems with sleep and concentration under functional, and feelings of frustration or that their pruritic skin condition will last forever under the emotional subdomain. Finally, we found differences in medical provider trust between pruritic and non-pruritic subjects; compared to non-pruritic API, pruritic subjects felt less comfortable telling their physicians “anything” (T = -2.07, p=0.04). However, pruritic API more strongly disagreed that “their physicians pretended to know something he or she did not know” (T=-2.60, p=0.011).

LIMITATIONS: Our study may not be generalizable because our samples were taken from one metropolitan population in the Southeast US and a US Veteran population.

CONCLUSIONS: Dissimilarities in the impact by chronic pruritus among different racial groups in specific emotional, functional, and symptomatic factors from their chronic pruritus are better highlighted with a larger API sample. Further exploration of potential sociocultural differences between API ethnicities that may mediate these disparities in pruritus are needed.

Capsule Summary

- Higher itch severity, younger age, and female sex were significantly associated with higher scores in the total and all three subdomains (symptoms, function, and emotion) of the ItchyQoL, a pruritus-specific QoL assessment, in the API population.
- API are significantly concerned about residual scarring, seasonal aggravation, economic costs, sleep disturbance, difficulty concentrating, and feelings of frustration or that their pruritic skin condition will last forever associated with their itch.

Key Words: Pruritus, Chronic Pruritus, Asian American, Racial Disparity, Quality of Life, Healthcare system distrust

Introduction

Chronic pruritus, more colloquially known as chronic itch, is the unpleasant, cutaneous sensation that causes the sufferer to scratch the area for greater than six weeks.[1] The symptom is common; data from the 1999-2009 United States (US) National Ambulatory Medical Care Survey (NAMCS) data found that approximately 7 million outpatients annually, or 1% of all outpatient medical visits involved the management of itch. Approximately one-third of these visits involved chronic pruritus.[2] In addition, chronic pruritus and chronic pain have been shown to have comparable impact on quality of life (QoL).[5] The suffering caused by chronic pruritus has also been associated with higher propensity towards sleep impairment, depression, distress, eating disorders, and even suicidal ideation.[7, 8]

A racial disparity in prevalence and QoL burden of chronic pruritus has also been reported. In an analysis of all ambulatory care visits in the United States for a complaint of itch, patients were 14% more likely to be Asian than Caucasian.[2] Davis et al. utilized NAMCS data between 1993 – 2009 to determine the leading dermatologic disorders for various racial groups in the US. Three of the top five diagnoses for African American and Asian and Pacific Islanders (API) respondents were dermatoses with significant pruritic components (unspecified dermatitis, seborrheic dermatitis, and psoriasis), while only one of the top five most common conditions for Caucasians was associated with pruritus.[53] Other studies have also reported higher prevalence and severity of itch amongst people of East Asian descent.[39, 40]

In addition to itch being more common in ethnic minorities, there is literature to suggest that minorities are also more significantly impacted by itch in terms of QoL. Our own previously published work on racial disparities in chronic pruritus QoL in a US veterans population, non-Caucasian subjects, which included “African American” (18%) and “Other” (12%) individuals, did in fact appear to be more highly impacted by their chronic pruritus in specific emotional, functional, and symptomatic QoL domains (i.e. concern about scarring, seasonal change, and concern for how others perceive them).[4] Although the “Other” cohort included Asians, the sample size was underpowered to make comparisons between Asians and other ethnic groups.

To address these gaps in the literature, we sought to examine itch and its QoL implications in the API population. Specifically, the first goal of this work is to conduct an in-depth comparison of the factors that impact QoL associated with chronic pruritus between various API subpopulations (Chinese, Korean, Taiwanese, etc.) living in Atlanta, Georgia. The second goal was to compare our API participants to the aforementioned veterans cohort through validated survey instruments. We hypothesize that API with chronic pruritus will report a greater impact on pruritus-related QoL compared to a racially heterogeneous veterans population. We also sought to investigate the potential association of healthcare provider trust and chronic pruritus status amongst API respondents.

Methods

Study Design

We conducted a cross-sectional survey study of API with symptoms of pruritus in metro and suburban Atlanta. All surveys were available in English and systematically translated using the

TRAPD (translation, review, adjudication, pretesting, and documentation) team translation model into various Asian languages, including Traditional Chinese, Simplified Chinese, Korean, and Hindi. This study was reviewed and approved by the Emory Institutional Review Board.

Context and Recruitment

Participants were required to have greater than or equal to 6 weeks of pruritus, be of at least partial Asian descent based on self-reported ethnicity, and be at least 18 years old. Individuals with pruritus for less than six weeks or subjects with physical or mental disabilities that would preclude the respondent from answering the survey were excluded. Potential participants were recruited with support from community social groups and outreach efforts. Atlanta-based community organizations, businesses, and healthcare private practices collaborated with our research team in engaging Asian Americans in the Atlanta and surrounding suburban communities. A combination of educational outreach events, flyer distribution, attendance of health fairs and community gatherings, local newspaper advertisements, and snowball sampling was employed (Figure 2.). Community partnership development and subject recruitment were conducted over a period from March 2016 to August 2017. During these events, typically a board-certified dermatologist from our research team would present a 30-minute talk on expected and concerning changes in skin with aging after which the dermatologist or a collaborating community leader would ask for any interested API who fit our inclusion criteria to seek one of the several research team members present to participate in the survey study.

Figure 2. Variety of recruitment efforts used to engage Atlanta API community

Severity

Patients indicated the severity of their symptoms on a scale of 0 (none) to 10 (worst itch ever experienced) for the past week using the ItchyQuant survey (Appendix I). Those with an itch severity of 0 were excluded from further analysis.

Quality of Life

Quality of life impact was assessed using the previously validated ItchyQoL^{TM}, a pruritus-specific instrument that measures the symptomatic, emotional, and functional quality of life impact of pruritus of any etiology (Appendix II). The ItchyQoL was validated in a sample containing 89 patients with chronic pruritus of varying etiologies. This population had a mean age of 58.1 years (SD=16.7), and the majority were female (60.7%), white (74.2%), and received a college education or greater (75%). The instrument was found to be reliable and internally consistent (Cronbach α: frequency 0.72-0.93 and bother 0.78-0.81) and demonstrated reproducibility (intraclass correlation coefficient: frequency 0.91 and bother 0.84-0.87). Further validation and psychometrics are detailed in the methods paper.[54] Each of the 22 items consisted of a response from 1 (never) to 5 (all the time). An overall score as well as three subscale scores (namely symptomatic impact, functional limitations, and emotional impact) were tabulated. Finally, individual ItchyQoL item scores were designated as drivers of an ItchyQoL subdomain if the item was found to have a mean score of at least one standard deviation above the subdomain mean.

