Feasibility Study: Culturally and Linguistically Congruent Survey for Intergenerational Dyads from Collectivist Cultures

By

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DEDICATIONS

I would like to dedicate this dissertation to my parents, Pao Lor and Mao Yang Lor, my grandma, Houa Lee, and my study participants.

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Abstract

Data collection, including survey studies is an integral part of health research needed to inform health interventions. Non-English speaking (NES) and non-literate (NL) older adults including those who are from oral and collectivist cultures have been largely excluded from health research due to literacy challenges in both English and their native language. Little research has examined ways to increase inclusivity of these populations. This study included development and testing of a data collection tool comprised of an audio-computer assisted self-interviewing with color labeled response categories and helper assistance (ACASI-H) with an NES/ NL older adult population, the Hmong. The purposes of this study were to assess the feasibility of using ACASI-H to complete a survey and to understand the interaction between the Hmong older adults and their helpers while completing the survey.

This dissertation includes three papers that address the following; (1) health status among the Hmong adult population, based on a review of literature, (2) the feasibility of ACASI-H with Hmong older adults and their helpers, and (3) the interactions between Hmong older adults and their helpers while responding to a 13-health item using ACASI-H.

Hmong older adults and helpers were recruited from one Midwestern city through word of mouth and directly from two commonly attended community centers. Thirty dyads (n=30 Hmong older adults; n=30 helpers) completed the ACASI-H survey followed by a face-to-face interview. All dyads were video recorded while completing the ACASI-H survey. The first paper presents a systematic review of relevant literature, using the PRISMA framework. The second paper reports conventional and directed content analyses of the face-to-face debriefing interviews. The third paper presents the results of an interaction coding and conversational analysis of video data. Overall findings from the three papers revealed: (1) Hmong adults

experience significant health disparities and survey methods used to understand Hmong adults' health only include those who are literate in English or Hmong, (2) Hmong older adults and helpers confirmed that ACASI-H was feasible, and (3) the interactions between Hmong older adults and their helpers were not consistent with the standard survey process--ideal paradigmatic sequence (where the question was read and the respondent was able to provide an answer as requested). Hmong older adults revealed seven common comprehension problem cues (e.g. seek clarification explicitly, state uncertainty, task uncertainty, pauses, fillers, and provide descriptive answer). In response, helpers used a range of strategies to assist the Hmong older adults and to elicit a response to the survey question. Findings support use of ACASI-H for engaging LEP and NL older adults in a survey interview. In addition, findings highlight the need for more cross-cultural interaction research on NES and NL populations, including the Hmong, to understand and improve survey data quality and to gather information that can be used to target population level interventions.

Chapter 1: Introduction

Background

Despite progress in reducing disparities in the United States (US), the magnitude has remained constant and is increasing in some critical areas (Institute of Medicine (U.S.), Institute of Medicine (U.S.), & National Academies Press (U.S.), 2012; Satcher et al., 2005; Smith et al., 2005). Foreign-born limited English proficient (LEP) older adults from collectivist cultures have been largely excluded from research, specifically survey research, a primary source of population health information. Adequate methods of data collection are needed to ensure minority representation and findings that are relevant and can inform nursing and public health interventions with diverse populations, ultimately reducing health disparities.

Survey data are fundamental to health research which is used to address health problems at the societal level. Policy and program planning decisions are often made based on the results of surveys. For example, national studies, such as those conducted by the Centers for Disease Control and Prevention (CDC) including the National Center for Health Statistics (NCHS) and Behavioral Risk Factor Surveillance System (BRFSS), provide a profile of the health status of populations, and subpopulations, as well as health-related risk behaviors, chronic health conditions, and use of preventive and curative services. The results of these surveys are used to set and monitor public health goals for the nation and to direct care and resources at a population level. In addition, investigators and policy makers rely heavily on the results of surveys, including survey research and program evaluations, to guide future initiatives. Failing to include LEP populations in national surveys, will result in sustained and possibly increased health disparities among these subgroups. Thus, it is imperative that LEP populations are included in population level surveys.

Significance

There are 25.7 million individuals ages 5 and older with limited English proficiency (LEP; Zong & Batalova, 2017). LEP is defined as "speaking English not well at all, not well, or well" (Whatley, Monica & Batalova, Jeanne, 2013). Many LEP individuals speak a language other than English at home and are foreign-born (Gambino, Acosta, & Grieco, 2014). According to Gambino and colleagues (2014), 85 percent of foreign-born populations speak a language other than English at home (Gambino, Acosta, & Grieco, 2014).

The foreign-born population made up 13 percent (42.4 million) of the total US population in 2014 and is continuing to increase (Grieco et al., 2012). From 2013 to 2014, there was an 11 percent increase from 1.2 million to 1.3 million foreign born individuals in the US. The immigrant population tends to be older than the US-born population. In 2014, 80 percent of foreign born were between 18 and 64 compared to 60 percent of those native born.

Of the LEP foreign-born populations, the majority of older adults are from collectivist cultures, Latin American (38%) and Asia (29%; Population Reference Bureau, 2013) and are not English literate. Language and cultural barriers create data collection challenges for researchers attempting to include older adults from these cultures in their studies (Areán & Gallagher-Thompson, 1996). Multiple problems in collecting data from older foreign-born adults have been documented: (a) recruitment and retention challenges (Levkoff & Sanchez, 2003; Moreno-John et al., 2004; Ness, Nelson, Kumanyika, & Grisso, 1997), (b) culturally-inappropriate research designs (Bell, Morse, & Shah, 2012), (c) translation and literacy challenges (Frayne, Burns, Hardt, Rosen, & Moskowitz, 1996), and (d) distrust of researchers (Ballard, Nash, Raiford, & Harrell, 1993), stemming from lack of information regarding the purpose and potential benefits of the study (Areán & Gallagher-Thompson, 1996; Ballard et al., 1993; Mindel & Kail, 1989; Moreno-John et al., 2004; Shavers, Lynch, & Burmeister, 2002; Swanson & Bailar, 2002;

Takeuchi, Sue, & Yeh, 1995; Yancey, Ortega, & Kumanyika, 2006). This study addresses one specific issue, that is, how to gather health information from the LEP older adults from collectivist communities.

While there are many definitions of collectivist cultures, this paper used Singelis' definition of collectivist culture, which is "flexible, variable self that emphasizes statuses . . . roles, and relationships, belonging and fitting in, [and] being indirect in communication" (Singelis, 1994, p. 581). In contrast, persons from individualistic cultures place greater value on personal goals (Triandis, McCusker, & Harry, 1990), are less likely to make in-group-out-group distinctions, and are more inclined to reveal information about themselves (Smith, Bond, & Kagitcibasi, 2006), suggesting they may be more willing to respond to research questions (Johnson, O'Rourke, Burris, & Owens, 2002). Conversely, persons from collectivist cultures place greater value on interpersonal harmony, and deference (Gudykunst, 1983; Triandis et al., 1990), disclosing less to outsiders (Smith et al., 2006), suggesting they may be less likely to respond to researchers. In other words, individuals from collectivist cultures are accustomed to making decisions in collaboration with other family members. No studies have examined whether or how family member assistance influences the survey completion process including item responses.

Furthermore, it is likely that family members, who are providing assistance to the foreign-born older adults with LEP may have a range of language proficiency in either their native language or English. Researchers have reported that educational level (Beckhusen, Florax, Graaff, Poot, & Waldorf, 2013; McArthur, 1993) and time spent living in the US are associated with English-speaking ability (Veltman, 1988). For example, 13 percent of foreign born who came to live in the US in 2000 or later spoke English "not at all" compared to 6 percent who

arrived prior to 1980 (Gambino, Acosta, & Grieco, 2014). In addition, younger people are more fluent in English than older adults in their native language (Gambino, Acosta, & Grieco, 2014). No research studies were found that addressed both the literacy level of the foreign-born older adults and their family members, particularly during the data collection process including surveys.

The most commonly used survey modes are paper/pencil and telephone (Dillman, 2000), although online survey use is increasing. These modes may discourage foreign-born older adults with LEP from participating due to the combination of poor translations, confusion over meanings, unfamiliar dialects, concepts, and modes of data collection that reflect individualist cultures and the need for assistance with survey completion. Audio computer-assisted self-interviewing (ACASI) is an aural mode of data collection used with low literacy populations and can be delivered in multiple languages or dialects (Estes et al., 2010; Reichmann et al., 2010). However, ACASI has not been developed for LEP or NL respondents. Although ACASI has not been used for LEP or NL respondents, ACASI has been used to achieve other things as well. For example, ACASI has improved the quality of behavioral health data gathering, reduced interviewer bias, standardized question administration, and eliminated skip pattern errors (Jarlais et al., 1999). While ACASI has been used with low literate populations, ACSI has not been tested with populations from collectivist cultures, who require family member assistance to respond to surveys and are accustomed to making decisions in collaboration with each other. Furthermore, ACASI has not been conducted with two languages simultaneously at the same time with respondents.

The Approach to the Problem

To increase survey research participation for LEP older adults from collectivist cultures, I proposed to focus on one racial/ethnic minority older adult group—the Hmong people. Specifically, to further investigate how researchers can successfully collect health information from Hmong older adults, who have LEP and come from a collectivist culture. Currently, 286,211 Hmong are living in the US (Pfeifer, Sullivan, Yang, & Yang, 2012) and over 97% of Hmong are foreign-born (National Asian Pacific Center on Aging, 2013). Although, older Hmong make up only 7% of the total Hmong in the US (Hmong National Development Inc., 2010), this number is expected to grow significantly as new waves of immigrants continue to arrive (Lee, 2010). Research on the foreign-born older Hmong population in the US is almost non-existent.

Hmong is a traditionally oral society (Thao, 2006). Written Hmong was only recently created, in 1952, and is unfamiliar to older Hmong (Duffy, 2007). In the US, 90% of older Hmong adults are LEP or not literate either in Hmong or English (National Asian Pacific Center on Aging, 2014) as well as having no literacy in Hmong. Consequently, even Hmong-language written materials are not understood by older Hmong. Thus, older Hmong often rely on translators in both research and practice settings. Formal and family member interpreters are typically younger, fluent in English, and often more comfortable working in English than in Hmong (Lor, Xiong, Schwei, & Jacobs, 2014; Yeo & Gallager-Thompson, 2013). Studies have documented serious shortcomings with translations (Lor & Chewning, 2014; Lor et al., 2014) in the areas of conceptual equivalence (meaning; Johnson, 2002; Lor et al., 2014), dialect differences, and generational differences in language and social context (Lor et al., 2014). Furthermore, younger Hmong tend to be proficient in English and comfortable with technology (Center for Disease Control and Prevention, 2013). Children and grandchildren often assist their

older family members to communicate with health care providers (Yeo & Gallager-Thompson, 2013).

Therefore, the purposes of my dissertation study were to address these shortcomings by: including a family member to acknowledge the collectivist culture and differences in language proficiency between the foreign-born older adult and family member in both their native or English language. Specifically, this study was conducted to determine the feasibility and acceptability of a specific technology, an audio-computer assisted self-interviewing mode (ACASI) with color labeled response categories and a family helper (ACASI-H) and to explore the impact of a family member on response item, consistent with collectivist cultures. This mode is culturally and linguistically appropriate for both members of a family dyad who may differ in familiarity with the native (Hmong) language and comfort with technology, and 2) who live within a collectivist culture. Older Hmong adults will be the focus of this study as they embody the characteristics of collectivist, older immigrant populations (Her & Buley-Meissner, 2012), and are non-literate (Yang, 1993). This study will focus the following aims:

Specific aim 1: To determine the feasibility and acceptability of a culturally tailored data collection mode (ACASI with color labeled response categories and inclusion of younger family member) for Hmong older adults.

Specific aim 2: To explore the interaction between Hmong older adults and their helpers while responding to a 13-health item using ACASI-H

To address the specific aims, I developed and tested a culturally and linguistically adapted data collection tool, audio computer-assisted self-interviewing mode (ACASI) to include a family helper and color labeled response categories named (ACASI-H). A pilot test was done to develop the ACASI-H. After ACASI-H was considered usable, I recruited participants from

the three community centers, with a large number of older Hmong adult attendees. In addition, I used snowball sampling to recruit potential participants. In other words, participants referred potential participants to the study through word of mouth. Data were collected in a private room either at the community center or at the participant's home. A laptop and speakerphone were given to the dyads to take the survey online through Qualtrics. A small digital camera was placed at the center of the laptop to record the interaction between the older Hmong adult and family helper during the survey process. After the survey process was completed, I conducted a follow-up interview to debrief about the dyad's experience with the survey.

The findings from this dissertation are reported in a 3-paper format. In the following section, I provide an outline of the 3-papers. Collectively, the 3-paper dissertation provides a descriptive overview of the research/knowledge gap concerning the older Hmong adult population and a possible solution to address the research gap. Specifically, the papers address methodological issues and strategies to increase research participation among the Hmong older adults.

Overview of the chapters

The chapters that follow provide detailed information and a discussion about the research that was conducted to prepare for future research with Hmong older adults in the US, examine the feasibility and acceptability of a specific technology, audio-computer assisted self-interviewing mode (ACASI) with color labeled response categories with a family member (ACASI-H), and to explore the interactions between Hmong older adults and their helpers while responding to a 13-health item using ACASI-H.

Chapter 2 provides a systematic review of Hmong health and identifies disparities related to health promotion and disease prevention. The aims were to provide an overview of what is known about the Hmong people's health status and identify implications for future research.

In Chapter 3, I report the descriptive findings for specific aim 1, determining the feasibility and acceptability of a culturally tailored data collection mode (ACASI with color labeled response categories and inclusion of family helper [ACASI-H]) for Hmong older adults. The findings from this study were informed by the data from the follow-up debriefing interviews after the dyad completed the ACASI-H instrument and the video recordings during the survey process. I used a combination of conventional and directed content analyses to analyze the interview data (Hsieh & Shannon, 2005).

In Chapter 4, I report the descriptive findings for specific aim 2, which was designed to explore interactions between older Hmong and younger family members while responding to a 13-health item instrument using an Audio Computer-Assisted Self-Interview (ACASI) with color labeled response categories and helper assistance. The findings from this study were informed by the video data of the interactions between the older Hmong adult and family helpers during the survey process. I focused on two sub-aims: 1) how do Hmong interviewers (also known as Hmong helpers) and Hmong older adult respondents interact while completing a 13-item survey using a commonly used survey, SF-12 General Health Survey (Ware, Kosinski, & Keller, 1996) and the one-item sensitive question? 2) What are the strategies used by Hmong interviewers during the survey process, when the Hmong older adult respondent displays comprehension problems?

Chapters 2-4 are presented in the form of publications. Each chapter has been written to reflect the requirements of the journals to which the paper will be submitted. Chapter 2 was

submitted to the Journal of Racial and Ethnic Health Disparities. Chapter 3 was submitted Research in Nursing & Health. Chapter 4 will be submitted to a survey journal, Field Methods. Each paper has a different format, including American Psychological Association, American Sociological Association, and the standard mathematical notation.

In Chapter 5, I discuss and summarize the findings from chapters 2 to 4 and present implications for future research.

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Chapter 2:

Review of Literature Regarding Health Disparities Related to Health Promotion and Disease Prevention among Hmong Adults in the United States

Title: Systematic Review: Health Promotion and Disease Prevention among Hmong Adults in the United States

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ABSTRACT

Although there are significant disparities in the burden of disease and illness experienced by major racial and ethnic groups in the United States (US), little is known about subgroups, including the Hmong population. This review sought to determine the current state of health related to health promotion and disease prevention among Hmong adults from 1975 through 2015. Seventy-one descriptive (qualitative and quantitative) studies were reviewed and reported on. The 71 studies focused on three common areas: (1) health status (mainly breast and cervical cancers); (2) protective behavior (mainly physical activity and diet); and (3) personal health behavior (mainly cancer and Hepatitis screening). This literature review confirms that Hmong adults experienced health disparities related to health promotion and disease prevention. A possible explanation for such disparities concerns the lack of health data collected on subgroup populations, which includes the Hmong adult population. More research and more comprehensive health policies at the organizational level are needed to allow data to be collected on sub-group populations in order to better understand the social determinants that place the Hmong people at risk.

Key Words: Hmong, Disease Prevention, Health Promotion, Systematic Review, Health Disparities

INTRODUCTION

Despite the clear health goals set out in Healthy People 2020, disparities in the health status among racial and ethnic groups in the United States (US) remain substantial [1–5]. Research has improved our understanding of existing health disparities, facilitating better planning for addressing the needs of various populations. However, much of the research has focused on large (umbrella) racial and ethnic minority categories such as "White, Black or African American, American Indian or Alaskan Native, and Asian in national studies" [6], making racial and ethnic minority subgroups invisible. Without research on racial and ethnic minority subgroup differences, disparities between racial and ethnic minority groups will continue to widen, limiting health care professionals' ability to engage in the development of health promotion and disease prevention programs for all populations.

"Asian American" is the umbrella term for all Asians in the US. According to the 2010 US Census Bureau, Chinese (3.79 million), Filipino (3.41 million), Indian (3.18 million), Vietnamese (1.73 million), Korean (1.7 million), and Japanese (1.3 million) are the largest Asian American groups [7]. However, there are many other sizable Asian American groups in the US: Pakistani (409,000); Cambodian (276,000); Hmong (260,000); Thai (237,000); Laotian (232); Taiwanese (230,000); Bangladeshi (147, 000); and Burmese (100,000) [8]. Each of these groups comes from a different cultural background, which encompasses diet, cultural practices, and geographical locations. Thus, 'determinants of health' such as income and education may vary considerably between and among each of these subgroups and could account for significant differences in health outcomes[9].

National research has been conducted with either Asian Americans as an aggregate group or with the six larger Asian American subgroup populations (Asian Indian, Chinese, Filipino,

Japanese, Korean, and Vietnamese) at a disaggregate level [6]. However, little is known about whether there are differences between the umbrella group and any of the subgroups or among the subgroups.

The few existing research studies on subgroups show that aggregating data from multiple racial and ethnic minority subgroups can provide a misleading picture of individual subgroups [10–12]. For example, liver cancer has been shown to disproportionately affect Asian and Pacific Islanders subgroups [13], with mortality rates varying significantly among each group when examined separately. For instance, liver cancer rates are higher for the Vietnamese, Korean, and Filipino populations compared with other Asian subgroups and non-Hispanic whites [13]. This study's findings exemplify the need for more research on subgroup populations. Thus, to fully understand the patterns of disease and to target prevention and intervention effectively, differences among subgroup populations need to be clearly established.

One of the least studied Asian American subgroups is the Hmong. According to Bachrach, Pfister, Wallis, and Lipson, almost 40% of health outcomes are closely linked to social factors [14]. The Hmong population has social determinants of health that are well known and that differ from Asian Americans as a whole, which may put them at risk for experiencing poorer health.

The Hmong

The Hmong people are an ethnic group that originated from southern China and later migrated to other parts of Asia. The Hmong in the US are primarily from Laos and were recruited by the US Central Intelligence Agency (CIA) to fight in the "Secret War in Laos"[15]. After the end of the Vietnam War in 1975, many Hmong fled to refugee camps in Thailand and then to the US. Currently, there are 260, 073 Hmong living in the US [16]. Eighty-seven percent

of Hmong in the US speak English “less than very well” compared to 60% of all Asian Americans who speak English less than very well [17,18]. The median household income of the Hmong was $45,776 compared to $66, 201 of all Asian Americans [19]. Additionally, only 24.9% of Hmong people have a high school education compared to 85% of all Asian Americans [20]. This demographic profile, which includes social determinants of health, suggests the Hmong population may bear a disproportionate burden of poor health.

To fully understand the extent of the disproportionate burden of disease that the Hmong population experiences, a systematic literature review was conducted to examine the current state of health of Hmong adults in living in the US, specifically related to health promotion and disease prevention. This research question is the first step to addressing Executive Order 13515 signed by President Obama in 2009 to establish strategies that will improve the health of Asian Americans and to seek data on the health disparities among Asian American subgroups [21].

METHODS

This systematic review is reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations [22,23]. This paper uses the National Institute of Health (NIH) definition of health promotion and disease prevention to select the most appropriate articles for review. NIH defines health promotion and disease prevention research based on the following categories of research: (a) “identification of modifiable risk and protective factors for diseases/disorders/injuries;” (b) “studies on assessment of risk, including genetic susceptibility;” (c) “development of methods for screening and identification of markers for those at risk for onset or progression of asymptomatic diseases/disorders, or those at risk for adverse, high-risk behaviors/injuries;” (d) “development and evaluation of interventions to promote health for groups of individuals without recognized signs or symptoms of the target

condition;" (e) "translation of proven effective prevention interventions into practice;" (f) "effectiveness studies that examine factors related to the organization, management, financing, and adoption of prevention services and practices;" and (g) "methodological and statistical procedures for assessing risk and measuring the effects of preventive interventions" [24]. Using NIH's definition is appropriate because it is one of the federal agencies that funds and prioritizes this area of research.

Data Sources and Search Strategies

Articles were searched in the following databases: PubMed; CINHAL; PsychInfo; SocINDEX; Medline; Health Source: Nursing/Academic Edition; Hmong Studies Journal; and gray literature, including Google Scholar, for articles published between 1975 and 2015. This time frame was selected because 1975 marks the beginning of the Hmong immigration to the US [25], and it allows the researcher to gain a thorough, historical representation of research conducted on Hmong health since their arrival in the US. Broader search terms, such as "Hmong," "health," "health promotion" OR "lifestyle" OR "diet OR nutrition," "disease prevention," and "screening" OR "cancer screening" OR "cardiovascular disease screening" OR "diabetes screening" OR "hypertension screening" were also used in the search databases. See Figure 1 for a flow diagram of the article selection process.

Ethics

Informed consent was not obtained for this paper because this paper is a review paper that collects and critically analyzes multiple research studies. However, informed consent was obtained from all individuals who participated in the studies that served as the primary sources of this review.

Study Selection and Data Extraction

Articles were included if they met the following criteria: (1) focused on Hmong adults; (2) peer-reviewed English-language publications; (3) conducted research in the US; (4) focused on adults defined as 18 years and older; (5) primary research studies including both qualitative and quantitative studies; and (6) contained data relevant to health promotion and disease prevention corresponding to the NIH definition. Articles were excluded if they: (1) focused on maternal/child health and mental health; (2) were review or commentary papers; (3) were from countries outside of the US; and (4) did not focus on Hmong adults. Maternal/child health and mental health were not a focus in this study because there have already been a large number of studies that focus on Hmong mental health and maternal/child health; there is no existing literature review on Hmong adults in the US. The author screened titles and abstracts using the inclusion criteria and the NIH definition of health promotion and disease prevention as stated above[24].

