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Stories of Us – Chuyện Kể Nhau Nghe
Building Community for Health through Stories

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Abstract

Stories of Us – Chuyện Kể Nhau Nghe
Building Community for Health through Stories

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Background: Research found that positive social connections are protective of health. For refugees and immigrants, whose established social ties are disrupted, strengthening existing social networks may promote population health.

Purpose: This dissertation presents in three manuscripts the results of *Stories of Us – Chuyện Kể Nhau Nghe*, a community participatory action research that examined the relationships between cultural displacement, community cohesion, and self-rated health (SRH), evaluated the effects of an intergenerational life review intervention on the above variables, and assessed the feasibility and acceptability of *Stories of Us – Chuyện Kể Nhau Nghe* among Vietnamese-Americans.

Methods: First, an integrative review of reminiscence literature on the effects of life review (LR) on social connections and health was conducted. Second, lessons learned from experiences of researchers in the literature and from *Stories of Us – Chuyện Kể Nhau Nghe* on conducting participatory research (PR) with Vietnamese-Americans were presented. Finally, results of a community survey and a one-group pre- post- LR intervention design were provided.

Results: First, the integrative review found strong evidence that LR interventions reduced and prevented depression by improving meaning in life, ego integrity, mastery, and positive thoughts. There was promising evidence that LR, particularly intergenerational LR, promoted participants' connections with each other and with other people. A conceptual framework for further research with refugees and immigrants was proposed. Second, the experiences of *Stories of Us – Chuyện Kể Nhau Nghe* researchers confirmed lessons learned from PR literature: (1) mutual respect and trust are essential and must be gained from long-term involvement with the community, (2) utilizing community existing resources to build capacity, facilitate empowerment, and promote ownership, and (3) committed time, expertise, and personnel are necessary to sustain health promotion activities and their impact over the long-term. However, all communities have unique characteristics. Applying successful strategies in other communities without learning about and considerations of the uniqueness of the community with whom the researchers will be working may be counterproductive. Finally, results from the community survey showed that cultural displacement negatively affected SRH and the effect is mediated by community cohesion. Post-intervention results showed no significant effects of *Stories of Us – Chuyện Kể Nhau Nghe* on cultural displacement, community cohesion, or SRH. Evaluation showed promising results that the intervention is feasible and desirable by Vietnamese-Americans in the Greater Seattle area.

Conclusion: *Stories of Us – Chuyện Kể Nhau Nghe* filled a community need. Future study with a larger sample, stronger design, and more sensitive instruments is needed to assess *Stories of Us – Chuyện Kể Nhau Nghe* effectiveness.

keywords: participatory action research, life review reminiscence, community cohesion, cultural displacement, self-rated health

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I cannot take leave without a special, special appreciation for the courage and generosity of the storytellers and those who participated in the storytelling sessions. The statistics and numbers, the few quotes and photographs cannot do justice to the energy and emotion that emanated from the stories and the sharing that followed. May yours be the first of many stories that will flow out of our community, like rivers that sustain and unite us all.

I am truly blessed.

DEDICATION

to all refugees
and
culturally displaced peoples
around the world

to my ancestors

Chapter 1. **Introduction**

With an aging population, the American public health system has been gearing up to promote healthy aging. Thanks to health promotion programs for seniors, many are living healthier and longer lives. However, it is unclear that ethnic minority elders who experience multiple disadvantaged statuses are benefiting from these programs.

Older ethnic Vietnamese adults are among those with many social disadvantages known to have negative effects on health. Population-based survey results showed 15% of Vietnamese adults live below the federal poverty line compared to the national average of 13% (Pew Research Center, 2013), and 88% older Vietnamese adults have limited English proficiency (National Asian Pacific Center on Aging [NAPCA], 2013). Both are associated with poorer health. Vietnamese older adults are most likely to rate their health as less than good compared to non-Hispanic Whites and other Asian groups (Zhang & Ta, 2009). Their advanced age, and minority and immigrant statuses also put them at higher probability of feeling a sense of alienation from the American society and a loss of culture and identity (Nicassio & Pate, 1984).

Community assessment of local Vietnamese seniors revealed that physical and social isolation are among the elders' top challenges, followed closely by the lack of connection to the younger generations due to cultural and language barriers (Đặng, 2012; Vietnamese Friendship Association [VFA], 2011). A study by Zhang and Ta (2009) showed that, compared to non-Hispanic Whites and other Asian groups, for Vietnamese older adults, social connections, particularly family cohesion, are strongly associated with good health. It seems prudent to leverage these protective factors to promote healthy aging for Vietnamese seniors.

The Vietnamese culture has a strong oral tradition. Reminiscing is a natural past-time for those who grew up in the culture (Jamieson, 1993). The younger generations of Vietnamese-Americans expressed the need and desire to learn more about the Vietnamese culture (VFA,

2011). Getting the young and old together to share life stories would meet the needs of the old to connect with the younger generations, and the needs of the young to learn more about their heritage. This sounds like an ideal strength-based approach. Would it be supported by the literature and by research?

The purpose of this dissertation research, the *Stories of Us – Chuyện Kể Nhau Nghe* community participatory action research study, is to examine the effects of reminiscence on social connections and health through existing literature and a demonstration study. The next three chapters consist of three manuscripts. The first is a report on the results of an integrative systematic review of life review, a structured form of reminiscence, on social connections and health. Next is a summary of the lessons learned regarding community participatory research with Vietnamese-American communities through the literature and the experiences of *Stories of Us - Chuyện Kể Nhau Nghe*. The third details the results of a community survey on the associations between cultural displacement, community cohesion, and health, and the effects of the intergenerational life review intervention *Stories of Us - Chuyện Kể Nhau Nghe* on cultural displacement, community cohesion, and health, and its acceptability and feasibility among Vietnamese-Americans.

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**Chapter 2. Life Review Reminiscence, Social Connections, and Health: An
Integrative Review and Conceptual Framework**

Abstract

Aims and Design: The purpose of this integrative review was to identify current knowledge about the impact of life review intervention on social connections and health across methodologies and to present a conceptual framework representing the results.

Data Sources: The data sources were Academic Search Complete, CINAHL, Health Source: Nursing/Academic Edition, Humanities & Social Sciences Index, MEDLINE, PsycARTICLES, PsycINFO, Social Work Abstracts, PubMed, and Web of Science.

Review Methods: This is an integrative review of studies that used life review as an intervention to affect social connections or health. Studies were evaluated using the Mixed Methods Appraisal Tool and findings were synthesized using content and thematic analysis.

Results: One hundred and one studies met the inclusion criteria. There is indication that life review improves participants' relationships with others by enhancing communication, creating opportunities for knowledge and cultural transmission, and promoting understanding and empathy. There is suggestion that life review promotes the sense of self in the society by affirming identity, promoting meaning in life, and improving life satisfaction. There are promising results that showed life review promotes well-being with the strongest evidence the reduction of depression. Meaning in life and mastery mediated this effect.

Conclusion: There is growing evidence that life review intervention promotes health directly and through enhanced social connections. Evidence is needed regarding its effects on minority populations, particularly refugees and immigrants whose sense of identity, mastery, and meaning in life are threatened due to life circumstances.

keywords: life review, reminiscence, social connections, health

No one leaves home, unless home is the mouth of a shark

Warsan Shire, *Home*, 2009

The words of British poet Warsan Shire, born in Kenya of Somali parents, became the rallying call for refugees, whose safety and physical suffering assail the world's conscience daily. The threats to their physical well-being were not the only danger to the refugees' health, however. Research has shown that social connectedness keeps people healthy longer (Inoue, Yorifuji, Takao, Doi, & Kawachi, 2013; Kim, Roux, Kiefe, Kawachi, & Liu, 2010; Kim, Hawes, & Smith, 2014) and facilitates their recovery when sick (Glass & Maddox, 1992; Kiecolt-Glaser, Page, Marucha, MacCallum, & Glaser, 1998). For refugees and immigrants, regardless of countries of origin or countries of resettlement, existing social networks are disrupted due to being uprooted. The loss of their family, country, and identity leads to depression, even despair, affecting their overall sense of well-being (Aylesworth & Ossorio, 1983). Language and cultural barriers hinder the development of new ties, and, for more established refugee and immigrant populations, prevent connections between generations. Available mental health services are under-utilized due to lack of cultural relevance.

What refugees and immigrants have in abundance are their memories, their life stories. The values of memories, and of sharing memories on health, depression and despair in particular, have been recognized by researchers the world over for more than half a century. Since gerontologist Robert Butler's seminal essay positing that reminiscence can be beneficial to the aging process (1963), scholarship on reminiscence has increased steadily. Studies have shown that reminiscence connects people, allows the transmission of life experiences and cultural values, elicits empathy, facilitates understanding, and helps reframe life events into meaningful

experiences, thereby improving well-being (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007; O'Rourke, Cappeliez, & Claxton, 2011; Westerhof & Bohlmeijer, 2014).

Studies have shown that when reminiscence intervention is structured and evaluative, covers the life span, incorporates negative and positive life events, and utilizes problem-solving, narrative, or creative therapeutic techniques, it is more effective than unstructured reminiscence (Bohlmeijer et al., 2007; Piquart & Forstmeier, 2012). Scholars differ in their terminology for this type of reminiscence. Some call it guided autobiography (Devries, Birren, & Deutchman, 1990). Others use life review (Burnside & Haight, 1992) or life review therapy (Piquart & Forstmeier, 2012). Some refer to it simply as reminiscence, even when all of the above components are present (Woods et al., 2012). Regardless of semantic differences, researchers agree that reminiscence functions as a way to assist the aged to find meaning in life and problem-solve current life issues, thus improving mental health, or to transmit cultural knowledge, create and strengthen human connections, among others (Cappeliez & O'Rourke, 2006).

Since positive social connections promote health (Zhang & Ta, 2009), reminiscence intervention may indirectly improve the sense of well-being via its human bonding functions (Cappeliez & O'Rourke, 2006). Due to low costs, low risks, and ease of implementation, reminiscence interventions have been used extensively with the aged in mainstream populations globally, from Asia (Chiang et al., 2010), to Europe (Korte, Bohlmeijer, & Smit, 2009), and the Americas (de Souza, 2011). Many refugee and immigrant groups came from cultures rich with oral traditions where reminiscence and storytelling are natural parts of community life, making reminiscence a logical choice for a community intervention to enhance social connections and promote health. However, studies of reminiscence interventions with refugees and immigrants

are rare, even though these populations may experience ill health disproportionately and may benefit from reminiscence interventions (Cho, Bernstein, Roh, & Chen, 2013).

The Review

Aims

Thus, the purpose of this review was to identify from the existing reminiscence literature what is known – and what remains unknown – about how life review reminiscence as an intervention affects social connections and health. From this review, a conceptual framework was developed to serve as a heuristic model for life review research with refugee and immigrant populations. To address this purpose, first, an integrative systematic review was conducted on the literature on the relationships between life review, social connections, and health. Second, gaps and issues were identified as a means of developing a conceptual framework of these relationships. Finally, the implications of this model for future research were explored.

The research questions were: Based on an integrative review of the literature

1. In what ways does life review intervention affect social connections?
2. Does life review affect health, and what are the mechanisms by which this occurs?
3. What are the gaps in knowledge and issues in the literature on the relationships between life review reminiscence, social connections, and health?
4. How do the relationships between life review, social connections, and health fit in the Nursing Human Response Model and the Intersectionality Framework?

Design

An integrative review of reminiscence literature was conducted to contextualize life review reminiscence interventions among a broad range of study designs from varying

disciplines to elucidate the factors and mechanisms by which life review contributes to a better sense of well-being and improves social connections. The review follows the guidelines proposed by Whittemore and Knafl (2005) for integrative review and adapts the PRISMA-P checklist (Shamseer et al., 2015). The review took place from February through October 2017.

Search Methods

To enable a comprehensive search of studies on life review as an intervention, the following search term combinations were used as key words while searching, without time limitation, Academic Search Complete, CINAHL Complete, Health Source: Nursing/Academic Edition, Humanities & Social Sciences Index, MEDLINE, PsycARTICLES, PsycINFO, Social Work Abstracts (all in EBSCOhost), PubMed, and Web of Science databases for published articles in English only:

Reminiscence AND intervention AND health

“Life review” AND intervention AND health

“Guided autobiography” AND intervention AND health

Although this review focuses on life review only, researchers are not uniform in their nomenclature. Therefore, the terms “reminiscence,” “life review,” and “guided autobiography” were used in the literature search in order to ensure the inclusion of as many studies that used life review as an intervention as possible. In addition to searching databases, the author combed the references of literature reviews, systematic reviews and meta-analyses that studied life review reminiscence as an intervention to find articles not found from the above searches. The blast of searches of the above databases took place in the month of February 2017. The retrieval of full-text publications lasted through August 2017. *Figure 1* shows the flow of study selection.

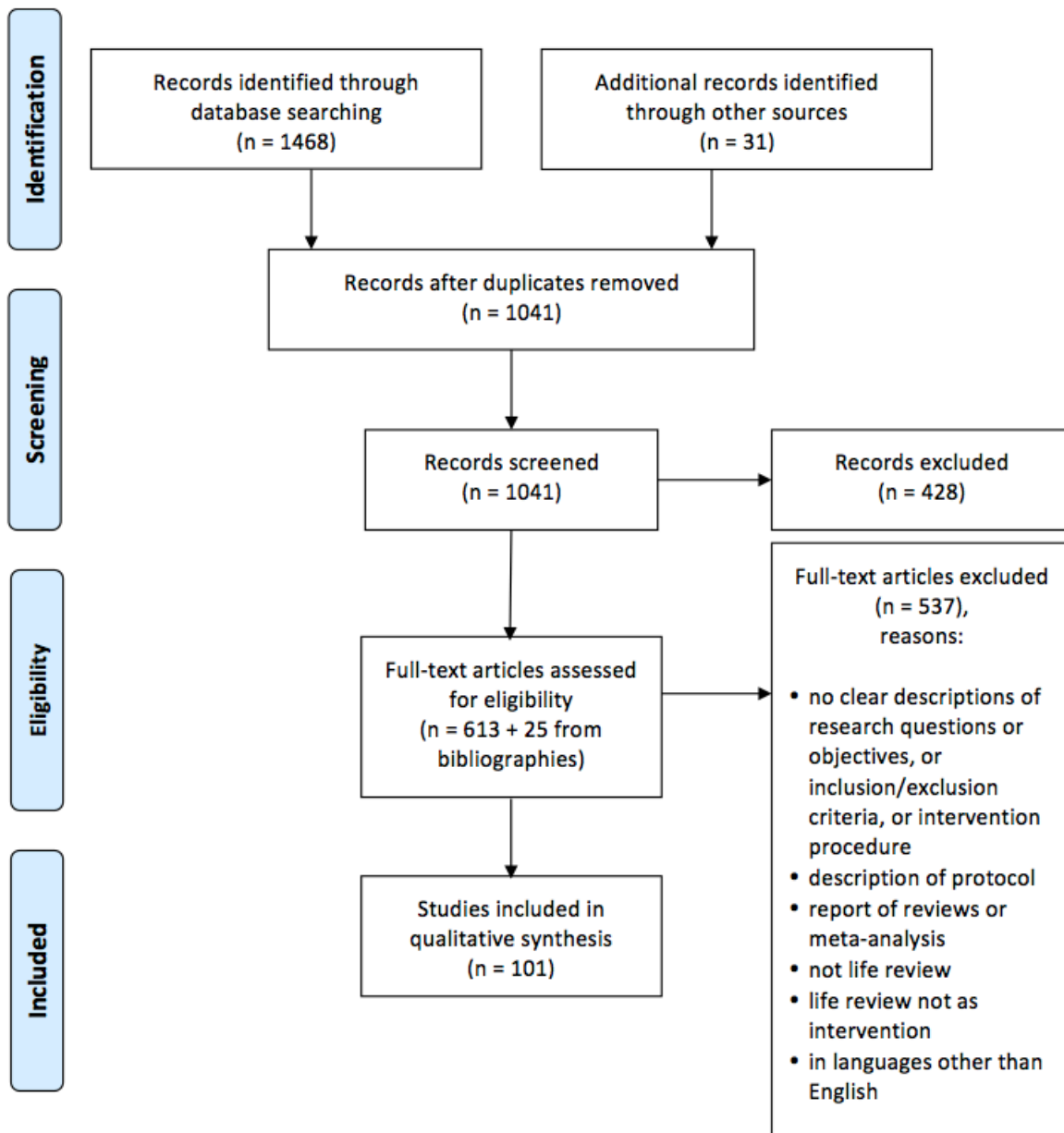


Figure 1. Flow of study selection.