All participants who selected “don’t know” or refused for more than one item in each subscore of the ItchyQoL survey were removed from subsequent analyses involving this scale. If a participant answered, “don’t know” or “refused” for one item within a given subscale of the ItchyQoL, a value was imputed for that question based on the median of that participant’s answers to the other questions within that subscale.

Race

Race was self-selected by each participant. A wide range of Asian ethnicities were available for selection, including Taiwanese, Chinese, Korean, and Indian among many others. An non-specified “other” category was available as well where a race not offered as an option could be written in. Participants who chose to not indicate their race were subsequently excluded from analyses.

Medical provider trust

A subset of questions was adapted from the Primary Care Assessment Survey that specifically assessed participants’ level of trust of their healthcare providers (Appendix III).[55] Responses were recorded on a Likert-scale based system from 1 (strongly agree) to 5 (strongly disagree).

This part of the survey was not pruritus specific and thus was provided to all API participants with chronic skin disease, regardless of pruritic symptoms.

Statistical Analysis

We describe normally distributed continuous variables with mean (standard deviation, SD) scores and non-normally distributed continuous variables with medians (standard error, SE). We used student's T-test or analysis of variance (ANOVA) to compare mean scores of continuous variables. We utilized nonparametric analysis when data were found to be non-normally distributed. We described all categorical variables as proportions. We used χ^2 analyses to compare categorical variables and Fisher's Exact Test for any analysis that had less than five subjects for a given condition.

Outcome variables for the regression model included ItchyQoL as a total impact score as well as its subscale (symptom, emotional, and functional impact) scores. Potential independent predictors included demographic data and the ItchyQuant. Lastly, we compared the individual item ItchyQoL scores from the API subjects with the ItchyQoL scores of the pruritic veterans population we previously studied. Analyses were performed using STATA (version 14.2, StataCorp, College Station, Texas). We considered a p-value less than 0.05 to be statistically significant.

Results

Population

Of the 292 potential participants across 10 educational and community outreach events the research team recruited a total of 47 pruritic and 30 non-pruritic API for the study. Of the 47 pruritic API participants, a majority were Taiwanese (45%) with the remaining population consisting of Chinese (15%), Indian (7%), and Korean Americans (36%). Select demographic characteristics of the subjects are summarized in Table I. The majority of the API population was female (64%) with a mean age of 60.1 years (SD=17.1). Relevant demographics for the chronic pruritus veterans population can be found alongside the API population's in Table I. Importantly, the veterans population as a whole was less likely to be female, college educated, or married. Complete demographics of the comparison population of veterans with pruritus have previously been published.[4, 56]

Itch Severity

The mean itch severity of the pruritic API cohort was 4.8 (SD=2.9). The mean itch severity of the veterans cohort was 5.2 (SD=2.3). Cohort itch severity was not statistically different (p=0.27).

Quality of Life

The API cohort's mean ItchyQoL total score and subdomain scores are shown in table II. Drivers of each subdomain included concern for scarring from their pruritic skin condition and aggravation with temperature or seasonal changes under the symptomatic subdomain, concern for economic costs of managing their itch, disturbances with sleep and concentration under the functional subdomain, and feelings of frustration or concern of their pruritic skin condition lasting forever under the emotional subdomain. Disturbances in sleep, concentration, frustration, and concern that their pruritus will last forever while they were drivers were either not significantly different or were significantly lower impact than that seen in the Caucasian and African Americans of the veterans population.

In univariate analyses, higher itch severity and female sex were significantly associated with all three ItchyQoL subdomain scores as well as total ItchyQoL scores in the API population ($p<0.05$). Itch severity was similarly predictive of ItchyQoL subdomain and total scores in the veterans population, but sex was not found to be a significantly associated in this population. Unlike in the veterans population, younger age was significantly associated with all three higher subdomain scores but not for overall higher ItchyQoL scores. Marital status was not significantly related to impact of pruritus on ItchyQoL score as was originally found in the veterans population.

Figure 3 depicts the mean ItchyQoL scores per item for API, Caucasian veterans, and African American veterans. Statistical differences in mean individual ItchyQoL item scores were detected between that of the API's and the Caucasian and/or African American veterans. Under the symptomatic subdomain, API reported significantly lower mean scores for burning and stinging associated with their pruritic skin and the need to scratch when compared to both the Caucasian and African American veterans cohorts. Scarring associated with their itch was highly impactful for both API and African Americans. Functionally, API and Caucasian veterans similarly reported less frequent use of special soaps, lotions, and detergents compared to the African American participants for their pruritic skin. However, API had an overall higher concern for financial burden associated with management of their pruritic skin condition when compared to Caucasian veterans. The majority of items with significant differences fell under the emotional impact subscale. API experienced significantly less frustration and feeling they "were driven nuts/crazy" by their pruritic skin condition compared to both the Caucasian and African American veterans, but differed significantly only from African American veterans with regards to anger/irritability and self-consciousness associated with their pruritic skin condition.