All articles that met the inclusion criteria were read and coded deductively for: (a) author(s); (b) years; (c) study purpose; (d) design; (e) research area of focus; (f) sample size; (g) major findings; and (h) findings relevant to this review. All data were entered into a table to facilitate an across article comparison. Articles were next organized by major concepts to compare and contrast findings across studies. The author coded the study findings and worked with her research team, which consisted of three doctoral students, a post-doctorate fellow, and her advisor, to review the codes. When disagreements occurred, consensus among the research group members was required before moving forward with analysis.

Quality Assessment

The author assessed the quality of each of the 71 articles included in this review. For the quantitative studies, the studies were analyzed to determine quality of research methods,

reliability and validity of measures, and relevance of findings to Hmong health promotion and disease prevention. For the qualitative studies, trustworthiness were assessed by the consolidated criteria for reporting qualitative research (COREQ) checklist to examine the quality of the qualitative studies [26].

RESULTS

Study Characteristics

Of the 71 articles, 33 studies were conducted in California, 17 in Minnesota, 10 in Wisconsin, 1 in Michigan, 4 in Oregon, 3 in Washington, and 3 did not specify the location. The study sample sizes were wide-ranging, from 4 to 217,738. The sample sizes across qualitative studies ranged from 5 to 292. In contrast, the sample sizes across quantitative studies ranged from 59 to 217,738.

Of the 71 articles, 37 were quantitative, 27 were qualitative, and 7 were mixed-method. Of the 37 quantitative studies, 19 used surveys/questionnaires**,** 3 used screening studies, 6 used chart review, and 7 used cancer registries.

The review of literature yielded three common categories: (1) research that describes differences in health risks, prevalence, and mortality of diseases (health status and health risks); (2) personal health behavior, including health knowledge, attitudes, and personal determinants of health to maintain good health; and (3) protective health behaviors, such as exercise and healthy eating. See Tables 1, 2, and 3 for findings of reviewed studies.

Health Status and Health Risks

Health status refers to research that describes differences in health risks, prevalence, and disease mortality. Eighteen studies addressed disease prevalence, incidence, risks, and mortality rates [27–44]. In these 18 studies, disease prevalence and health risks among Hmong adults were

examined using surveys; whereas, disease incidence and mortality rates were examined using a combination of registries, serologic tests, chart reviews, and surveys. Cancer (mainly breast and cervical cancer); Hepatitis; and cardiovascular diseases, including Diabetes and Hypertension, were the focus of most (15) studies.

Of the 18 studies, four studies examined Hepatitis prevalence among Hmong adults [31,37–39]. Three studies reported a high prevalence of Hepatitis B virus, ranging from 3.41% to 16.7%, compared with the 0.15% to 1.27% documented with other Asians, Caucasians, African Americans, Hispanics, and Native Americans [37–39]. In addition, 17% (47 of 77) of Hmong patients aged 20 years and older were infected with the Hepatitis B virus, and 48% (130 of 183) had developed immunity to the Hepatitis B virus [31].

Four of the 18 studies addressed cancer incidence, reporting that the Hmong have an elevated incidence of hepatic, gastric, cervical, nasopharynx, stomach, liver, pancreas, leukemia, and non-Hodgkin lymphoma compared to Asian/Pacific Islanders and non-Hispanic whites [30,34–36,43,44]. Six studies reported that Hmong also have a high incidence of advanced stage and grade of cervical cancer [43], gastric cancer [44], nasopharyngeal cancer [30], and hepatocellular cancer [33]at diagnosis (e.g. stages 3-4 and grade 3) compared to Asian/Pacific Islanders and non-Hispanic whites [30,33–35,43,44].

Four studies focused on cancer mortality rates [33,42–44]. These studies found Hmong to have higher mortality rates of all neoplasm, circulatory, and respiratory diseases [33], [42]. In addition, nasopharyngeal cancer mortality rates are 10.4 for Hmong compared to 0.2 and 1.7/100,000 for non-Hispanic whites and Asian/Pacific Islanders, respectively [33]. Further, Hmong women experience cervical cancer mortality rates three to four times higher than Asian/Pacific Islanders and non-Hispanic white women [43].

Four studies focused on cardiovascular disease prevalence. Three of the four studies examined diabetes prevalence [27,32,40,45]. Researchers reported that diabetes prevalence among Hmong ranged from 11.3% [40] to 41% [32] compared to 6% of non-Hispanic white population [40].

Three studies examined cardiovascular risks of the Hmong compared to other Asian groups [29,46,47]. For example, Hmong have a greater risk for diabetes when compared to Chinese, Vietnamese, and Filipinos [48]. With no comparison group, one study reported that 63% of Hmong adults were either overweight or obese [49].

Another study focused on prevalence of gout [50]. In a 2010 study, Wahedduddin and colleagues reported that the Hmong had a 31.5 % incidence of tophaceous gout compared to 10.7% of Caucasians [50].

Two studies focused on the prevalence of smoking [28,51]. Constantine and colleagues reported in 2010 that the Hmong have the lowest smoking prevalence compared to all the Southeast Asian populations [28]. Finally, one study focused on health risk factors related to safety and health hazards [52].

Personal Health Behavior

Personal health behavior includes health knowledge, attitudes, and personal health determinants to maintain good health. Personal health behavior has received the most attention from researchers. Of the 71 studies, 25 studies focused on personal health behavior, and these studies focused on three main topics: (1) screening behaviors (n=15); (2) health treatment seeking behavior (n=3); and (3) chronic disease management (n=7).

Screening behaviors. Of the 15 studies conducted on health screening, 13 focused on breast or cervical cancer screenings; one on Hepatitis B screening [53]; one on osteoporosis

screening; and one on immunizations [54]. Three general areas related to screening behavior were identified: (a) knowledge and attitudes; (b) behavioral predictors; and (c) screening barriers. In most studies, knowledge, attitudes, and barriers to screening behaviors were examined together.

Overall, researchers reported that the Hmong have low screening rates, specifically for breast and cervical cancer and Hepatitis B. Two California-based studies found that the proportion of Hmong women who reported ever having had a clinical breast exam ranged from 50% [55] to 73% [56]. In addition, the proportion of Hmong women in this study who had had a Pap test in the last three years ranged from 61% [57] to 67% [58] in comparison to 86% of Californian women overall.

Knowledge and Attitudes. Four studies reported that Hmong adults have no knowledge of cancer or the causes of cancer and, consequently, did not understand the importance of screening [59–62]. There is no word for 'cancer' in the Hmong language [63].
Similarly, one study reported that 38% of Hmong participants were unaware of the causes of osteoporosis, attributing it to fate, chance, or luck compared to 18% of Vietnamese participants with similar beliefs [64]. In 2012, Maxwell and colleagues revealed that only 45% of Hmong reported having ever heard of hepatitis B [65].

Four studies documented negative attitudes toward screening among older Hmong. For example, many Hmong women expressed embarrassment about screening, as well as fear of dealing with the screening results [56,59,63,66].

Predictors of Behaviors. Only three studies examined predictors of screening behaviors of Hmong women, including obtaining clinical breast exams and pap tests [56,57]. The Hmong women's screening behaviors were associated with age, cultural factors (e.g. fatalism, modesty,

prevention orientation, use of traditional medicine, and family support), and language. For example, one study reported that cultural factors, including modesty, were significant predictors of Hmong women's receipt of clinical breast exams [56]. Furthermore, participants' age (older women) and those who used the questionnaire in the Hmong language were negatively correlated with having a clinical breast examination [56].Younger Hmong women (age 21-30) were more likely to have had a recent Pap test [57].

One study examined predictors of perceiving barriers to immunizations among parents of Hmong in California [67]. Researchers reported that the socio-economic position and the use of traditional health care (e.g. consulting with shamans and herbalists) were significant predictors of perceived barriers for Hmong parents to immunize their children [67].

Barriers to screening. Ten of the 15 studies also focused on barriers to screening [56,57,59–62,66,68–70]. The two most commonly reported barriers were: (a) cultural practices and beliefs and (b) language barriers.

Cultural Practices & Beliefs. Six studies reported that the Hmong participants' cultural practices and beliefs were barriers to screening [56,63,71–75]. Cultural beliefs about the privacy of body parts and the common practice of women deferring to their husbands and children often prevented women from seeking breast and cervical cancer screening [75,76]. Peers, healthcare professionals, and the internet were reported as sources of information for Hmong adults [77].

Language barrier. Language was also a barrier identified in nine studies [54,55,63,71,74,78–81]. Specific to language, women reported three types of barriers: (1) a lack of specific language for discussing cancer and health screening; (2) hurtful experiences related to their status as English language learners; and (3) inaccessible or poor quality interpreters.

Health Treatment Seeking Behaviors. Five studies focused on health treatment seeking behaviors of Hmong adults [30,33,44], [78,82]. Of the five studies, two examined general health treatments [78,82] and three examined cancer treatments [30,33,44]. Researchers reported that Hmong typically sought care for physical, emotional, and psychological complaints first from a shaman, before seeking care from a western care provider [78,82]. However, relating to cancer treatment, Hmong adults were less likely to receive cancer treatment compared to Asian/Pacific Islanders and non-Hispanic whites [30]. For example, over 97% of Hmong patients in California chose no treatment for nasopharyngeal cancer compared to only 25.6% of Asian and Pacific Islanders and 30.3% of non-Hispanic white patients [30]. Similarly, one study in California reported that only 3% of Hmong received local surgical treatment, resection, or liver transplantation for hepatocellular carcinoma compared with 22% of Asian Americans[33].

Chronic Disease Management. Seven studies focused on chronic disease management among Hmong adults. Six focused on diabetes management [83–88] and one focused on hypertension management [89]. Overall, these studies reported that medication compliance was an issue in managing chronic disease for Hmong adults. One study conducted in California reported over 50% of the 323 Hmong adults were non-compliant with their prescribed hypertension medications [89]. Another study reported that the Hmong prefer traditional Hmong remedies such as herbs, including plants and tree roots, to treat diabetes [90].

Barriers to Chronic Disease Management. Barriers identified in managing chronic diseases among Hmong adults were: (a) no knowledge and (b) cultural factors.

No Knowledge. Two studies reported that Hmong participants did not know what diabetes[85] and hypertension [91] were, did not understand that they were often preventable,

and often believed it could be cured, making chronic management unnecessary. This often resulted in poor management [89].

Cultural Factors. Wong and colleagues reported that Hmong participants believed hypertension was caused by 'bad blood' [89]. Hmong participants believed diabetes was caused by a change in weather and environment, as well as stress [83,92].

Personal Health Protective Behavior

Of the 69 studies, eight focused on personal health protective behavior. Healthy eating and physical activity were the main focus of this research on Hmong adults. Six studies examined eating practices [93–97]; two examined physical activity [98,99]; and one examined healthy aging [100]. These studies investigated how different factors influence health. For example, the studies were concerned with food habits, food culture, acculturation, health [97], and environmental factors influence eating habits and body mass index, and how all of these factors affect health [101,102]. These studies also looked at ways to promote physical activity [103].

Researchers found that acculturation and environmental factors limited the Hmong people's ability to engage in health protective behavior, documenting that Hmong generally perceived Hmong food as healthy and American food as not healthy [97]. However, acculturation and environmental change affected Hmong adults' eating habits [93,97,104,105]. Specifically, Hmong have transitioned from a food insecure environment to "a more food-secure, obesogenic environment" that has negatively affected their eating and purchasing habits [97,104].

In addition, one study of physical activity found that safety concerns and lack of public spaces for physical activities were significant barriers to health protective behaviors [103].

Moreover, two studies reported that utilizing personal protective equipment was uncommon among the Hmong while farming [98,106]. However, Nguyen and Seal reported in 2014 that Hmong elders highlighted positive family relationships, maintenance of group harmony, family interdependence, and filial piety as protective factors to healthy aging [100].

DISCUSSION

This systematic review confirmed that health disparities exist among the Hmong adult population in the US. This review also identified a variety of factors (e.g. no knowledge, cultural factors, and language barriers) that may contribute to health disparities among the Hmong adult population.

Information about protective health and personal health behavior came from a combination of interviews and surveys. Survey studies were typically self-reports without verification. For example, most of the surveys conducted with Hmong participants were not pilot-tested, and researchers did not report on the instruments' psychometric properties, including validity and reliability of its original source. Moreover, the survey studies mainly targeted individuals who could read and write in English. This current, traditional methodology approach in the collection of data among Hmong adults may not be culturally appropriate because they have an oral culture with no written language [107]. Consequently, this method excluded individuals who cannot read or write.

From the literature review, researchers have reported that chronic diseases such as hypertension and diabetes are unfamiliar to the Hmong. One explanation could be that the Hmong might have been healthier prior to coming to the US and had no experience with some chronic illnesses such as diabetes. Previous research has documented that refugees and immigrants arrive in the US with generally better health compared to US citizens [108].

However, as immigrants adapt to the Western culture, including diet and activity level, they have a propensity to gain weight and develop chronic disease [109–112]. Moreover, evidence has shown that inequities accrue over time from exposure to multiple health, environmental, and social risks; as a result, changes manifest in one's initial health status over the life course [113]. More research is needed to better understand how inequities may accrue over time for the Hmong adults in the US.

This literature review found that of the states with a higher Hmong population, California contributes the most Hmong health data, followed by Minnesota and Wisconsin [16]. Despite the fact that there is a lack of systematic data collection and robust research support, the current level of knowledge can still afford opportunities for interventions that may address some of the disparities identified in this review.

Implications for Applied Practice

This systematic review revealed that health registries and charts from the state and within health organizations have allowed researchers to disaggregate data to understand Hmong people's health. However, there is still an underlying problem of data collection -- measures of race and ethnicity is not collected from all racial and ethnic groups, including subgroup populations, at all levels. Thus, it is critical that health care systems make data collection on race and ethnicity, including subgroups, a standard of practice. For example, health care systems, including hospitals and public health departments, could collect data on race and ethnicity during admission for hospitalization or during enrollment in health programs. This will be crucial as big data advances and progresses, emphasizing the need for data to be collected at the clinical level.

At the national level, clinicians, researchers, and policy makers could aim to work together to change how data are collected and shared. Specifically, a culture of data-sharing and

common data collection standards between cancer registries, vital records, Medicare and Medicaid data, Behavioral Risk Factor Surveillance, and hospital discharge data is needed to understand the health disparities among and between racial and ethnic minorities, including subgroup populations.

Limitations of this Literature Review

There are limitations to this research review. Because this paper only focused on the adult population, findings cannot be generalized to the entire Hmong population in the US. Because I used broad search terms: "health," "health promotion," "health risks," "disease prevalence," "screening," and "disease prevention," I may have missed some research related to health promotion and disease prevention. In addition, because the NIH's definition of health promotion and disease prevention did not provide a specific definition for each domain, I may have excluded other relevant studies that may not fall under the NIH's definition.

CONCLUSION

This systematic review confirms that the Hmong adult population experiences health disparities. Efforts are urgently needed to increase research to better understand in more depth the health issues of the Hmong adult population and to develop culturally salient and linguistically responsive health interventions for them. Policies are also needed to allow data to be collected on sub-group populations. The inability to collect data and identify the Hmong population within large surveys will contribute to the widening gap of health disparities in subgroup racial and ethnic minority populations as they become invisible to policy makers, researchers, and funders.

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PRISMA 2009 Flow Diagram

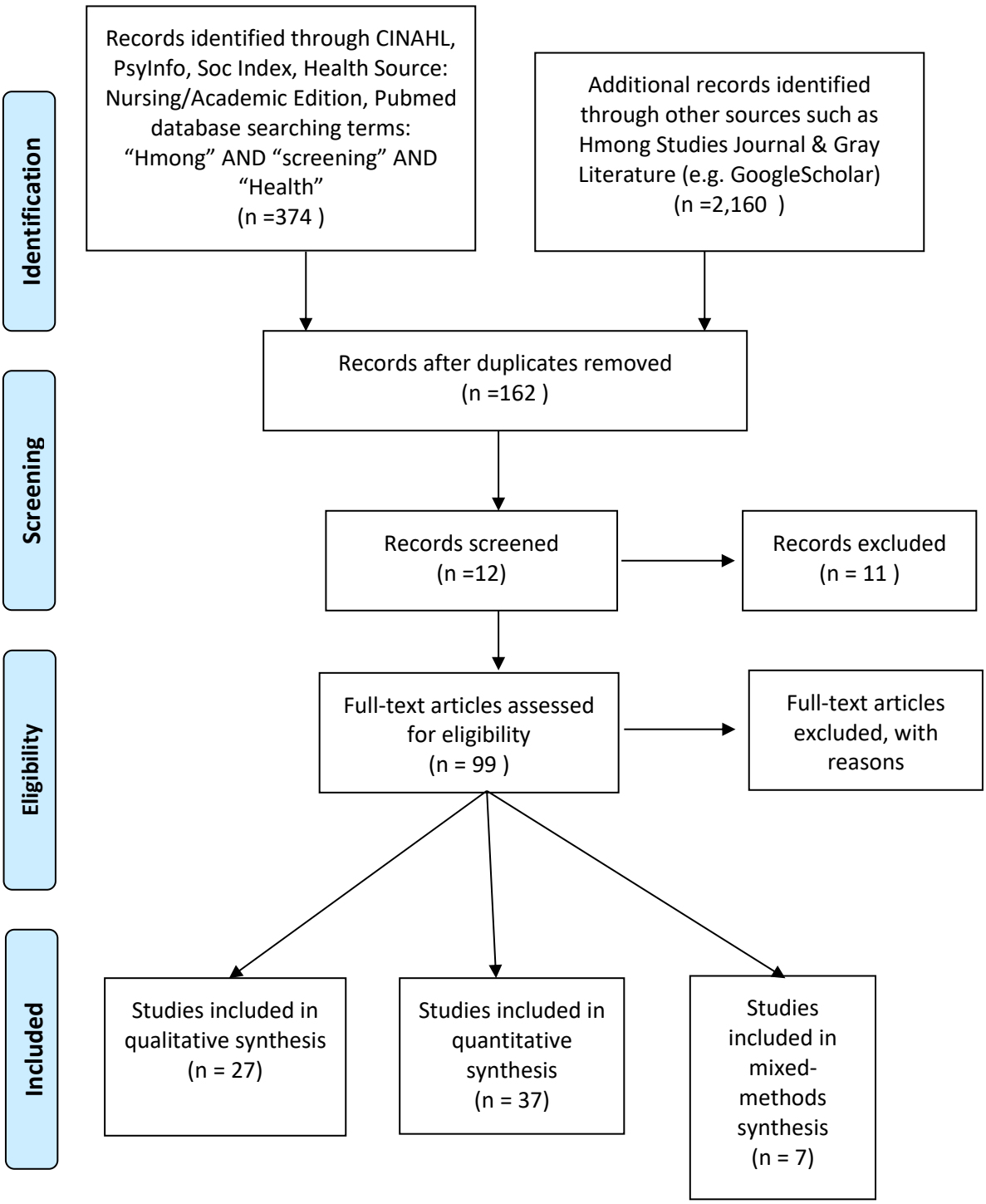

Table 1. Qualitative Studies

Authors	Study Purpose	Sample	Setting	Design	Analysis	Results
Baisch, Vang, & Peterman, 2008	Explored the perspectives of Hmong women on cancer, using focus groups as the research method.	10	WI	Qualitative study	Inductive content analysis	There is no Hmong word for 'cancer.' Hmong participants have 'fatalistic' beliefs about cancer. Misunderstandings occur because of misunderstandings due to inadequate translations. Women are embarrassed to discuss about their body parts and male leaders controlled women's health care decisions.
Barrett, Shadick, Schilling, Spencer, del Rosario, Moua, & Vang, 1998	Examined interaction between Hmong patients and their health care providers and identified specific factors that either enable or obstruct health care delivery	47	WI	Complementary qualitative method including participant observation, focus groups, and literature review	Transcripts were analyzed by a multidisciplinary team	Hmong patients and their health care providers have different health beliefs systems. Translation was reported as a challenge, specifically for linguistic and cultural translation. The majority of Hmong patients identified kindness, caring, and a positive attitude as important provider characteristics. Providers reported that Hmong patients lack understanding of the following concepts: acute versus chronic diseases, illness prevention, and pain, both physical and psychological.
Burgess et al., 2008	Explored beliefs and experiences related to smoking and cessation among the Hmong population in the United States	18	MN	Qualitative using focus groups	Used Patton (2002)'s qualitative analysis methods	Barriers to smoking cessation were different based on gender and acculturation. For example, women were concerned about having their smoking status revealed if they were to seek help, because of cultural prohibitions against female smokers. Less acculturated Hmong believed U.S. commercial tobacco to be more addictive than the homegrown tobacco they were used to. Participants were strongly influenced by smokers in their social networks. A powerful obstacle to quitting was addiction or "cravings".
Burgess et al., 2014	Examined how tobacco use patterns in Minnesota's Southeast Asian communities (Minnesota's Hmong, Khmer (Cambodian), Lao, and Vietnamese)	60	MN	Qualitative	Used a standardized framework for ethnographic analysis called a face sheet comparison to look at each	Among the Hmong participants, regular consumption of tobacco was unacceptable. Consumption of tobacco was rarely seen until the civil war in Laos when a number of Hmong soldiers became smokers. Social norms of smoking have begun to shift, with smoking becoming less acceptable. Although older male smokers felt social pressure to quit, they reported that

	have been shaped by culture, immigration, and adjustment to life in America.				interview as a whole and to compare interviews to find similarities and differences	smoking reduced their stress of social isolation, economic hardship, prior trauma, and the loss of power and status.
Culhane-Pera & Lee, 2006	Explored Hmong patients and family members' explanatory models, decision-making processes, and experiences with the health care system.	34	Not specify	Qualitative study	Analyzed major themes related to ideas of etiology, patho-physiology, signs/symptoms, course, and preferred treatment; reaction to health care system and medical decision	Hmong people's concepts of kidney function and explanatory models of kidney stones are both from traditional and biomedical concepts. Hmong understood kidney stones as acute health problems caused by hard substances in water and food that stick to the kidney, which weak kidneys cannot excrete. People who had kidney stone did not know they had stones until they passed a stone or they saw stones on X-rays. They preferred medications, including herbal medicines, to invasive urological procedures.
Culhane-Pera, Her, & Her, 2007	Increased understanding about Hmong cultural model of type 2 diabetes	39	MN	Qualitative		Hmong adults attribute their diabetes to their refugee experience. They also reported that feeling out of balance, defined as not fitting with the food, activity, weather, or community in the U.S., combined with emotional losses of being refugees, resulted in the development of diabetes. Hmong adults' interpretation of diabetes was related to their traditional health model of balance and in the context of their loss place as refugees.
Devlin, Roberts, Okaya & Xiong, 2006	Explored health-related beliefs and experiences of African American, Hispanic/Latino, American Indian, and Hmong people with diabetes and engage community members in improving diabetes care.	80	MN	phenomenological approach using focus groups	Data were organized into similar or contrasting groups of themes using Krueger (1998) team-based analysis strategy approach	People reported a loss of health, healthy habits, and traditions through the exposure of American lifestyle, particularly with the lack of physical activity and poor diet resulted in the development of diabetes. Participants also reported a lack of confidence in the medical system. Participants also expressed the importance of spirituality, which shaped their experiences and self-care practices.