Source: Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. The PRISMA Group. (2009).

Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement.

PLoS Med, 6(7), e1000097. DOI:10.1371/journal.pmed1000097

Inclusion and Exclusion Criteria

This integrative review examines current knowledge on the effects of life review reminiscence on social connections and health. Hence, the author included in the review studies that met the following criteria:

- Participants: No restriction
- Intervention: Reminiscence interventions that
 - cover the life span in essence
 - can be thematic or chronological
 - can be expressed visually, in words, or as performances
 - are reflective and evaluative, connecting past events and current life situations
 - include positive and negative life events
 - may or may not include a creative means to express recollection or reflection
 - may use individual, group, or family format
- Comparisons: No restriction or requirement
- Outcomes: Studies that include outcome variables or phenomena pertaining to
 - connections with other people, for example, teaching, promoting understanding or communication, relationship building, etc.;
 - connections between self and the social environment, for example, meaning in life, life satisfaction, identity, ego integrity, self-esteem, social isolation, etc.; and
 - health, for example, self-rated health, the presence or absence of bio-physical, psychological, or spiritual well-being, such as depression, dementia, mobility, etc.
- Study designs: There was no restriction on study designs so long as the criteria for intervention and outcome variables were met.

In short, the author included studies that examined the effects of life review on social connections, namely relationships with other people and with society, and on health. Life review interventions were defined as programs that facilitate the participants to recall life events, whether in words, or visually as a lifeline, or a sketch, or a collage of artifacts, or as a performance; reflect on and relate past events to current life situations and future planning. Health was defined broadly as a sense of well-being, including subjective self-rated health, and the presence or lack of physical, spiritual, emotional, or psychological symptoms.

On connections to society, the author was interested in the effects of life review on cultural displacement, defined as a sense of otherness, of unshared values, disconnection with the mainstream culture, and disempowerment. However, she found no study that addressed the effects of life review on cultural displacement. Therefore, in order to have a comprehensive look at whether life review might affect cultural displacement, she defined connections with society broadly to include concepts that may stem from being culturally displaced or its opposites, such as empowerment, identity, self-worth, meaning in life, or life satisfaction.

The author excluded descriptions of study protocol (Woods et al., 2009) or life review process (Piderman, et al., 2015), studies of unstructured reminiscence (Chao et al., 2006) even if the author termed it life review (Plastow, 2006), or reminiscence that went through life stages in an unstructured way without reflection, evaluation, or connection between past events and current life situations (Hsu & Wang, 2009), studies that used life review purely as a data collection method (Ando, Tsuda, Morita, Miyashita, Sanjo, & Shima, 2014), or as one component of a multi-intervention program (van Schaik, et al., 2014 and van Beljouw, et al., 2015). Furthermore, the author excluded literature reviews, systematic reviews, and meta-analyses, as well as those for which full text access was not available.

Search Outcomes

Searches of the databases produced the following results, after duplicates were removed.

Reminiscence AND intervention AND health yielded 616 unique abstracts (from the original 662 EBSCOhost, 192 PubMed, 127 Web of Science).

“Life review” AND intervention AND health returned 385 unique abstracts (from the original 329 EBSCOhost, 97 PubMed, 54 Web of Science).

“Guided autobiography” AND intervention AND health came back with 9 additional non-duplicating abstracts (6 EBSCOhost, 2 PubMed, 1 Web of Science).

During the retrieval of articles from the databases, there were suggested related articles from which the author identified 31 more abstracts. The author reviewed the abstracts of these 1,041 unique articles, excluded 428 abstracts that did not include reminiscence as an intervention. The author screened the full texts of the remaining 613 abstracts. She scanned the articles to determine whether the interventions were structured, covered the life span, either thematically or chronologically, and were evaluative or reflective. The author included those that met these criteria, regardless of whether the articles used the terms “life review” or not. While scanning articles, the author combed the references of literature reviews, systematic reviews, and meta-analysis that included life review as an intervention. She retrieved 25 articles in this process and added them to the full text articles to be screened.

The author selected 138 articles after this initial screening. She reviewed each article more thoroughly and excluded 37 that met the exclusion criteria. The final selection included 101 articles. *Figure 1* (above) shows the flow of study selection and its results.

Quality Appraisal

Due to the diverse methods of studies included in this review, the author used the Mixed Methods Appraisal Tool (MMAT) (Pluye & Hong, 2014), to guide the quality assessment of the studies reviewed. Studies that did not meet the screening questions, not having clear research questions or objectives, or data collected not adequate to address the research questions, were excluded. For the remainder of the studies, the author used a star system to assess the strength of the evidence from one star (*) for one criterion met to four stars (****) for all criteria met (Pluye & Hong, 2014). To reduce bias in rating, the author performed the quality appraisal independent of the data extraction process to avoid inadvertently favoring studies with positive outcomes. During quality appraisal, she read the articles only to ascertain whether they met the MMAT criteria, which concern only about the methodology, not the outcomes, except the completion rate. No studies were excluded due to their rating.

The MMAT system has several advantages. It offers tools to appraise qualitative, quantitative experimental, quantitative non-experimental, quantitative descriptive, and mixed methods designs. It assesses the methodological quality of the study, based on the four most salient criteria to minimize biased findings for each type of study design. The tool is simple to use while ensuring methodological standards appropriate for the philosophical and practical underpinnings of each study design. Publications on the same study are listed separately to help ease the locating of the articles.

Data Extraction and Synthesis

The author developed a template indicating the types of data to be collected for the review. In addition to the brief citations, the data table includes characteristics of the study participants, the interventions, outcome measures, and the results, plus the star system from the

MMAT guidelines. Additionally, the author grouped studies by outcomes pertaining to connections to other people, connections to the society, and health. Finally, the author separated out studies that elucidated the mechanisms by which life review affects health.

Results

Study Characteristics

Overall, the studies reviewed are diverse in designs, settings, types of participants, intervention formats, outcome measures used, and analysis methods. There were 58 articles reporting on studies using experimental designs, and 13 quasi-experimental (non-randomized comparison groups), 17 descriptive quantitative (mainly one group, pre- post- design), and 13 qualitative inquiries using various methods but most common were phenomenology and text analysis. Nine articles on mixed methods studies gave qualitative insight into the statistical results. In all, 33 studies took place in Asia, including the Middle East, 27 in Europe, and 41 in the Americas. There were 37 studies on institutionalized participants and 68 on those who lived in private homes or in retirement communities, including six that included both. Thirty-eight studies involved life review intervention with individual participants; nine in dyads, triads, or family units; and 58 in groups, among which nine were with intergenerational participants. Of the 101 studies, five focused on minority populations (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008; Bernstein et al., 2016; Cho et al., 2013; Shellman, 2016; Shellman, Mokel, & Hewitt, 2009), two of which are immigrants (Bernstein et al., 2016; Cho et al., 2013). More than half of the studies (61/101 or 58%) had depression as the primary outcome variable. One-fifth (21/101 or 20%) focused on persons with dementia. Twelve articles reported on studies that concentrated on the spiritual well-being for participants receiving end-of-life care or bereaved family members. These make up one third of studies that focused on spiritual well-being, measured by

meaning in life. Table 1 summarizes the types of study designs included in this integrative review.

Table 1

Summary of the Studies Reviewed by Designs and MMAT Scores

MMAT Score	Randomized Controlled Design	Non-randomized Comparison Design	One-Group Pre- Post- Intervention Design	Qualitative	Mixed Methods	Total by MMAT score
* MMAT	0	0	0	0	0	0
** MMAT	14	4	8	0	2	26
*** MMAT	16	11	11	5	5	43
**** MMAT	28	0	0	4	0	32
Total by design	58	15	19	9	7	101

Note: Mixed methods included 6 studies using one-group pre- post-intervention design and 1 study using a non-randomized comparison group design, all with a qualitative component. The quantitative designs are counted under the respective quantitative columns as well as in the Mixed Methods column.

There were more outcome measures (129) used than there were studies. Ninety percent of the studies examined the effects of life review (LR) on social connections and 88% studied its effects on health. Some did both. Two kinds of social connections were examined: (1) connections to other people, such as the participants' relationships with other people, communication, understanding, appreciation, etc., and (2) connections to society, or how the participants perceived the self vis-à-vis the social environment, such as self-esteem, ego integrity, meaning in life, or life satisfaction, etc. Studies that looked into the effects of LR on the participants' health, considered unwell conditions such as depression or dementia, or aspects of wellness, such as psychological well-being, or spiritual well-being, etc. Table 2 summarizes selected characteristics of the studies included in this review.

Table 2

Summary of Selected Characteristics of the Studies Reviewed

Study Characteristics	Randomized Controlled Design	Non- randomized Comparison Design	One-group Pre- Post- intervention Design	Qualitative	Mixed Methods	MMAT Score			Total	
						(**)	(***)	(****)		
All	58	15	19	9	7				101	
Settings	Institutionalized	25	3	8	1	4	11	13	13	37
	Community- dwelling	35	14	12	13	5	16	32	20	68
Format	Inter- generational	2	2	3	2	1	2	5	2	9
Participants	Minorities	2	2	0	1	0	2	2	1	5
Primary Outcome Variable	Health	56	12	17	4	6	23	35	30	89
	Connections to society	48	13	13	7	6	18	34	29	81
	Connections with others	18	10	9	9	4	12	21	14	47

Note: Six studies included both community-dwelling and institutionalized participants. The total of studies in both settings will be more than 101. Mixed methods included 6 studies using one-group pre- post-intervention design and 1 study using a non-randomized comparison group design, all with a qualitative component. The quantitative designs are counted under the respective quantitative columns as well as in the Mixed Methods column.

Life Review and Social Connections

Ninety percent (91/101) of the articles reviewed examined the effects of LR on social connections. Studies considered a range of variables and used a diverse number of instruments to measure those variables. Fewer articles (47) evaluated the effects of LR on the participants' relationships with other people than those that studied participants' relationships with society (81). Some (8) considered both. There did not seem to be any pattern between the length of the intervention and its effectiveness in social connections.

Connection to other people. The majority of studies that examined the effects of LR on connections to other people were group, dyad, triad, or family interventions. Qualitative results of group intervention studies showed participants having appreciation for each other, improved empathy and understanding, and improved communication, particularly intergenerational studies (Chippendale & Boltz, 2015a). Although small in number, the evidence on the effects of LR on human connections came from studies with strong MMAT scores, i.e. sound methodology. Among them, seven mixed method studies, including two randomized controlled trials (Allen et al., 2008; Chippendale & Boltz, 2015a), had qualitative components that corroborated and elaborated quantitative findings of improved human connections. In an experiment in a group home with an attention control group, the author found that, by the end of the LR intervention, members of the intervention group attended group activities more and socialized with more people than before the intervention, whereas the attention control group did not (Fielden, 1990). The author postulated that "reminiscing enabled people to relate to each other and encouraged a socialization process" (Fielden, 1990, p. 32).

The results of three studies in this group stood out as different from the rest. One study found that LR did not have significant effect on any of the study's variables, except for family

relationship (Charlesworth et al., 2016). However, this effect may not be attributable to LR (Charlesworth et al., 2016). This study was a large experiment (n=291 dyads) with factorial design and four MMAT stars. Two other studies found no significant improvement in human connections in LR participants, one was a randomized controlled trial with an attention control and a no-intervention control, using individual LR format (Lai, Chi, & Kayser-Jones, 2004) and one involved a one-group pre-post design, using group LR format (Lin, Li, & Tabourne, 2011). These three studies differed in the primary measures used for human connections but all worked with people with dementia.

The remainder of the studies (44/47) reported that LR had a positive association with improvement in the relationship of participants with other people closest to them or around them, or with other LR participants. The participants ranged from seriously-ill patients (Ando, Morita, Akechi, & Takashi, 2012), bereaved family members (Ando, Sakaguchi, Shiihara, & Izuhara, 2015), institutionalized elderly people with or without dementia (Chiang et al., 2010; Dahley & Sanders, 2016; Fielden, 1990; Wren, 2016), to people with and without depression living in the community (Arkoff, Meredith, & Dubanoski, 2004; Binder et al., 2009; Chung, 2009; Keisari & Palgi, 2017; Subramaniam, Woods, & Whitaker, 2014; Tabourne, 1991; Zuccherro, 2009). Nine studies were with intergenerational participants by design.

Connection to society. Eighty percent (81/101) of all articles reported on the examination of LR on participants' connections to society. Individuals' relationships with society often manifest in how the individuals feel about themselves in society. Constructs such as self-esteem, ego integrity, social identity, quality of life, life satisfaction, meaning in life, or purpose in life all represent how the individuals perceived themselves and their life in the context of societal norms and expectations, and societal treatment of them. Studies used more than fifty

different instruments to measure these constructs. Some commonly used ones were Ego Integrity Scale (EIS; Boylin, Gordon, & Nehrke, 1976), Purpose in Life (PIL; Crumbaugh & Maholick, 1964), Pearlin Mastery Scale (PMS; Pearlin & Schooler, 1978), and the Rosenberg Self-esteem Scale (RSES; Rosenberg, 1965).

The results for the effects of LR on participants' connections to society were more mixed than were connections with other people. Approximately 37% (30/81) of the articles reported null effect of LR on some aspects of the participants' connection to society, 40% (12/30) of the interventions were individual format, while the remainder were of group, dyad, or triad formats. Among these articles, 73% (22/30), received three or four stars on the MMAT quality appraisal system. Conversely, 65% (53/81) of the articles reported significant expected effects on various aspects of connections to society, with no null effect, 47% (25/53) of which were of individual format and 62.5% (40/53) of which scored three or four MMAT stars.

Life Review and Health

Eighty-eight percent (89/101) of the articles reviewed examined the effects of LR on health. The majority of these articles (70/89 or 79%) used depression as the primary outcome, sometimes alone, other times with other outcomes such as anxiety or life satisfaction. Articles on studies in spiritual well-being, which was defined as having meaning in life, a purpose for living, and peace of mind, or having a relationship with a transcendent being (Ando, Morita, Miyashita, et al., 2010), overlapped with connections to society and were included in the previous section. Twenty-two percent of the articles on health (20/89) focused on the effects of LR on people with dementia. Fifty-seven percent of articles (51/89) that studied the effects of LR on health received three or four stars on the MMAT system.