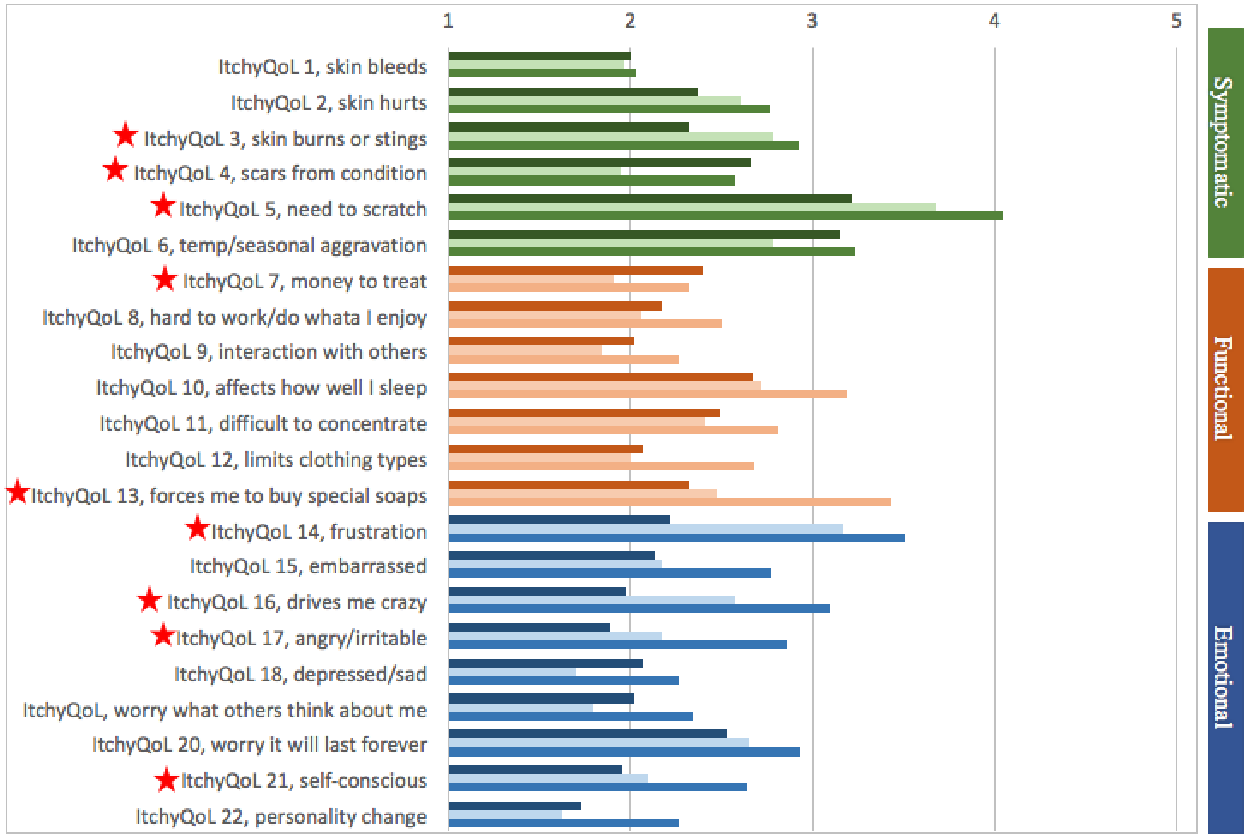

Figure 3. Mean ItchyQoL scores per item for API, Caucasian veterans, and African American veterans. From top horizontal bar to bottom horizontal bar in each triplet per item are API,

Caucasian veterans, and African American veterans, respectively. Stars indicate differences that were statistically significant by ANOVA.

Medical Provider Trust

Table 3 includes healthcare provider trust survey results, which reveal that chronic pruritus status is associated with differences in certain aspects of the patient-provider relationship. Compared to non-pruritic API, pruritic subjects felt less comfortable telling their physicians “anything” (T = -2.07, p=0.04). However, pruritic API more strongly disagreed that “their physicians pretended to know something he or she did not know” (T=-2.60, p=0.011). Pruritic and non-pruritic API did not significantly differ in their overall self-rated trust of their physician (pruritic API mean=7.5, SD = 2.3 vs. non-pruritic API mean= 7.5, SD=1.9; p > 0.05).

Discussion

Racial disparities between white and non-white populations in chronic pruritus incidence and prevalence as well as impact on quality of life is an emerging area of focus in dermatology. While disparities in dermatologic disease among API are currently under-described in the literature, the results of our study serve as an initial foray into investigating factors that appear to underlie the observed differential impact from chronic pruritus in this population. Although our previous study in a veterans population was representative of the racial distribution of the current US population, the results of this study help us understand a population that will become more prevalent in the coming decades. By moving towards a larger sample of API, including Chinese, Taiwanese, Indian, and Korean Americans, we are better able to highlight dissimilarities in the impact by chronic pruritus among different racial groups in specific emotional, functional, and symptomatic factors from their chronic pruritus.

While specific demographic factors were again found to be associated with higher quality of life impact in all three domains among chronically pruritic API as was found in the veterans population, significant differences were found as well. The association between age or sex and more severe disease experience is not unprecedented in dermatology. Zachariea et al. reported that younger and female patients were generally more distressed by their skin conditions than older and male participants from a sample of over 300 outpatient and inpatient dermatology patients.[57] In a pruritus specific study, female participants more often reported localized itching attacks associated with stinging, warmth, and painful qualities. They were also more commonly found to have pruritus sequelae such as prurigo nodularis and chronic excoriations when compared to male subjects. Overall, the researchers found that female subjects were likely to have higher QoL impact and higher visual analogue scale scores than the male subjects.[32, 58] Our findings suggest that ethnicity may interact with this apparent sex specific difference in impact on QoL from itch as sex was not found to be a significant predictor in our veteran cohort but was so in the broader API group.

Factors found to drive impact on chronic pruritus quality of life among API are consistent with clinical experience and current literature as well. Of the individual ItchyQoL items that significantly differed between API and either or both Caucasian and African American, concern for scarring and the financial burden of managing their chronic itch were the only items with API having the highest absolute means. The higher relative concern for scarring associated with pruritic skin in non-whites was appreciated in the veterans populations as well. We maintain that this finding is likely a reflection of the increased incidence of post-inflammatory hyperpigmentation – a well-recognized disparity in individuals of skin of color.[59] As mentioned previously, current therapy of chronic pruritus is often expensive and accompanied by a high failure rate. Concern among East Asian populations, such as Chinese Americans, with specific for economic costs of managing their itch has been previously reported and is mirrored in our sample.[49] This finding may also have a basis in the previously reported discrepancy in perceived or expected quality of healthcare for similar utilization or out-of-pocket costs between Asians and Hispanics as compared to Caucasians and African American patients.[60]