Fang & Baker, 2013	Explored barriers and facilitators of cancer screening among women of Hmong origin	44	CA	Qualitative study using community -based participator y research approach	Krippendorff guidelines : used for reliability & reliability Social determinant of health framework used to guide probe and discussion during focus group and to capture key themes (analysis)	Sociocultural barriers to screening included a lack of accurate knowledge about the causes of cervical cancer, language barriers, stigma, fear, lack of time and embarrassment. Structural barriers to screening included attitudes and practices of health care providers, lack of insurance (for college & professional women), and quality of service provision at clinics for the uninsured
Fu et al., 2007	Explored minority smokers including Hmong's experiences and beliefs about guideline-recommended smoking cessation treatments	95	MN	Qualitative using focus groups	Used Patton (2002)'s qualitative analysis method	Hmong participants reported that it was unlikely for the older Hmong generation to seek smoking cessation help from doctors due to the lack of awareness of the services.
Helsel, Mochel, & Bauer, 2004	Examined Hmong Shaman respondents' understanding and management of their illnesses.	11	CA	Explorator y qualitative	Grounded theory	Hmong shamans are influential individuals within the Hmong community and are often the resource persons to whom patients turn to for information on health. Hmong participants do not understand the concept of chronic illness, as a result, Hmong participants have sporadic medication and dietary regimens. They also lack awareness of potential complications, and persistently believed that chronic diseases could be cured rather than managed.
Johnson, 2002	Determined Hmong perspectives and beliefs that influence the Hmong experience in Western medical situations.	19	CA	Ethnograph y study	No information on analysis	Hmong language lacked terminology of biomedical body physiology and anatomy. Medical terms and diagnoses lack direct translation and require extensive nondirect terms to approximate meaning.

Lor et al., 2013	Described the beliefs, feelings, norms, and external conditions regarding breast and cervical cancer screening in a sample of Hmong women.	16	WI	Descriptive study, guided by the Theory of Care Seeking Behavior	Directed content analysis	Hmong women's beliefs about breast and cervical cancer screening were based on their earlier experiences with breast and cervical symptoms. Many Hmong women felt embarrassed about breast and cervical cancer screening. They also fear about dealing with the results. Hmong women's cultural norms about undressing for an exam and listening to authority figures were different from Western norms. Hmong women reported that difficulties in communicating with interpreters and clinicians were external conditions that influenced their screening behaviors.
De Castro, Krenz, & Neitzel, 2014	Investigated agricultural-related safety and health issues among Hmong refugees working on family-operated farms.	11	WA	Photovoice methodology	Used a group analysis using Wang & Burris, 1997's coding method	Hmong participants shared that their farm work put them at risk for musculoskeletal problems (e.g. chronic pain). Participants reported that handling and operating heavy machinery resulted in physical injuries. Participants also reported problems related to heat and cold stress and respiratory exposures. Pest management was reported as a challenge for Hmong farmers. Due to Hmong farmers' socioeconomic status and language barriers, they reported difficulty in affording crops and communicating with supply stories and companies.
Nguyen & Seal, 2014	Elicited the definitions of successful aging according to Chinese and Hmong elders living in Milwaukee, WI.	44	WI	Exploratory qualitative	Used Grounded Theory principles for analysis (Corbin & Strauss, 2990; Strauss & Corbin, 1994)	Hmong elders reported concerns about having good physical health, strength, and energy. They also reported having harmonious family relationships were important to them and feeling love is an important part of healthy aging. Hmong elders' source of happiness included having children and having loving relationships with siblings and extended relatives. Elders expect to live with their children and for their children to provide tangible forms of support such as buying groceries, paying bills, and household chores.
Perez & Cha, 2007	Investigated knowledge, beliefs, and treatment of diabetes in the Hmong	33	No specificity	Qualitative using focus groups	Used Miles and Huberman (1984) and Patton (1990) for dealing with	Findings from this survey revealed that the majority of study participants had no knowledge of the disease. Results from the survey also revealed misconceptions about the disease (e.g., believing a person can catch the disease by eating too

	community in Fresno County				qualitative data	many sweet foods). The study also revealed that the majority of study participants utilize traditional Hmong remedies such as herbs, including plants and tree roots for diabetes treatments
Perez & Thao, 2009	Documented barriers to addressing diabetes in the Hmong community.	10	CA	Photovoice, a qualitative	Code for issues, themes, and theories in the documented stories	Barriers to diabetes prevention included 1) the environment, 2) personal choices, habits, and life style and, 3) lack of a safe environment to access physical activity as factors contributing to the potential for developing diabetes.
Perez, Moua, & Pinzon-Perez, 2006	Identified risk factors for food-borne illness, knowledge of safe food handling practices, and understanding that transmission of food-borne diseases among Hmong.	25	CA	Qualitative	Data were coded into themes	Participants did not understand the direct relationship between bacteria and food borne illnesses. Participants were more likely to report reliance on traditional medicine to address foodborne illnesses.
Pham, Harrison, & Kagawa-Singer, 2007	Explored Hmong parents' and youths' knowledge, attitudes, opinions, and behavior about health and healthy lifestyles.	84	CA	Qualitative	Data analyzed using inductive approach	Hmong valued physically active lifestyles and dietary patterns as well as fresh foods. Barriers to a healthy lifestyle included limited access to safe spaces, time for adequate physical activity, access to land to grow fresh produce, and time for home preparation of food.
Plotnikoff et al., 2002	Increased understanding of the process and meanings of shamanic care from patient complaint through diagnosis, treatment, and outcome.	36	CA	Descriptive qualitative study	Grounded theory	Hmong patients sought shamanic help for different types of care including physical, emotional, and psychological complaints.
Thorburn, Kue, Keon, & Zukoski, 2012	Explored family and clan influences on Hmong women's breast and cervical cancer screening	83	Oregon	Exploratory study	Content analysis	Hmong women make their own independent decisions about breast and cervical cancer screening. Half the women shared that their family encouraged/supported them in getting screened. However, some shared that elders discouraged screening. Hmong families do not

	attitudes and behavior.					discuss about breast and cervical cancer screening because they see it as a way for their family and clan to influence their attitudes.
Thorburn, Kue, Keon, & Lo, 2012	Explored medical mistrust and trust of Western medicine and the health care system among Hmong women and men as well their experiences with discrimination in health care, and how these factors may influence Hmong women's breast and cervical cancer screening behavior.	83	Oregon	Exploratory study	Did not specify type of data analysis method	Hmong distrust their doctors. Sources of mistrust included lack of understanding and negative impressions of Western medicine and the health care system. In addition, having a positive experience with providers created trust with some Hmong participants. However, participants reported that mistrust/trust did not have any effect on their decisions to get breast and cervical cancer screenings. A few Hmong participants reported being treated differently when they obtained their screening. This experience of discrimination affect Hmong participants' behavior in willing to seek care.
Thorburn, Keon, et al., 2013	Explored sources of information about breast and cervical cancer, including screening, and identify barriers to seeking such information fir Hmong women & men	83	Oregon	Qualitative descriptive study	Content analysis	Health care providers and the Internet were the most frequently cited sources for obtaining information about breast and cervical cancer for Hmong. Barriers to seeking information included fear of knowing they had the disease or of inviting it
Van Duyn et al., 2007	Examined how best to adapt proven, evidence-based strategies to increase physical activity for use with underserved racial or ethnic groups.	292	CA	Qualitative study using focus groups	Did not specify	Media messages in the Hmong native language were important. Hmong families reported that community campaigns to increase physical activity could be done at Asian grocery stores, community organizations, churches, and festivals. Hmong gatekeepers reported they had little ability to change their environments (e.g. workplace, schools). Hmong reported safety concerns as a barrier to access their resources because they live in communities with high crime rates.

Vang, 2009	Explored factors that influence Hmong women‘s willingness to be screened for breast cancer	15	WI	Qualitative	Used grounded theory to guide analysis	Breast health messages influenced Hmong women’s decisions about obtaining a mammogram. Hmong women only sought care when they were symptomatic (e.g. there is a visible sign or symptoms of illness). Instrumental barriers were reported to influence screening including lack of tangible aid and services, language barriers, and lack of insurance and transportation. Sociocultural influence such as family influences (e.g. husbands’ approval) on decisions to seek screening.
Vue, Wolff, & Goto, 2011	Examined perspectives on food habits, acculturation, and health among Hmong women with young children in northern California.	15	CA	Qualitative	Data analysis done using principles of Grounded Theory	Participants reported that Hmong food culture is a healthful lifestyle and helps them maintain their self-identity. Hmong mothers encountered enormous challenges in bridging two extreme generations; the less acculturated immigrant adults and the highly acculturated, US-born children in their households.
Xiong & Westberg, 2012	Determined perceptions of the Hmong population about Type 2 Diabetes	9	MN	Qualitative using focus group	Looked for common themes	Participants lacked knowledge about diabetes including different types of diabetes, risks of diabetes, causes, and treatment for diabetes. As a result, many participants were upset about taking the medication for the rest of their life and were reluctant to take their medications as prescribed.
Yang, Xiong, Vang, & Pharris, 2009	Explored how to better care for Hmong women with diabetes using nursing theory praxis.	5	MN	Qualitative phenomenologic design	Data were analyzed using Newman's (1994) hermeneutic-dialectic method	Hmong participants viewed causes of diabetes from culture change and hardships. Further, also described a direct connection between their loss, depression, deep grief, worry, stress, and diabetes.

Table 2. Quantitative Studies

Authors	Study Purpose	Sample	Setting	Design	Results
Prevalence Studies					
Albright, 2010	Examined the prevalence of excess body mass (XBM), poor oral health (POH), and stress in a secluded population of aged (≥60 years) Hmong immigrants	877	CA	Survey study	The prevalence of diabetes among Hmong elders were 24% while the prevalence of POH was 41%. The prevalence of stress was 27% and prevalence of XBM was 87%. POH was related to the presence of diabetes.
Constantine et al., 2010	Measured the prevalence of smoking among the Hmong, Vietnamese, Lao, and Cambodian communities	1,628	MN	Cross-sectional survey study	The Hmong have the lowest prevalence rate of smoking across all the SEA populations. The majority of Hmong smokers began smoking in the United States. Hmong women also started smoking at a much younger age (14 years) than males (21 years).
Culhane-Pera DeFor, & Desai, 2009	Measured prevalence of CVD and CVD risk factors in Hmong refu-gees newly arriving from Wat Tham Krabok, Thailand 2004–2006	1,462	MN	Cross-sectional study including screening exam	48.7% of older people (ages 14-41) were overweight, obese, or morbidly obese by WHO categories. Hmong refugees had significant CVD risk factors on arrival. Specifically, men in the older group have a higher cardiovascular disease risk factor compared to women, particularly for hypertension, hyperlipidemia, and hyperuricemia.
Gjerdingen & Lor, 1997	Determined hepatitis B status, by age, of Hmong patients	1,585	MN	Chart review	Hepatitis B infection is prevalent in the Hmong population. 18% of the Hmong patients had positive HBsAg test results. 85% tested positive for anti-HBs. People from age 15 to 19 have the highest frequency of acute or chronic hepatitis B infection (28%) compared to 18% of the entire sample.
Sheikh et al., 2011	Determined the prevalence of HBV among Hmong immigrants in the San Joaquin Valley of California.	534	CA	Cross-sectional study	Eighty-nine Hmong were tested positive for HBsAg; a prevalence of 16.7%. The majorities of HBsAg positive patients were ≥40 years (64.2%), married (66.7%), born in Laos (87.3%), and had lived in the United States ≥20 years (62.5%). Only 37.5% of the participants reported having a primary care physician. One out of every six Hmong immigrants was infected with HBV when they were screened.
Sheikh, Atla, Raoufi, Sadiq, & Sadler, 2012	Examined chronic hepatitis B virus (HBV) prevalence and its trends in Hmong donors in the Central Valley	821	CA	cross-sectional review study	The overall prevalence of HBV in Hmong donors was 3.41% compared to 0.06% in donors of all ethnicities from 2006 to 2010.
Sheikh, Atla, Ameer, Sadiq, &	Evaluated the prevalence of hepatitis B virus (HBV) and hepatitis C virus (HCV) in	217,738	CA	Review of blood donor laboratory	Hmong had the highest HBV prevalence of 7.63% with a peak prevalence of 8.76% among the 16- to 35-year-old age group compared to other Asian subgroups.

Sadler, 2013	healthy blood donors in the Valley.			screening records from Central California Blood Center	
Thao, Arndt, Tandis, & Hanrahan, 2015	Compared the prevalence of diabetes between Hmong and non-Hispanic white patients of the University of Wisconsin departments of family medicine, pediatrics, and internal medicine clinics	964	WI	Electronic health record data	The total prevalence of diabetes in the Hmong patient population was 11.3% compared to 6.0% in the non-Hispanic white patient population. The prevalence of diabetes in Hmong adult patients was 19.1% compared to 7.8% in white adult patients.
Incidences					
Dodge, Mills, & Yang, 2005	Identified nasopharyngeal cancer in the California Hmong	59	CA	Case series design	Hmong had an incidence of 23 times greater of nasopharyngeal cancer compare to non-Hispanic whites. Nasopharyngeal cancer mortality rates were 10.4 for Hmong compared to 0.2 for Asian Pacific Islanders and 1.7/1,000 for non-respectively. Hmong were more likely to be diagnosed with later stages and less likely to receive treatment.
Mills, Yang, & Riordan, 2005	Examined cancer incidence rates in the Hmong in the state of California for the years 1988–2000	749	CA	Cancer registry	A total of 749 Hmong in California were diagnosed with invasive cancer. There was 284 per 100,000 population age adjusted rate of cancer for the Hmong compared to 362.6 and 478 per 100,000 in the API and NHW populations, respectively. Specifically, there were elevated for hepatic, gastric, cervical, and nasopharyngeal cancers and for leukemia and non-Hodgkin lymphoma (NHL) among the Hmong. Cervical cancer incidence increased, rates of NHL declined, and rates for colorectal cancer remained steady between 1988 and 2000. The Hmong were diagnosed at later disease stage with poorer grade of disease diagnosis than other API.
Mills & Yang, 1997	Examine cancer incidence in the Hmong population	183	CA	Retrospective study using cancer registry	There were six elevated rates of cancer sites in the Hmong: nasopharynx, stomach, liver, pancreas, leukemia, and non-Hodgkin's lymphoma. Hmong women have elevated cervical cancer incidence and invasive cervix cancer. Hmong also experienced advanced stage and grade of disease at diagnosis for many cancer sites in addition to cervical cancer.
Ross, Xie, Kiffmeyer, Bushhouse,	Examined cancer incidence in the Hmong population	186	MN	Cancer registry	The Hmong population had increased proportional incidence ratios for nasopharyngeal cancer, gastric cancer, and

& Robison, 2003					cervical cancer compared to all Minnesotans.
Portis, Hermans, Culhane-Pera, & Curhan, 2004	Examined whether the Hmong have a high rate of uric acid stone disease was evaluated.	204	MN	A retrospective chart review was performed	Of the 204 patients, 94 Hmong (46%) and 23 non-Hmong (11%) patients had stone disease. Staghorn calculi were found in 21 Hmong (24%) and 0 non-Hmong patients. Surgical treatments differed between Hmong and non-Hmong. Nine (43%) Hmong patients refused treatment for staghorn calculi.
Rooney & Choudhary, 2009	Examined correlates of tobacco use among Hmong people residing in Wisconsin.	2,856	WI	Survey study	The overall prevalence of daily tobacco use for adults was 25.3% for males and 12.4% for females. Males aged 51-83 had the highest rate of daily and ever use of tobacco. In contrast, females aged 18-35 reported the highest prevalence for daily and ever use of tobacco. People with no formal education were at the highest risk for using tobacco, with a decrease in the odds of smoking as the number of years of education increased.
Mortality					
Kwong, Stewart, Aoki, & Chen, 2010	Analyzed the differences in survival of Californians of Asian ancestry with hepatocellular carcinoma (HCC)	6,068	CA	Use cancer registry	Laotian/Hmong had significantly higher cause-specific mortality HCC compared to all ethnic groups. Forty-three percent of Hmong patients had disease spread to remote sites, with only 3% receiving local surgical treatment, resection, or liver transplantation.
Yang, Mills, & Nasseri, 2010	Examined causes of death (COD) and compare age-adjusted mortality rates (AAMR) in the Hmong with those of non-Hispanic white (NHW) population in California	2,744	CA	Retrospective study using data from the California Center for Health Statistics	Hmong and NHW have the highest AAMR in neoplasm, circulatory and respiratory diseases. Hmong experienced 1.3–1.9 times higher mortality rates for certain COD, compared to NHW. Hmong have 1.3–1.9 times higher mortality rates for injuries and poisonings, digestive diseases, prenatal conditions, ENMID (endocrine, nutritional, metabolic, immunity disorders), infections and parasitic illnesses, and congenital anomalies when compared to NHW. Hmong men were observed to be at statistically significantly higher mortality risk for just infections and parasitic diseases when compared to NHW men.
Yang, Mills, & Riordan, 2004,	Examined cervical cancer incidence, mortality, and other tumor characteristics in the Hmong female population of California between 1988 and 2000.	102	CA	Cancer cases obtained from the population-based California Cancer Registry (CCR)	Hmong women experienced incidence and mortality rates of cancer three and four times higher than Asian/Pacific Islander and non-Hispanic white women, respectively. Fifty-one percent of Hmong women chose no treatment, compared to 5.8% for Asian/Pacific Islander women and 4.8% for non-Hispanic white women. Hmong women are more likely to be diagnosed with cervical cancer at later stages and poorer histologic grades, and had a lower survival rate than younger Hmong females.
Yang, Mills, &	Examined gastric adenocarcinoma	66	CA	Data obtained	From 1988-2000, there were 66 gastric cancer cases diagnosed of Hmong living in

Riordan, 2005	incidence, mortality, and tumor characteristics in the Hmong population of California, 1988–2000.			from California Cancer Registry (CCR)	CA. Over 97% of these cases were malignant tumors. Hmong have high incidence rate of stomach cancer (26.9,100000) compared to Asian Pacific Islanders (19.8/100000) and non-Hispanic Whites (8.4/100000). Hmong were more likely to be diagnosed with cancer at later stages. More than 97% of Hmong patients chose no treatment, compared to only 25.6% of API and 30.3% of Non-Hispanic Whites patients.
Risk Factors					
Bates, Hill, & Barrett-Connor, 1989	Screened for heart disease risk factors	117	CA	Cross-sectional study	The Hmong, compared with other Indochinese, had a significantly lower mean cholesterol level, which remained after adjusting for age and body mass. High rates of cigarette smoking were found among Vietnamese men and young Indochinese men.
Her & Mundt, 2005	Quantified the proportion that may be at risk for developing type 2 diabetes among of Hmong adults in Wisconsin	144	WI	cross sectional risk prevalence survey	Forty-one percent had positive blood glucose screens on survey. Waist-to-hip ratio was a stronger predictor of a positive screen than the ADA Risk Test.
Relationships/Associations					
Albright, Woo, Ji, Sun, Lang, & Albright, 2013	Investigated associations between type 2 diabetes (DM) and several variables (e.g. poor oral health and overweight (OW)/ obesity among a group of elderly Hmong	495	CA	Survey	DM was correlated with poor oral health (POH). There was a strong correlation between concurrent POH and OW and the presence of DM: all subjects with both POH and OW had DM. There was a significant association between the presence of DM and concurrent OW and POH, controlling for OW, POH, age, years of residence in California, and stress level.
Waheddud din et al., 2010	Compared characteristics of gout in Hmong patients versus Caucasians and examined if Hmong ethnicity is associated with risk of tophaceous gout.	89	MN	A retrospective chart review	The Hmong who were diagnosed with gout was younger (58.3 years old), had an earlier onset of symptoms (37.4 years old) and higher mean serum uric acid levels during follow-up (9.1 mg/dl). There were higher rates of tophaceous gout (31.5%), including hand tophi (21.3%) among Hmong. Hmong ethnicity was significantly associated with risk of tophaceous gout after adjusted for age, sex, hypertension, diuretic use and kidney function,
Factors Associated with Health Behavior					
Baker, Dang, Ly, & Diaz, 2010	Explored factors associated with perception of barriers to immunization among parents of Hmong	417	CA	Cross-sectional survey	Socioeconomic position and use of traditional Hmong health care (i.e., consulting shamans and herbalists) significantly predicted higher perceived barriers to immunization. Nativity (e.g. years in the United States), age of arrival in the United States, and English language fluency, did not predict perceived barriers.