All but two studies found some significant effects of LR on the health indicators used. One of the two studies that did not find any effect (Lai et al., 2004) used an individual intervention format, measured health by the Well-being/Ill-being Scale (WIB; Beavis, 1998), and received three MMAT stars. The other (Lin et al., 2011) received two MMAT stars, used a group intervention format, and measured health by the 36-item Short Form Health Survey (SF-36; Ware, Snow, Kosinski, & Gandek, 1993). Participants in both studies were people with dementia (Lai et al., 2004; Lin et al., 2011).

Studies that used depression as a measure of health found near universal positive effects of LR. Participants ranged from healthy, community-dwelling, non-depressed adults over age 50 (Latorre et al., 2015), to people at risk of developing depression such as wives of individuals with alcoholism (Cho, 2008), empty-nesters (Choy & Lou, 2016), new residents of long-term-care facilities (Haight, Michel, & Hendrix, 1998), bed-bound terminally-ill cancer patients (Ando, Morita, & Akechi, 2010), bereaved caregivers of someone who died of cancer within the last 2 years (Ando, Marquez-Wong, Simon, Kira, & Becker, 2015), adults with mild to moderate depression living at home (Mastel-Smith, McFarlane, Sierpina, Malecha, & Haile, 2007), immigrant Korean-American women with depression (Cho et al., 2013), and war veterans with PTSD (Daniels, Boehnlein, & McCallion, 2015). Studies that reported effect sizes found medium to large effect (Cohen's $d=0.5$ to 1.13) (Cho et al., 2013; Pot et al., 2010; Preschl et al., 2012) and maintained significance at 3 months post-intervention (Preschl et al., 2012). Some of the commonly used measures of depression were the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977; Hann, Winter, & Jacobsen, 1999), the Geriatric Depression Scale (GDS; Yesavage et al., 1983), the Hospital Anxiety and Depression Scale (HADS, Zigmond &

Snaith, 1983), and the Hamilton Rating Scale for Depression (HRSD; Hamilton, 1992). There was no discernable pattern between the length of the intervention and its effectiveness on health.

Mechanisms of the Effects of Life Review on Health

Four of the articles reviewed examined the mechanisms through which LR affected depression (Korte, Cappeliez, Bohlmeijer, & Westerhof, 2012; Korte, Westerhof, & Bohlmeijer, 2012; Lamers, Bohlmeijer, Korte, & Westerhof, 2015; Westerhof, Bohlmeijer, van Beljouw, & Margriet, 2010). The researchers found that LR was associated with depressive symptoms and that this effect was mediated by other processes. In a randomized controlled trial (RCT), Westerhof and colleagues (2010) found that the effects of the 12-session LR intervention called “Looking for Meaning” on the depression of 171 participants were mediated by meaning in life partially immediately post-intervention and fully at 9-month-post-intervention follow-up. In two separate articles, researchers (Korte, Cappeliez, et al., 2012; Korte, Westerhof, et al., 2012) reported on another RCT with 202 participants, using the 8-session LR intervention called “The Stories We Live By.” The researchers found that the effect of reminiscence on depression and anxiety was mediated by meaning in life, mastery, and positive thoughts, with positive thoughts being the most significant mediator. Meaning in life, mastery, and positive thoughts all reduced depression and anxiety. Testing the same intervention, “The Stories We Live By,” with an attention control and a wait-list control, Lamers and colleagues (2015) found ego integrity and rumination partially mediated the effects of LR on depressive symptoms. Taken together, these studies showed that life review interventions promoted the psychological well-being of participants by enhancing their perceptions of themselves and their lives in the context of the larger society, or their connection to society.

Discussion

Research Question 1: How Does Life Review Affect Social Connections?

Results from this review showed promising effects of life review on social connections.

Connection with other people. Reminiscence scholars have theorized that two of the three groups of reminiscence functions were social: transferring knowledge and wisdom and connecting with others through stories (Cappeliez, O'Rourke, & Chaudhury, 2005). Therefore, it was curious that only a small number of studies reviewed stated their primary purpose was to improve the participants' relationships with others. Even when studies did not have connection with other people as a purpose, if there was a qualitative component in the study or if findings were verified by observations from staff of residential homes, positive effects were found with participants having greater appreciation for each other, improved empathy and understanding, particularly intergenerational studies (Kim & Lee, 2017). In addition, residents of long-term care facilities became more socially active (Fielden, 1990; Tabourne, 1995; Wren, 2016). Most noteworthy is the dearth of validated measures to quantify this effect.

Connection to society. In contrast, studies that examined the effects of LR on connection to society employed a myriad of instruments—more than 50—to measure a variety of constructs. Examples of these constructs are life satisfaction, quality of life, ego integrity, self-esteem, mastery, meaning in life, sense of purpose, and more. The mixed results for this effect may be due to the different ways the phenomenon was defined and measured. Other possible explanations are the diversity of the population under study, the variety of the interventions employed, with duration from 30 minutes to 2 hours, and number of sessions from 2 to 72.

Haslam and colleagues (Haslam et al., 2010; Haslam et al., 2014) suggested another possible reason. Studying the effect of social identification and group LR interventions, the

researchers found initial identification with the study group and identification with the care community predicted greater positive effects of LR on life satisfaction and cognitive functioning (Haslam et al., 2010; Haslam et al., 2014). This maybe the reason for the mixed results from different RCTs; perhaps participants did not identify with the group they were part of.

Furthermore, researchers found that integrative reminiscence, reminiscence to constructively reframe past experiences and find meaning in life, was more effective and sustained the effects better than instrumental reminiscence, which uses past experiences to problem-solve current and future issues (Watt & Cappeliez, 2000). This may partially explain the mixed results that studies in this review presented. Interventions used by studies in this review varied in their emphases regarding the different functions of reminiscence.

Research Question 2: How Does Life Review Affect Health? Through Which Processes?

There is strong evidence that life review reduces depression in a wide range of populations, from community-dwelling people (Latorre et al., 2015; Serrano et al., 2013) to those in long-term care facilities (Morgan & Woods, 2012; Su, Wu, & Lin, 2012; Wren, 2016), from young people with life-limiting health conditions (Ando, 2003) to the elderly, and the middle aged (Lamers et al., 2015), from the terminally-ill to the bereaved family members (Ando, Marquez-Wong, et al., 2015; Ando, Morita, & Akechi, 2010). Effect sizes (Cohen's *d*) ranged from 0.50 to 1.13, which are comparable to the overall effect size found by previous meta-analysis (Bohlmeijer, Smit, & Cuijpers, 2003). Moreover, the reduction in depression due to LR was maintained at 3-month and one-year follow-ups. Findings from respectably sized RCTs suggest that LR reduces depression by enhancing the participants' connections to society, specifically meaning in life, mastery, ego integrity, and positive thoughts, and by reducing rumination. Korte and colleagues (Korte, Bohlmeijer, Cappeliez, Smit, & Westerhof, 2012;

Korte, Majo, Bohlmeijer, Westerhof, & Smit, 2015) found that participants in LR were twice more likely than controls to move out of clinically depressed designation based on CES-D scoring. Calculating the total costs of the intervention, the researchers estimated that for a 5-point reduction of CES-D score, the costs were approximately US\$ 10,000 per year per person.

Research Question 3: What Are the Gaps and Challenges?

Life review to promote holistic health and population health. Most studies reviewed considered one aspect of health, such as decreased depression, better cognitive functions, psychological well-being, or spiritual well-being. While there is evidence that psychological well-being and spiritual well-being do affect bio-physiological well-being, nearly no study explored the effects of life review on holistic health. One study (Lin et al., 2011) used the SF-36 measure (Ware, Snow, Kosinski, & Gandek, 1993), which includes the one-item holistic self-rated-health question, plus 35 other questions pertaining to various aspects of a person's quality of life. Furthermore, there is a dearth of studies on healthy people and those under age 50. For young and healthy populations, interventions that promote general sense of health may be more applicable than prevention of unwell conditions.

Furthermore, the majority of the studies reviewed focused on individual health. At the very most, life review in long-term care facilities might be considered population health focused. In long-term care facilities, the social connection effects of life review on participants diffused into the institutional environment and impacted the whole institution. Very few studies measured this impact other than anecdotal comments from participants, their families, and the staff. With its promising effects on social connections, it would be prudent to examine the effects of life review on the social environment with a focus on population health.

Intergenerational life review to promote social connections and health. Given that intergenerational life review studies received excellent evaluations from participants and achieved positive qualitative results, this is an area worth exploring further with validated instruments to measure social connections and holistic health. Furthermore, an intergenerational approach to life review may be beneficial for interventions to promote population health and to impact the social environment given its capacity for the diffusion of effects.

Life review for refugees, immigrants, and culturally displaced populations. Despite the ongoing crisis of displaced people, including refugees, immigrants, and otherwise culturally displaced populations, there is a dearth of studies on the efficacy of LR intervention on the health of these populations. Moreover, these populations often came from an oral tradition, which lends itself well to LR intervention. Only two studies in this review examined the effects of LR on an immigrant population, Korean-American women. These studies found lower depression and higher meaning in life in participants of LR compared to comparison groups, with an effect size of 0.50 (Bernstein et al., 2016; Cho et al., 2013). Given that there is much discord among generations of culturally displaced populations, having intergenerational LR research on their holistic health and social connections may help reduce the health equity gap experienced by these populations. In addition, LR is a promising intervention to help restore meaning in life and self-worth to populations that suffered unimaginable loss of identity, dignity, and livelihood.

Research Question 4: Proposed Conceptual Framework for Future Research

In short, findings from this review show that LR creates opportunities for enhanced interactions between the storytellers and the listeners. It connected people by eliciting empathy and facilitating understanding. It helped people reframe life events into meaningful experiences, thus improving their sense of self, meaning in life, and perceived ability to manage their

environment (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007; Westerhof & Bohlmeijer, 2014), leading to reduced depression and better health.

Based on the evidence presented, the following conceptual framework is proposed to study the effect of intergenerational life review on social connections and health for refugees, immigrants, and other culturally displaced populations. In this framework, social connections are represented by two constructs: (1) connections with other members in their community or community cohesion, and (2) dis-connections with society or cultural displacement. Health is denoted by the holistic measure self-rated health.

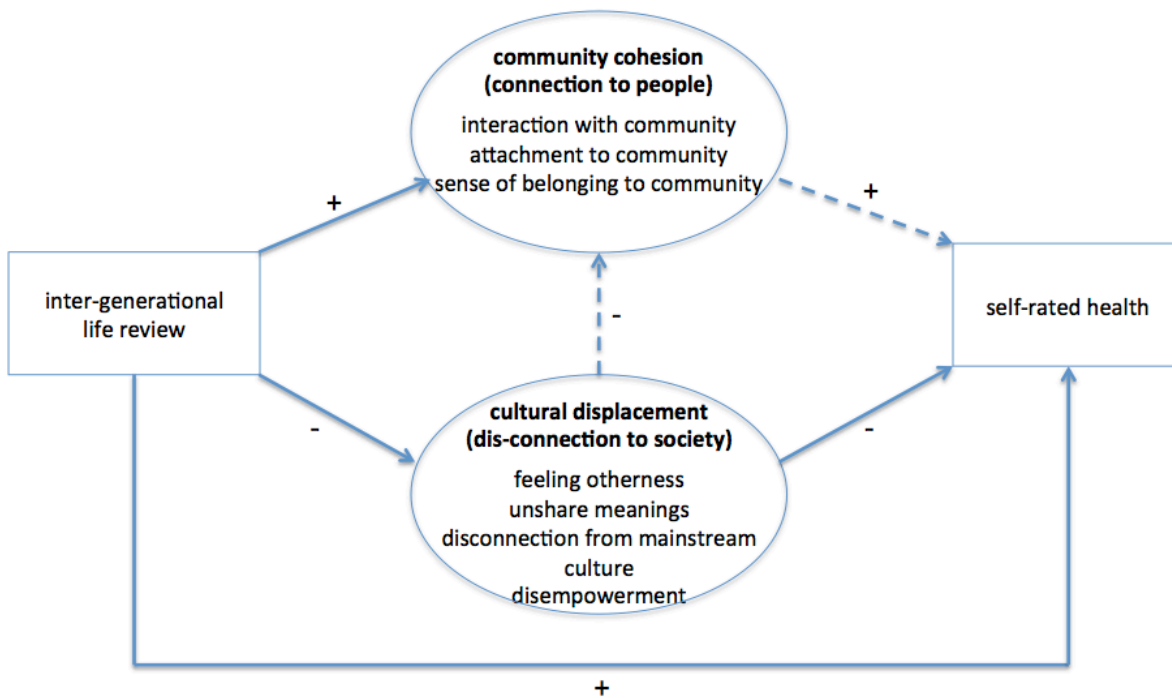


Figure 2. Model of Intergenerational Life Review and Health.

Arrows indicate the paths and directions of influence. Signs represent positive (+) vs. negative (-) relationships. Dashed lines signify hypothesized relationships not from the results of this review.

The Human Response Model

The Nursing Human Response Model (Heitkemper & Bond, 2003) consists of three interrelated components. The person factor is characteristics of the individuals, families, populations, or communities under study, such as age, gender, being disabled, or feeling culturally displaced, that make the “person” susceptible to or protected from ill health. The environment factor is an attribute of the physical or social milieu in which the individuals, families, populations, or communities function that may jeopardize or promote their health. Such attributes include, but are not limited to, clean air, safe neighborhood, and cohesive community. The human response factor, manifested as health, is comprised of physiological, experiential, psychological, or behavioral conditions. Self-rated health, as demonstrated by quantitative and qualitative work of many researchers, is the inclusion of all these aspects of health, the physiological (Jylha, 2009), experiential (Weerasinghe & Mitchell, 2007), and behavioral (Bailis, Segall, & Chipperfield, 2003). Thus, in *Figure 2*, cultural displacement represents the person factor, community cohesion represents the environment factor, and self-rated health represents the human response factor in the Human Response Model.

The Intersectionality Framework

The choices of variables for the model reflect principles of the Intersectionality Framework, which posits that: (1) people’s experiences are multi-dimensional and situated at the intersections of multiple socially constructed identities such as gender, race, ethnicity, socioeconomic status, or cultural displacement; (2) those experiences are influenced by complex socio-cultural contexts in which the identities exist, such as a cohesive community; and (3) the experiences of marginalized populations be discussed from their vantage points and their contexts, not as deviance from a reference group (Bowleg, 2012). The model focuses on how the

researched population feel living in the dominant culture (cultural displacement), how they feel towards their community (community cohesion), and how they perceive their own state of well-being (self-rated health) with the proposed intervention that builds on their assets (their life stories). By examining the relationships between cultural displacement and community cohesion, instead of acculturation and health behaviors, the proposed framework acknowledges and focuses on the social-cultural conditioning that rendered certain differences as inferiority and being The Others, creating the feeling of cultural displacement, or a sense of otherness in the mainstream society. Potentially, cultural displacement adds greater significance to the role of community cohesion on health, where people feel a sense of belonging to their community compensating for the sense of otherness from the mainstream society. The selection of intergenerational life review as an intervention acknowledges that agency exists within these marginalized populations, and that potential solutions may not depend entirely on assistance from helping professionals or the more privileged sections of society.