With a larger API sample, the differences in emotional impact from chronic itch between our populations deviated from our previous findings. The finding that our API sample was significantly less likely to report being frustrated, “driven crazy”, angry or irritable, or self conscious from their pruritic skin than the “other” veterans cohort was compared to the rest of the veterans sample may reveal a previously underappreciated difference. The finding that API were found to be consistently less impacted emotionally, when compared to the veterans cohort was surprising. One explanation is that poor social support and/or higher rates of mental distress, all of which are associated with pruritus prevalence, are found at higher rates among veterans relative to the general population.[61] In addition, the use of complementary and alternative medications and mindfulness meditation, more common among APIs, has been found to improve QoL in patients with skin disease and even improved light treatment outcomes of pruritic skin diseases.[62, 63] Whether the lower impact of chronic pruritus on emotional QoL in our API cohort could be partly attributed to the use of meditation and mindfulness of the body and self that is prevalent in Asian religious practices requires further research in the appropriate patient population. However, another conceivable etiology to this lowered expression of emotional distress with their itch may be unfortunately rooted in the belief that no beneficial help is available in healthcare and the perceived futility to finding healthcare providers who will address mental distress.[64]

Pruritus status appears be associated with API's trust of their healthcare providers. Based on our findings, an important distinction exists for API patients with chronic skin disease between information that is conveyed from the patient to the provider and vice versa. Non-pruritic API appear to be more suspicious of the information conveyed to them from the provider which was significantly less apparent in the pruritic API. API with chronic itch were less candid with revealing information about their personal health to the providers. Generally, Asian Americans have been found in previous studies to report that their regular healthcare providers did not understand their background and values, did not listen them, or involve them in decisions about care as much as they wanted.[49] However, they were not significantly less likely than whites to trust their doctors.[65] This was supported by our study's overall high trust rating from both pruritic and non-pruritic API. Thus, it is possible that Asian Americans may harbor discontent with their medical care but overall were still trusting of their doctors and chose to remain in their care. Importantly, healthcare providers and especially dermatologists should be aware that API with chronic itch may be less reluctant to reveal information about the impact of their skin disease, and further work is necessary to elicit what methods may be used to increase comfort in the clinical encounter or factors that promote this hesitation. Previous research outside the realm of pruritus has emphasized the positive effects on health outcomes among API by providers and researchers understanding and incorporating health paradigms indigenous to the patient's background into health management.[66] Patient-physician communication barriers are a critical factor in determining patients' perception of provider cultural competence and should be a focus in healthcare systems improvement.[67] Steps previously used to address barriers for API involvement in academic research may also be translated to the clinical realm, such as documentation translated to meet cultural conceptual equivalence, bilingual interpreters present in each encounter, and if possible, use of prior ethnographic observation or activities with the community of interest.[68]

Limitations

Our research team encountered significant barriers to engaging the local Asian American community in our research study. A systematic review of academic research among US minorities found multiple barriers for different ethnic groups from comfortably being involved with both clinical and basic science research. Commonly cited barriers for Asian American populations – that our research team also commonly encountered – included mistrust related to purposeful mistreatment or experimentation, mistrust with signing informed consents for fear of relinquishing their rights, unintended outcomes due to unfamiliarity with academic research, or lack of access to information due to language or other socioeconomic barriers.[69] We modified our community approach strategy to include shared meals with target populations, attendance at community events and health fairs, and emphasis of one-on-one encounters with a board-certified dermatologist for private question and answer sessions. This proved fruitful in increasing our recruitment rates per event.

Despite being traditionally grouped into a single racial group, API is heterogeneous and consists of an ethnically diverse range of populations. Our study cohort, while representing more API ethnicities than our previous pruritus study, has much room to expand to other API populations. Our results may also not be generalizable because our samples were taken from one metropolitan population in the Southeast US and a US veterans population. Furthermore, there were significant differences in sample characteristics, including sex, marital status, and education, which individually may be associated with QoL determinants such as socioeconomic status and social support. The Primary Care Assessment Survey (PCAS) subscale used to investigate healthcare provider trust among pruritic and non-pruritic API did not differentiate between primary care healthcare providers and specialty healthcare providers that the participants may not have had a longitudinal care relationship with. Thus, the trust placed in a provider that is regularly seen may have been conflated with specialists, such as dermatologists, who are instrumental in addressing chronic pruritus. Finally, quantitative data collection with validated survey instruments, while appropriate and valuable with specific end points, limits our findings to what is being measured. Qualitative research methods, such as focus groups, may have facilitated greater understanding of the potential cultural and social influences on chronic itch experience and healthcare seeking behaviors.

Conclusions

Chronic pruritus is an underappreciated symptom with high prevalence across global populations, significant impact on QoL, and high economic burden that make it a significant public health issue. Non-white populations are at higher risk for health-related complications associated with chronic itch. Our findings merit further exploration of potential differences between API ethnicities and related sociocultural factors that may mediate these disparities in pruritus to promote cultural competent healthcare for chronic itch and public health initiatives to avoid a parallel evolution of inadequate management to that seen in chronic pain.

Our collective research in chronic itch disparities has revealed that African Americans appear to be more emotional impacted from their pruritic skin than API, but API have significant concerns regarding pigmentation changes and the potential financial burden of long term management associated with their chronic itch. The latter population would likely benefit from public awareness efforts and personal counseling on the financial burden of pruritus management, post inflammatory hyperpigmentation associated with itching and scratching, its medically benign nature, and the expected time course for recovery after symptom management.

In addition, API have been found to be less likely to seek Western healthcare services, which stand to stifle healthcare and public health work for this population. Barriers that appear to be amenable to public health efforts include language barriers, transportation concerns, cost, time, cultural norms related to thresholds for need of care, preference for self over professional care, and distrust of Western biomedicine. The fact that API are also less likely to engage in academic research potentially lays the foundation for continued decline in dermatologic and other health disparities. Healthcare providers and especially dermatologists should be aware that API with chronic itch may be less reluctant to reveal information about the impact of their skin disease, and further work is necessary to illicit what methods may be used to increase comfort in the clinical encounter or factors that promote this hesitation. Hopefully by applying mixed quantitative and qualitative research methods, our field will be better positioned to understand and advance dermatologic health outcomes.