Fang, Lee, Stewart, Ly, & Chen, 2010	Examined baseline data on the proportion of Hmong women who reported they had a Pap test for the early detection of cervical cancer	402	CA	Cross-sectional questionnaire	Only 74% of Hmong women had ever had a Pap test. 61% of Hmong women had a Pap test in the previous three years. Women were more likely to have had a recent Pap test if they were younger (e.g. age 21-30 or 31-40). Hmong women who were single were or born in the U.S. were less likely going to have a Pap test.
Lee & Vang, 2013	Examined how cultural factors were associated with breast cancer screening utilization, specifically clinical breast exam (CBE)	164	MN	Cross-sectional survey	73 % of Hmong American women reported ever having had a CBE. Hmong women's modest views were the greatest barrier to ever having had a CBE. Age and language preference were also found to be significant predictors of past CBE use.
Lee, Yang, Lee, & Ghebre, 2015	Investigated Hmong-American immigrant women's utilization of cervical cancer screening	164	CA	A cross-sectional survey research design	About 67.1% had received a Pap test within the last 3 years. Fatalism, modesty, education, and marital status were significantly correlated with receiving a Pap test.
Maxwell et al 2012	Examined relationships using Health Behavior Framework factors across four Asian American groups (Vietnamese-, Hmong-, Korean- and Cambodian-American) to advance the development of theory-based interventions for HBV testing in at-risk populations.	1,735	Washington, DC & Washington State	Survey	Only 45% of Hmong who had heard of hepatitis B. Perceived susceptibility was lowest among Hmong.
Nguyen & O'Connell, 2002	Determined Asian and Asian-American college students' knowledge of osteoporosis prevention, risk factors, and treatment.	168	MN	Cross-sectional survey	Thirty-eight percent of Hmong participants thought osteoporosis was attributed to fate, chance, or luck. In contrast, Vietnamese participants attribute osteoporosis to diet. Most participants (63%) did not know whether their culture objected to estrogen replacement therapy, and 42% said menopause was a natural occurrence for which pharmacologic treatment should not be administered.
Okunseri, Yang, Gonzalez, LeMay, & Iacopino, 2008	(1) Described the self-rated oral health (SROH), self-rated general health (SRGH), and use of dental/physician services; and (2) identified the factors associated with SROH among Hmong adults.	118	WI	A cross-sectional study	Of the 118 participants, 49% rated their oral health as poor/fair and 30% rated their general health as poor/fair. Thirty-nine percent of Hmong reported that they did not have a regular source of dental care, 46% rated their access to dental care as poor/fair, 43% visited a dentist and 66% visited a physician within the past 12 months. Access to dental care, past dental visits, age and SRGH were significantly associated with SROH. There was a strong association

					between access to dental care and good/excellent SROH.
Story & Harris, 1989	Obtained information changes in food habits.	60	N/A	Survey study	Southeast Asian refugee families including the Hmong have maintained strong ties to their native foods and traditional diets. Rice remains the main food in their diet. Although most adults prefer eating their native foods, their children prefer both American and native foods.
Sugerman, Backman, Foerster, Ghirardelli, Linares, & Fong, 2011	Gained opinions from low-income, limited-English-speaking Hispanic and Asian immigrants for formative research in a social marketing campaign.	905	CA	Descripti ve study	Hmong reported receiving most of their information from the radio. Hispanics, Koreans, and Vietnamese thought diabetes was the greatest health issue in California while Hmong thought high blood pressure was the greatest health issues. Among Hmong, 83% thought fruits and vegetables were too expensive, and 49% of Vietnamese thought good quality, affordable fresh FVs were too hard to find
Tanjasiri et al., 2001a	Examined Hmong women's breast cancer screening behaviors—breast self-examination (BSE), clinical breast examination (CBE), and mammography	201	CA	Survey	Over 50% of all respondents reported they had ever performed BSE. Among respondents aged 40 or older, 52% had ever had a CBE and only 30% had ever had mammography.
Vang & Pinzon-Perez, 2006	Examined nasopharyngeal cancer (NPC) knowledge among a rural Hmong community in California	145	CA	Cross-sectional survey study	The participants' knowledge of cancer varied with age and educational level. Middle-aged generations had the highest level of knowledge on nasopharyngeal cancer compared to older generations. Participants with no school were the least knowledgeable about nasopharyngeal cancer. Those participants with the highest formal education were most knowledgeable about the disease. There was no difference between Hmong males and females on knowledgeable of nasopharyngeal cancer.
Wong, Mouanoutoua, Chen, Gray, & Tseng, 2005	Assessed contexts of adherence with hypertension care among Hmong Americans	323	CA	Cross-sectional survey study	Only 27% of Hmong reported having control over their blood pressure and over 50% reported non-adherence with hypertension care. Respondents who were 50 years of age or older, had no physical illness, did not know that hypertension was preventable, or believed that American medicine was too strong, were more likely to report non-adherence with proper medication consumption.
Wu, Hsieh, Wang, Yao, & Oakley, 2011	Examined the role of ethnicity in explaining multiple cardiovascular disease risk factors after controlling for demographic and access to care variables	388	MI	Cross-sectional surveys and blood tests	Hmong participants had the highest risk of diabetes among the Hmong participants compared to four other Asian groups (e.g. .

Yang, Mills, & Dodge, 2006	Examined patterns of cancer screening, reproductive history, and cancer health behaviors among the Hmong adults	248	CA	Cross-sectional survey	No one ever received colorectal exam. Only 30% have ever did a self-breast exam and only 15.8% received a mammogram.
Yang & Mills, 2008	Examined Hmong dietary and lifestyle patterns	248	CA	Descriptive study	Over 63% of Hmong adults were either overweight or obese. Hmong identified rice, chicken, beef, and eggs as the most frequently eaten items. Fruits and vegetables were also identified.

Table 3. Mixed Methods Studies

Author	Study Purpose	Sample	Setting	Design	Results
Franzen & Smith, 2010	Investigate influences on shopping and eating behavior of Hmong adults living in St. Paul/ Minneapolis, Minnesota	69	MN	Questionnaire, focus group, and community mapping	St. Paul, MN has the highest density of the Hmong population as well as Hmong/Asian grocery stories. The current consumer price index (CPI) was only available for a limited number of foods which means there were less ethnic food for Hmong. Those who were born outside of the US and lived less than 5 years in the US reported significant increase of some American food. In contrast, those who were born outside of the US and lived more than 5 years reported increased consumption of all foods after moving to the US. Moreover, those born in the US reported to eat less produce food, hunt food, and drink milk.
Goto, Vue, Xiong, & Wolffa, 2010	Examine perspectives on food, culture, and health and nutrition education among Hmong mothers with middle school children	40	CA	Q methodology included sorting and ranking statements regarding food culture, acculturation, child obesity, and health and discussing in depth their choices	Mothers fell into three groups based on their perspectives: (1) traditional food culture preservers (n = 20), (2) financially struggling health-conscious mothers (n = 11), and (3) mothers concerned about a parent-child generational gap (n = 4). There was no significant difference between these three groups. Mothers in group 1 reported enjoying cooking and eating Hmong food. They disagree that Hmong food are cheaper than American food. Mothers in group 2 reported a lack of financial assistance to acquire fruits and vegetables. These mothers were concerned about excessive snacking that may led to future health problems and strongly agreed that it is important to encourage physical activities among their children. Mothers in group 3 shared that there is a different food preference between them and their children (Hmong food vs American food).

Grazier, Armenian, & Vohra, 2014	Examined a case of life-threatening cinchonism from illicit purchase of chloroquine and survey local ethnic markets to determine what medications are sold without a prescription.		MN	Case report and survey	Ethnic markets sold discontinued FDA prescription medications. Five were identified as discontinued by the FDA: diphenidol, phenacetin, metamizole, phenylbutazone, and sibutramine.
Ikeda et al., 1991	Collected information necessary to design effective nutrition education programs that would meet the unique needs and interests of the Hmong.	205	CA	Used focus groups interviews and administered two questionnaires:1) Food and Habit Questionnaire; 2) the Adult EFNEP Family Record Form	Over 50% of Hmong reported consuming two meals per day. Hmong people's meals consist of white rice, vegetables, and meat. Snacking was not common. Eighty-four percent of Hmong males reported that food was prepared by their wife.
Kue & Thorburn, 2013	Explored Hmong women and men's knowledge of hepatitis B, their screening, and vaccination behavior.	83	Oregon	Questionnaire and qualitative interviews Interview questions were guided by Kleinman's explanatory models approach	Ninety-six percent participants have heard Hepatitis B. Fifty-three percent have been screened for Hepatitis B. Fifty percent reported being vaccinated. There was low knowledge about transmission of Hepatitis B. Participants reported lack of word in their Hmong language about their illness. Participants reported fearing about the cost of treatment and the effects of cancer treatment on their bodies.

Neitzel, Krenz, & de Castro, 2014	Developed an observation-based methodology to evaluate occupational health and safety hazards in agriculture, and pilot-tested this on several small-scale Hmong farming operations.	9	WA	Semi-quantitative observational tool	Observations revealed that the most common hazards Hmong farmers faced were bending at the back while lifting <50 pounds, using sharp tools without adequate guarding mechanisms (e.g. awkward posture), and lifting >50 pounds.
Schroepfer, Waltz, Noh, Matloub, & Kue, 2010	Assessed the Hmong population's stage of readiness to address cancer and understand what factors contribute to their stage of readiness.	9	WI	Scale and interviews	Hmong's stage of readiness to address cancer was "vague awareness." There were six themes that contributed to the Hmong's stage of readiness including: (1) new home, illness, and healthcare system; (2) Hmong healthcare beliefs and practices; (3) newness impacts resources needed and their access; (4) community view of cancer; (5) issues of trust; and (6) reliance on Hmong medicine.

Chapter 3:

Feasibility of Audio Computer Assisted Self-interviewing with Color-Coding and Helper Assistance (ACASI-H) Among Hmong Older Adults

Title: Feasibility of Audio Computer Assisted Self-interviewing with Color-Coding and Helper Assistance (ACASI-H) Among Hmong Older Adults

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Abstract

The US is a multicultural society, with increasing numbers of older adult immigrants. Many older adult immigrants, such as Hmong older adults, have limited English proficiency (LEP), and cannot read or have difficulty reading even in their first language; and are non-literate (NL) in any language. Little has been done to identify feasible data collection approaches for including LEP or NL populations in research, leaving a gap in knowledge about their health**.** This study's purpose was to test the feasibility of culturally and linguistically adapted audio computer assisted self-interviewing (ACASI) with color labeled response categories and helper assistance (ACASI-H) to collect health data with Hmong older adults. Thirty dyads (older adult and a helper) completed an ACASI-H survey with 13 health questions and a face-to-face debriefing interview. ACASI-H survey completion was video recorded. ACASI-H interviews and debriefing interviews were audio recorded and transcribed. Directed and conventional content analyses were used to analyze the interviews. All respondents completed the interview and reported ACASI-H survey questions were consistent with their health experience. They lacked computer experience. ACASI-H's interface was user friendly. Ninety-seven percent of dyads used the Hmong oral translation. Some Hmong older adults struggled with the color labeling at first, but helpers guided them to use the color correctly. All dyads liked the color labeled response categories and confirmed that including a helper during the survey process was necessary. Findings support use of oral survey question administration with a technologically competent helper and color labeled response categories for engaging LEP older adults in a survey interview.

Key words: Hmong, collectivist culture, audio computer self-interviewing mode, family helper

More than four million foreign-born older adults live in the United States (US; Population Reference Bureau (PRB), 2013). The number of foreign-born older adults in the US increased from 2.7 million in 1990 to 4.6 million in 2010 and continues to grow (PRB, 2013). The majority are from Latin America (38%) and Asia (29%; PRB, 2013) and most have limited English proficiency (LEP; PRB, 2013), defined as an inability to 'speak or read English well' (Whatley & Batalova, 2013). Despite this rapid growth in the number of foreign-born older adults, little is known about their health status or service use, which is due at least in part to data collection difficulties (Frayne, Burns, Hardt, Rosen, & Moskowitz, 1996; Gayet-Ageron, Agoritsas, Schiesari, Kolly, & Perneger, 2011). While it is a national and international goal to reduce social and ethnic health inequalities (Center for Disease Control and Prevention (CDC), 2013; World Health Organization(WHO), 2009), there is an increasing need for reliable data to monitor the health status and behavior of ethnic minorities, particularly those with LEP and who are foreign-born. Little is known about data collection methods that could maximize response rates and data quality for this population. Securing participation and obtaining reliable information from these groups requires culturally appropriate data collection tools and techniques.

LEP minority groups are poorly represented in research (Frayne, Burns, Hardt, Rosen, & Moskowitz, 1996; Gayet-Ageron et al, 2011), as "English proficiency" is a common inclusion criterion (Frayne et al., 1996). Link and colleagues (2006) assessed the effects of race, ethnicity, and linguistic isolation on the rate of participation in the Behavioral Risk Factor Surveillance System, a federal government survey that collects state data about US residents regarding health-related risk behaviors, chronic health conditions, and the use of preventive services. They reported that poor English proficiency was associated with the lowest rates of participation (Link

et al., 2006). Gayet-Ageron and colleagues (2011) found limited language proficiency to be one of the top five barriers to participation in mail surveys.

LEP older adults tend to come from collectivist cultures, where family members are highly interdependent and where the group is the unit of survival (Chen & West, 2008). LEP older adults often live in multigenerational households (Gurak & Kritz, 2010) and rely on their adult children to communicate with people outside their community or to make decisions (Casado & Leung, 2002; Wilmoth, 2001). However, younger family members who appear to be fluent in both their native language and in English may actually have limited literacy (e.g., cannot read or write, miss nuances) in their native language (United States Census Bureau, 2015), thus possibly affecting the accuracy of translations. We were unable to find any research examining data collection methods for LEP older adults that adapted the data collection process to accommodate these language limitations or that encouraged the active participation of older adults. Therefore, it is critical for researchers to develop a data collection tool that acknowledges and accommodates differences in language proficiency between younger family helpers and older adults and that supports the active participation of the older adults.

Rarely acknowledged is the further complication of collecting data from people generally unfamiliar with written language. Currently, 757 million people worldwide aged 15 and older are illiterate (United Nations Educational, Scientific and Cultural Organization (UNESCO), 2016). Many of those who are illiterate are older and come from oral cultures (UNESCO, 2016), and it is important to develop data collection strategies that do not exclude them. Researchers have not examined how to promote research participation in non-literate (NL) or oral cultures, such as the Hmong culture (Thao, 2006). The written Hmong language was created in 1952 and is unfamiliar to most older Hmong (Duffy, 2007). In the US, 90% of older Hmong adults have LEP (National

Asian Pacific Center on Aging, 2014) and are NL (Duffy, 2007). Consequently, even Hmong language written materials are indecipherable for older Hmong adults. In both research and practice settings, these individuals rely on translators who are often family members (Ryan, 2013; Yeo & Gallager-Thompson, 2013). By contrast, younger Hmong tend to be proficient in English and comfortable with technology (Centers for Disease Control and Prevention, 2008).

The Hmong live in small, tight communities where everyone can trace their family lines. There is a strong sense of family bonding. Both immediate and extended family members are very involved in each other's lives, and everyone is involved in each other's care. Therefore, to improve participation and elicit responses from LEP Hmong and other LEP older adults, researchers must develop effective data collection modes and tools to effectively communicate with LEP participants and accommodate the different language proficiency levels of older Hmong and younger family members who are likely to be helping them.

One data collection mode, audio computer-assisted self-interviewing (ACASI), has been increasingly used for research with low-literacy populations (Estes et al., 2010; Minnis et al., 2007; Reichmann et al., 2010). This oral delivery mode of data collection allows self-administration with low-literacy populations. ACASI can be delivered in multiple languages or dialects and improves the quality of behavioral health data gathering, reduces interviewer bias, standardizes question administration, and eliminates skip pattern errors (Jarlais et al., 1999). Different types of ACASI have been used in research, including telephone ACASI (Cooley et al., 2001; Villarroel et al., 2006) and color-coded ACASI (Bhatnagar, Brown, Saravanamurthy, Kumar, & Detels, 2013; Kauffman & Kauffman, 2011). These modes of ACASI were developed for low-literate individuals and not for LEP or NL respondents.

In addressing literacy barriers, Kauffman and Kauffman (2011) developed and used a color-coded ACASI component, where participants successfully responded using a separate customized data entry device with seven color-coded keypads. While this color-coded ACASI method was effective, it may not be practical for people without access to a separate customized data entry keypad with color-coded keys, which is not a part of the keyboards for the computers in home settings. In addition, we found no studies on the effect of color-coded response categories in survey research.

To address the identified gaps in culturally appropriate data collection methods for LEP and NL older adults, we developed a data collection tool that could promote survey participation for this group. In addition, the data collection tool can accommodate people who live in multigenerational households and receive assistance from younger family members whose language proficiency may differ from that of the older people. Therefore, the purpose of this study was to test the feasibility of a culturally and linguistically adapted ACASI with Hmong older adults in a natural setting. The current adaptation of the data collection mode, the audio computer-assisted self-interviewing with color-labeled response categories and helper assistance (ACASI-H), was designed to collect health data from people who cannot read in either English or in their native language, including people from oral cultures. Two adaptations were made to the original ACASI system, as shown in Table 1. First, a helper who routinely assists the older adult with English documents was formally included. The inclusion of a helper was selected as a strategy compatible with the Hmong's collectivist culture (Centers for Disease Control and Prevention, 2008). Different from individualistic cultures, older adults from collectivist cultures often confer with family as opposed to strangers before answering questions (Chen, Lee, & Stevenson, 1995). Second, there was a simultaneous spoken presentation (pre-recoded oral

translation) in the Hmong language, written text in English, and color coding corresponding to response items to facilitate communication. The system allowed all participants to use their communication mode of choice (spoken Hmong with corresponding color coding, written English and response options, or spoken Hmong combined with written English response items). ACASI-H was designed to accommodate any combination of language proficiency. As seen in Figure 1, written response categories were labeled with color in a column bar above the written English text response options on the screen. For example, the pre-recorded oral translation says, "In general, would you say your health is: excellent (mark yellow), very good (mark green), good (mark blue), fair (mark red), or poor (mark black)." The corresponding English text allows helpers to assist the Hmong older adults in selecting appropriate responses and to confirm their responses, despite their use of different response options. This study examined the feasibility and usability of ACASI-H, including the pre-recorded oral translation color-labeled response categories, and the effectiveness of having a helper with differing language proficiency.

Methods

Design

This study used a cross-sectional mix of qualitative and quantitative design to test the feasibility of ACASI-H in a natural setting. A convenience sample of 30 Hmong dyads (older adult and a helper) was recruited from two community centers in a Midwestern state.

Ethics

This study was approved by the Minimal Risk Health Sciences Institutional Review Board (IRB) of the University of Wisconsin. This study sample was a vulnerable population by virtue of there being language and literacy barriers. Thus, the researcher used oral consent to accommodate them. To ensure that the participants were informed and that their participation

was voluntary, the researcher did four things. Firstly, participants initiated contact with the researcher if they were interested in participating in the study after the oral descriptions at the senior program sessions. Secondly, the researcher explained the study at three different points upon initial contact, during telephone follow-up screening, and at the time of data collection. At each of these times, participants were reminded that participation was voluntary and they can stop at any time during the study. Thirdly, participants had the option of going with audio and video recording of the interviews. Fourthly, the researcher, who was bi-cultural and bilingual, fluent in both Hmong and English, provided the information in the participants' preferred language (Hmong or English) and an informational form in English was given to each member of the dyad after the oral reading of the document. The informational form was approved by the IRB.

Sample

The sample included Hmong older adults. Eligibility criteria were being 50 or older, self-identifying as Hmong, and the availability of the usual helper. Inclusion criteria for the helpers were being 18 years or older, self-identifying as able to read and understand English, being identified by the older participant as routinely helping him/her with English documents, and being comfortable with using the Internet. For both groups, willingness to participate in the ACASI-H interview and in a face-to-face debriefing were necessary for inclusion.

Recruitment. Participants were recruited during senior program sessions at two predominantly Hmong community centers in Wisconsin and by snowball recruitment (also known as word of mouth). Specifically, the researchers attended scheduled senior program sessions at two Hmong community centers and provided oral descriptions of the study's purpose and procedures. This type of community-based approach is consistent with Hmong culture, as

Hmong prefer to discuss and learn from each other in groups (Lor & Bowers, 2014). Word of mouth was also used by the researcher, encouraging participating Hmong older adults to recruit other participants. The participating Hmong older adults provided names and phone numbers to the researcher. Follow-up telephone calls were made to people interested in participating, and the following question was asked: "Is there someone you generally go to for help in completing forms who is able to read in English?" Those who answered "yes" were invited to participate. Those who answered "no" were excluded.

Data Collection

After screening telephone calls, the researcher scheduled appointments to conduct the interview. Participants chose the location—either the community center or their home. The researcher first provided general instructions, answered questions, and obtained audiotaped oral consent in participants' preferred language (Hmong or English). The oral consent included permission for videotaping and interviewing. Oral consent was done together with the dyad. Next, the researcher provided the survey link and demonstrated the use of screen display, accessibility features, and navigation options. Before the dyads began, a small digital camcorder was placed at the center of the laptop in front of the dyads to capture facial expressions and interactions during completion of the ACASI-H survey. The entire process was recorded using the digital camcorder. Video recordings were used to explore communication between the dyads and how technology was used.

ACASI-H Survey Administration in a Natural Setting. ACASI-H survey was conducted in as natural a setting as possible. Therefore, the Hmong older adults and helpers were instructed to complete the ACASI-H survey the way they would have at home and without a researcher present. Both members of the dyad were instructed to proceed in whatever way they

chose, answer only questions they would answer in a natural setting, and skip any questions they preferred not to answer. A speakerphone was used for the oral Hmong translation instead of headphones, allowing the researcher to capture whether and how often the dyad used the pre-recorded translation.

Description of ACASI-H Survey. Twenty six-items were included in the ACASI-H survey; 12 items were from the Acute Short Form Health Survey (SF-12; Ware, Kosinski, & Keller, 1996), one sensitive question ("Do you have a problem with urinary urgency? Yes or No?"), and eight demographic questions were asked of the Hmong older adults. As the purpose of the study was to explore response processes using the SF-12 and the one sensitive question, the content of responses was not the focus of study. However, one health-related question known to contain what an older Hmong would consider sensitive (Lor, Khang, Xiong, Moua, & Lauver, 2013) was added to observe whether the sensitivity of the question might influence the response process, specifically how the older person interacted with the helper. Demographic questions for the Hmong older adults included age, sex, educational level, income, health insurance, level of literacy in both English and Hmong, and length of residence in the US. Five other questions asked the Hmong older adults about their use of technology. Six demographic questions were also asked of the helpers, including age, sex, relationship to the Hmong older adult, level of literacy in both English and Hmong, and length of residence in the US. SF-12 was selected because it is generic and has been validated with other cultural groups with internal consistency reliability estimates of 0.65–0.93 (Han, Lee, Iwaya, Kataoka, & Kohzuki, 2004; Lam, Gandek, Ren, & Chan, 1998; Lewin-Epstein, Sagiv-Schifter, Shabtai, & Shmueli, 1998).

Design of ACASI-H Survey. The 26-item survey, including response categories and instructions, was first translated into Hmong, colors were added to the response categories, and a

bilingual and bicultural female Hmong researcher pre-recorded an oral Hmong version of each question and response option.

Translation. *A* team approach rather than the more commonly used back translation was used for survey translation. This approach uses a team of translators and translation reviewers, and decisions are made by consensus about the translation quality, with continual modifications (Mohler, Dorer, Jong, & Hu, 2016). Our team included three bilingual Hmong health researchers (e.g., nurse, public health professional, and a professional interpreter). This approach is recommended by cross-cultural survey researchers because it has been found to provide rich outputs of options for translation and a balanced critique of translational versions compared to back translation (Guillemin, Bombardier, & Beaton, 1993; Harkness, Pennell, & Schoua-Glusberg, 2004; Mohler et al., 2016).