Strengths and Limitations

The major strength of this review is also its limitation. The broad inclusion criteria allow for a selection of studies with diverse designs, theoretical underpinnings for the intervention, and study populations. As such, the studies included provide an overview of the range of therapeutic and format possibilities of life review that are applicable to a variety of disciplines and research interests. The inclusion of qualitative studies and case examples helped elucidate the inner processes of the effects seen in quantitative results, which were sometimes not statistically significant but were of importance to the study participants. The diversity of study designs, intervention formats, and study populations also limits the ability to compare results and draw definitive conclusions about the effectiveness of life review intervention on social connections

and health. Although comprehensive, the design of this integrative review meant that an unknown number of works on the effects of life review were left undiscovered by the author. Unpublished dissertations and non-academic reports were not included. Studies not in English or not indexed in the databases to which the author had access were left out. Although not exhaustive, this review highlights where the strengths of evidence on the efficacy of life review are, namely, its protective effects on depression and its therapeutic capacity among the elderly and the cognitively impaired, and where opportunities for future research lie: life review impact on social connections and holistic sense of health, on population health, on the young and healthy, and the culturally displaced populations.

Conclusion

In the words of psychologist Miller Mair (1990),

“Our lives are... shaped in the stories we live, and the quality of our experience is textured by the stories we tell and the ways in which telling is allowed. When a person is not able to tell her story, she is impoverished and crippled. When a person does not hear herself reflected in the stories being told about her kind, she is deprived of elements of awareness that give legitimacy and perspective and a certain reality to her life” (p. 123).

For refugees and immigrants, especially in today’s culture of vilifying them and their pursuit of life, the stories that they do not hear being told in the mainstream discourse negate their very existence. For the first generation of refugees and immigrants to be able to tell the younger generations of their experiences, and for the youngsters to tell their elders of their experiences, is to affirm that their lives exist, their experiences matter, and their stories invaluable. The current integrative review adds to the growing literature on life review with a focus on its effects on social connections, which mediates life review protective effects on well-

being. The review highlights the opportunities for future studies on the effects of life review, particularly the intergenerational format, on population health, on promoting a general sense of health among the young and healthy, as well as healthy elderly, and on the culturally displaced. The author proposed a conceptual framework for this line of inquiry, the Model of Intergenerational Life Review and Health.

*I do not know where I am going,
where I have come from is disappearing,
I am unwelcome and
my beauty is not beauty here.
My body is burning
with the shame of not belonging,
my body is longing.
I am the sin of memory
and the absence of memory.*

Warsan Shire, Teach My Mother To Give Birth

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**Chapter 3. Community Participatory Action Research Among Ethnic
Vietnamese in the U.S.: Challenges and Opportunities**

Abstract

Vietnamese-Americans rate poorly on many health indicators compared to other ethnic groups. Researchers have conducted several community participatory research projects with Vietnamese-American communities with positive health outcomes and enhanced community capacity, contributing to narrowing the health equity gaps. *Stories of Us - Chuyện Kể Nhau Nghe* uses a community participatory action research (CPAR) approach to bring generations of Vietnamese-Americans together to share stories, promote social connections, and improve health. Lessons learned from the CPAR approach include: mutual trust and respect gained from long-term community involvement facilitated access to community groups; recognition and application of community untapped resources to address community issues created ownership, promoted a sense of empowerment, and helped build capacity; dedicated, consistent, and persistent investment of time and expertise contributed to the sustainability of health promotion activities and their impact. Others can apply these strategies to narrow the health equity gap for their communities.

keywords: participatory action research, community-based participatory research, community participatory action research, health equity, health promotion, community empowerment

Introduction

Along with other minority groups, Vietnamese-Americans experience health inequities acutely. They have high rates of lung cancer, liver cancer, cervical cancer, and depression (Nguyen, McPhee, Bui-Tong, et al., 2006). Vietnamese-American elders have among the lowest general health (Zhang & Ta, 2009) and among the highest rate of depression and perceived cultural gaps with their adult children (Mui & Kang, 2006). Researchers found that family cohesion is a protective factor in the health of Vietnamese-American elders (Zhang & Ta, 2009).

Furthermore, several reviews found that community-engaged research using a participatory approach whereby the community plays active roles in the research process shows promising results to narrow the health equity gaps, but the evidence is still insufficient for conclusion (Braun et al., 2015; Cargo & Mercer, 2008; De Las Nueces, Hacker, DiGirolamo, & Hicks, 2012). There have been several community-based participatory research projects with Vietnamese-American communities in different parts of the U.S. to address the cancer health equity gap with positive results (Nguyen & Belgrave, 2014; Nguyen, McPhee, Gildengorin, et al., 2006; Nguyen-Truong et al., 2012). However, to date, there is a paucity of research to improve the general health of Vietnamese-Americans or to promote social connectedness or community cohesion.

Stories of Us - Chuyện Kể Nhau Nghe is a community participatory action research project that builds on community tradition and utilizes community assets to strengthen intergenerational bonds within the community; thereby creating a socially cohesive environment that promotes general health. The purpose of this chapter is to examine the experiences of researchers applying the community participatory research approach with ethnic Vietnamese and compare the experience of the *Stories of Us - Chuyện Kể Nhau Nghe* to glean lessons learned for

future community participatory research to help narrow the health equity gap. The chapter will begin with definitions and set the contexts for community participatory research in order to answer the following research questions:

1. What is the current knowledge regarding employing community participatory action research with ethnic Vietnamese in the U.S.?
2. What are successful strategies employed by researchers in overcoming the challenges of conducting community participatory action research among ethnic Vietnamese in the U.S.?
3. How does the experience from the *Stories of Us* study compare to those described in the literature?
4. What new lessons can be learned from *Stories of Us* in implementing community participatory action research among ethnic Vietnamese in the U.S.?
5. How can these lessons be generalized to the implementation of community participatory action research among other immigrant and refugee populations? Other minority groups?

Current Knowledge in the Literature

Definition and Context

In this dissertation, “community” denotes the population who is the center of the research and whom the research is intended to benefit; “participatory” indicates that the community will be active players in the research process; and “action” connotes implementing solutions to community-identified issues. Community participatory action research falls under the umbrella of a group of studies that subscribe to the school of thought in which the researched are not mere subjects under study but active participants throughout the stages of the research (Cargo &

Mercer, 2008). Furthermore, while striving to maintain scientific integrity, community participatory action research emphasizes implementing solutions to address community issues (Cargo & Mercer, 2008).

This broad umbrella can be called participatory research (PR), which includes research by many names – community-based participatory research (CBPR), participatory action research (PAR), emancipatory research, and more (Wallerstein & Duran, 2008). Researchers traced PR research to three movements, the 1940s with Kurt Lewin’s quest for research to solve problems, the 1970s with Paulo Freire’s influence to turn the researched from objects to be researched on to partners to do research with (Wallerstein & Duran, 2008), and the self-determination movement of indigenous peoples worldwide (Cargo & Mercer, 2008). Regardless of its name and roots, participatory research (PR) can be broadly defined as the “systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of ... effecting change” (Cargo & Mercer, 2008, p. 327).

Stories of Us - Chuyện Kể Nhau Nghe is termed community participatory action research to emphasize both the active participation of the community and the action-oriented nature of the study with the community as the driver of the process, albeit with co-pilots such as scientific rigor and ethical considerations in research.

Participatory Research in General

Participatory research has three core elements: (1) mutual respect and trust; (2) capacity building, empowerment, and ownership; and (3) accountability and sustainability (Cargo & Mercer, 2008). The degree to which these elements exist in research occurs on a continuum with the ideal end entailing an equitable partnership between the researcher and the researched that is built on mutual respect and trust. In such climate of mutual respect and trust, the partnership

creates equitable opportunities for power sharing and governance, and for the researchers to build capacity to conduct PR and work with the community, and the researched to build capacity in all aspects of the research process. Members of the partnership are accountable to each other and to the funders to achieve the research goals and sustain the partnership, its capacity, infrastructure, and the research products beyond one funding cycle (Israel, Eng, Schulz, & Parker, 2012).

There are other ways to describe PR, such as the nine key principles for conducting CBPR (Israel, Schulz, Parker, Becker, Allen, & Guzman, 2008). Except for the first principle, recognizing the community as a unit of identity, the remaining eight principles can be applied to operationalize the aforementioned three elements. For example, the second principle states that CBPR builds on strengths and resources exist within the community. By recognizing community strengths and resources, the researcher is more likely to earn trust and respect from the community. By building on those strengths and resources, the researcher can work toward empowerment and ownership, and facilitate the sustainability of the project and its impact. The author uses the three core elements outlined by Cargo and Mercer (2008) for their parsimony.

In the U.S., PR has gained notice among mainstream researchers only recently, mostly under the rubric of CBPR. Evaluations of efforts to apply CBPR to improve health equity among underserved communities, including racial and ethnic minorities, credited the active participation of the community in the research process to strides made in research methods among previously under-researched communities (Braun et al., 2015). Those improvements included increasing recruitment, retention, and data completeness; creating more culturally relevant measurements and interventions; consequently, improving community knowledge on the health issues under study; and increasing and expanding the capacity of community partners,

including the training of new minority researchers (Braun et al., 2015). Still, very few CBPR studies reported engaging the community in data analysis or dissemination (De Las Nueces et al., 2012). To succeed, PR requires time and resource commitment, an iterative power sharing process, and the balancing of research needs with community need for action. Moreover, the researchers should understand that the community definition of “community” may change and differ from the researchers’ (Braun et al., 2015). PR adds value to both academic and non-academic partners. Future PR efforts should focus more on the balance of scientific standards with social and cultural validity, the measurement of intervention effects, the improvement of empowerment and ownership, and the generalizability of the research findings (Cargo & Mercer, 2008).

Participatory Research with the Vietnamese Populations

A search of the databases—Academic Search Complete, CINAHL, MEDLINE, and Web of Science—for publications on PR among Vietnamese yielded 57 articles that reported on studies using PAR or CBPR with the Vietnamese populations. Some PR studies on Vietnamese outside of the U.S. were reviewed. There may be useful cultural considerations in working with Vietnamese in Việt Nam, where Vietnamese are the majority. In many cases, researchers from affluent nations conducted PR studies with Vietnamese in Việt Nam. The challenges that they encountered may be similar to mainstream researchers working with Vietnamese minority elsewhere. Therefore, articles about PR work in Việt Nam were included. Vietnamese immigrants and refugees around the globe share the sense of displacement as well as other disadvantages of being in the minority. Therefore, studies with Vietnamese immigrants and refugees outside of the U.S. were included.

Nearly all studies on health focused on specific conditions, such as asthma (Ngo, Kilgore, Tran, & Galant, 2014), cancer screenings (Nguyen & Belgrave, 2014), tobacco cessation (Burgess et al., 2014), or exposures to occupational and environmental hazards (Azaroff, Hoa Mai, Do, Gore, & Goldstein-Gelb, 2011). A subset of these also worked on affecting changes at the system levels, such as establishing a patient navigator program (Nguyen, McPhee, Bui-Tong, et al., 2006) and advocating at the local and federal levels to protect workers' health (Quach et al., 2012). A few focused on health literacy (Goeman et al., 2016), stigma (Gaudine, Gien, Thuan, & Dung, 2009), disaster preparedness (Nepal, Banerjee, Slentz, Perry, & Scott, 2010), and empowerment (Yang, Wang, Lee, Lin, & Lin, 2015). One cross-sectional study examined social connectedness and depression among elders (Kim et al., 2015). There was no intervention study using PR to promote the general sense of well-being and community cohesion among ethnic Vietnamese.

Articles vary regarding the level of details provided on the PR process. Some did not define PR or describe the process (Humphreys & Wyatt, 2014; White & Oosterhoff, 2013). When defined, the three core elements of PR—(1) mutual respect and trust; (2) capacity building, empowerment, and ownership; and (3) accountability and sustainability—were reflected on a continuum from none (Humphreys & Wyatt, 2014; White & Oosterhoff, 2013) to full articles (Quach et al., 2012). Some defined and described the community partners and how they were involved in the research but did not elaborate on the relationship building or power sharing process, and did not offer any lessons learned from the process (Gregg, Nguyen-Truong, Wang, & Kobus, 2011).

The following sections describe how the three core elements of PR were reflected in study reports of PARs or CBPRs conducted with the Vietnamese populations.

Mutual respect and trust. Mutual respect and trust are the foundation for a successful partnership (Minkler, 2010), which is the cornerstone for PR. Most articles did not mention mutual respect and trust. When mentioned, it was about the research participants expressing feeling respected and the researchers being successful at gaining trust from the community (Yang et al., 2015). It was rare that articles stated unambiguously that respect and trust were mutual. Commonly, respect and trust must be inferred from the description of the relationship building process (Nguyen & Belgrave, 2014) and the involvement of the community partners (Quach et al., 2012). In some articles, trust and respect for the community must be deduced from the choice to solicit community input into instrument and/or intervention development (Crawford, Frisina, Hack, & Parascandalo, 2015). In such articles, there was no indication of an attempt to gain respect or trust from the community before data collection. It is possible that mutual respect and trust had been cultivated and established. These elements just were not stated plainly in the reports.

Successful strategies to earn respect and trust. Nevertheless, a few articles described in detail successful strategies to build and nurture trust and respect. Without exception, these projects had key personnel who were bilingual, bicultural Vietnamese-Americans who have had long-term involvement in the community and have earned widespread trust and respect from the community (Nguyen & Belgrave, 2014). For projects not having such insiders on staff, Nepal and colleagues (2010) recommended cultivating and building relationships with community-based organizations (CBOs) who serve the populations of interest. They found using facilitators from the community to conduct focus groups in the language of the community more effective in gaining trust than contracting professional interpreters. However, they stressed the importance of finding someone familiar with the research process. In one of the long-standing and

successful health promotion PR, to demonstrate trust and respect, researchers remarked that members of the research-community partnership shared funding to remunerate partners for expertise and services delivered and to defray the costs of participation (Nguyen, McPhee, Bui-Tong, et al., 2006).

In Santa Clara County, California, researchers found some unique aspects in gaining trust and respect and relationship building with the Vietnamese-American community there (Bang Hai, Nhien Thien, Kim Thien, Marlow, & Quyen Ngoc, 2016). While conventional wisdom recommends formalization of partnerships in writing, spelling out clearly expectations and responsibilities, Bang Hai and colleagues (2016) intimated that the community partners of the Vietnamese Reach for Health Coalition preferred informal relationships without written documentation. The authors remarked “Honoring the expectations without writing them down conveys a deep and intimate sense of trust that is influenced by shared cultural understandings rather than directed by research or institutional framework” (Bang Hai et al., 2016, p. 213). While some studies reported that personal relationships within a partnership hindered inter-organizational relationships (Wells, Ford, McClure, Holt, & Ward, 2007), within the Vietnamese Reach for Health Coalition partners, deep inter-personal relationships based on long-time collaborations nurtured inter-organizational relationships (Bang Hai et al., 2016).

Capacity building, empowerment, and ownership. With mutual respect and trust, the community-research partnership can create structures for equitable decision-making power, capacity building, empowerment, and ownership. All are parts of the key principles of participatory research (Wallerstein & Duran, 2008). Similar to mutual respect and trust, in the articles reviewed, description, reflection, and evaluation of capacity building, empowerment, and

ownership span a continuum from none (Canfield et al., 2016) to the entire article (Connie Kim Yen, Tang, & Hsiao, 2017; Nguyen, McPhee, Bui-Tong, et al., 2006; Quach et al., 2012).

In most articles, it was unclear what kind of power sharing took place, if any. In one study, the authors implied having focus group facilitators that spoke the language of the community as representation and power sharing (Crawford et al., 2015). There was no indication in the article on what made these facilitators representatives of their communities other than their ethnicity alone, and what decision-making power they had other than being the focus group facilitators. Others (Yang et al., 2015) described incorporating participants' feedback on the intervention curriculum, previously determined by the researchers, into subsequent sessions as a demonstration of empowerment and equalizing the power differential between the researchers and the community.