Table I: Select demographic information of pruritic API cohort vs. veterans cohort

Table 1. Sociodemographic Characteristics of Study Participants for Different Samples

Characteristic	Asian and Pacific Islanders with Chronic Pruritus (N=47) n (%)[a]	Veterans with Chronic Pruritus (N=404) n (%)[a]	Asian and Pacific Islanders without Chronic Pruritus (N=28) n (%)[a]
Age*			
Mean (SD)	60.1 (17.1)	60.7 (13.0)	65.3 (13.3)
Sex			
Male	20 (36)	374 (93)	9 (32)
Female	27 (64)	30 (7)	19 (68)
Race			
White	-	298 (74)	-
African American	-	76 (19)	-
"Other"	-	30 (7)	-
Taiwanese	21(45)	-	12 (43)
Korean	17 (36)	-	9 (32)
Chinese	7 (15)	-	5 (18)
Indian	2 (4)	-	2 (7)
Marital Status			
Married	34 (85)	230 (57)	25 (89)
Not married	7 (15)	174 (43)	3 (11)
Highest level of education			
High School Diploma/Equivalent (such as the GED) or lower	9 (20)	283 (70)	3 (11)
Bachelor's (4-year college) Degree or higher	37 (80)	121 (30)	25 (89)
Itch Severity*			
Mean (SD)	4.8 (2.9)	5.2 (2.3)	-

[a] Percentages may not sum to 100 due to rounding.

*Presented as mean (SD) and not number (percentage)

Table II: Analysis results of ItchyQoL and predictor variables

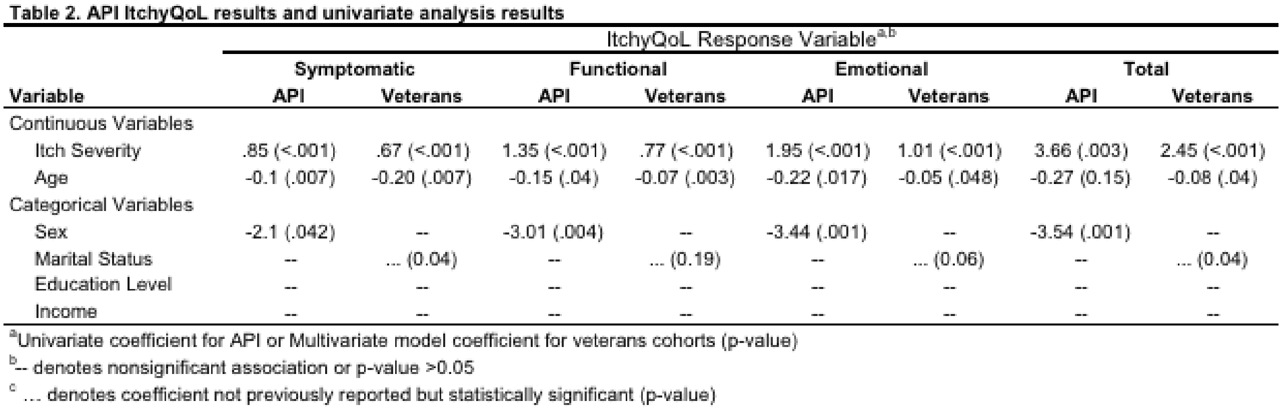

Table 2. API ItchyQoL results and univariate analysis results

	ItchyQoL Response Variable[a,b]							
	Symptomatic		Functional		Emotional		Total	
Variable	API	Veterans	API	Veterans	API	Veterans	API	Veterans
Continuous Variables								
Itch Severity	.85 (<.001)	.67 (<.001)	1.35 (<.001)	.77 (<.001)	1.95 (<.001)	1.01 (<.001)	3.66 (.003)	2.45 (<.001)
Age	-0.1 (.007)	-0.20 (.007)	-0.15 (.04)	-0.07 (.003)	-0.22 (.017)	-0.05 (.048)	-0.27 (0.15)	-0.08 (.04)
Categorical Variables								
Sex	-2.1 (.042)	--	-3.01 (.004)	--	-3.44 (.001)	--	-3.54 (.001)	--
Marital Status	--	... (0.04)	--	... (0.19)	--	... (0.06)	--	... (0.04)
Education Level	--	--	--	--	--	--	--	--
Income	--	--	--	--	--	--	--	--

[a] Univariate coefficient for API or Multivariate model coefficient for veterans cohorts (p-value)

[b] -- denotes nonsignificant association or p-value >0.05

[c] … denotes coefficient not previously reported but statistically significant (p-value)

Table III: Medical provider trust results

Table 3. Analysis of 8-item Healthcare Provider Trust Between Pruritic and Non-pruritic API

PCAS Statement*	Student T-test Value	p-value	Item Details
PCAS 1	-2.1	0.04	I can tell my doctor **anything** even things that I might not tell anyone else
PCAS 2	-2.6	0.01	My doctor sometimes **pretends** to know things when he/she is really not sure
PCAS 3	-0.95	0.34	I completely trust my doctor’s **judgments** about my medical care
PCAS 4	-0.82	0.41	My doctor cares more about **holding down costs** than about doing what is needed for my health
PCAS 5	-0.4	0.7	My doctor would always tell me the **truth** about my health, even if there was bad news
PCAS 6	1	0.32	My doctor cares **as much** as I do about my health
PCAS 7	-0.98	0.33	If a mistake was made in my treatment, my doctor would try to **hide** it from me
PCAS 8	-0.56	0.58	All things considered, how much do you trust your doctor?

*See under item details for corresponding PCAS statement

CHAPTER 4: Recommendations

Our study sought to characterize the factors that impact QoL in an API sample with chronic pruritus in Atlanta, Georgia compared to a previously studied nationally sampled veterans group. Observations and hypotheses generated through this research support the following interrelated immediate and longer-term action, research, and policy recommendations. As some of these measures may already be in place or development, these recommendations should serve as re-enforcement of their importance.

1. Recognize racial disparities in chronic pruritus as a significant public health issue: Chronic pruritus is an underappreciated symptom associated with a wide ranging spectrum of systemic and primary cutaneous disorders, including anxiety, asthma, and obesity. Its high prevalence across global populations, significant impact on QoL, and high economic burden make it a significant public health issue. Racial disparities in chronic pruritus prevalence and impact are likely multifactorial, including a significant biological variation component in skin structure and physiology as well as sociocultural factors. Non-white populations are at higher risk for health-related complications associated with chronic itch. With minority populations in the US population projected to increase substantially in the coming decades, more research must be conducted into the various ethnicities to promote cultural competent healthcare for chronic itch and public health initiatives to avoid a parallel evolution of inadequate management to that seen in chronic pain.