Colored band development. When the translation of questions was deemed understandable and of high quality, a color-labeled band was placed above the text response items. Response categories (e.g., yes/no) were each linked to a unique color and read in Hmong to the participants to accommodate their inability to read either Hmong or English. In addition, colors were used to facilitate communication between the helper and the older person. The computer screen displayed the question and color-labeled response band options above the English written response category texts. As the audio recording of each question was played, it was accompanied by a presentation of the response categories in two forms: (a) English text and (b) a colored band above the English text; the pre-recorded audio translation included instructions for selecting the color corresponding to each response category. This combination of screen display and audio instruction allowed Hmong older adult participants to select a response by color, while the helper could view the response in English written text to confirm that the

older adult's intention had been achieved. This procedure accommodated the common differences in fluency levels between the older adult and the helper. The survey was programmed using Qualtrics.

After the survey was programmed in Qualtrics, the researchers piloted the program with eight participants and asked them to provide feedback on comprehension, clarity of translation, and the color-labeled response categories. The feedback revealed that some colors elicited emotional responses from the Hmong older adult participants. For example, lighter colors were perceived as positive and darker colors as negative. As a result, the researchers made changes, making response items consistent with the feedback about colors. Brighter colors (e.g., yellow, blue, green, pink) were used for positive response categories, and darker colors (e.g. black and red) were used for negative response categories (see Figure 1).

Semi-Structured Debriefing Interviews. Immediately following completion of the online ACASI-H survey, the researcher conducted a follow-up face-to-face debriefing interview with the dyads to explore their experiences with ACASI-H, specifically in terms of feasibility; see Table 2. The older adults and the helpers took turns providing responses. The order of the questions varied based on what the participants shared to prevent the repetition of questions and to enhance rapport during the interview. For example, when we asked the participants "What was it like for you?" and the participants responded with "I could not use the computer but I like the questions asked" we would not ask the question "Can you use a computer?" Instead, we followed up with "Tell me more about your experience with technology." Following the debriefing interview, the researcher and the dyads reviewed videos of the dyads completing the ACASI-H survey and explored the interactions between the Hmong older adults and their helpers. For example, the dyads were asked, "How did you decide who would complete the form?" followed

by probing questions based on the video content. Four dyads opted not to review the videos with the researchers, leaving 26 dyads that reviewed and accepted the videos. All interviews and video reviews were audio-recorded. At the end of the interviews, the Hmong older adults and helpers were each given $20 and were offered a copy of the video. Twenty-six dyads accepted the offer to keep a video copy.

Data analysis

Descriptive statistical analyses were performed using NCSS 9.0. Video data was used to complement participants' responses during the debriefing interviews. A team approach was used to analyze recorded interview data, which was transcribed in Hmong and then translated into English. Translations were based on meanings rather than literal translations (Harkness, Pennell, & Schoua-Glusberg, 2004). The team consisted of a translator (undergraduate honors student), and two reviewers (a Hmong nurse researcher and a professional Hmong translator), ensuring that spoken terms and expressions were both technically correct and consistently translated by the majority of the people.

Initially, two coders, who were both bilingual and bi-cultural in the Hmong and English, separately coded the transcripts by first reading through each transcript from beginning to end. Each coder highlighted and wrote notes in the margins of the text identifying key words, phrases and concepts that seemed to capture Hmong participants' descriptions of experience with the ACSAI-H survey. Conventional and directed content analyses were used to analyze interview transcripts and videos (Hsieh & Shannon, 2005). Conventional content analysis (open ended/non-directive questions) was used to understand the responses related to participants' overall experience. For example, participants were initially asked a broad, non-directive question, "Tell me what it was like for you," to obtain a sense of the whole. The open-ended

question yielded very little responses, other than general acceptability of their experience. The responses from the participants did not provide additional information to the specific qualitative interview questions. For instance, a participant commented that “the questions correspond to my health.” This response was coded as “survey content was consistent with health.” After we coded all responses to the open-ended question, we sorted the codes into categories based on the relationships and linkages among the codes using an iterative process. The subcategories were then organized into the “General Experience” theme.

Next, directed content analysis was used to categorize responses to specific questions using predetermined category guides (Hsieh & Shannon, 2005; Graneheim,& Lundman, 2004). For example, participants were asked about (a) the usability of technology, (b) the usability of the pre-recorded oral translation, (c) the usability of response categories labeled with color, and (d) the inclusion of helpers. Participants’ responses aligned well with questions. However, there were very few details offered. For example, relating to the implementation of technology, we asked participants “Did you have any technical difficulty taking the survey (e.g. browser problem, audio problem)? Tell me about the challenges.” The responses to this were coded under the “usability of technology” category. For example, one participant responded, “Your recording, when we press play, it goes for two seconds and it stops. And then it kind of stops loading.” This statement was coded “survey loading error” under the category “usability of technology.” The codes and categories were presented to a larger research group consisted of five members including a qualitative expert and four PhD students trained in both qualitative and quantitative research methods to reach consensus on codes.

Results

Thirty dyads (n=30 Hmong older adults; n=30 helpers) participated in the study. Twenty of the 30 (67%) completed the survey in their homes and 10 (33%) at the community center. Table 3 shows that the majority of Hmong older adult participants were female (73%; n=22), married (60%; n=18) with no formal education in the US (75%; n=21), and had lived in the US for an average of 23 years. The majority of Hmong older adults did not read Hmong well or at all (70%; n=21) and did not write Hmong well or at all (77%; n=23). Table 4 shows that the helpers were mostly female (90%; n=27) with a mean age of 29.3, with most having between one and three years of college education (47%; n=14).

There were zero missing data for the 12-item survey and sensitive question; however, data were missing from the older adults' demographic items: age (13%; n=4), marital status (3%; n=1), income (40%; n=12), years of education in the US (7%; n=2), and number of years lived in the US (7%; n=6). Survey completion time ranged from 11 to 50 minutes, with a mean of 20 minutes.

The face-to-face debriefing interviews revealed five major themes concerning the ACASI-H experience. They were: (a) general experience with ACASI-H, (b) usability of technology, (c) usability of pre-recorded oral translation, (d) usability of color-labeled response categories, and (e) inclusion of helpers.

General experience with ACASI-H

All participants reported a positive experience with the ACASI-H survey. They found the process of survey taking to be "easy," stating that they would not change anything about it. All Hmong older adult participants reported they would take the ACASI-H survey again if it were given to them in the future.

Acceptability of ACASI-H Survey Questions

All older Hmong participants described the survey questions as consistent with their health experience and described the survey questions as easy to answer. One Hmong older adult stated that "…The questions were good. For us elders, it's correct about what the questions asked." All participants described the length of the ACASI-H survey as "just right." One participant stated "This [survey] is perfect. This is doable and usable. It is not too long or too short." Additionally, none of the Hmong older adults reported the survey questions to be sensitive or embarrassing. Another participant said "There is nothing that is embarrassing."

Despite this expressed ease and acceptability, many Hmong older adults described being unfamiliar with surveys and having difficulty choosing a response from the response categories offered. One Hmong older adult stated that "since this is my first time, I didn't really know how to answer." Another Hmong older adult explained that "I have never done something like this before. So I am not able to measure myself … whether it [my stress] was a lot or a little."

Usability of Technology

Every Hmong older adult referenced their inability to operate the laptop or use the mouse, and all reported lacking experience and being generally uncomfortable with technology. As one Hmong older adult said "It is too difficult. I don't even know how to turn on the television." Another Hmong older adult stated "…I have never touched it [the laptop] before…I don't even know where to start." In all instances, only the helper operated the laptop and mouse. One Hmong older adult said "…we need a child to help us use it [the laptop]."

All helpers agreed that their older adults were unable to use the technology and agreed that their presence was required to complete the survey. One helper said "I prefer to be here to help my mother because she doesn't know how to use technology." Despite the fact that Hmong

older adults could not operate the technology, all helpers described the technological components of the ACASI-H survey (e.g., going to the next question) as easy to navigate.

In contrast, four dyads experienced technical difficulties at the start of the survey. These difficulties included not being able to advance to the next question and not being able to hear the audio translation for one question. One helper said "…there were like two or three of them [questions]…it wouldn't load. It keeps saying, 'Block'…".

Usability of the Hmong Pre-Recorded Oral Question Translation

Twenty-nine of the 30 (97%) dyads reported using the Hmong pre-recorded oral translation for all ACASI-H survey items. Only one helper translated the complete ACASI-H survey without using the pre-recorded oral translation. She read the English text and then translated each response option into Hmong for her mother, explaining that it was what she always did and what her mother preferred.

Although 29 dyads reported consistently using the Hmong pre-recorded oral translation, four of the helpers described having to translate orally when the oral translation failed to load. Significantly, all four helpers reported discomfort translating as they were not fluent in either Hmong or English and were uncertain about the accuracy of their translation. One helper said "I only know what it is but don't know how to verbally translate it out so that people will know and understand it." This was because, although the helpers appeared to be fluent in English, 26 (87%) Hmong helpers reported they did not read English well at all.

The 29 Hmong older adult participants (97%) and their helpers all described the oral translation as clear and understandable and said it worked well for the Hmong older adults who were not able to read. One helper stated that "…the audio recording, reading of the questions, that I think is something that is good for people who do not really know how to read text."

Ninety-seven percent of helpers reported that the pre-recorded oral translation was also helpful to them. Of the 29 Hmong older adults, 25 described the volume of the pre-recorded audio translation as good and four described it as "not loud enough." Of the four older adults who described the volume as not loud enough, three were in the oldest age category (age greater than 70) and one had a hearing problem.

Usability of Response Categories Labeled With Color

All Hmong older adult participants reported that the color-labeled categories were useful for substituting written response category options. One Hmong older adult said "If there are the colors then it is much easier." The majority of helpers agreed. In addition, some Hmong older adults reported that colors helped them recall the response categories better. One helper said "…That's a great idea because a lot of them [Hmong older adults], they cannot remember what you said, but they remember the colors ... It does match up." Another Hmong older adult said "…for those who do not know how to read or write at all, responding based on the colors will help." Another Hmong older adult stated that "I do like it. If there are no colors then I wouldn't know how to answer."

Despite the dyads' positive perception of the usability of response categories labeled with colors, there were two distinct differences in the Hmong older adults' initial reactions to the color-labeled response categories. Twenty-five (83%) Hmong older adult participants understood the correspondence between the responses and the color labels. This reaction was coded "Effective color-labeled categories." However, five (17%) Hmong older adults *initially* responded to the cultural meaning of the colors rather than to the content of the corresponding response labels that were read to them. This reaction was coded "Ineffective color-labeled categories: initial response."

Effective Color-Labeled Categories. The color-labeled categories were effective in helping 25 (83%) Hmong older adults respond to the question items. These Hmong older adults reported not needing the helper to explain how to select the appropriate color-labeled response categories. They understood the relationship between the colors and the content of the response categories.

Furthermore, the color-labeled categories helped the Hmong older adults and the helpers who were not fluent in either Hmong or English. The helpers reported that the color-labeled categories sped up the interview process. One helper who was not fluent in Hmong stated "I really liked it. It was all color-coded. I think that was very helpful for me as a helper too [helper laughs], especially not knowing and not being fluent [in Hmong], you know, it really helped navigate everything along."

Ineffective Color-Labeled Categories: Initial Response. The color-labeled categories were initially ineffective for five Hmong older adults. The strong, traditional meanings of colors caused initial confusion for some Hmong older adult participants. Five Hmong older adults (17%) responded to the cultural meaning of the color, noting what the color meant to them rather than the content of the response labels. These Hmong older adults required multiple reminders from their helpers about how to respond, that is, not to base their responses on preference for a color and to focus on the content of the question. In this situation, the helpers clarified the intended meaning of colored labels by re-explaining the relationship between the color and the content of the response categories. One helper explained stated:

> We listened to the translation that you recorded and then when you say the colors, she keeps looking at the colors to see what she wants to choose. So I told her

> ‘Listen, it is not about picking the color. You have to listen to the color and what each response is.’

Five Hmong older adults did not understand this distinction until the third question in the survey. Once the Hmong older adult participants understood the instructions, they found the color-labeled response categories to be helpful in answering the questions.

Inclusion of Helpers

Acceptability. All Hmong older adults and helpers confirmed that having helpers present during the survey process was acceptable and necessary. Both the Hmong older adults and the helpers reported a strong preference for the helpers to assist the Hmong older adults complete this or any future surveys. All Hmong older adults reported that they were comfortable having their helpers assist them. All helpers acknowledged their older adults’ literacy and technology limitations and that their older adults’ lack of familiarity with surveys made it necessary to have a helper present.

Practicality. The Hmong older adults reported several benefits to having their helpers participate in the ACASI-H response process, including assisting in navigation (e.g., laptop, mouse, online ACASI-H survey), identifying when the older adult did not understand the questions, clarifying questions, explaining how to respond to the colored labels, and helping them select the most accurate response for each question when they encountered a challenge (e.g., not sure how to communicate their true state using the response categories available to them).

Navigating Technology. All helpers described their role in navigating the technology, included playing the audio and clicking the response for the Hmong older adults because they were unfamiliar with technology. One helper described her assistance as follows:

> …I helped her click and use the mouse and to click to go to the next questions, and click the audio for her. I usually let her listen to the audio first… Then she will tell me, 'oh, this is more of me.' Then I will click the color option for her.

Providing Clarification and Explaining How to Respond. Both the Hmong older adults and helpers shared that the helpers played an important role in helping the older adults understand the question items and color-labeled response categories when the older adults appeared to be confused. For example, helpers clarified the meaning of color-labeled response categories for the Hmong older adults: "If there is a question, even after listening to the translation, and you still don't understand, they [family/child helper] can explain it to you."

The helpers also used their personal knowledge of the older adults as a basis to compare the older adults' answers and to help them to decide on a response. One helper stated that:

> I tried to explain it to her to make sure that she understands and knows what it is before answering. If she doesn't answer correctly and I think that it doesn't really match her then I tried to re-explained it to her so they she can understand better.

Helping Select the Most Accurate Response. Five Hmong older adults who had difficulty selecting a response reported that the helpers were needed to classify their responses when they had a difficult time choosing the appropriate response item. One helper stated that "sometimes I made the decision for my mom like this answer fits you best and then I will tell her to pick that one. When two colors are close to one another then I say maybe one of these two colors is accurate to you and then she will choose between the two."

Discussion

This study assessed the feasibility of using ACASI-H for data collection with Hmong older adults who are not literate in Hmong or English. Building on the strong family ties and the multigenerational, linguistically diverse households that are common in collectivist cultures could be an effective and acceptable approach to collecting health-related data from this difficult-to-reach population. This may be particularly useful when the helpers and older adults differ in language proficiency and comfort with technology. The expectation in collectivist cultures that family members are highly interdependent and where the group is the unit of survival creates an opportunity for researchers to reach this population (Chen & West, 2008).

The ACASI-H functioned without many problems on the laptop computer carried house to house and community center to community center for data collection. Some Hmong older adults and helpers only reported loading problems with the oral translation. There are always technology problem, having a back-up option in this case, a helper was helpful. In addition, because the Hmong older adults were unfamiliar with computers, the helpers provided the support they needed to make the ACASI-H survey process effortless and manageable. Consequently, this study is the first to provide evidence that using ACASI-H with Hmong older adult/helper dyads is feasible and may also have relevance for other non-literate populations from oral, collectivist cultures. Asians and Hispanics comprise the largest collectivist cultures in the US (Population Reference Bureau, 2013), with many continuing to live in multigenerational households characterized by differing language proficiency.

The Hmong older adult participants fell into two distinct groups in terms of their reactions to and use of the colored label response categories at the beginning of the survey in this study. The first group (n=25) understood what they were asked to do and responded to the content of the question with no difficulty. However, the second group (n=5) initially responded

to the cultural meaning of the colors and ignored the content of the verbal response labels read to them. An explanation for why five Hmong older adults had difficulty responding to the colors cannot be provided here but raises important questions for future survey development. Despite initially struggling with distinguishing between the meaning of the colors and the content of the response categories, when debriefed, all participants preferred to have the color-labeled response categories in the survey. They described the color-labeled response categories as helpful in communicating their answers to the helpers. A similar result was found in studies of a previous version of the colored ACASI (C-ACASI), which uses colored stickers on specific keyboard keys (Bhatnagar et al., 2013; Kauffman & Kauffman, 2011). Furthermore, because it took some older Hmong adults over four minutes to respond correctly to the first three questions in the survey, future research could focus on developing practice questions for Hmong older adults to answer in the first five minutes prior to answering the actual questions. This would allow them to become familiar with and understand the content of the survey and the colored label responses. This study also revealed a new finding, which is that colors have cultural meanings that can influence participants' responses to research items. More studies are needed to examine how color influences survey responses.

This study adds a new component to survey research by including a family helper during the completion of ACASI. In this study, the family helpers improved the feasibility and acceptability of ACASI-H for the older Hmong participants. In particular, the helpers played an important role in ensuring good quality data by providing clarification when the older adults did not understand the questions by explaining how to respond to the color coding, clarifying the meaning of the colored labels for response categories, and helping the older adults select the most accurate response for each question when they encountered difficulty. Although the helpers

appeared to improve the data collection and quality, future research could examine how helpers might contribute to bias and random error or whether their interpretation actually increases quality.

It took the dyads in this study an average of 20 minutes to complete the 26 items in this survey. This increased length of time is expected because the ACASI-H survey in this study includes a helper to aid communication in a complex cultural interaction where there may be cultural or conceptual issues that may be related to language and cultural barriers. In addition, Hmong older adults may not be familiar with answering questions in a survey with color-labeled response categories. Therefore, it may require more working memory to understand the questions and consequently take a longer time for them to provide a response. We found no studies that have examined how long it takes for other racial and ethnic groups or older adults to complete the survey. Therefore, future research could examine the time it takes for older adults to respond to the survey. This finding also has implications for ensuring that there are time allowances and practice questions for studies like this one.

There are several limitations in this study. The ACASI-H survey was not compared to and tested with other forms of data collection (e.g., ACASI-H survey vs. a paper survey) for this population, and so we cannot conclude that in the context of language and culture, the ACASI-H survey offers the best method for collecting health data for NL populations. Based on the findings of this study, it appears to be a method worth exploring in more detail in future research. In addition, we did not standardize the interview process or control what the family helpers could or could not do. As a result, measurement error in this procedure could be different from that in a more standardized procedure. However, the benefits of designing a natural setting for respondents allowed the researchers to know what to do when a survey is completed by people in

their homes. Additionally, the ACASI-H survey was only tested with one LEP and NL older adult group—Hmong older adults. Future studies are needed to test how well this mode of data collection works with other groups with LEP, such as Spanish speakers or speakers of other Asian languages. Because the ACASI-H survey accommodates for the collectivist nature of the Hmong culture by including a family helper, privacy may be a limitation. However, we do not think privacy is of concern because family members are individuals in whom Hmong older adults confide. Future studies are needed to assess measurement error with this method and compare it to other implementations and to assess whether the helper could introduce bias. It might be possible that having the video camera in front of the dyads could have influenced their behavior and/or responses. However, we do not think this is a problem because many of the dyads were unaware of the presence of the camera during the process. This is based on videos of the participants wondering aloud whether they were being recorded yet.

Conclusion

This is the first study to report the development, implementation, and perceptions of the adapted data collection method of the ACASI-H survey for use with Hmong older adults with limited English. The Hmong dyads (older adult and helper) found ACASI to be easy to use and were comfortable. Findings also indicate that the ACASI-H survey is a feasible and acceptable method for collecting data from non-English speaking populations. This data collection method can be useful to increase survey research participation for non-English speaking populations.

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Table 1

Audio Computer Assisted Self-interviewing with Color-Coding and Helper Assistance (ACASI-H) Features

Original ACASI	Adapted ACASI-H	Justification for Adaptation
Has recorded audio survey questions while the corresponding text is displayed on the computer monitor in the language of the participants	Has recorded audio survey in Hmong language while the corresponding text is displayed on the computer monitor in English	Hmong older adults are not literate in Hmong and English. Helpers are fluent in Hmong and English but cannot read or write in Hmong. The corresponding English text allows helpers to assist the Hmong older adults in selecting appropriate responses and to confirm their responses.
Written response categories in the participant's language or response categories were linked to a unique color that was also displayed on a specific alphabet/symbol button on the keyboard, using colored stickers	Written response categories written in English and have color-labeled response categories band above English text on the computer screen	To accommodate the Hmong participants' inability to read either Hmong or English and facilitate communication between the helper and the Hmong older adult.

Each question presented on a separate screen	Each question presented on a separate screen	
Use keyboard, mouse, and headphones to advance through the survey	Use keyboard, mouse, and speaker phones to advance through the survey	A speaker phone was used to allow elder and helper to listen to the question at the same time.
Self-administered	Helper assist	Simulate a natural environment and address Hmong's collectivist cultures

Table 2

Sample Debriefing Interview Questions

Feasibility Category	Who	Interview Questions
Overall Experience	Older adult & helper	1. Tell me what it was like for you? 2. What did you like? Can you tell me why? What didn't you like? Can you tell me why? 3. Would you do something like this if it was given to you again? Tell me why or why not?
Survey Experience		4. What are your thoughts about the length of the survey? For example, was it too long? Too short?
Usability of Technology	Older adult & helper	5. Did you have any technical difficulty taking the survey (e.g. browser problem, audio problem)? Tell me about the challenges?
	Older adult	6. Can you use a computer? 7. How easy was it for you to hear and answer the questions using the computer? Tell me more. 8. How comfortable did you feel entering your answers into the computer? Tell me more.
Usability of Pre-Recorded Oral Translation	Older adult & helper	9. Did you use the audio recording or did your relative/helper help you in translating the survey? ** Ask If Participants Use Audio Survey:

		1. Now that you have gone through the survey with the audio reading, what was it like for you to hear and answer the questions using the computer/tablet? 2. Would you like the audio recording to be simultaneous with the written text? Tell me more. 3. Would you still take this survey with another person or would you take it alone? Why or why not?
Usability of Response Categories Labeled with Colors	Older adult & Helper	10. What was your experience with the color labeled response categories?
Practicality of Including Helpers	Helper	11. What role did you as the helper/family member play? For example, what did you help with (e.g. technology, answering questions, and/or interpretation)? 12. What was it like for you as a family helper? Would you prefer to be present during the survey? What do you think was your most important contribution?