Quite commonly, the involvement of the Vietnamese community was described to reflect a standpoint that they are valued as partners in producing culturally appropriate and relevant contents for an intervention (Goeman et al., 2016; Humphreys & Wyatt, 2014). Beyond that, the learning occurred only one way, the community learned from the researchers and/or the research. There was no sense in the articles that the community was considered a partner in knowledge creation. There was no indication that capacity building in the community was a goal or an aspiration in these projects (Goeman et al., 2016; Humphreys & Wyatt, 2014).

Successful strategies for capacity building, empowerment, and ownership. Some research projects demonstrated significant investment in capacity building, empowerment, and ownership with substantial returns. In Santa Clara County, California, the Vietnamese Reach for Health Coalition involved members of the coalition, which included community members and CBOs, in all stages of the research process, from identifying the health issues to planning, data

collection, data analysis, and dissemination (Bang Hai et al., 2016). Community partners were compensated for their expertise, services, and participation. Having a seat at the table, community partners contributed their voices to the research process. Being heard and having a voice in the coalition, community partners were emboldened to expand their leadership to advocating for the community at the local, regional, and national levels. Likewise, in nearby Alameda County, California, nail salon workers and owners expanded their voices in the local research project to testify at policy hearings at the local and federal levels resulting in a city ordinance to reward salons that use green products and federal regulations that impact the manufacturing of products used in nail salons (Quach et al., 2012). The common key ingredients for success were sustained and authentic engagement of community partners with shared resources and decision-making power, as well as training Vietnamese-speaking community researchers with knowledge of the Vietnamese culture on the research process and methods, project management, advocacy, and grant writing (Bang Hai et al., 2016; Nguyen, McPhee, Bui-Tong, et al., 2006; Quach et al., 2012).

Accountability and sustainability. With improved capacity in research and decision-making, members of the community-research partnership are more able to be accountable to each other and to the funding agencies to reach their research goals and take steps to maintain the partnership, its capacity and infrastructure, and the research products beyond one funding cycle. Even more articles failed to mention accountability and sustainability than the other two core elements. In Santa Clara County, California, researchers with the Vietnamese Reach for Health Coalition struggled with sustaining engagement from small CBOs due to lack of funding and high staff turn over (Nguyen, McPhee, Bui-Tong, et al., 2006). Notably, representatives from small CBOs were unable to carry out the coordination responsibilities of the partnership,

resulting in the hiring of a research institution to perform the role. Consequently, with less responsibility in the partnership, small CBO representatives became less involved in the decision-making process (Nguyen, McPhee, Bui-Tong, et al., 2006). At the same time, the Vietnamese Reach for Health Coalition also had successes when some coalition members received funding to carry out more work after the funding cycle for the current project ended (Nguyen, McPhee, Bui-Tong, et al., 2006).

Successful strategies for accountability and sustainability. For articles that addressed accountability and sustainability of the participatory research enterprise, the authors remarked on their intensive investment of efforts and resources to train and compensate community partners (Nguyen, McPhee, Bui-Tong, et al., 2006). The authors also identified the importance of forming a coalition with appropriate stakeholders. They recommended that members of the coalition have shared decision-making power, shared resources, and active participation in the research to enrich the capacity of the coalition and enhance the sense of ownership. The authors also pointed out that a commitment to evaluation is necessary to ensure accountability. In addition, they recommended a small annual stipend of approximately USD 2,000 per coalition member to sustain the coalition during the grant writing process.

Stories of Us - Chuyện Kể Nhau Nghe Experience

The Project

Stories of Us - Chuyện Kể Nhau Nghe is a community health research project that applies the community participatory action research (CPAR) approach with two goals: to promote connections and understanding across generations of Vietnamese-Americans through stories and to build community capacity on participatory action research. *Stories of Us - Chuyện Kể Nhau Nghe* consists of two phases. Phase I was a community survey to examine the relationships

between community cohesion, cultural displacement, and the holistic sense of health. Phase II involved getting different generations of Vietnamese-Americans together to hear elders tell life stories and discuss those stories within their social, historical, and cultural contexts. Phase II has a one group pre- post- design using the same instruments as in Phase I. Phase I occurred between January and April 2017 at established community events. Phase II took place on four consecutive Saturdays in June 2017. The research team collected 301 surveys and conducted four intergenerational bi-lingual storytelling sessions in which a total of 55 people ages 17 and older attended. During the evaluation at the end of the four storytelling sessions, participants supported overwhelmingly the continuation of the sessions. One participant suggested the training of more facilitators to conduct similar sessions with different community groups. Data analysis is in progress for both Phases I and II.

Prior to the implementation of *Stories of Us - Chuyện Kể Nhau Nghe*, the investigator had been active in the local Vietnamese-American community for nearly two decades. She trained a team of young community researchers to conduct linguistic and cultural validation of the instruments used in *Stories of Us - Chuyện Kể Nhau Nghe*. Furthermore, she mentored team members on writing and submitting abstracts to present at professional conferences as well as manuscript to submit for publication in a peer review journal.

The current *Stories of Us - Chuyện Kể Nhau Nghe* project began after the cultural validation of the instruments. The investigator continues to cultivate and nurture a team of Vietnamese-American community health researchers to maintain the work in their community. She trained and mentored team members on aspects of the research project that fit team members' interests and needs. In turn, the team contributed to the project according to their ability, availability, and interest. In the process, team members added to their knowledge bank

Vietnamese history and culture, the history of the Vietnamese diaspora, the diversity and complex dynamics within the Vietnamese-American communities in general and in the Puget Sound region specifically. They also learned about the research process and the community participatory action research approach.

A community advisory board governs the general directions and approach of the project. It is comprised of members of the Vietnamese-American community from different ages and genders who want to contribute positively to the community and are passionate about bridging the generational gap. The community advisory board is working on the vision, mission, and values of *Stories of Us – Chuyện Kể Nhau Nghe* for a consistent approach for the project going forward.

The Experience

Mutual respect and trust. Congruent with observations by Bang Hai and colleagues in Santa Clara County, California (Bang Hai et al., 2016), *Stories of Us - Chuyện Kể Nhau Nghe* researchers built partnerships entirely on inter-personal relationships with community members and formal and informal community leaders. Honoring the partners' preference, *Stories of Us - Chuyện Kể Nhau Nghe* did not enter into formal written agreement with community groups and organizations. The only written agreements were between the investigator who is also the lead researcher and the research team members, each with specific assets, learning aspirations, and complex schedules. These agreements helped the research team better utilize team members' assets and meet individuals' specific needs.

The lead researcher attempted to find a CBO with whom to work as a primary community organizational partner. However, due to the complex dynamics between groups within the local Vietnamese-American communities, she maintained the status of her academic

institution as the project official affiliation. During the data collection process, in the presence of the *Stories of Us - Chuyện Kể Nhau Nghe* research team, several community groups gave one of the reasons that the team could be trusted was that they were not associated with any particular Vietnamese community group and that they were trying to work with everyone. The other reasons were the lead researcher's long-term involvement in the community and the younger team members' commitment to learning more about their heritage.

Lessons learned from *Stories of Us - Chuyện Kể Nhau Nghe* on mutual respect and trust. The experience with *Stories of Us - Chuyện Kể Nhau Nghe* confirms the experience of other successful PR projects that long-term, committed involvement in the community and deep personal relationships with key members of the community serve as the key to unlock the gates into sectors in the community that could have been otherwise hard-to-reach, even to an insider. While it is still desirable, and probably crucial, for some partnerships to have clearly written agreements spelling out roles, responsibilities, and expectations of all partners from the beginning, *Stories of Us - Chuyện Kể Nhau Nghe* is one more community participatory research project with the Vietnamese-American community, in addition to the Vietnamese Reach for Health Coalition, for which that wisdom is not appropriate.

Capacity building, empowerment, and ownership. *Stories of Us - Chuyện Kể Nhau Nghe* has had a long incubation period. Although it was borne out of the community's expressed needs and there was a lot of support for it, the lead researcher needed to devote much time and energy to train a team of young, talented, and committed community researchers whose interests and life circumstances were ever changing. Therefore, turn over was inevitable.

The lead researcher spent much time recruiting and training new team members, even with the help of the outgoing team members. With more experienced team members, she

invested time in coaching them leadership skills and self-governance from the onset, in addition to research skills. Although team members might have felt burdened by the expectations, they felt empowered, rose to the challenge, and performed admirably, including initiating and instituting a formal process to recruit new members. After concluding their active involvement in *Stories of Us - Chuyện Kể Nhau Nghe*, former team members have taken on informal leadership roles at their workplace and other community work. With less experienced team members, the lead researcher took charge at first, while coaching and encouraging team members to take small leadership roles with project tasks. Gradually, she delegated more responsibilities as team members were more ready. This strategy has worked well thus far.

Understanding the need to have a project coordinator to keep the project moving, the lead researcher recruited and trained a project coordinator. The project coordinator-in-training was a peer with other team members. She was highly capable and motivated. However, the lead researcher did not invest enough time and effort to support until the project coordinator-in-training garnered adequate authority with team members before handing over complete leadership responsibilities. As a consequence, the team's initial enthusiasm and commitment wavered and gave way to other interests. The lead researcher had to rebuild the team from scratch. In the end, even when there was support from the community for a project like *Stories of Us - Chuyện Kể Nhau Nghe*, it was the story-sharing part that the community wanted, not the research. Even when the lead researcher made authentic and significant effort to train a cadre of young community researchers and coached them in leadership skills to take over the helm, the lead researcher needed to have sustained that effort perhaps a year or two, in order for the effort to come to fruition.

Lessons learned from *Stories of Us - Chuyện Kể Nhau Nghe* on capacity building, empowerment, and ownership. Having a sense of ownership and empowerment is necessary. However, efforts to build capacity must be sustained long-term to make an impact. There must be strong, continuing, and consistent leadership over a period of two or three years to build long lasting capacity that would sustain the project. In addition, capacity building and empowerment must be done deliberately and start from where the community is to be successful.

Accountability and sustainability. To keep the research team accountable to the community's needs, the lead researcher invited key community members who were interested in the project and attended the story-sharing sessions to serve on the community advisory board. The lead researcher was intentional in balancing the power differentials between the aged and the young, male and female. The community advisory board consisted of seven members: two seniors—one male and one female, and five young adults—two males and three females. The role of the community advisory board was to provide general oversight and direction for the project, making sure that the community's needs were addressed in a culturally sensitive way.

To hold the project management, of which the lead researcher is the only member currently, accountable to team members, the lead researcher signed a Commitment Agreement (see [Appendices](#)) with each team member outlining what each team member's learning needs and assets are and what the lead researcher could provide to make the team member's participation in the project worthwhile. We revisited this agreement as needs arose or circumstances changed. To hold team members accountable, project management included, the whole team developed and approved by consensus the ground rules for all to follow (see [Appendices](#)). The team intended to review these rules at every meeting.

Due to the volunteer nature of the project, there was high turn over. The team will be working on a toolkit documenting the process and lessons learned of *Stories of Us - Chuyện Kể Nhau Nghe* and making it available online to allow for institutional memory to exist, despite who is in charge. The toolkit will be available for other communities to access and adapt as appropriate. The toolkit will include a training manual on the research process and facilitation skills, including the intervention session protocol with suggestions for possible variations to adapt to the specific community or situation.

Lessons learned from *Stories of Us - Chuyện Kể Nhau Nghe* on accountability and sustainability. It was apparent with *Stories of Us - Chuyện Kể Nhau Nghe* that even when a project responded to the community's needs in the way the community wanted, it was critical to have strong and committed leadership that provided consistent and sustained efforts to move the project along. The project needed to have an experienced and authoritative project manager in place to allow the lead researcher time to tend to other responsibilities such as relationship building, recruitment, and training. At the very least, having funding to remunerate an experienced project manager would enhance the sustainability of the project.

Thus far, *Stories of Us - Chuyện Kể Nhau Nghe* has been sustained on volunteer efforts one hundred percent. It will take time, intense efforts, and financial resources to build it up to the point where it can continue to serve the community on a consistent and continuous basis. This confirms the lessons learned from other successful community participatory projects in general and with the Vietnamese-American communities in particular (Bang Hai et al., 2016).

Implications for Future Research

In comparing the experience of *Stories of Us - Chuyện Kể Nhau Nghe* with other community participatory research projects, whether they work with the Vietnamese immigrant

and refugee populations in the U.S. or elsewhere in the world, or with other immigrant and refugee or minority populations, it was clear that there are commonalities. In all projects, it is crucial that the researchers show respect and trust for the community in the way that the community perceives trust and respect. Only then do researchers earn the respect and trust from the community.

With mutual respect and trust, the researchers can work together with the community to identify relevant solutions to salient issues as defined and desired by the community. To ensure the sustainability of the project, there must be processes and systems put in place to build community capacity, facilitate empowerment, and promote community ownership of the project. Furthermore, those processes and systems must include measures to enable and ensure accountability of all parties involved to the community, to each other, as well as to the community participatory approach, for example, routine process and outcome evaluation.

This is where the commonalities stop. How to show and earn respect and trust may differ, as well as what processes work best to build capacity, facilitate empowerment, promote community ownership, ensure accountability and sustainability may vary from one community to the next, depending on many factors. The researcher who is genuine about applying the community participatory approach would do well to select a community liaison from the community who has insight into the culture of the community, is familiar with the intra-community dynamics, knows who is who in the community, and is well-respected by the community. Communities often have complex histories and intra-community dynamics. It might be important for the researcher to cultivate relationships with multiple community liaisons who represent different groups in the community. The community liaisons serve as advisors to provide the researcher with a fuller picture of the community. It is important to have the right

people at the table, including those who may pose a challenge to the project. It is advantageous to have dialogues among all stakeholders to work out differences before committing much effort, time, and resources to conduct a project that may encounter challenges further in the process because certain parties were not invited to the table.

With any community, one thing to keep in mind is that, no matter how disadvantaged, how much trauma, or injustice a community has suffered, it always has traditions, strengths, and assets upon which to build. A researcher with a genuine desire to conduct community participatory action research can work with the community to identify those traditions, strengths, and assets to serve as resources to develop feasible and sustainable solutions to community issues. In doing so, the research team and the community are likely to establish processes that make the research culturally relevant.

Conclusion

In short, the Vietnamese communities in the Puget Sound region may have different characteristics than Vietnamese communities around the U.S. and the world. They may differ in some ways from other immigrant and refugee communities, or other minority populations. However, like all communities that have survived adversities and injustices, they have agency and will to come together for the betterment of their people. This should serve as the foundation upon which community participatory action research is built.

This chapter adds to the scant literature on community participatory research with Vietnamese-Americans and with immigrants and refugees. *Stories of Us - Chuyện Kể Nhau Nghe* has a unique contribution on several fronts. It is a CPAR project that operates from a community strengths perspective. It has been enriching the Vietnamese-American community almost completely on internal community resources. *Stories of Us - Chuyện Kể Nhau Nghe* may

be among the first CPARs that work with Vietnamese immigrants and refugees to strengthen community bonds by sharing life stories across generations to promote health.

It would be beneficial to have further research to scale up this pilot project with the larger community, a comparison community, and measurement of the intervention effects. Replicating the *Stories of Us - Chuyện Kể Nhau Nghe* process whereby the community's untapped resources are identified and utilized to address the community's salient issues by other immigrant or refugee communities, and other minority populations would help determine whether this is a generalizable approach. If this approach is successful in helping communities to leverage their internal resources to respond to their issues to improve the health and life of the people in their communities, one more tool is added to the toolbox to narrow the health equity gap and tame the run-away healthcare costs in the U.S.