2. Appreciate the various factors that influence quality of life in chronic pruritus: As illustrated in the expanded Verhoeven's Biopsychosocial Model of Itch, a multitude of factors help determine quality of life in patients with chronic pruritus. These factors vary in according with ethnicities but clinicians, public health practitioners, and researchers should appreciate the expansive diversity of cultures independent of race as well. Our collective research in chronic itch disparities has revealed that African Americans appear to be more emotionally impacted and more commonly develop anger, frustration, feeling of being "driven crazy", and self consciousness associated with their pruritic skin. API are less emotionally impacted but have significant concerns regarding pigmentation changes and the potential financial burden of long term management associated with their chronic itch. Thus, API may benefit from discussions emphasizing expected financial burden of managing pruritus long term and how that can be addressed. This population could also benefit from public awareness efforts and personal counseling on post inflammatory hyperpigmentation associated with itching and scratching, its medically benign nature, and the expected time course for recovery after symptom management. Finally, while African Americans are more likely to require special soaps, lotions, and detergents in response to chronic itch, the role of complementary and alternative medicine – including meditation – should not be ignored in public health research and how this influences engagement with Western healthcare practices in the US.

3. Increased engagement of API in healthcare and public health work: Previous research shows that API are less likely to seek less likely to have a general practitioner or seek other healthcare services, especially amongst the older Chinese immigrant population in one study. This finding appears to be rooted in a multifactorial issue of API populations and trust of

Western healthcare and medical services. Barriers that appear to be amenable to public health efforts include language barriers, transportation concerns, cost, time, cultural norms related to thresholds for need of care, preference for self over professional care, and distrust of western biomedicine. The fact that API are also less likely to engage in academic research potentially lays the foundation for continued decline in dermatologic and other health disparities as this population grows in the US and continues to be a significantly composed of immigrants. Importantly, healthcare providers and especially dermatologists should be aware that API with chronic itch may be less reluctant to reveal information about the impact of their skin disease, and further work is necessary to illicit what methods may be used to increase comfort in the clinical encounter or factors that promote this hesitation. A concerted effort in public health and healthcare to engage API at multiple levels to reduce barriers to access to care and research.

4. Integrate qualitative research into cultural disparities in dermatology disease investigation: Dermatology is a field that is impacted by culture by culture in a unique way. While mortality is often the measure used in other fields of medicine, dermatology is unique in the sense that much of skin disease has a substantial morbidity component without being a direct cause of death. Despite races and cultures being intimately associated, they are not always rigidly coupled. Quantitative data collection and analysis with validated survey instruments, while appropriate and valuable with specific end points, limits our findings to what is being measured. Oftentimes in this method of study, race can be used as proxy for culture but never as a substitute. Qualitative research methods, such as focus groups, present an important medium to facilitate greater understanding of the potential cultural and social influences on chronic itch experience and healthcare seeking behaviors. Outside the context of chronic itch, dermatology stands to gain by implementing qualitative research into further investigating the impact on quality of life from different dermatoses. In this fashion, mixed methods research with quantitative and qualitative components should be utilized to understand and advance dermatologic health outcomes.

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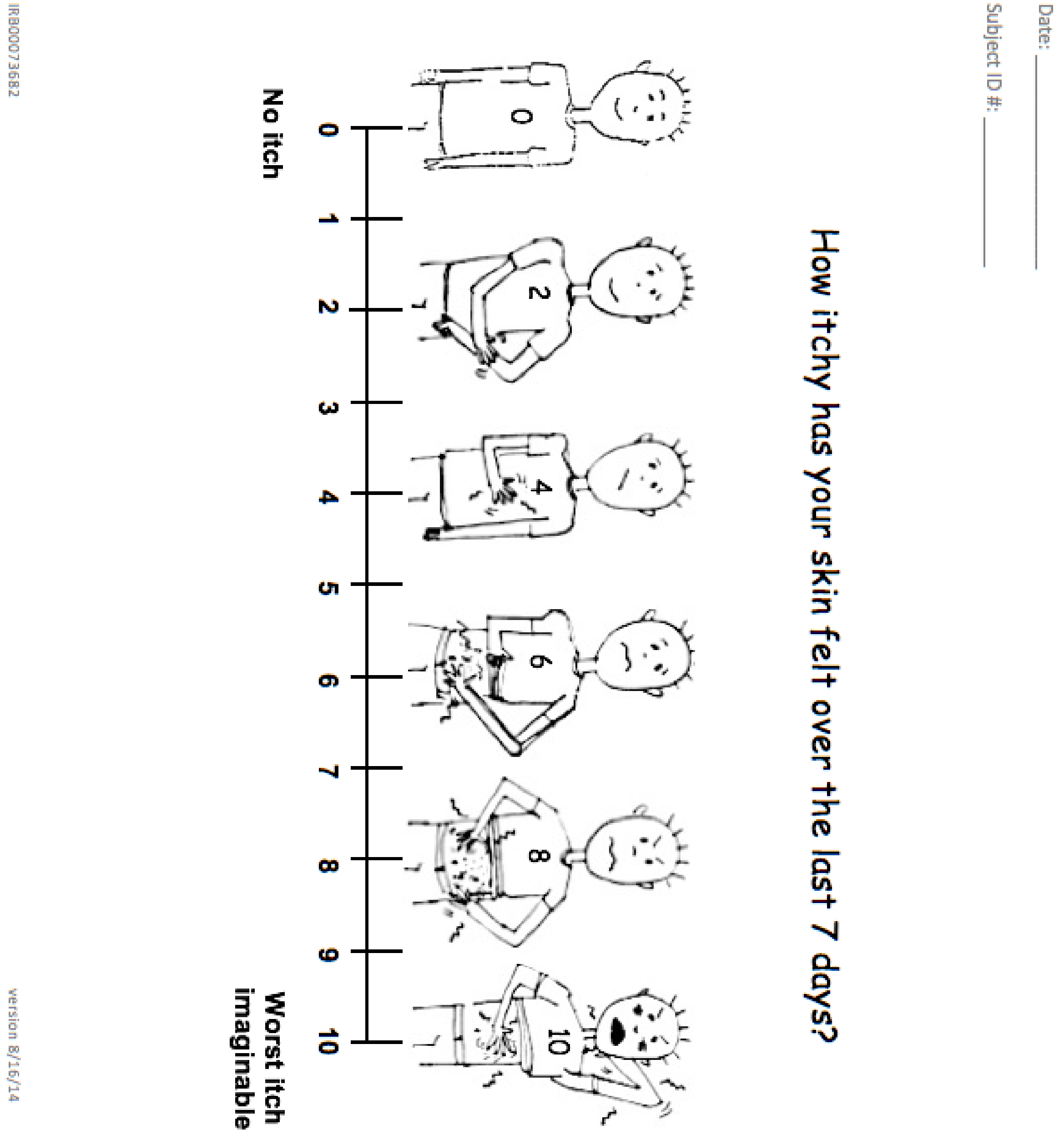
APPENDIX I: ItchyQuant