Table 3

Demographic of Hmong Older Adults (N=30)

Variables	n (%)
Sex	
Female	22 (73.33)
Male	8 (26.67)
Range of Age	47*- 77
Marital Status	
Married	18 (60)
Divorced	3 (10)
Widowed	7 (23.33)
Separated	1 (3.33)
Never been married	0 (0)
Number of Years of Education in US	
0	21 (75)
1	3 (10.71)
2	1 (3.57)
4	1 (3.57)
7	2 (7.14)
Range of Number of Years Lived in US	9-36
How well do you read Hmong?	
Not at all	21 (70)
Not well	2 (7)

Well	4 (13)
Very well	3 (10)
How well do you write Hmong?	
Not at all	23 (77)
Not well	3 (10)
Well	3 (10)
Very well	1 (3)
How well do you read English?	
Not at all	26 (87)
Not well	3 (10)
Well	1 (3)
Very well	0 (0)
How well do you write English?	
Not at all	25 (83)
Not well	4 (13)
Well	1 (3)
Very well	0 (0)

* Note: Our inclusion criteria require Hmong older adults to be 50 and above. However, age is very complicated for the Hmong older adults. From our video and interview analysis, we learned that when we recruited them, they reported their age as documented for government purposes. Thus, they met our eligibility criteria. However, when they participated in the survey, some reported their cultural age, which was marked by events. For example, there was a participant, who told us that ‘on paper’ she is 52 but her actual age, she believes, is 47.

Table 4

Demographic of Helpers (N=30)

Variables	n (%)
Sex	
Female	27 (90)
Male	3 (10)
Range of Age	18-54
Education	
Never Attended School	3 (10)
Grade 1 through 8	0 (0)
Grade 9 through 11	1 (3.3)
Grade 12 or General Educational Development (GED)	9 (30)
College 1 Year to 3 Year	14 (46.67)
College 4 Year or More College	3 (10)
Mean Range of Number of Years Lived in US	19.14
Relationship to Elder	
Daughter	15 (55.55)
Son	3 (11.11)
Daughter-in-law	3 (11.11)
Grand-daughter	2 (7. 41)
Step-daughter	1 (3.70)
Outreach coordinator	3 (11.11)
Missing	3 (10)

Figure 1
Presentation of Audio Computer Assisted Self-interviewing with Color-Coding and Helper Assistance on Laptop Screen

Note: This is a screen shot of what the dyad (older adult and a helper) see on their laptop screen. On the screen, there are three presentations: (a) a pre-recorded oral Hmong translation for the elder (spoken Hmong; numbered 1a at the top of the screen); (b) is the original question written in English text for the helper (numbered 2 on the screen); and (c) is the colored band above the written English response categories text designed for the elder (numbered 1b). Each response is linked with a color as seen in this visual. For example, excellent is link with yellow; very good is link with green; good is link with blue; fair is linked with red; and poor is linked with black. When the dyad plays the oral translation, it reads in Hmong: "In general would you say your health is excellent mark yellow, very good mark green, good mark blue, fair mark red, or poor mark black."

Chapter 4:

What Interaction Occurs When a Family Helper/Third Party Assists a Non-Literate/Non-English Speaking Respondent During the Survey Completion Process?

Title

What Interaction Occurs When A Family Helper/Third Party Assists a Non-Literate/Non-English Speaking Respondent During The Survey Completion Process?

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Abstract

Although current survey interviewing process relies on standardized interviewers, it does not take cultural differences into account. Some cultures particularly collectivist and oral cultures may require a family member (known as a third party or bystander) to be involved during the survey process to assist with answering questions. Little is known about what interaction takes place between the family member and respondent in this situation. Recognizing this gap, an observational study was undertaken to explore interactions between older Hmong and younger family members while responding to a 13-health item instrument using an Audio Computer-Assisted Self-Interview (ACASI) with color-labeled response categories and helper assistance (ACASI-H). ACSAI-H survey completion was video recorded. Videos were analyzed using Noldus Observer X. Statistics describing the behaviors that indicate older Hmong older adults are having comprehension problems and the strategies of helpers for responding to these comprehension problems were calculated in NCSS. Of the 30 dyads (Hmong older adult and helper), the behavior of 7 of the dyads was consistent with the practices of standardized interviewing (paradigmatic sequence) for all of the 13 health questions in the interview while 23 dyads departed from the paradigmatic sequence. For at least once of 13 health questions, 19 (63%) respondents sought clarification from the interviewer; 10 (33%) expressed lack of comprehension of the question (state uncertainty) and 14 (47%) expressed uncertainty about which response category best described their situation (task uncertainty). The helpers used several strategies to address comprehension problems: re-playing the pre-recorded Hmong audio translation, paraphrasing the question and/or response categories, asking for clarification, reminding the elder to think about their response, and confirming the elder's response. These findings could have implications for using helpers in the survey interview process in populations where helpers are culturally appropriate and linguistically necessary.

Key words: interaction coding, inclusion of family helper, comprehension problem

Interaction coding has been done to understand how respondents comprehend and interpret survey items through examining the interaction between the respondent and interviewer (Fowler and Cannell 1996; Holbrook, Cho, and Johnson 2006; Schaeffer, Dykema, and Maynard 2010; Sykes and Morton-Williams 1987). Because some behaviors during the interview have been shown to be associated with the validity or reliability of the data that result from the interaction (Schaeffer et al. 2010), studying the interaction allows researchers to better understand data quality and identify problematic questions (Dykema, Lepkowski, and Blixt 1997; Hess, Singer, and Bushery 1999).

Researchers have studied comprehension problems and how respondents indicate these problems by studying which spoken or behavioral cues of respondents during the question-answer process interviewers treat as indicating a need for clarification. These include respondent's disfluencies and discourse cues such as pauses, tokens such as "um" or "uh," and gaze aversions (Bortfeld et al. 2001; Schober and Bloom 2004; Schober, Michael et al. 2012); these behaviors suggest respondents' uncertainty or lack of confidence in what they are saying (Brennan and Williams 1995; Smith and Clark 1993). Although researchers have studied behaviors that provide the interviewer cues that there might be a comprehension problem, there is limited knowledge about their relevance for populations who do not speak English or for whom English is not the first language (NES). We also lack information about whether interviewers who have not been trained would use these spontaneous cues effectively to diagnose and respond to problems in comprehension. Understanding the interviewing process in such populations is important because these populations are underrepresented in surveys.

It may be impossible for NES and non-literate (NL) respondents to take surveys without including people from their social context. For instance, there are populations who are from

cultures that value interdependence (Hofstede 1984), live in multigenerational households, come from an oral culture, and are unfamiliar with surveys. Consequently, such NES and NL respondents who require assistance from a third party, often rely on a family member to participate in a survey. This may be a common practice with such populations because personal or family-related information might be shared socially between community members, specifically in more collectivistic cultures (Hofstede 1984). Thus, it may also be easier for both the NES and NL respondent and their family member to complete a survey together.

The 'inclusion' of bystanders or third parties as an active participant during survey interviews is uncommon. A third party present during a social research interview is likely to be a spouse or another family member (Pollner and Adams 1997; Zipp and Toth 2002). The most common method of survey interviewing is standardized interviewing. Standardized interviewing involves a trained interviewer, who conducts an interview with a respondent, without people 'present' (Fowler Floyd and Mangion 1990). However, a third party has been allowed to participate in selected and standardized portion of at least one self-administered event history calendar study (Quetulio-Navarra, van der Vaart, and Niehof 2015).

Nonetheless, the 'presence' of a third party during face-to-face interview is common (Pollner and Adams 1997; Reuband 1992; Zipp and Toth 2002). For example, Smith (1997, p. 36) reported that a third party was present in from 45 to 57 percent during interviews conducted as part of the National Election Studies in the United States. Similar rates were also reported in two other studies done in some countries in Europe including the British Household Panel Study in the UK (Zipp and Toth 2002) and the Living in Ireland Survey in Ireland (Cantillon and Newman 2005). Specifically, Zipp and Toth (2002) examined data from the British Household Panel Study and reported that interviewers noted that the husband was present for 40 percent of

married female respondents and the wife was present for 50 percent of married male respondent (p. 184). Likewise, Cantillon and Newman (2006) reported that during the 1999 Living in Ireland Survey, interviewers reported that wives were present for 56 percent of married male respondents and husbands were present 43 percent of married female respondents (p. 36). Furthermore, in Pollner and Adams (1997)'s study at the Epidemiological Catchment Area Program, there was variation in time spent by a third party from approximately 30 percent of the interview to the entire interview (p.620).

Researchers have studied whether the presence of the third party has any effect on the respondents' answers. The literature revealed mixed results. Some researchers reported that the presence of a third party results in respondent reporting in a socially desirable way (Boeije 2004; Diop, Le, and Traugott 2015; Edwards, Slattery, and Ma 1998; Reuband 1992; West and Kreuter 2013). Furthermore, West and Kreuter (2013) reported that interviewers made false negative errors in reporting whether children were present during the screening stage, prior to the interview. In contrast, some researchers reported that the presence of a third party had no negative impact on data quality (Aquilino 1994; Boeije 2004). In fact, Aquilinio (1993) reported that when a spouse was present during the interview,reporting of sensitive factual information about the martial relationship was higher. Lau and colleagues (2016) also reported that third parties did not affect responses, including the numbers of 'don't know' responses. Despite these findings, no studies have examined the impact of a third party, who is 'included' in the 'entire' survey interviewing process, assisting the respondent. Specifically, there is limited knowledge about interactions between the third party and respondent, who are unfamiliar with surveys and are NES and NL, during the survey interview.

Recognizing that researchers do not know what happens during the survey process when a third party such as a family member is ***a participant*** and what kinds of comprehension problems the NES and NL respondent have during the interview, this study focuses on one NES and NL group—the Hmong older adults. We designed a natural setting study in which a family helper had a formal role during the whole survey completion process. In addition, we designed a data collection tool that accommodates the difference in language proficiency between the family helper and the respondent.

In the U.S., the Hmong older adults have been excluded from national survey research as they are not 'proficient in English.' Ninety percent of older Hmong adults are non-English speaking (NES) (National Asian Pacific Center on Aging 2014). The Hmong language was not created until 1952, and consequently, written Hmong is unfamiliar to most older Hmong (Duffy 2007). They are unable to read materials written in Hmong; instead they rely on family members, who are typically younger and fluent in English, as translators in both research and practice settings. In the U.S., older Hmong adults often live in multigenerational households (Lee 2010).

To address the Hmong older adults' inability to read in English and Hmong, we used: (a) an audio-computer assisted self-interviewing mode, extensively adapted to include a family helper (ACASI-H) to address translation and other issues within the context of the respondent's collectivist culture, (b) pre-recorded oral question delivery in the respondent's language (Hmong) and visual display of the question in the helper's language (English), and (c) response categories labeled with color, designed for the older Hmong adult with accompanying written English text designed for the family helper**.** See Lor and Bowers (In Press) article for details of ACSAI-H. The system allowed both the older Hmong adults and family helpers to use their communication mode of choice (spoken Hmong with corresponding color coding, written

English and response options or spoken Hmong combined with written English response items). ACASI-H was designed to accommodate any combination of language proficiency.

The purpose of this study is to explore interactions between older Hmong and younger family members while responding to a 13-health item instrument using an Audio Computer-Assisted Self-Interview (ACASI) with color labeled response categories and helper assistance (ACASI-H). The instrument consisted of 13 commonly used survey items, the SF-12 General Health Survey (Ware, Kosinski, and Keller 1996) with the addition of a sensitive question, followed by questions about social characteristics. The research questions are: 1) how do Hmong helpers and Hmong older adult respondents interact while completing these questions about health? 2) What behavioral cues do Hmong adults display to show that they are having comprehension problems? 4) Do comprehension cues displayed by Hmong older adults differ with the response format of the question? 3) What are the strategies used by Hmong lay helper-interviewers during the survey process when the Hmong older adult respondent displays comprehension problems?

METHODS

The investigation presented in this article is part of a larger study that examined the feasibility of collecting data from 30 NES Hmong older adults using: (a) an audio-computer assisted self-interviewing mode, extensively adapted to include a family helper (ACASI-H) to address translation and other issues within the context of the respondent's collectivist culture, (b) pre-recorded oral question delivery in the respondent's language (Hmong) and visual display of the question in the helper's language (English), and (c) response categories labeled with color designed for the older Hmong adult with accompanying written English text designed for the family helper**.** Video data of the survey interview process was reviewed to assess how Hmong helpers-interviewers interacted with older adults Hmong respondents. This study was approved

by the Minimal Risk Health Sciences Institutional Review Board (IRB) of the University of Wisconsin.

Design

Using a cross-sectional, descriptive design, this study was conducted in a natural setting, either the home of the Hmong older adults or a community center attended by the Hmong older adults, simulating a realistic situation. The data were collected April 2015 to December 2015.

Eligibility Criteria for Participants

Hmong older adults were eligible to participate in this study if they: (1) were age 50 or older, (2) self-identified as Hmong, and (3) had an available or usual family helper. The age 50 was chosen because it is a cultural age that marks a person as an "older adult" (Lee 2010). Inclusion criteria for family helpers included: (1) at least 18 years old, (2) able to read and understand English, (3) identified by the older Hmong as someone who has helped them with their English documents, and (4) had internet experience. The dyad also had to be willing to participate in both the ACASI-H interview and a follow-up debriefing interview. Dyads were excluded if they were not willing to participate in both the interviews (ACASI-H and debriefing) or if they refused to be videotaped. Only one dyad was excluded because they refused to be videotaped.

Data Collection

Recruitment. The researcher recruited a convenience sample of participants through informational meetings at two community centers and by word of mouth. The word-of-mouth recruiting was initiated by the researcher, who encouraged participating Hmong older adults and helpers to identify and recruit other potential participants. Potential participants were directed to provide their names and telephone numbers to be contacted for a telephone eligibility screen and

further explanation of study purpose and procedures. At the follow-up telephone call, participants were asked in Hmong: “Is there someone you generally go to for help in completing forms who is able to read in English?” Participants who answered “yes,” were scheduled to participate in the study and were given a choice of where to participate—at the community centers or their homes. Convenience samples are commonly used for developmental work of this sort that does not aim to produce population estimates, but instead provide a laboratory for developing an innovative interviewing process – which could be assessed later using traditional evaluation methods. The goal of recruitment, in this case, is to obtain cases that reflect the variability that is likely to occur in the population so that the study provides sufficient challenges for the method being developed.

ACASI-H instrument. Thirteen health items were included in the ACASI-H instrument. This study did not address the content of responses, but only response process. The instrument was comprised of 12 items from the 12 item Short Form (SF-12) Health Survey and an additional item about incontinence, chosen because it was potentially sensitive (SF-12; Jr, Kosinski, and Keller 1996). A sensitive question was added to observe whether the sensitivity of the question might influence the response process, specifically how the older person interacted with the helper. The SF-12 was selected because it is widely used, has been validated with other cultural groups, and is reliable (alpha=0.65-0.93; Han et al. 2004; Lam et al. 1998; Lewin-Epstein et al. 1998). Both Hmong older adults and family helpers were also asked eight social characteristic questions including age, gender, educational level, income, health insurance, level of literacy in both English and Hmong, and length of residence in the United States. The researcher provided a laptop for the participants to use during the survey.

Response Format. Every survey question is written for a specific type of answer, for example, "yes" or "no." This design feature of the question is referred to as the question's "response format." The SF-12 has four different response formats. This included: 1=yes, 2=no; *ordered selection with three categories* such as 1=yes, limited a lot; 2=yes, limited a little, and 3= no, not limited at all;[1] *ordered selection with five categories* such as 1= extremely, 2= quite a bit, 3=moderately. 4= a little bit, or 5= not at all; and *ordered selection with six categories* 1=none of the time, 2= a little of the time, 3= some of the time, 4= good bit of the time, 5= most of the time, or 5=all of the time.

Design of ACASI-H. The 13-item health instrument, including the response categories and instructions to the Hmong participants, were translated into Hmong for the pre-recorded audio delivery of the questions by a female bilingual, bicultural Hmong researcher. The instrument was translated to retain the conceptual meaning of each item, rather than the literal translation (Harkness and Schoua-Glusberg 1998).

Translation and Conceptual Problems. The Hmong language is a monosyllabic and tonal language. Each of the syllables in the language has a distinct tone. When there is a change in the tones, it results in a change in the meaning of the word. The tones are represented by the consonant at the end of each word. Phonologically, the Hmong language is an extraordinarily elaborate sound system. The language's sound inventory consists of eight vowels, fifty-seven consonants, and seven lexical tones. The basic word order of the Hmong language is subject, verb object. Table 1 presents some examples of the structure of the Hmong language and English.

[1] This version of the SF-12 included some "hybrid" items that combined a "yes-no" filter question and a "how much" follow-up question in a single presentation. This is not a standard response format, but the respondent was presented with three combined categories to choose from, and so we refer to this as an ordered selection question with three categories.

Table 1. Comparison Examples of Hmong vs English Sentence Structure

	Hmong sentence structure	English sentence structure
Basic word order: subject verb object	I go store You do what?	I am going to the store What are you doing?
Tense/aspect markers precede the verb phrase	Yesterday, I go store	Yesterday, I went to the store
Adverbs may precede or follow verbs (depending on particular adverb)	We go far far	We are going very far

Table 2 presents some examples that were particularly difficult to translate because there was no equivalent translation. Thus, the translation aimed for conceptual equivalence. In Table 2, the underlined English words do not have an equivalent in the Hmong language.

Table 2. Example of Conceptual Translation Equivalence

Example Question Item	Translation to Hmong
Do you have any problem with urinary urgency?	When you have to urinate, can you hold it?
Didn't do work or other activities as carefully as usual	Can't do the work or other activities as you used to do
Have you felt calm and peaceful?	You still and peaceful?

Consent. Prior to the administration of ACASI-H, the researcher used oral consent for permission for videotaping and interviewing. Oral consent was done together with

the older Hmong adult and helper. Using oral consent was appropriate because there were language and literacy barriers among the Hmong participants. To ensure that the participants were informed and that their participation was voluntary, the researcher did four things. Firstly, participants initiated contact with the researcher if they were interested in participating in the study after the oral descriptions at the senior program sessions. Secondly, the researcher explained the study at three different points upon initial contact, during telephone follow-up screening, and at the time of data collection. At each of these times, participants were reminded that participation was voluntary and they can stop at any time during the study. Thirdly, participants had the option of going with audio and video recording of the interviews. Fourthly, the researcher, who was bi-cultural and bilingual, fluent in both Hmong and English, provided the information in the participants' preferred language (Hmong or English) and an informational form in English was given to each member of the dyad after the oral reading of the document.

ACASI-H administration. Researchers intended the process of completing the instrument to be congruent with the way the Hmong older adults and their family helpers would normally complete such a task at home, so that the spontaneous, natural processes could be observed and described. Thus, the researcher did not provide specific instructions or training to the helpers about what he or she should do during the completion of the ACASI-H instrument. The researcher emphasized that the dyad should complete the ACASI-H instrument as they would if they were completing it at home, without a researcher present. Further, dyads were reminded that it was not necessary to answer questions if they would not normally answer them and could skip any questions they did not want to answer. The dyads were informed that they could choose whether to listen to the pre-recorded translation of the questions through the speaker on the computer, or have the helper read and translate the question and response categories to the

Hmong elder. Speakerphone was used instead of headphones, allowing the researcher to capture the process.

Figure 1 displays the ACASI-H instrument. The ACASI-H screen first displays the player bar to select the Hmong audio recording, allowing the dyad to play the pre-recorded Hmong audio translation of each survey item. A female voice reads a question out-loud, in Hmong. For example, the voice reads in Hmong: "Does your health now limit you in moderate activities such as moving a table, pushing a vacuum, or bowling? If so how much?" Next, the same female voice provides instruction for selecting the color that corresponds to each response category (e.g., "To indicate 'Yes, limited a lot' select 'black', 'yes, limited a little select red, or 'not, not limited at all' select 'yellow"). An English written text version also appears on the screen with the English question including the response categories and colored labels for the response categories. The color-labeled response categories displays and audio instruction allowed Hmong older adults to select a response category by color, while the family helper could confirm the respondent's choice by reading the English label. This procedure accommodated differences in fluency levels for the older adult and helper. The instrument was programmed using Qualtrics.

Before the dyads began, a small camcorder was placed at the center of the laptop, in front of the dyad, to capture their facial expressions and interactions during ACASI-H instrument completion. At the end of the ACASI-H instrument completion, the researchers turned off the camcorder. The survey process was videotaped for all 30 dyads. Each participant (Hmong older adult and family helper) received $20 and was offered a copy of the video at the end of the interview.

Figure 1.Presentation of Audio Computer Assisted Self-interviewing with Color-Coding and Helper Assistance (ACASI-H) on Laptop Screen

Note: This is a screen shot of what the dyad (older adult and a helper) see on their laptop screen. On the screen, there are three presentations: (a) a pre-recorded oral Hmong translation for the Hmong older adult (spoken Hmong; numbered 1a at the top of the screen); (b) is the original question written in English text for the helper (numbered 2 on the screen); and (c) is the colored band above the written English response categories text designed for the Hmong older adult (numbered 1b). Each response is linked with a color as seen in this visual. For example, excellent is link with yellow; very good is link with green; good is link with blue; fair is linked with red; and poor is linked with black. When the dyad plays the oral translation, it reads in Hmong: "In general would you say your health is excellent mark yellow, very good mark green, good mark blue, fair mark red, or poor mark black."

Behavior Coding

The videos were downloaded into Noldus Observer X, a software program designed for analysis of observational data (Noldus 1991). Helper-older adult interactions for all 13 items in each of the 30 cases were coded. Two coders independently coded behavior of Hmong older adults' response to the question and the Hmong helpers' behavior with the older Hmong.

To understand how Hmong helpers and Hmong older adult respondents interact while taking the 13-item survey, I first examined the interaction between the helper and the Hmong older adult respondent directly, looking at the interaction sequence. The most common form of interactional sequence observed during survey response is referred to as "paradigmatic" (Schaeffer and Maynard 1996). The paradigmatic sequence defers to question-answer sequences in the survey interview in which the interviewer asks a question as written, the respondent answers the question in the format which is requested, and the interviewer may acknowledge the answer neutrally. Thus, I examined the interaction for these 13 items between all 30 dyads to determine if the dyads exhibited a paradigmatic sequence, and to describe and categorize any deviations that occurred. For example, if the dyad (older adult and helper) played the audio translation or the helper read the question verbatim in Hmong to the older adult, and the older adult respondent answered to the question with one of the offered response categories, then the sequence was coded as paradigmatic. Specifically, if the respondent states or indicates one of the given categories or colors when responding then it was considered a codable answer. If the dyad played the audio translation or the helper read the question verbatim in Hmong to the older adult, but the older adult respondent provide a response not consistent or not from the offered response or if the older adult cannot provide a response then it was coded as a non-paradigmatic sequence.