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APPENDICES. Selected Project Documents

Volunteer Community Researcher Commitment Agreement

The *Chuyện Kể Nhau Nghe - Stories of Us Community Health Research Project* aims to promote community well-being by using life stories to improve understanding and strengthen connections between generations in the community.

As a volunteer community researcher, I am an important member of the research team and act as a representative of the research project to the community at large. I will define my commitment and contribution, and inform project management of my needs.

The *Chuyện Kể Nhau Nghe - Stories of Us* project management strives to optimize my experiences and time by outlining project needs and timeline, and providing me with resources, support, and coaching or training as appropriate.

I, _____, commit to contribute to the *Chuyện Kể Nhau Nghe - Stories of Us Community Health Research Project* by performing the following:

1. Represent the project team to the community with integrity and an open-mind;
2. Practice and promote behaviors consistent with the core values of *Stories of Us*;
3. Build and maintain trust and respect for all team members;
4. Be prepared for, attend, and actively participate at all times;
5. **Seek support and inform project management** when I require assistance;
6. **Request resources** I may require to perform my tasks and reach my goals;
7. Insist upon adequate preparation of other volunteers and project management;
8. Recognize that this is a community research project with evolving timeline and tasks depending on many factors, including those beyond project management's control;
9. Actively engage and complete orientation and training requirements;
10. Uphold the confidentiality requirements of the project;
11. Adhere to research protocols as instructed;
12. Write a one-page reflective paper on the project and my participation in it, at the end of each phase of the project.
13. Provide project management with an email address from which I read email daily;
14. Create personal goals to achieve and maintain in my participation with the project;
15. Commit to an average of _____ hours / week to the project from _____ to _____;
16. Inform project management directly as soon as I know of changes in my goals, commitment, or availability to participate in the project.

From the date I sign this agreement until December 31st, 2017, I am not available to participate on the *Chuyện Kể Nhau Nghe - Stories of Us* Project on the following dates:

By participating in the *Chuyện Kể Nhau Nghe - Stories of Us* Project, I have the following learning objectives and am particularly interested in the following project activities.

My Learning Objectives for Participation in the Stories of Us Project:

1. _____
2. _____
3. _____
4. _____
5. _____

For the following, please make one clean line across the inappropriate part.

I **seek / do not seek** academic credits for my participation in the project.

I would like to participate and gain experience in the following project activities:

- project planning and management
- data collection for community survey in person
- story collection from community members
- community outreach activities
- writing abstracts regarding the project for conferences
- writing articles for publications
- presenting on project activities at community events
- presenting on project activities at professional conferences

Other than the above activities, I am interested in the following areas:

I have the following experiences and skills that would help me contribute to the project:

The *Chuyện Kể Nhau Nghe - Stories of Us* Project commits to create and maintain the best possible environment for the project team, including all its members, to achieve individual and project goals as related to participation in the project by performing the following:

1. Outline project goals, timeline, and needs;
2. Communicate changes to project goals, timeline, needs to all team members;
3. Provide ongoing support, coaching and training relevant to team members’ roles and help ensure team members’ professional development;
4. Answer any and all questions that team members have regarding the project;
5. Provide information on opportunities in areas that might interest team members.

The project team includes all team members. Team members include all volunteers, interns, and project management. Project management includes the lead researcher, Hoàng t. Diệu-Hiền, and the project coordinators, if any.

I, _____, have read the Commitment Agreement form and fully understand my responsibilities as a volunteer researcher/intern and team member of the *Chuyện Kể Nhau Nghe - Stories of Us* Community Health Research Project. ^[]_{SEP} I agree to fulfill my commitment to the *Chuyện Kể Nhau Nghe - Stories of Us* Project.

Signature of volunteer/intern

Signature of project management

Date

Date

Core Values & Ground Rules



1. Work as a team
2. Be on time, notify team if late
3. Be prepared
4. Be accountable
5. Be flexible
6. Be respectful
7. Be positive
8. Be supportive
9. Take on only what you can manage
10. Ask for help when needed
11. Ask questions; do not assume
12. Communicate: Keep each other updated
13. Move forward together: Stay on the same page
14. Consider all opinions fully before making decisions
15. Listen attentively to and value all perspectives, voices, opinions, and contributions
16. Step up (take initiative), step back (allow others to grow)
17. Maintain the confidentiality of team members as well as of research participants
18. Have fun

Chapter 4. *Stories of Us – Chuyện Kể Nhau Nghe*: Intergenerational Life

Review to Build Community for Health in a Culturally

Displaced Population

Abstract

Aims: This study explores the relationships between cultural displacement, community cohesion, and self-rated health and the effects of an intergenerational life review intervention on these variables.

Background: A positive social environment has been found to be protective of health. For refugees and immigrants whose established social connections are disrupted, strengthening existing social connections may help reduce the health equity gaps.

Design: *Stories of Us – Chuyện Kể Nhau Nghe* was a community health research project. Phase I was a cross-sectional community survey (N = 301). Phase II was a one-group pre-post intervention design using quantitative and qualitative methods to evaluate intervention effects, determine intervention feasibility and acceptability among Vietnamese-Americans in Puget Sound, and estimate intervention effect size for the design of future studies (N = 15).

Methods: Phase I: Convenience sampling was used at public events. Data collection took place January through April 2017. Phase II: Four weekly intergenerational life review sessions were conducted in June 2017. Data collection took place before the first session and at the end of the fourth session.

Results: Phase I: Cultural displacement negatively affected health. This effect was mediated by community cohesion, which positively affected health. There was a differential effect on health by level of cultural displacement. Phase II: *Stories of Us – Chuyện Kể Nhau Nghe* intergenerational life review sessions did not have significant effects on cultural displacement, community cohesion, or health, possibly due to small sample size. The intervention was feasible, well-received, and evaluated highly by participants, though completion rates were low (27 %).

Conclusion: Intergenerational life review holds promise to improve social connections for Vietnamese-Americans, possibly other refugee and immigrant populations. More research is needed with larger sample sizes to help determine the effectiveness of the intervention.

keywords: community participatory action research, intergenerational life review, cultural displacement, community cohesion, self-rated health, Vietnamese-American

Introduction

With evidence accumulating about the lasting impact of the social environment on health outcomes, the Robert Wood Johnson Foundation initiated a movement to build a culture of health across the United States (Plough, 2015). One priority for action is building social cohesion where individuals “feel a sense of community and believe they can be engaged members of the community” (Plough, 2015, p. S151). The current demonstration research, *Stories of Us - Chuyện Kể Nhau Nghe*, examined the relationships between community cohesion and self-rated health among a culturally displaced population, and the effects of a structured intergenerational life review reminiscence intervention on cultural displacement, community cohesion, and self-rated health.

The purpose of this chapter is to describe the rationale and methods for the *Stories of Us - Chuyện Kể Nhau Nghe* study, and to present the results of the study through exploration of the relationships between cultural displacement, community cohesion, and health, and the role of intergenerational life review reminiscence intervention on these relationships.

Background and Significance

While population data indicated that Asian Americans have better health outcomes than other racial groups (Trinh-Shevrin, Islam, & Rey, 2009; Tseng, 2009), disaggregated data showed that Vietnamese-Americans have some of the worst health, such as the highest rates of hepatitis B, hepatic and cervical cancer (CDC, 2007; Walsh, Torr, & Bui, 2010) and a high prevalence of depression (Leung, Cheung, & Cheung, 2010). Vietnamese rated their overall health lowest compared to other racial groups and other Asians (Almgren, Magarati, & Mogford, 2009; Walsh et al., 2010). Social factors affecting the health of Vietnamese-Americans include low socioeconomic status, low health literacy, and limited English proficiency, which hinders

effective communication with healthcare providers and access to health promotion information (Zhang & Ta, 2009).

The Vietnamese-American Context

In depth studies of Vietnamese-Americans revealed contextual issues that may affect their health. Vietnamese-Americans arrived in the U.S. in multiple waves over four decades and on different U.S. immigration programs (Chan, 2006). People from different waves came with different types of trauma and socio-economic statuses, giving them differing levels of coping and adjustments to the U.S. No matter in which waves they came, generations of Vietnamese-Americans acculturate to the mainstream culture at different rates, creating discordances in language and culture. These factors created barriers to community cohesion (Chan, 2006; Chong & Ta, 2003). Moreover, perceived differences in political alignment vis-à-vis the war-time South Vietnamese and current Vietnamese governments resulted in political assassinations within the Vietnamese-American communities in the 1980s and character assassinations that continue today, causing mistrust among Vietnamese-Americans, further hindering community cohesion (Getler, 2015; Rowley, Thompson, Lyman, Kolker, & Gibbons, 2016).

Community Cohesion

Zhang and Ta (2009) found protective effects of social cohesion and support from friends and relatives on Vietnamese-Americans' self-rated health. Furthermore, they found that Vietnamese-Americans valued highly family cohesion. Yet, a recent assessment of the Vietnamese-American community in the Greater Seattle area revealed that intergenerational gaps, which resulted in reduced family as well as community cohesion, were among the top five issues that community members, young and old, would like to address (VFA, 2011).

Community cohesion is an attribute of a community in which members feel a sense of belonging,

interact with each other, and participate in community activities, and desire to continue such interactions and participation for the long-term.

Cultural Displacement

Like other refugees and immigrants, ethnic Vietnamese in the U.S. experience a sense of cultural displacement, a feeling of otherness and disconnection from the American mainstream society, having to subjugate their culture in everyday life (Ishiyama, 1995). The culturally displaced persons must redefine their sense of identity, belonging, and self-worth, or feel their sense of self invalidated by the prevalent societal norms and values. They struggle to find meaning in life. This feeling of loss jeopardizes their overall well-being, which is reflected in poor self-rated health (Aylesworth & Ossorio, 1983; Ishiyama, 1995). Cultural displacement is the feeling of otherness, unshared meaning, disempowerment, and disconnectedness with the culture in which an individual lives.

Self-rated Health (SRH)

Self-rated health is a holistic conception of health and a robust measure of well-being (Benyamini, 2011). It is predictive of morbidity (Subramanian, Subramanyam, Selvaraj, & Kawachi, 2009), mortality (DeSalvo, Bloser, Reynolds, He, & Muntner, 2006), changes in biomarkers (Bardage, Svedberg, & Pedersen, 2003), and changes in health status (Bailis, Segall, & Chipperfield, 2003). It is also a stable measure of well-being in adolescents (Bauldry, Shanahan, Boardman, Miech, & Macmillan, 2012). In short, self-rated health represents the overall health status, taking into account a person's health condition, health behaviors, and subjective feelings not accessible to the clinicians or the researchers (Jylha, 2009) and is compatible with the World Health Organization's definition of health as "a state of complete

physical, mental and social well-being and not merely the absence of disease or infirmity” (Herrman et al., 2005).

Life Review Intervention

For Vietnamese-Americans, the elders attributed their poor health to loneliness, the result of disconnection with the younger generations (Đặng, 2012). Younger Vietnamese-Americans yearned to connect to their Vietnamese heritage (VFA, 2011) as evidenced by the growing number of projects by Vietnamese-Americans to share life stories, such as StoryCorps’ First Days Project (“First Days Story Project,” 2015), and other efforts in California (“Vietnamese American Oral History Project,” 2015), Texas (“Vietnamese American Heritage Project,” 2015), Minnesota (“Vietnamese Community Oral History Project,” 2010), and among Chinese-Vietnamese-Americans (Huynh, 2015). Locally, there are the Sticky Rice Project, which connects generations of Vietnamese-Americans through food, and the Second Wave podcast in which a Vietnamese-American journalist tells stories of the Vietnamese-American experience.

Scientifically, fifty plus years of scholarship shows that reminiscence allows the older generations to transmit life experiences and cultural values, connects generations, elicits empathy, and helps people reframe life events into meaningful experiences, thus improving their sense of well-being (Bohlmeijer et al., 2007; Westerhof & Bohlmeijer, 2014). All are essential for healthy aging (Erikson, 1998). Studies found that life review combined with cognitive, problem-solving, narrative, or creative techniques grounded in a therapeutic theoretical framework is the most effective form of reminiscence to promote well-being (Hallford, Mellor, & Cummins, 2013; Pinquart & Forstmeier, 2012). Life review, which can take place individually or in groups, is a structured reminiscence that involves remembering and sharing

memories that covers the life span and includes the reflection, evaluation, and reframing of life events into a coherent whole (Haber, 2006).

Stories of Us - Chuyện Kể Nhau Nghe Study

This demonstration study utilized life review as an intervention to connect generations of Vietnamese-Americans and facilitate the sense of purpose in life in a population that feels its identity challenged, with the aim of promoting health. This study examined the associations between community cohesion, cultural displacement, and self-rated health (SRH), and the effects of *Stories of Us - Chuyện Kể Nhau Nghe*, an intergenerational group life review intervention, on these variables. It was hypothesized that *Stories of Us - Chuyện Kể Nhau Nghe* would have a direct effect on SRH as well as an indirect effect through community cohesion and cultural displacement, as depicted in *Figure 3*. *Stories of Us - Chuyện Kể Nhau Nghe* differed from the aforementioned projects in its aim to promote health by strengthening community bonds using intergenerational life review.

The study tested the following hypotheses:

- H1. Cultural displacement will be negatively associated with community cohesion.
- H2. SRH will be negatively associated with cultural displacement and positively with community cohesion.
- H3. Community cohesion mediates the relationship between cultural displacement and SRH.
- H4. Compared to pre-test, after attending the *Stories of Us - Chuyện Kể Nhau Nghe* life review sessions, participants will show significant decreases in cultural displacement and increase in community cohesion and SRH.

In addition, the study sought to determine the feasibility and acceptability of *Stories of Us - Chuyện Kể Nhau Nghe* among the Vietnamese-American communities in the Puget Sound region. If so, how it can be improved?

In short, *Stories of Us - Chuyện Kể Nhau Nghe* focused on how Vietnamese-Americans felt as individuals living in a dominant culture (cultural displacement), their connection with and feelings towards their ethnic community (community cohesion), and their perception of well-being (self-rated health), the inter-relationships among these variables, and the effects an intergenerational life review have on these feelings and perceptions.

Conceptual Framework

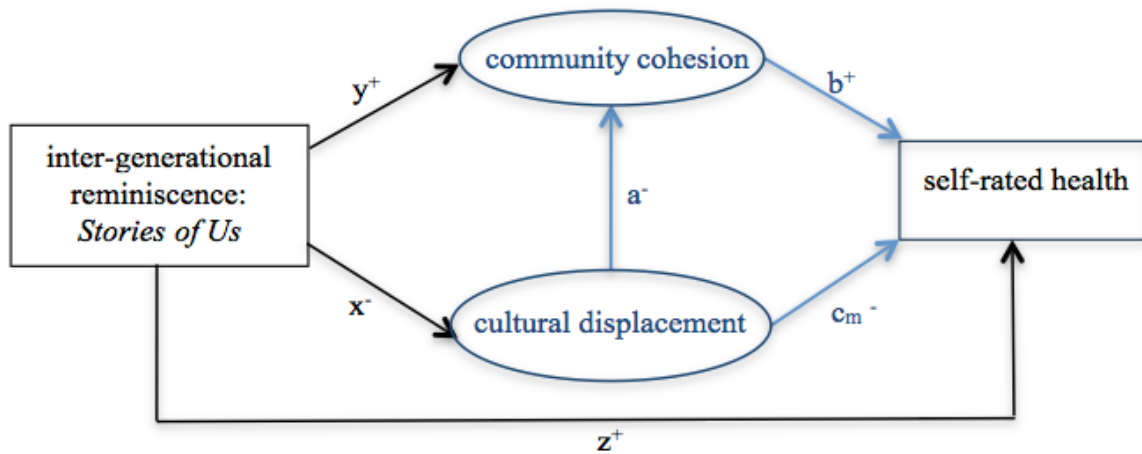


Figure 3. Model of Intergenerational Reminiscence and Health (MIRH)

In this figure, arrows represent paths of influence, that is the directional relationships among variables, with signs indicating positive (+) versus negative (-) influences.