Date: ____________

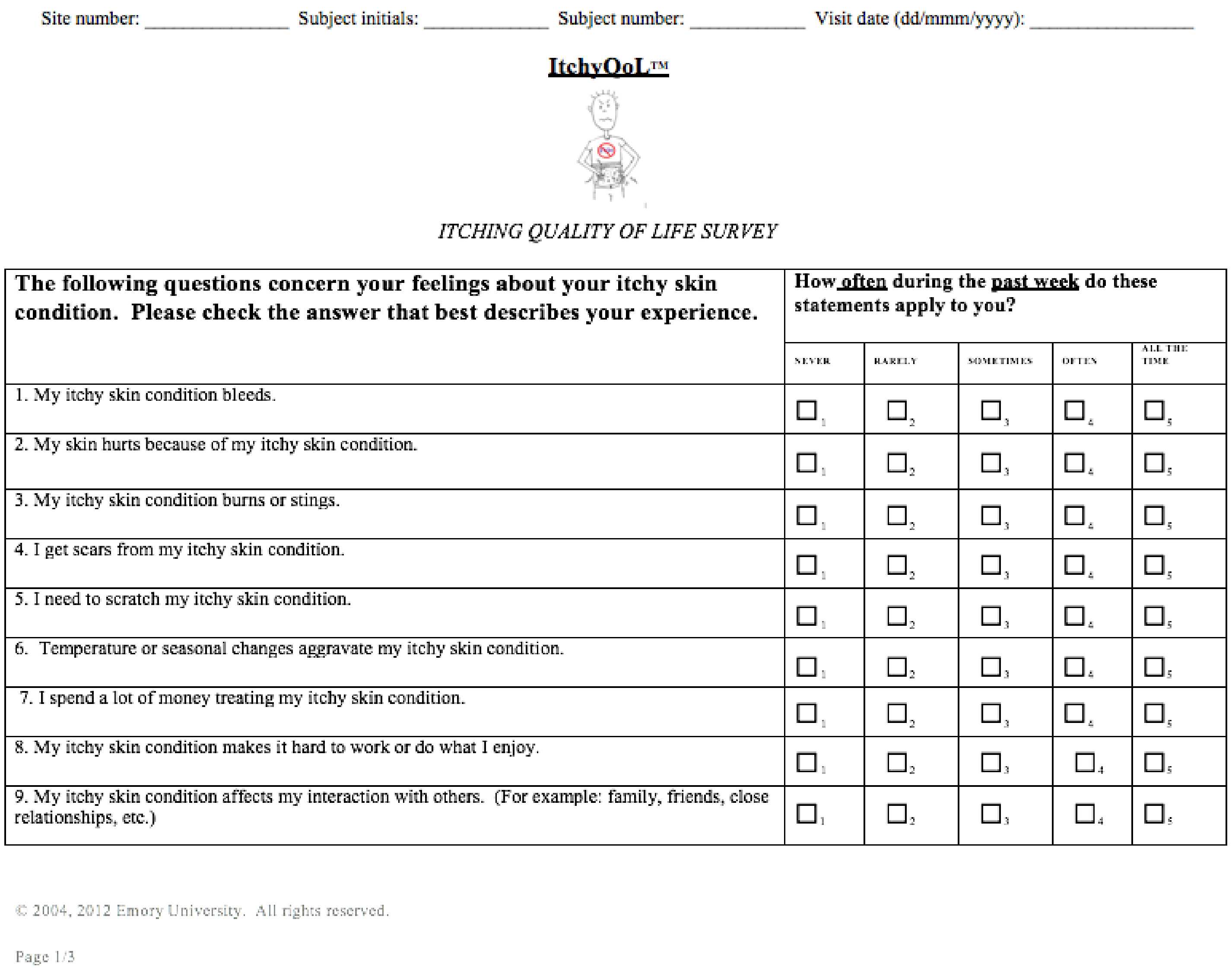
Subject ID #: ____________

How itchy has your skin felt over the last 7 days?

IRB00073682

version 8/16/14

APPENDIX II: ItchyQoL Sample (English and Korean Sample)



Site number: ______________ Subject initials: _____________ Subject number: ____________ Visit date (dd/mmm/yyyy): _________________

ItchyQoL™

ITCHING QUALITY OF LIFE SURVEY

The following questions concern your feelings about your itchy skin condition. Please check the answer that best describes your experience.	**How often during the past week do these statements apply to you?**				
	NEVER	RARELY	SOMETIMES	OFTEN	ALL THE TIME
1. My itchy skin condition bleeds.	☐1	☐2	☐3	☐4	☐5
2. My skin hurts because of my itchy skin condition.	☐1	☐2	☐3	☐4	☐5
3. My itchy skin condition burns or stings.	☐1	☐2	☐3	☐4	☐5
4. I get scars from my itchy skin condition.	☐1	☐2	☐3	☐4	☐5
5. I need to scratch my itchy skin condition.	☐1	☐2	☐3	☐4	☐5
6. Temperature or seasonal changes aggravate my itchy skin condition.	☐1	☐2	☐3	☐4	☐5
7. I spend a lot of money treating my itchy skin condition.	☐1	☐2	☐3	☐4	☐5
8. My itchy skin condition makes it hard to work or do what I enjoy.	☐1	☐2	☐3	☐4	☐5
9. My itchy skin condition affects my interaction with others. (For example: family, friends, close relationships, etc.)	☐1	☐2	☐3	☐4	☐5

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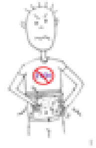
싸이 트 번호: ______________ 과제 첫머리 글자: ____________ 과제 번호: ___________ 방문 날짜 (일/월/년): ________________