Table 3 displays the behaviors that were used as indicators of comprehension problems. A 'behavior' was defined as an action that was treated by participants as indicating a comprehension problem. For example, a strategy meant to clarify what the question "meant." There were two conditions that confirms the display of comprehension problems: (1) if the behavior was consistent with either previous experimental studies or previous conversational analysis studies; and (2) if helpers often respond with treating the behavior as indicating a

comprehension problem. If both the conditions occurred then we coded the behavior as indicating a comprehension problem. A question-answer sequence was defined as beginning with the turn in which the interviewer (helper) reads or plays the audio for the question, and ending with the turn in which the respondent provided an answer. A turn was defined as a change of speaker. Coding of the behaviors was done directly from the videotapes in Noldus Observer X.

Table 3. Codes for Behaviors that Provides the Interviewer a Cue That the Respondent Has a Comprehension Problem

Behavioral Cue	Description	Examples
Explicit request for clarification	Respondent ask for clarification of the question and/or response categories	"Those last two [responses] means it is not good right?"
Pauses	Respondent pauses or hesitates lasting longer than 2 seconds	[Pause]
Fillers	Respondent states “uhm, ums”	"uhm”, “huh”, “uhuh"
Other uncertainty	Respondent provides an ambiguous statement that does not allow the coder to determine whether she or he has task uncertainty or state uncertainty	“I don’t know” or “I don’t really have any feelings about that”, “that doesn’t apply to me”, “I am not sure how to answer”, or “it depends”
Task uncertainty	Respondent is not sure how to communicate their true state using the standardized response category	“Pick the color red or green first then.”
State uncertainty	Respondent is uncertain of his or her “true” state	Question: In general, would you say your health is: excellent select yellow, very good select green, good select blue, fair select red, or poor select black? Respondent answered: “I am living. I am no longer like when [I] am younger. I am sick.”
Report	Respondent provides a descriptive answer not within the requested answer	Question: Does your health no limit you in moderate activities such as a table, pushing a vacuum, or bowling? If so how much?

	Respondent answered: "Right now I cannot carry more than 10 pounds because if I do then my leg hurts a lot."

In addition to the behaviors being coded, the conversations were transcribed at a level of detail that captured all audible words and word fragments. Non-lexical fillers (such as "uh") and other vocalizations (such as laughter if present) were also transcribed. A bilingual student highly fluent in both Hmong and English transcribed the conversations, followed by the researcher reviewing each transcript, re-listening and re-viewing the tapes. The bilingual student and researcher addressed any discrepancies by re-listening to the audio recording and discussing the concepts until agreement was reached. The transcripts were used to conduct more in-depth analysis and to provide examples of the interaction. Almost all interaction, including the reading of the survey questions, was in Hmong; italics in the transcripts below indicate talk in English.

To understand the strategies Hmong interviewers used during the survey process when the older person is having difficulty responding, I used behavior coding. I first watched all 30 videos to identify common behavioral strategies that the helpers used. Then I created a systematic coding scheme. Table 4 displays codes for the helper's behavioral strategies, specifically what the helper is responding to address some of the older Hmong respondents' comprehension issues.

Table 4. Codes for Strategies that Helpers Use to Address Comprehension Problems

Strategies	Definition
Strategies for Re-reading	
Read question item verbatim	Helper reads/repeats question item exactly like the pre-recorded audio translation
Replay audio completely	Helper replays the whole audio recording at once to the elder

Replay audio question	Helper replays only the question reading of the recording to the elder; helper only plays the audio recording (standard) of the question portion and not the whole thing
Replay audio response	Helper replays only the response reading of the recording to the elder
Read response items verbatim	Helper re-reads response exactly like the pre-recorded audio translation
Strategies for Rewording	
Replace word in question item	Helper replaces original concept word with a different word in native language
Narrows down concept to one domain	Helper narrows down the health question to one domain (e.g. could be physical, emotion, etc.)
Omits time in question item	Helper rewords translation by eliminating time sequences
Provide context	Helper provides a connection of the question to a real life experience or helper provides an example.
Paraphrase question	Helper states the question item in a different way from the original pre-recorded audio translation or helper using another meaning/concept to describe the original one
Paraphrase response categories	Helper translates the response item in a different way from original pre-recorded audio translation; using another meaning/concept to describe the original one
Omit some response categories	Helper re-reads response categories by omitting/deleting 1 or more response categories
Omit all response categories	Helper re-reads only question item and omit reading of response categories
Change question structure to elicit binary response	Helper changes the question structure to get a binary response (e.g. yes or no)
Reminder about time	Helper reminds elder about the time frame the questions is asking
After Receives Response	
Asks for clarification of exact response	When elder provides two responses, helper ask for elder to provide one response

Confirms response	Helper confirms response elder's selected response or confirm response helper selected for elder if correct/ok
Re-classify description as a codable answer	Helper takes what elder describes and put it into codable answer
Reminds elder to focus on self	Helper reminds the elder to think about her/his self in the context of the question; reminds elder it is not about the colors
Selects response	Helper selects response for elder because elder couldn't pick or doesn't provide an answer or helper cannot translate to elder due to technological difficulty and just selects for elder; elder tells helper to help select response
Clarify meaning of color & answer	Helper clarifies what the link between the color and the answer category

Analysis. The coded data in Noldus Observer X was exported and then imported into Number Cruncher Statistical System (NCSS) 11 statistical software. Descriptive statistics-- including frequencies, proportions, standard deviations, and means – were computed in NCSS. To analyze whether comprehension cues experienced by Hmong older adults differ with response format type, I recreated new codes for the response format of the questions. Then I ran a frequency analysis linking each type of the response format with the older adults' behaviors.

RESULTS

Thirty Hmong dyads including 30 older Hmong respondents and 30 family helpers participated in this study. Characteristics of the respondents and helpers are presented in Table 4. Most participants, both older adults and helpers, were female (73% older adults; 90% helpers). Most helpers are not fluent in both languages and older adults do not read Hmong or English 'well at all' (see Table 5). It took the dyads to complete each of the 13-items ranging from 3 seconds to 353 seconds.

Table 5. Social Characteristics of Hmong Older Adults and Helper

	Hmong Older Adult (N=30)		Helper (N=30)	
	N	Percent	N	Percent
Sex				
Female	22	73	27	90
Male	8	27	3	10
Age range (mean)	47-85 (66.5)		18-54 (29.2)	
Range of Number of Years Lived in US (mean)	9-36 (22.9)		10-30 (19.1)	
How well do you read Hmong?				
Not at all	21	70	8	27
Not well	2	7	7	23
Well	4	13	13	43
Very well	3	10	2	7
How well do you write Hmong?				
Not at all	23	77	8	27
Not well	3	10	9	30
Well	3	10	11	37
Very well	1	3	2	7
How well do you read English?				
Not at all	26	87	0	0
Not well	3	10	9	30
Well	1	3	8	26
Very well	0	0	13	43
How well do you write English?				
Not at all	25	83	1	3
Not well	4	13	9	30
Well	1	3	8	26

Very well	0	0	12	40

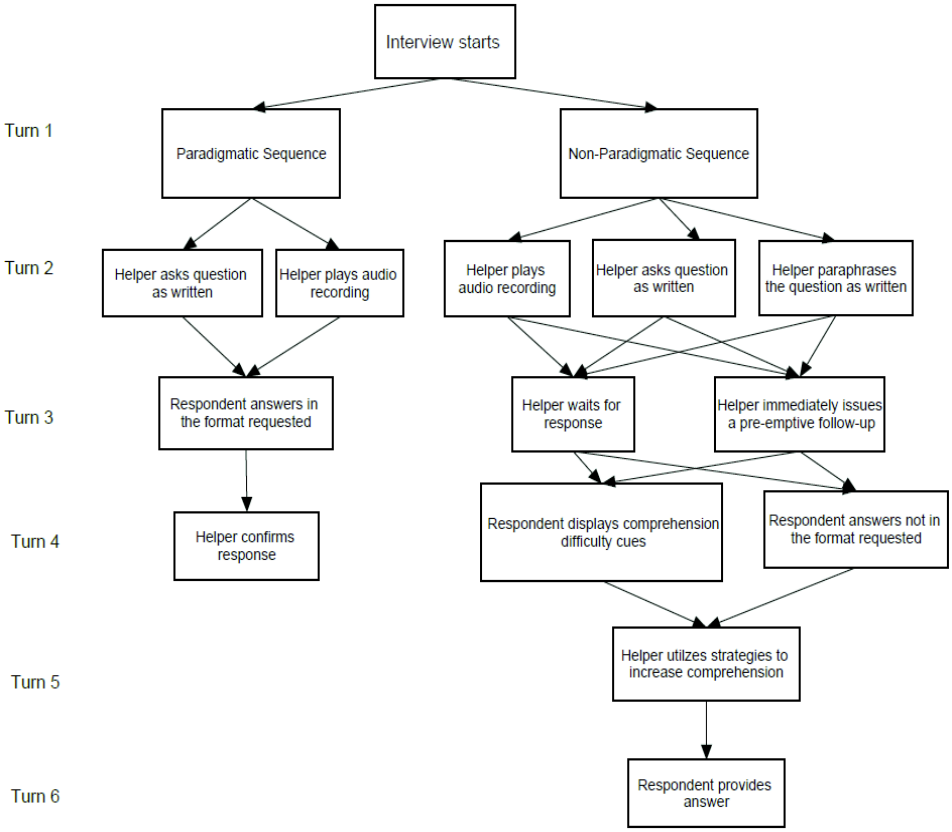
Interactions between Helpers and Respondents

Turns. There was a total of 1573 turns across all question-answer sequences during the interviews for the Hmong older adults and helper together (range 5-82 turns). Of the 1573 turns, in 866 the speaker was the Hmong older adult, and in 708 the speaker was the helper.

Interactions between Helpers and Respondents

Figure 2 provides an overview of the two types of sequences-paradigmatic and non-paradigmatic between the helper and the older Hmong respondent that were tracked for this study.

Figure 2. Simplified Interaction Sequence between Helper and Respondent



Paradigmatic Sequence

Among the 30 interviews, there were 7 dyads (older Hmong and helper) that followed the standardized (paradigmatic) sequence, in which the question is read and the respondent is able to provide a codable answer, for all 13 health items. Segment 1 presents a paradigmatic standardized question-answer sequence: the helper plays the Hmong audio recording of the question (line 2-4) while it appears in English text on the screen, and the respondent chooses one of five response categories, "red," immediately after the question reading, with no hesitation (line 3). The helper then records the answer and moves on to the next question (lines 6-9).

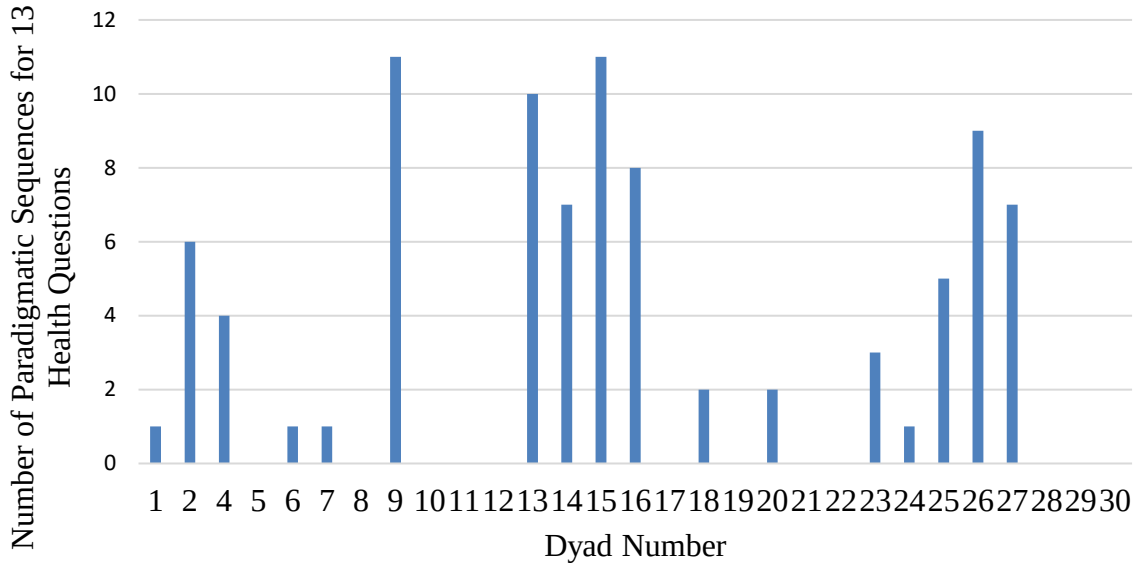
Segment 1 Helper #19 Question Number 1

Lines	**Speaker**	**Content**
2	Helper:	[Plays audio recording for question 1: In general, would you say
3		your health is: excellent select yellow, very good select green, good
4		select blue, fair select red, or poor select black?][2]
5	Respondent:	Select red.
6	Helper:	[Plays audio recording for question 2: Does your health now limit
7		you in moderate activities such as moving a table, pushing a vacuum,
8		or bowling? If so how much? Yes, limited a lot select black, yes,
9		limited a little select red or no, not limited at all select yellow.]
10	Respondent:	Select red for that.
11	Helper:	Okay.

Similar paradigmatic question-answer sequence occurred for at least one question for 17 other dyads. Figure 3 displays the number of paradigmatic question-answer sequence that occurred among the 13 health questions for each dyad. For example, dyad 1 only had one paradigmatic question-answer sequence out of the 13 health questions. In contrast, dyads 9 and 15 had 11 paradigmatic question-answer sequences out of the 13 health questions, and 13 of the dyads had no paradigmatic sequences.

[2] The underlined words are translations of the original English question item and response categories. The square bracket indicates the action of the interviewer—whether she or he plays the audio recording for the question, reads the question exactly as written, or paraphrased the question item.

Figure 3. Number of Counts of Paradigmatic Sequence Per Question Item Across Dyads



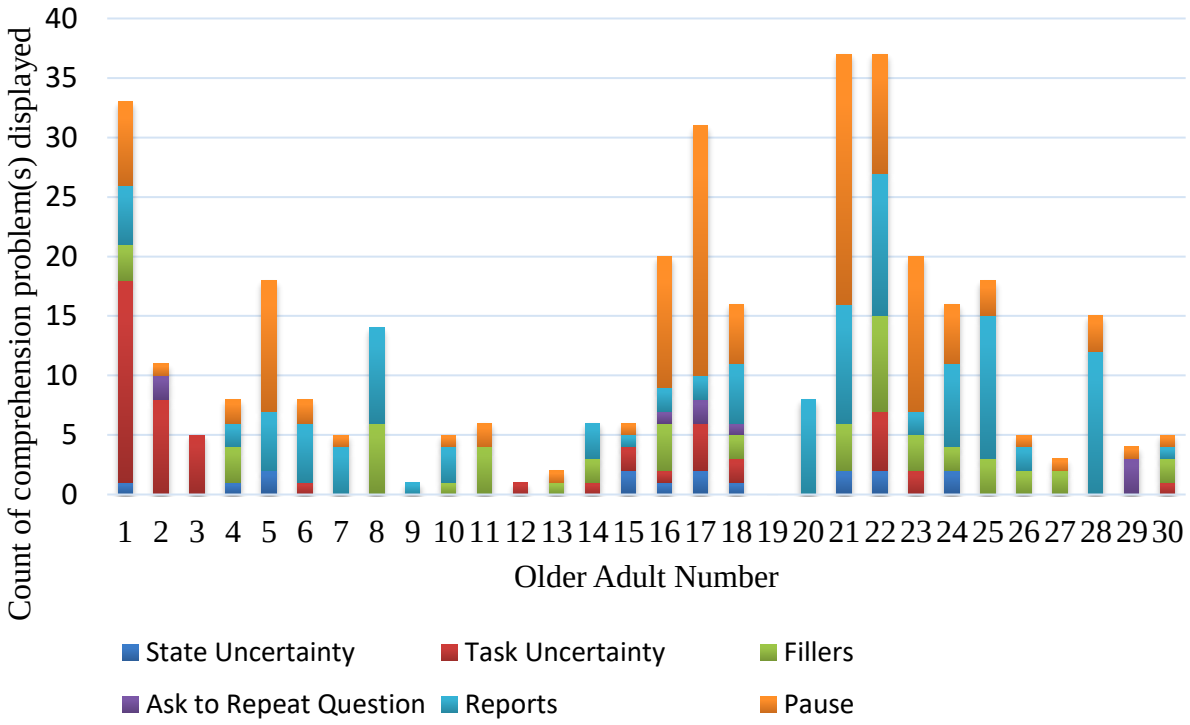
Non-Paradigmatic Sequence

Twenty-three dyads departed from the paradigmatic sequence for at least one question-answer sequence. All but one of the dyads began the interview with a standardized approach, playing the Hmong audio recording; one helper began the interview by translating the questions instead of using the supplied Hmong audio in a standardized (paradigmatic) way. Other departures from standardization occurred because respondents did not provide codable answers. The helpers' initial action after reading the question sometimes contributed to deviations from the paradigmatic sequence. First, in some instances, the helper immediately paraphrased the question, apparently assuming the Hmong older adult respondent had comprehension problems. Of the 23 helpers, 12 (52%) helpers immediately issued a pre-emptive follow-up for one or more questions (Schaeffer & Maynard 2002), without waiting for the respondent to provide an answer. These helpers immediately paraphrased either the question or the response categories.

In contrast, 11 (48%) helpers waited for the older Hmong respondents to display comprehension difficulty following the question reading and then used strategies to decrease comprehension problems for one or more questions. There were seven behavioral indicators of comprehension difficulties that may have contributed to departures from the paradigmatic sequence. For instance, the older Hmong respondents' pauses (silence) were the most frequent behavior compared to fillers, state uncertainty, task uncertainty, report, and ask to repeat questions that helpers treated as indicating comprehension problem. Thus, if there was a silence then the helper always interpreted the silence as indicating a comprehension problem. Figure 4 shows the number of each behavior that helpers treated as indicating a comprehension problem, summed across 13 questions for each respondent.[3] From Figure 4, it is evident that respondents number 1, 17, and 22 displayed the most comprehension problems across 13 questions. Comprehension problem cues such as pauses, seeking clarification, and report were the most common behaviors that were often treated as indicating comprehension problems across all 30 respondents.

[3] There is more than one behavior for each older Hmong adult for each question as indicated by the color type in the figure.

Figure 4. Number of Each Behavior That Indicates a Comprehension Problem, Summed Across 13 Questions, for Each Respondent



Twenty-three (77%) respondents were unable to select a response from the response categories offered for at least one item and, as a result, provided a response that was not consistent with the requested response format. Instead the Hmong older adult respondents provided a response (report) that described his or her current state of health. In addition, nineteen (63%) respondents sought clarification from the helper for one or more items. Respondents' inability to select a response from the categories offered, which could be related to either not understanding the question (state uncertainty) or uncertainty about which response category was appropriate for their true value (task uncertainty) (Schaeffer and Thomson 1992).

Segment 2 shows a departure from the paradigmatic sequence. Specifically, Segment 2 illustrates how not understanding the question and not understanding the response categories can stimulate interactions between the Hmong older respondent and the helper. On line 8, the

respondent explicitly states she does not understand the question. The helper played the audio again (line 10-12) and explained the question by improvising a definition of health as "ability to do something." The helper then explained the response categories by providing context including providing definitions or providing examples. For example, the helper linked the response category "excellent" to the "absence of an illness" (lines 14-16). The respondent followed up with a clarification question about the response (line 17). The helper explained the response categories. The respondent then selected a response category by referring to its location, "in the middle" (line 20); the helper's follow-up action offered the color label for the middle category ("blue," line 22) to confirm the older Hmong respondent's choice; the older Hmong respondent then spontaneously offered a think-aloud explanation of how she arrived at her answer. Thus, when the older Hmong respondent displayed state and task uncertainty, it clearly led to an interaction that deviates from the paradigmatic sequence.

Segment 2 Helper #5

Lines	**Speaker**	**Content**
1	Helper:	Aunt, this is say in English, but I will press this [button to start audio
2		reading] because the researcher [name] already translated it into
3		Hmong for you to listen. Then you can decide what you choose or
4		choose which color.
5		[Plays audio recording for question 1: <u>In general, would you say</u>
6		<u>your health is: excellent select yellow, very good select green, good</u>
7		<u>select blue, fair select red, or poor select black?</u>]
		Do you understand aunt?
8	Respondent:	[I] don't understand. [laughs]
9	Helper:	Don't understand then? It says that do you, uh, you listen to it again.
10		[Replay audio again for question 1: <u>In general, would you say your</u>
11		<u>health is: excellent select yellow, very good select green, good select</u>
12		<u>blue, fair select red, or poor select black?</u>]
13		The researcher [name] translates the question that, about your health
14		or ability to do things within your body, ok? If it is good, there is no
15		illness or anything then it is yellow. [Helper points to the screen]This
16		is excellent, this is good, this is good a little, this is little, and this is
		not good at all.
17	Respondent:	Good and not well?
18	Helper:	This is a little, you are a good only a very little. But this is saying not

19		good at all. See if you are excellent or…
20	Respondent:	I am like in the middle I would say.
21	Helper:	If in the middle then it is the blue band then right?
22	Respondent:	So I am doing well but I have high blood pressure and high blood
23		sugar so I am a bit more stressed.
24	Helper:	Ok, so it's where?
25	Respondent:	It's in the middle.
26	Helper:	In the middle? Okay.

Response Format & Comprehension Difficulty

Because it appeared that the response format of the question could contribute to the respondents' comprehension problems, I analyzed the respondent's behavior by the response formats. Table 6 presents the number of respondents who indicated at least one comprehension problem cue across the four response formats in the SF-12 survey. In addition, the total proportion of each type of comprehension for each question format was also calculated. From table 6, the ordered selection 5 categories have higher proportions of ask to repeat question, seek clarification, pauses, fillers, task and state uncertainty compared to other formats. However, the ordered three categories have the highest proportions of report.

Helpers' Strategies

Figure 5 presents the number of strategies the helpers used to attempt to improve comprehension among the Hmong older adult respondents. The four most frequently used strategies were paraphrasing the question (n=80), asking for clarification of exact response[4], in a non-directive way (n=71), clarifying link between color and response option (n=62), and providing context to the question[5] (n=60). In addition, the complete audio translation was

[4] Asking for clarification of exact response occurs when the older Hmong respondent provides two codable answers. The interviewer then asks for which answer exactly.

[5] Providing context for the question occurs when the interviewer gives a real life example to provide context to the respondent to answer the question.

replayed 42 times for 19 older Hmong adults. Figure 6 presents the number of respondents who had replay the audio at least once for each question item. For example, for question 1, there were 4 out of 30 respondents, who replayed the audio at least once. Question 5 was replayed the most by helpers.