The *Stories of Us - Chuyện Kể Nhau Nghe* study is anchored on the Model of Intergenerational Reminiscence and Health (MIRH), which is built on the work of giants from disciplines such as social epidemiology, medical sociology, social psychology, psychotherapy, gerontology, nursing, and more. Detailed description of the model is provided in another paper.

The linkages of the model are derived from empirical evidence that found protective effects of social cohesion (Bruhn, Philips, & Wolf, 1982; Kawachi & Berkman, 2014) and deleterious effects of cultural displacement (Aylesworth & Ossorio, 1983; Ishiyama, 1995) on health. Life review for the purpose of instructing, connecting with others, meaning making, and reframing the past had positive impacts on the well-being of participants, particularly those who had experienced life-changing trauma (Bohlmeijer et al., 2007; Chin, 2007; Pinguart & Forstmeier, 2012).

Reflected in the choices of the variables to be examined and the community participatory action research (CPAR) approach, *Stories of Us - Chuyện Kể Nhau Nghe* is grounded in the Intersectionality Framework (Bowleg, 2012). The variables represent acknowledgement of the influence of socio-cultural factors on health and are defined from the perspectives of those being researched. The intervention comes from within the community being researched and is implemented by members of that community for their community. The triad structure of cultural displacement – community cohesion – self-rated health represents the three inter-related elements person – environment – health depicted in the Human Response Model (Heitkemper & Bond, 2003). Thus, *Stories of Us - Chuyện Kể Nhau Nghe* is guided by the Model of Intergenerational Reminiscence and Health, which is based on empirical evidence and is grounded in theory.

Methods

Stories of Us - Chuyện Kể Nhau Nghe was a two-phased study. Phase I included a cross-sectional survey. Phase II was a demonstration project using a one-group pre-post intervention design. *Stories of Us - Chuyện Kể Nhau Nghe* was a community intervention that implements a structured intergenerational life review group intervention to effect changes in cultural

displacement, community cohesion, and self-rated health. The research approach for both Phase I and Phase II was community participatory action research. A summary is provided below.

Phase I examined the associations among the key variables community cohesion, cultural displacement, and self-rated health. Phase II evaluated the effects of the *Stories of Us - Chuyện Kể Nhau Nghe* intervention on these variables.

Research Approach

Stories of Us - Chuyện Kể Nhau Nghe applies the community participatory action research (CPAR) approach throughout the research process. CPAR falls under the umbrella of participatory research with eight key principles (Wallerstein & Duran, 2008). *Stories of Us - Chuyện Kể Nhau Nghe* emphasized the following principles from participatory research: participation and partnership, reciprocal learning, capacity building, and power sharing, and balancing between research and action. Description of *Stories of Us - Chuyện Kể Nhau Nghe* CPAR process is detailed in another paper. Briefly, the lead researcher came from the community and has been active in the community for many years. She recruited, trained, and supervised a team of community researchers who are community members. The community researchers engaged in all aspects of the research project that fit their interests, learning needs, and time availability.

Design

Phase I was a cross-sectional community survey. Phase II was a one-group pre-post intervention design using qualitative and quantitative components to evaluate intervention effects, determine intervention feasibility and acceptability among Vietnamese-Americans in Puget Sound, and estimate intervention effect size for the design of future studies.

Population and Settings

The study population included individuals ages 15 and older who came from or whose family came from Việt Nam and who are living in the Puget Sound region of Washington State. This study focused on improving community cohesion along generational lines. Therefore, it was important to include different age groups to examine differences, if they exist.

Furthermore, in the mainstream American culture, adolescence is a transitional phase when the teenager prepares to move from childhood to independent adulthood, whereas in traditional Vietnamese culture, independence and adulthood are not achieved until a person begins a family. Even then, the Vietnamese culture values interdependence and mutual support. Therefore, adolescence may be the time when the intergenerational gap widens in the Vietnamese-American families as the teenagers and their parents negotiate differing cultural values and practices. Thus, collecting data from youth ages 15 and older helped capture the shifting generational dynamics to identify appropriate strategies for prevention. It would have been beneficial to collect data at an earlier age. However, for this demonstration study, it was more feasible, yet still beneficial, to include youth 15 years and older.

Phase I. The study sample was drawn from the Puget Sound region of Washington State where there are community events with large number of ethnic Vietnamese participating and where the research team received permissions to collect data from the organizations in charge.

Phase II. For logistical reasons, the study sample was the Greater Seattle metropolitan area. The study site was a public space near where many of the senior participants lived and where the research team received permissions to conduct the storytelling sessions.

Sampling

This study combined purposive, snowball, and simple convenience sampling. However, every effort was made to collect data from as wide a range of participants as possible. Inclusion criteria for Phase I and Phase II included non-institutionalized people who (1) self-identified as ethnic Vietnamese, or Vietnamese-Americans, or of Vietnamese descent, or descendants of immigrants or refugees from Việt Nam, (2) were 15 years of age or older, (3) lived in Washington State permanently or at least nine months out of a calendar year, and (4) were fluent in either English or Vietnamese. Exclusion criteria included people who could not speak fluently either English or Vietnamese.

Phase I. For the cross-sectional community survey, the research team recruited 261 study participants at established community activities or events plus 40 non-duplicating participants from pre-intervention measurement making the total $N = 301$.

Phase II. For evaluating the *Stories of Us - Chuyện Kể Nhau Nghe* intervention, the research team recruited participants of different age groups from 15 years of age and older from existing community social networks ($N = 55$).

Sample Size

Phase I. For $\alpha = 0.05$, power = 0.80, which is acceptable for a demonstration project (McCrum-Gardner, 2010), to achieve effect size $f^2 = 0.05$ (Cohen, 1988), the statistical program “G*Power” calculated that a sample size of 125 is needed. The study sample of 301 exceeded the recommended figure.

Phase II. For dependent before-after means t-test, with estimated power = 0.80, $\alpha = 0.05$, two-tailed, a sample size of 33 would be required (G*Power 3.1 statistical program) to detect a medium effect size of 0.50. Although a total of 55 participants attended at least one

intervention session, and 53 completed pre-test surveys, only 15 pre-post sets of data were collected.

Data Collection & Procedure

The University of Washington Human Subjects Division approved all procedures outlined below.

Phase I. Data collection was in-person, pen and paper questionnaire, in English or Vietnamese, and self-administered or completed with an interviewer per the respondents' preference. The research team identified community events to include diverse groups in terms of age and religion. Once permissions were received, the team attended events, provided a brief introduction to *Stories of Us - Chuyện Kể Nhau Nghe*, distributed an Information Statement about *Stories of Us - Chuyện Kể Nhau Nghe* and the survey in both English and Vietnamese. The team requested referral to other Vietnamese-Americans who did not usually interact with other Vietnamese but did not receive any. Surveys were collected from secular community events as well as from different faith-based groups. In addition, pre-intervention data from non-duplicating cases in Phase II were also included in the analysis. These data were not collected from established community events, but at the beginning of the storytelling sessions conducted by the research team.

Phase II. All participants in the *Stories of Us - Chuyện Kể Nhau Nghe* intervention group were asked to complete the questionnaire before their first intervention session and after the end of the last session. Nearly all participants chose to self-administer. Three participants requested help to complete the questionnaire from the research team or another participant due to poor eyesight or inability to read. Each copy of the questionnaire had a unique code, which was

recorded in an attendance log. The research team matched the code for each participant for the post-intervention questionnaire.

Measurement

All measures described below, except the evaluation questions, were used in both Phase I and Phase II. The evaluation questions were process-related questions, asked at the end of each intervention session, and were used in Phase II only. The focus group discussion guide was used at the end of the last intervention session. Together, the instruments below consisted of 29 questions plus the demographic and background questions.

Outcome variables.

Self-rated health (SRH). Health was measured by a single item, “In general, how would you rate your health? Very good, good, fair, poor, or very poor, rated from 1 to 5 with higher scores indicating better general health.” SRH is a robust holistic measure of the general sense of well-being (Benyamini, 2011) and is predictive of changes in health status (Bailis et al., 2003). It has high face validity as a measure of overall current health status, taking into account a person’s health condition, health behaviors, and subjective feelings not accessible to the clinicians or the researchers (Jylha, 2009). The test-retest reliability coefficient is 0.92 (Lorig et al., 1996, p. 25).

SRH has been validated with different ethnic and language groups (Chandola & Jenkinson, 2000) with no systematic difference in the way U.S.-born and foreign-born Asian Americans, including Vietnamese, reported their self-rated health (Erosheva, Walton, & Takeuchi, 2007). Its use among Vietnamese-Americans has been limited mostly to large surveys such as the National Latino and Asian American Study (NLAAS) (John, de Castro, Martin, Duran, & Takeuchi, 2012), the California Health Interview Survey (CHIS) (Sorkin, Nguyen, &

Quyen, 2011), and the Orange County Health Needs Assessment Survey (OCHNA) (Walsh et al., 2010). These studies did not report any problems with validity, reliability, or cultural appropriateness, including language issues, in the use of SRH with Vietnamese-Americans in either language.

Cultural displacement. Cultural displacement, a measure developed for this study (8 items total), was measured by three indicators: (1) sense of otherness (2 items), (2) disconnection between generations (3 items), and (3) social isolation (3 items). Examples of the items are “I feel like an outsider in the mainstream American society,” “I feel understood by other generations in my family,” and “I feel lonely and have no friends.” Social isolation is measured using a 3-item scale adapted from the 20-item UCLA Loneliness Scale (Hughes, Waite, Hawkley, & Cacioppo, 2004) and has been shown to be reliable and comparable to the full version, with Cronbach’s $\alpha = 0.72$ (Hughes et al., 2004). This scale was pre-tested with the Vietnamese-Americans in Washington State and had an internal consistency coefficient of 0.90 (Diệu-Hiền et al., 2014). Items for these three indicators were combined as the measure of cultural displacement.

Community cohesion. Community cohesion was adapted from the Neighborhood Cohesion Instrument with an internal consistency coefficient of 0.95 (Buckner, 1988). Face validity and cultural validity was conducted with Vietnamese-Americans in Washington State and had Cronbach’s $\alpha = 0.90$ (Diệu-Hiền et al., 2014, unpublished). Community cohesion was measured by three indicators of (1) sense of belonging (3 items), (2) attachment to the community (3 items), and (3) interaction with the community (4 items), making 10 items total.

All item measures for self-rated health, cultural displacement, and community cohesion use 5-point Likert response options.

Adjustment variables.

Depression and anxiety. Depression and anxiety are potential confounding variables, measured by a modified 10-item version of the 20-item Self-Reported Questionnaire (SRQ-20) (Beusenberg & Orley, 1994). SRQ-20 has been translated and validated for Vietnamese, and used extensively (Murphy et al., 2015). Examples of questions include, “Have you lost interest in things?,” “Do you feel that you are a worthless person?,” and “Do you sleep badly?” The internal consistency of the original English SRQ-20 is $\alpha = 0.81$. The reliability of the Vietnamese version is 0.87 (Stratton et al., 2013). With a cut off point of 7/8, SRQ has a sensitivity of 73% and specificity of 82% (Tuan, Harpham, & Huong, 2004). Ten items from SRQ-20 were selected to reduce respondent burden and improve response rate. Items chosen had stronger loadings (Stratton et al., 2013) and were deemed culturally relevant by the translators.

Demographic and background variables. These included age, gender, race/ethnicity, education, country of birth, year family arrived in the U.S., program under which the family immigrated to the U.S., zip code of place of residence, and frequency and types of interactions with the Vietnamese community. These variables may be associated with cultural displacement, community cohesion, and SRH. They were used to describe the sample as well as included in the analyses for associations and intervention effects.

Stories of Us - Chuyện Kể Nhau Nghe Intervention

The intervention involved procedures adapted from guided autobiography groups (Birren & Cochran, 2001), using cognitive, visual, problem-solving, and narrative (oral and written) techniques to facilitate the remembering and sharing life stories in an intergenerational group of Vietnamese-Americans. The themes were modified to be relevant to the Vietnamese-American

experience (VFA, 2011; Đặng, 2012) and respond to feedback from a test session in April 2015 (unpublished). The number of sessions was shortened to four from ten to accommodate the scope of this demonstration research.

The life review sessions took place on four consecutive Saturdays from 8:45 am until 1:00 pm. Each session started with a light breakfast and ended with a light lunch consisting of Vietnamese and American food. The research team and participants socialized during these times. The main program conformed loosely to the following structure: (1) introductory activity (such as name a game you used to play as a child); (2) brief overview of the social, historical, and cultural contexts of the stories; (3) story sharing; (4) clarifying questions to the storytellers; (5) exchange of thoughts, feelings, impressions about the stories; (6) reflection on and association with own life, everyone sharing stories; (7) feedback; and (8) closing. Steps 5, 6, and 7 occurred in small groups with the facilitation of the research team. All sessions were conducted in both English and Vietnamese.

The themes for the four sessions were (1) a memorable experience in your youth, (2) a memorable story from your adult life, (3) an experience that was a significant marker in your life, and (4) a memorable event that touched you after you arrived in the U.S. The story sharing sessions began with five elders sharing their five-minute-long stories according to the theme of the week. These stories served as a springboard from which participants related their own experiences, exchanged thoughts, feelings, and impressions, and shared their own stories in small groups of eight to twelve.

Data Analyses

Data quality assurance and data cleaning. At least 10% of the data collected from each site were randomly selected for examination of data entry quality. Write-in data were

standardized and grouped. For example, place of birth was a write-in response; responses such as “Seattle,” “California,” or “U.S.” were grouped into the “U.S.” category.

Year of birth was another write-in response for which many respondents entered their full dates of birth. The research team entered data as written. In the cleaning process, only the year of birth was retained. Due to the intergenerational nature of this study, age was an important variable and went through a few more transformations for the data analysis process. The continuous numeric variable “age” was calculated by subtracting the year of birth from 2017, the year data collection took place, and was used in the regression analyses. The categorical variable “age.grp” was created to determine the number of respondents and their characteristics by age groups (see **Table 3**).

Once data were cleaned, the lead researcher examined the pattern of missingness in the dataset. Some variables with high missingness are not useful for further analyses other than the description of the sample. For example, race and ethnicity had 19% (57) and 18% (55) missingness, respectively. Of those who responded, 93% (279) said they were Asian and 89% (268) identified as ethnically Vietnamese. Other categories had too few counts, 1s, 2s, and 3s, to yield meaningful analyses. One variable, immigration program under which the respondents’ or their families arrived in the U.S., had incomplete information on 44% (132) of the respondents—11% (34) “don’t know” and 33% (98) no answer. It is plausible that the reason for missingness in this case was because the respondents did not know the answer. Those who were very old or very young at the time of immigration may not know under which program their families entered the U.S. because someone else in the family handled the paperwork. In addition, those who were born in the U.S. may not know this information either. It is also possible that there were a number of respondents who overstayed their visas and did not want to answer this question.

Regardless of the reason, for the purpose of this dissertation, it may not be possible for further meaningful analyses with the variable “immigration program.” Therefore, the lead researcher decided to do nothing about the missingness of race, ethnicity, or immigration program variables.