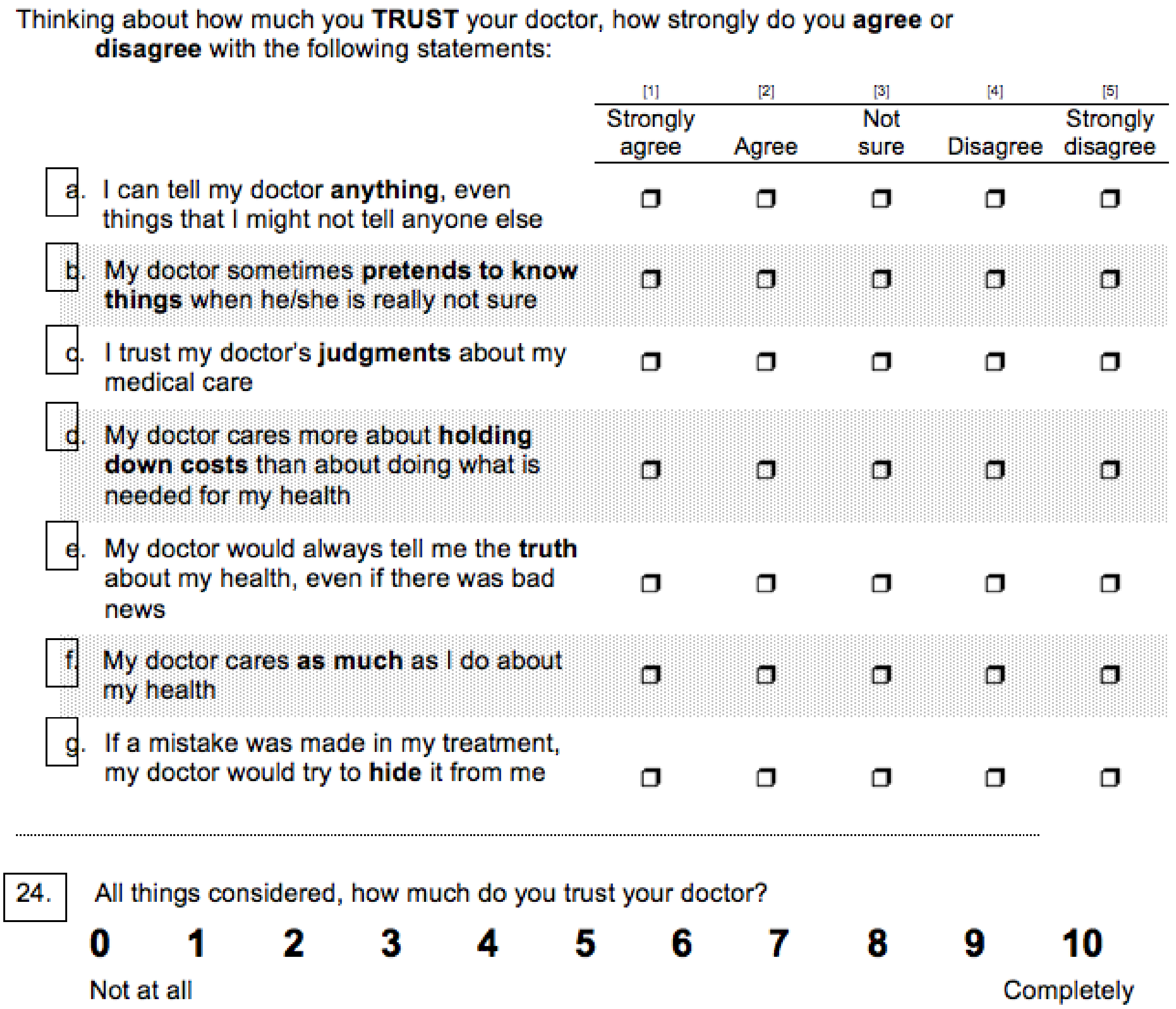
ItchyQoL™



가려움에 관한 생활 설문지

다음 문제들은 당신의 피부 가려움에 대한 문제입니다. 읽고 해당하는 사항에 표시하여 주십시오.	최근 일주일 동안 얼마나 문제가 있으셨습니까?				
	그렇지 않음	드물게 발생함	가끔씩 발생함	자주 발생함	항상 발생함
1. 피부 가려움으로 인해 피가 나옴	□1	□2	□3	□4	□5
2. 가려움으로 인해 피부의 고통이 있음	□1	□2	□3	□4	□5
3. 가려운 피부가 따갑거나 불에 타는 느낌을 받음	□1	□2	□3	□4	□5
4. 가려운 피부에 상처나 흉터가 남음.	□1	□2	□3	□4	□5
5. 가려운 피부를 긁어야 함.	□1	□2	□3	□4	□5
6. 온도나 환경변화가 나의 가려운 피부를 악화시킴.	□1	□2	□3	□4	□5
7. 가려운 피부를 치료하기 위해 많을 돈을 씀.	□1	□2	□3	□4	□5
8. 가려운 피부로 인해 내가 즐기거나 해야 할 일은 하지 못함.	□1	□2	□3	□4	□5
9. 가려운 피부는 내 인간관계에 영향을 끼침(가족, 친구, 친척, 등.)	□1	□2	□3	□4	□5

APPENDIX III: PCAS Component: 8-Item Healthcare Provider Trust



Thinking about how much you **TRUST** your doctor, how strongly do you **agree** or **disagree** with the following statements:

	[1] Strongly agree	[2] Agree	[3] Not sure	[4] Disagree	[5] Strongly disagree
a. I can tell my doctor **anything**, even things that I might not tell anyone else	☐	☐	☐	☐	☐
b. My doctor sometimes **pretends to know things** when he/she is really not sure	☐	☐	☐	☐	☐
c. I trust my doctor's **judgments** about my medical care	☐	☐	☐	☐	☐
d. My doctor cares more about **holding down costs** than about doing what is needed for my health	☐	☐	☐	☐	☐
e. My doctor would always tell me the **truth** about my health, even if there was bad news	☐	☐	☐	☐	☐
f. My doctor cares **as much** as I do about my health	☐	☐	☐	☐	☐
g. If a mistake was made in my treatment, my doctor would try to **hide** it from me	☐	☐	☐	☐	☐

24. All things considered, how much do you trust your doctor?

0 1 2 3 4 5 6 7 8 9 10

Not at all … Completely