Table 6 Number and Proportion of Respondents Who Displayed Each Behavior Indicating a Comprehension Problem for Each Question Within One Response Format

		Ask to Repeat Question		Seek Clarification		Pauses		Fillers		Task Uncertainty		State Uncertainty		Report	
Response Format	Question item	Count (n*)	Total Proportion	Count (n*)	Total Proportion	Count (n*)	Total Proportion	Count (n*)	Total Proportion	Count (n*)	Total Proportion	Count (n*)	Total Proportion	Count (n*)	Total Proportion
Yes/No (5)	4	0	0.01	0	0.0	4	0.24	1	0.08	1	0.07	0	0.04	5	0.207
	5	1		0		8		3		4		3		9	
	6	1		0		7		2		2		1		3	
	7	0		0		6		3		0		0		7	
	8	0		0		9		3		3		2		7	
Ordered selection: Three categories (2)	2	0	0.00	0	0.0	5	0.15	2	0.05	4	0.08	1	0.03	8	0.35
	3	0		0		4		1		1		1		13	
Ordered Selection: Five categories (3)	1	0	0.04	5	0.13	10	0.28	11	0.22	5	0.11	4	0.04	8	0.22
	9	3		6		9		7		3		0		6	
	13	1		1		6		2		2		0		7	
Ordered selection: Six categories (3)	10	2	0.03	0	0.00	6	0.16	3	0.13	4	0.01	1	0.02	8	0.22
	11	1		0		3		7		3		1		7	
	12	0		0		5		2		2		0		5	

Note: n* refers to the number of times each behavior occur

Figure 5. Number of Each Strategy Summed Across 13 Questions for Each Helper

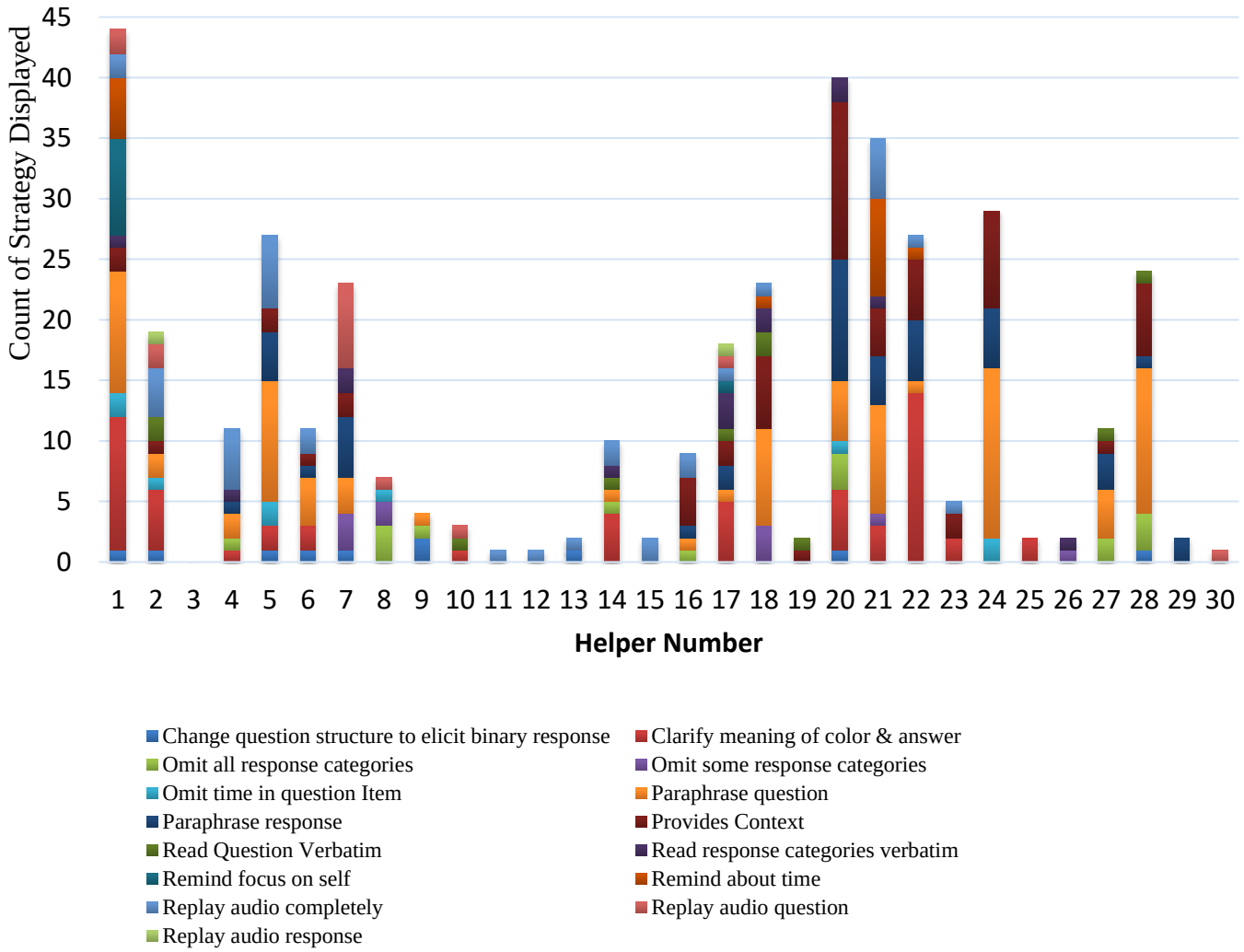
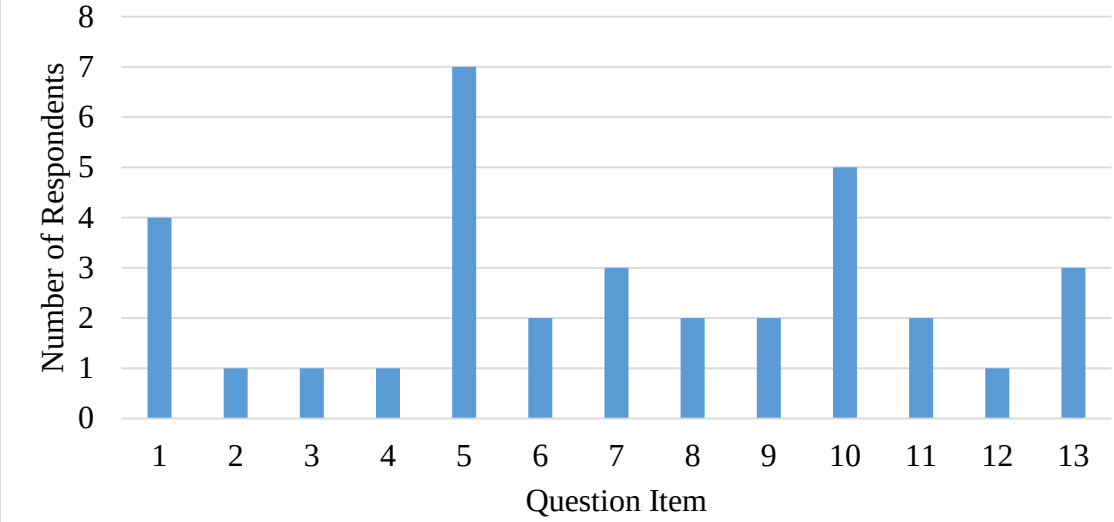


Figure 6. Number of questions for which audio was replayed one or more times



Segment 3 illustrates how the helper paraphrased response categories for the respondent when the older Hmong respondent was not sure how to communicate her true state, using the offered response categories (task uncertainty; line 84). Lines 87 to 90 show the helper paraphrasing the response categories by restating the categories and repeating the concept. Specifically, the helper slips the word "energy" into the description of the response categories as a way of reminding the underlying concept of the question to help the older person understand how to pick the response categories. In lines 88-92, the helper added the word "energy" to each response category as she restated them to the older Hmong respondent. By doing this, the helper was able to elicit a codable answer (line 93).

Segment 3 Dyad # 24

Lines	**Speaker**	**Content**
77	Helper:	[Plays audio recording for question 11: <u>During the past 4 weeks, how</u>
78		<u>many times did you have a lot of energy? None of the time pick black,</u>
79		<u>a little of the time pick pink, some of the time pick red, a good bit of</u>
80		<u>the time pick blue, most of the time pick green, or all of the time pick</u>
81		<u>yellow</u>.] Do you understand what it asked you?
82	Respondent:	I do understand but…
83	Helper:	About picking your response, do you understand which color to pick?

84	Respondent:	I don't know how to explain it. [laughing]
85	Helper:	For example, in the past 4 weeks, do you have a lot of energy?
86	Respondent:	Oh.
87	Helper:	Like if there is none at all then you pick black, there is only a little
88		then you pick pink, or if there is only sometime then you pick red, if
89		you have most of the time with your energy then you pick green, if
90		you have a lot of energy all the time then you pick yellow. So what do
91		you think in terms of your energy, how many times do you have? So
92		like a little, a lot, none.
93	Respondent:	I have sometimes only.
94	Helper:	Sometimes then?
95	Respondent:	Yes.
96	Helper:	Okay.

DISCUSSION

This study makes several contributions our knowledge about the interaction between NL and LEP Hmong older adults and their helpers during the survey completion process. Specifically, this study examined the interaction between younger and older family members while responding to a 13-health item instrument using an Audio Computer-Assisted Self-Interview (ACASI) with color-labeled response categories and helper assistance (ACASI-H). Findings revealed that the ideal paradigmatic sequence is uncommon with the Hmong older adults in this study, highlighting a difference in responding to questions and interactions.

The deviations from the ideal paradigmatic sequence were generated in two ways in this study. First, when the Hmong older adult respondents' initial answers did not match to the scripted offered response categories, a non-paradigmatic sequence resulted. The mismatched answers were often reports, in which the older Hmong respondents provide a descriptive answer rather than an answer from the offered response categories. Second, the mismatch answers were also linked to the helper's problematic deviations. Specifically, in some instances, helpers either immediately paraphrased the question, assuming that the older Hmong respondent had comprehension problems or waited for the older Hmong respondents to display comprehension

difficulty following the question reading. The mismatched answer could be explained by Dijkstra and Ongena (2007) proposed factors: (1) cognitive processing and (2) conversational practices. Dijkstra and Ongena (2007) argued that there increased cognitive processing occurs when respondents do not have the necessary information in their memory to answer the question; consequently, the respondents provide verbal, think aloud response that resulted in an inadequate answer (e.g. a mismatched answer). In addition, the mismatch answer could also be a conversational problem. For example, even when the information to answer a question is readily available and not associated with memory problems, a mismatch answer could occur because the respondent may treat the interview as a 'kind of everyday' conversation. Hence, respondents cannot provide a precise answer. Conversational practices could explain why the older Hmong respondents' provide a descriptive answer (report). The Hmong come from an oral culture, where they are more used to providing narrative than discrete answers; thus, it may seem more natural to them to provide a narrative answer.

The older Hmong adult respondents' uncodable answer could also be influenced by the lack of focus on the task (e.g., providing a precise answer within the scripted response categories). Researchers have reported that the lack of focus on the task has been associated with the respondents' characteristics including age and question characteristics. Older respondents may be less likely to focus on the task than younger respondents (Cho et al. 2006) . This may have been the case for the older Hmong respondents in this study. Specifically, because the older Hmong respondents in this study are unfamiliar with taking survey (Lor & Bower, In Press); thus, they may have had more difficulty focusing or completing the task.

Furthermore, the lack of focus on the task could also be linked with the questionnaire design (Dijkstra and Ongena 2006). This study also revealed that Hmong older adult respondents

struggled with the higher ordered selection 5 categories question format. This finding is inconsistent with other racial/ethnic minorities, where yes-no questions showed some cultural variation in comprehension problems (Johnson et al. 2006). More research is needed to examine how translation of yes/no questions can affect responses among the Hmong.

This study also found that most Hmong helper helpers were instrumental in recognizing and tailoring strategies to address comprehension problems of the older Hmong respondents. It is possible that helpers were likely to observe and identify comprehension problems more easily than standardized helpers because the helper helpers are familiar with their older Hmong relatives' cognitive ability and have a bicultural perspective. Thus, they may be more likely to identify a comprehension problem and react to it in a more sensitive or tailored way. In comparison, if standardized helpers, who were native English speakers, were used in this study, it might have been difficult for them to identify and address some comprehension problems sensitively. For example, if the older Hmong respondents run into problem of "I have no idea to do the task because it is not part of my culture," it might be difficult for the standardized helper to offer a sensible solution. Thus, the helper helpers are in a position to identify the lack of fit.

Interestingly, in some cases, the Hmong helpers spontaneously used strategies to increase the Hmong respondent's comprehension that are similar to those used by trained interviewers (e.g. reading the question exactly or re-reading the question, Fowler and Mangione 1990). An explanation for this could be that these helpers are probably acculturated in similar tasks or are familiar with the genre of survey interviewing. Despite the fact that most helpers behave similarly to trained interviewers for most questions, there was large number of helpers, who self-reported that they do not read or write Hmong and English well.

There are some limitations to this study. Firstly, because I did not ask the respondents specifically about comprehension; it is unclear if the comprehension problems (e.g. pauses, seeking clarification, task uncertainty, state uncertainty, filler, and report) truly mean that the respondents have comprehension problems. Conversational practices are learned through everyday interaction; thus, they may vary across people, culture, and settings. Future studies could conduct a qualitative study to gain a better understanding of the meaning of these disfluencies. Secondly, there was no comparison group (e.g. Hmong older adult without a helper), making it difficult to compare the extent of the disfluencies and comprehension problems. In this study, the coding behaviors for comprehension problem cues came from the literature done with mainstream populations. Thus, it may be possible that we missed other cultural relevant comprehension cues. Future studies could examine potential comprehension problem cues related to how one would translate the comprehension problem with other cultural groups. Furthermore, this study did not distinguish between comprehension problems related to translation issues. Thus, future studies could also examine comprehension problems related to concepts that were difficult to translate or did not have a cultural equivalence when translated from English to the Hmong language. This study did not do a comparative study with the use of standardized interviewers with family helpers to assess the impact on survey response. Future studies could examine how each type of interviewers (e.g., standardized interviewers vs helpers) interviewers) is similar or different in their identification and strategies to address comprehension issues. This would shed light on measurement error (e.g. bias) in response.

Implications

What can we learn from the study findings? This study has implications for the inclusion of a usual untrained family helper and strategies to maximize comprehension.

For having an untrained helper assist in the interview process:

1. Researchers could identify any barriers that might keep a family helper from being able to maximize the quality of the interviewing process. For example, in this study, when the older Hmong respondent did not understand the concept like "health", the helper narrowed down to a specific example/definition of health. Thus, researchers could prepare a list of potential examples of the concepts being measured to prevent bias.
2. Researchers could try to communicate clearly (in writing and orally) expectations and goals of the survey. Because of literacy challenge (e.g. respondents are not English literate and some helpers are not literate in their native language), a video could be developed to communicate expectations and goals of the research study. This would be useful in cases where the researchers cannot be visibly present at the home.

Strategies to maximize comprehension of older Hmong adults and family helpers:

1. Researchers could embed definitions of the concept for the question item on the screen to allow the dyads to read when they need clarification. This would also allow the untrained helper to translate more accurately.
2. It would be helpful to set a well-balanced boundary in which the dyad (respondent and helper) can still maintain their normal way of filling out survey and still be able to provide good translation. One way to do this could require the researcher to ask the helper not to translate or define, but to play the recording again.
3. Researchers could write the survey in lay terms in English. This would address the variation in language proficiency within the untrained helper population.
4. Researchers could make sure that the English survey has response categories that correspond to the respondents' cultural context. For example, the response category

concepts have to fit within the respondent's mental framework. They have to be concepts that exist in the respondent's language.

CONCLUSION

This study describes the interaction between the Hmong older adult and their helpers and strategies the helpers used to assist the respondent. Despite the limitations mentioned above, the ability to identify behaviors by the helper and Hmong older adults during the survey process has potential applications for future studies—for example, focusing on measurement error of the inclusion of an untrained family helper.

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Chapter 5:

Discussion and Future Research

This dissertation contributes to the field of survey methodology and health disparities. Specifically, this dissertation study is the first study to include and study the addition of a family helper during the survey process. It is also the first study to develop a data collection tool that accommodates for differences in participants' language proficiencies—the Hmong older adult presented with an oral audio pre-recorded translation and the family helper presented with written English text simultaneously presented in a survey. In addition, it is the first study to use color labeled response categories. Understanding how these components operate, related to language and cultural barriers, and provides insights into better ways to collect health information, which can be used to improve population health programs and individual patient care. The study also helped identify important future areas of research for such populations.

The purposes of my dissertation study were to determine the feasibility and acceptability of a specific technology, audio-computer assisted self-interviewing mode (ACASI) with color labeled response categories and a family helper (ACASI-H), and to explore the impact of including a family member helper in responding to survey items. This dissertation has revealed some novel findings about both the data collection tool, ACASI-H, and the inclusion of a family member during the survey process.

Summary of Findings

From the systematic review (paper 1), I learned that the Hmong adult population experiences health disparities. However, the nature and extent of health disparities among the Hmong adult population is unknown. For example, the distribution of diseases among the Hmong adult community remains unclear compared to other racial/ethnic minority populations. In the systematic review, cancer has been the only well studied disease in the Hmong adult population. Thus, we are left with three important unanswered questions: (1) what are the major

health problems among the Hmong adult population in US? For example, what are specific health problems/ diseases that are most prevalent in this population? To what extent are they affected by these health problems/diseases compared to other racial/ethnic groups? (2) What are the causes of these problems? For example, what particular determinants of health are most salient with Hmong adults? Are there changeable factors associated with personal health and health-related behavior? Both sets of questions stem from a failure to include the Hmong population in national research studies. Thus, this systematic review provided evidence for the importance of this dissertation study.

The findings from the feasibility study of audio-computer assisted self-interviewing mode with color labeled response categories and helper assistance (ACASI-H; paper 2) revealed a promising platform to increase inclusivity of limited English proficient and non-literate populations in survey research. Specifically, both Hmong older adult and helper participants in this study reported that ACASI-H was culturally and linguistically acceptable, despite a few practical technological issues at the start (e.g. problem loading the pre-recorded audio translation). Overall ACASI-H was reported to be usable. Participants reported that they would participate in future studies using such a mechanism.

From the feasibility study, I learned that the family helper has a significant impact on the ability of the older adult to complete the survey. In particular, both the Hmong older adults and helpers reported that the helpers were instrumental, vital, in assisting with navigation (e.g. laptop, mouse, online ACASI-H instrument), identifying when the older Hmong adult did not understand the questions, clarifying the question, explaining how to respond to the colored labels, and helping the older adult select the most accurate response for each question when they encountered a challenge.

In addition to learning about the role of the family helper during the survey process, I also examined interactions between the helper and the older Hmong respondent (paper 3) during the survey process. The findings showed that the dyads completed the survey in a way that is inconsistent with the traditional ideal paradigmatic survey completion process. Seventy percent (n=21) of Hmong older adults were unable to provide a response that was consistent with those offered in survey. Furthermore, the study showed that older Hmong respondents have the most difficulty responding to higher ordered selection 5 categories question format.

Consistently, throughout two of the studies, ACASI-H appears to be a promising solution to address data collection challenges associated with language and cultural barriers. However, an interesting finding was that I did not observe what I expect to see in terms of collectivist cultures influence on survey (Gudykunst, 1983; Ho & Chiu, 1994; Triandis, 2001; Triandis, McCusker, & Harry, 1990) during the survey process. In the feasibility and interaction studies, most of the Hmong older adults displayed considerable independence in providing answers to the survey items, without confirming the response or conferring with the helpers.

Implications

This study suggests the importance of increasing Hmong older adults' familiarity with surveys. One way to do this could be to provide some practice questions for Hmong older adults prior to taking the actual survey. From the findings that Hmong older adults have more difficulty selecting yes-no questions, it appears that the Hmong language is less direct and specific than English. Thus, to address the use of specific language, survey researchers could provide an example with specific context to the question as a "definition" tab on the computer screen to help

the Hmong older adults understand the concepts being asked. The same could be applied to the question, specifically with key concepts such as 'health.'

Furthermore, the finding that older Hmong adults are able and willing to make their own autonomous decisions when answering the survey questions highlights that their collectivist culture may not be relevant in such a setting. A possible explanation for this could be that the collectivist culture operates specific to the context. Thus, completing a survey is about one's health, a very personal matter that others do not have access to information about, and as a result may not need to discuss before responding. However, the group-based decisions may be seen more in situations that are perceived as life-threatening (Lor, Xiong, Park, Schwei, & Jacobs, 2016) or related to decisions about health treatments (Lor, Khang, Xiong, Moua, & Lauver, 2013). Thus, having a family member present during the survey process may not be problematic in terms of measurement errors.

The findings from this study highlight the importance of including family members during the survey completion process, particularly with older adults who are LEP, where they are used to collaborating together, and are unfamiliar with technology. Because the survey process was not standardized and helpers were not directed to follow specific protocols helpers engaged in a range of behaviors. For example, some helpers paraphrased the questions; some replayed the pre-recorded oral translation; and some omitted information from the question when paraphrasing the question or response categories. Thus, researchers could provide a more specific protocol for what family members could or could not do during the survey completion process in future studies, thus increasing standardization. Although this study did not assess measurement error or bias, having a specific protocol could help prevent measure error or response bias.

Future Directions for Research

This study creates a foundation for future studies with populations who are LEP, non-literate and from a collectivist culture. From study findings, Hmong older adults did not perform within the question-answer sequence (paradigmatic sequence) as one would expect. Thus, future studies can examine how different communication styles affect the use of ACASI-H. Researchers could also examine the use of colors, the impact of colors on response, and effect of practice questions in surveys. For example, researchers can examine how color influence response. In addition, we did not control the environment or standardize the helpers' role to learn more about what helpers might do when they are included in the survey process. Future research could retest ACASI-H in both a natural vs a more controlled environment with standardized protocols and without standardized protocols to examine how different settings and protocols influence response. In this study, I did not compare the differences between the pre-recorded oral survey translations to the helpers' translations. Thus, it is unclear how accurate the helpers' translation is in regards to maintaining conceptual equivalence (e.g. if the translation of an item is still in the same concept in English and Hmong). Conceptual equivalence is important because there may be varying proficiencies in the two languages—Hmong and English, for helpers. Future research could examine whether or not the survey translations conducted by the helpers maintain conceptual equivalence. Researchers could also conduct comparative studies with other LEP groups using ACASI-H. Future research could test ACASI-H in clinical settings rather than home setting to determine if it can be disseminated in clinical settings. There is also a need for further research to explore just how and when the collectivist culture operates in relation to health issues because this study did not seem to reflect collectivist culture during survey response

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