For the 29 questions that constituted the primary and adjustment variables, self-rated health, community cohesion, cultural displacement, and depression and anxiety, missing data ranged from 1% (3 missing cases) to 3% (11 missing cases). Missing data for these items were imputed by multiple imputation using the function `imp.amelia` of the Amelia package for the statistical program R (Honaker, King, & Blackwell, 2017). Multiple imputation is one of the recommended methods by Schafer and Graham (Graham, 2009; Schafer & Graham, 2002). The program uses bootstrapping algorithm to impute the missing data.

The lead researcher also inspected data of the primary and adjustment variables for outliers. She did not detect a pattern to the outliers.

Phase I. With Phase I survey data plus Phase II pre-intervention data (for non-duplicating cases), correlational analyses and multivariate regressions were conducted to determine associations between cultural displacement, community cohesion, and self-rated health, addressing hypotheses 1 and 2. Differences in the associations of cultural displacement, community cohesion, and self-rated health were tested for group identity and for those who participated in the intervention versus those who did not. Potential confounders such as depression, anxiety, demographic, and other background variables were added to the regression models one at a time to check for confounding.

By convention, confounding occurs if the regression coefficients of the predictor variable change by 10% when comparing the linear regression model with the term of interest added.

Assumptions of linear regressions (normality, linearity, and homogeneity of variance with

scatterplots, and multicollinearity with variance inflation factor (VIF) were explored. For hypothesis 3, the presence of mediation was evaluated by applying the difference of coefficients methods suggested by Judd and Kenny (1981) and Baron and Kenny (1986). The confidence levels of mediation were estimated using bootstrapping using percentile methods.

Phase II.

Estimated intervention effect. For hypothesis 4, paired t-tests examining differences between pre- and post-intervention measures of cultural displacement, community cohesion, and self-rated health were performed to determine if there were changes in these variables post-exposure to *Stories of Us - Chuyện Kể Nhau Nghe* intervention. To estimate effect sizes for future studies, post-intervention means were subtracted from those of pre-intervention and divide by the standard deviations at pre-intervention (Durlak, 2009).

Acceptability and feasibility. Content analysis was used to analyze data gathered from post-intervention focus group discussions, focusing on meanings and explanations, and deriving major themes. Then, findings from the focus group discussions were compared with results from multiple choice process questions gathered at the end of the fourth session to discover whether findings from the focus group discussions complement or extend the closed ended questions. As with other analyses, differences by age groups were examined as well.

Legal and Ethical Considerations

All members of the research team received certification for the completion of training in human subjects protection provided by the National Institutes of Health. *Stories of Us - Chuyện Kể Nhau Nghe* received approval from the University of Washington Human Subjects Division for legal and ethical plan of conduct of the research. The research team provided the participants in both Phase I and Phase II with oral introduction to the research as well as a written

Information Statement. Participation in Phase I was voluntary and anonymous with steps taken along the way to avoid coercion. The completed survey served as consent to participate.

Participation in Phase II was voluntary and confidential. Records linking participants to their answers or participation were accessible exclusively to the research team and for research and training purposes only. Community members' presence and participation in the intervention sessions served as consents to participate. An experienced health care professional, the lead researcher, was present and available at all intervention sessions to provide initial care giving should any untoward event occurred during the sessions.

All members of the research team were from the Vietnamese-American communities in the Puget Sound region. An experienced bilingual and bicultural person provided team members with guidance on Vietnamese cultural practices and community-specific dynamics. The research team conducted linguistic and cultural validation and field-tested the survey in English and Vietnamese. All oral and written information was in English and Vietnamese. Life review sessions were conducted in English and Vietnamese. The research team took care to encourage the participation and protect the identity of respondents who might not be able to complete the survey on their own.

Results

Sample

Phase I. The research team collected 261 surveys during data collection at public events and another 40 non-duplicating surveys during pre-test in Phase II, making the total sample for analysis for Phase I is 301. The mean age of the respondents was 43 years, ranging from 13 to 92, with 50% younger than 40 and 33% age 60 and older, leaving 17% in their 40s and 50s. Forty-nine percent of the completed surveys were in Vietnamese. One hundred percent of those

born in the U.S. and 23% of those born in Việt Nam completed the survey in English. Of those born in Việt Nam who completed the survey in English, the majority were under 40 years old, but 5 people (3%) were in their 60s or 70s. Nearly 59% of those who reported their gender identified as female; one person identified as other. Table 3 summarizes selected characteristics of the respondents. Included under “Others” for race and ethnicity were other Asian, African, American, Australian, and European; for countries of birth were Australia, Austria, Cambodia, Germany, and Japan; for religion were Agnosticism, Atheism, Confucianism, and combinations of religions, such as Buddhism and Christianity, Judaism and Christianity. It is common in Vietnamese households where the parents have different faiths that the descendants would attend services for both, continue through their adult life, and pass down the practices to their offspring. Sometimes, parents do also.

Table 4 provides the means and standard deviations of the primary variables and the indicators that comprise them. *Figure 4* further illustrates the weight and spread of self-rated health, community cohesion, cultural displacement, and depression and anxiety by age groups. Outliers exist in each variable and not in any discernable pattern.

Table 3

Survey Respondents' Characteristics for the Whole Sample and by Language Preference

<u>Variable</u>	<u>n (%)</u>		
	<u>Vietnamese</u> (n = 151)	<u>English</u> (n = 150)	<u>All</u> (N = 301)
Age in years	60.96 (17.02)	25.66 (11.95)	43.37 (22.99)
Age group			
under 20	2 (1%)	50 (33%)	52 (17%)
20s and 30s	18 (12%)	78 (52%)	96 (32%)
40s and 50s	35 (23%)	17 (11%)	52 (17%)
60s and 70s	81 (54%)	5 (3%)	86 (29%)
80s and older	15 (10%)	0	15 (5%)
Gender (N = 279)			
Female	84 (72%)	79 (54%)	163 (58%)
Male	50 (43%)	66 (46%)	116 (42%)
Other	-	-	1 (0%)
No answer	17 (11%)	5 (3%)	22 (7.31%)
Marital status (N = 251)			
Never married	11 (9%)	108 (84%)	119 (47%)
Divorced/Separated/Widowed	32 (26%)	7 (5%)	39 (16%)
Married	78 (64%)	14 (11%)	92 (37%)
No answer	30 (20%)	20 (14%)	50 (17%)
Education (N = 300)			
No school	7 (5%)	1 (0.7%)	8 (3%)
1-5 years	22 (15%)	1 (0.7%)	23 (8%)
6-11 years	20 (13%)	30 (20%)	50 (17%)
High school graduates	45 (30%)	16 (11%)	61 (20%)
Some college	21 (14%)	46 (31%)	67 (22%)
Bachelor's degree or higher	35 (23%)	56 (37%)	91 (30%)
No answer	1 (0.7%)	-	
Religion (N = 252)			
Buddhism & ancestor veneration	45 (33%)	65 (56%)	106 (42%)
Cao Đài	19 (14%)	9 (8%)	19 (8%)
Christianity	67 (50%)	34 (29%)	101 (40%)
Other	4 (3%)	9 (8%)	15 (6%)
No answer	16 (11%)	33 (22%)	49 (16%)
Country of birth			
U.S.	0	100 (67%)	100 (33%)
Việt Nam	151 (100%)	45 (30%)	196 (65%)
Other	0	5 (3%)	5 (2%)

Note: Percentages were based on the number of responses within the respective columns. Percentages for “no answer” were based on the total number in the respective columns.

Table 4

Means and standard deviations of the primary variables by language preference

Variable	mean (std.dev)		
	<u>Vietnamese</u> (n = 151)	<u>English</u> (n = 150)	<u>All</u> (N = 301)
Age in years	60.96 (17.02)	25.66 (11.95)	43.37 (22.99)
Cultural Displacement	2.02 (0.61)	2.40 (0.55)	2.31 (0.68)
Otherness	2.12 (0.89)	2.77 (0.73)	2.45 (0.88)
Intergenerational disconnection	2.02 (0.75)	2.42 (0.75)	2.22 (0.77)
Social isolation	1.92 (0.80)	2.01 (0.83)	1.96 (0.82)
Community Cohesion	4.45 (0.59)	4.07 (0.60)	4.26 (0.62)
Attachment	4.52 (0.65)	4.35 (0.66)	4.44 (0.66)
Interaction	4.42 (0.72)	3.98 (0.76)	4.20 (0.77)
Sense of community	4.40 (0.68)	3.89 (0.68)	4.14 (0.72)
Self-rated health	3.47 (0.99)	3.95 (0.85)	3.71 (0.95)

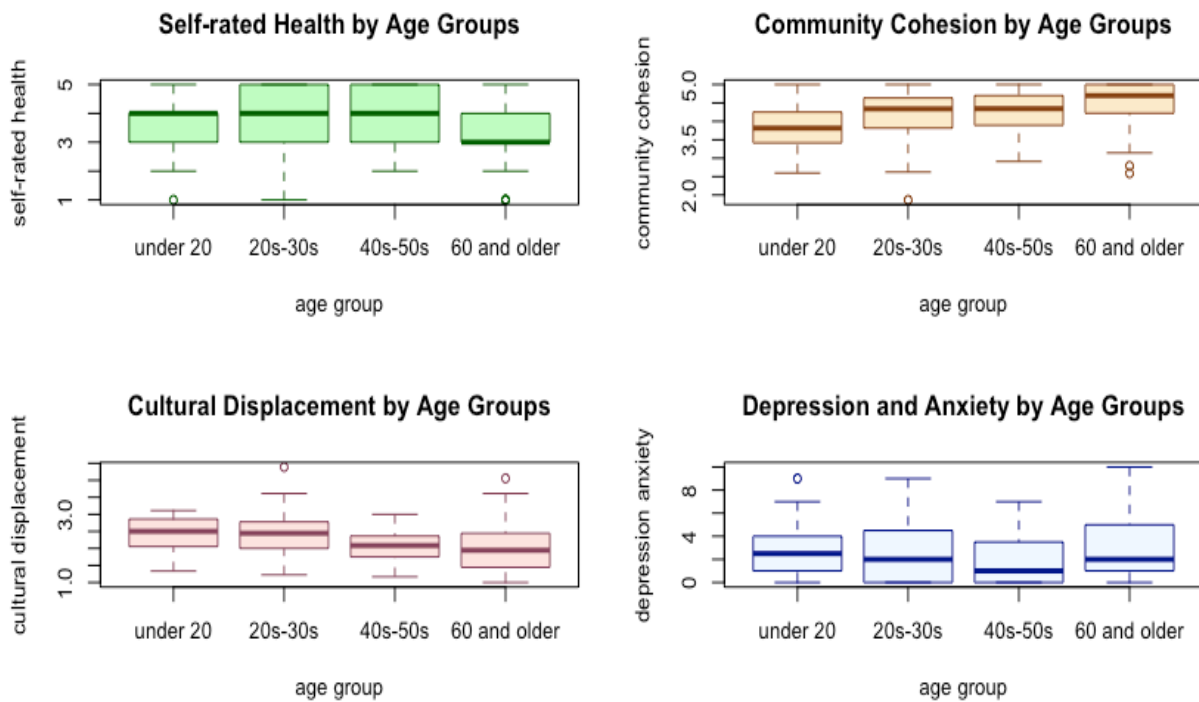


Figure 4. Selected variables by age groups for the community survey sample.

Means, quartiles, and ranges of self-rated health, community cohesion, cultural displacement, and depression and anxiety by age groups for the community survey sample.

N = 301 for the whole sample, $n_{\text{under 20}} = 52$, $n_{\text{20s-30s}} = 96$, $n_{\text{40s-50s}} = 52$, $n_{\text{60 and older}} = 101$

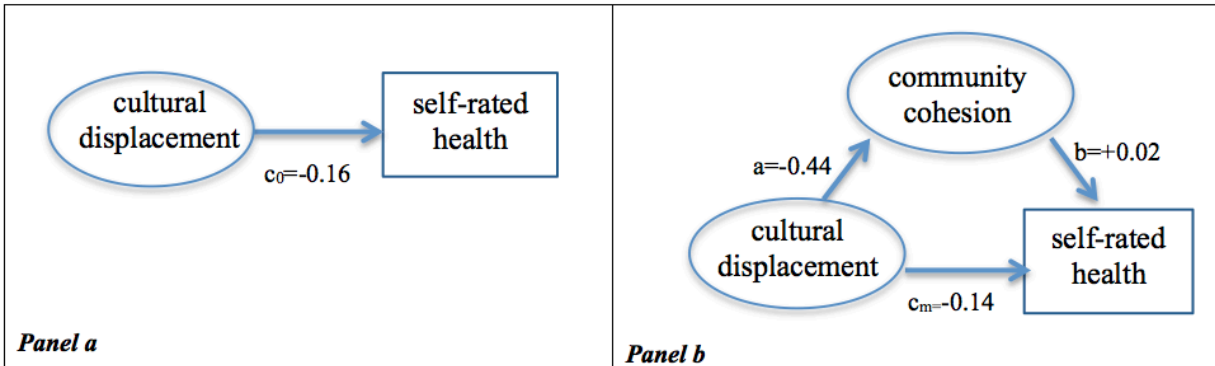


Figure 5. Paths of influence. Panel a. Total Effect. Panel b. Mediated Model.

Figure 5 represents hypotheses H1 to H3, illustrating the direct (paths *a*, *b*, and *c_m*) and indirect effects (paths *a*b*), which were tested using multiple-step regression analyses.

Table 5

Correlation Matrix of Selected Variables

<u>Variables</u>	<u>Self-rated health</u>	<u>Displacement</u>	<u>Cohesion</u>	<u>Age</u>	<u>Depression</u>
Self-rated health	1.00				
Displacement	-0.16**	1.00			
Cohesion	0.02	-0.44***	1.00		
Age	-0.26***	-0.32***	0.34***	1.00	
Depression	-0.36***	0.23***	0.08	0.09	1.00

Note: ** $p < 0.001$, *** $p < 0.0001$

Hypothesis 1. Cultural Displacement and Community Cohesion

Simple bivariate regression of cultural displacement on community cohesion (path *a*) showed a negative relationship significant at $p < 0.0001$. When adjusting for depression and anxiety, age, gender, language preference, and country of birth, the relationship remained significant at $p < 0.0001$ although the slope reduced from -0.36 (95% CI -0.45; -0.26) to -0.29 (95% CI -0.40; -0.18), showing significant confounding effects of these variables. In this model, age was the only other variable that showed a significant relationship. The null hypothesis can be rejected with 95% confidence.

Hypothesis 2. Self-rated Health, Community Cohesion, and Cultural Displacement

Cultural displacement and self-rated health. Likewise, cultural displacement was negatively associated with health (path c_0) in bivariate regression as well as in multivariate regression with the above adjustment variables. The coefficient for cultural displacement increased from -0.21 to -0.33 (57% increase in slope) and increased in level of significance with the adjustment variables in the model. Depression and anxiety, age, Vietnamese language preference, and being born in the U.S. also showed significant negative relationships to health, showing significant confounding effects of these variables.

Community cohesion and self-rated health. Similarly, after adjusting for depression and anxiety, age, gender, language preference, and country of birth, community cohesion did not have a significant correlation with self-rated health among those with low cultural displacement but did have a positive correlation with self-rated health among those with high cultural displacement ($B = 0.25$, 95% CI 0.02; 0.49, $p < 0.05$). Depression and anxiety, age, and being born in the U.S. all had significant negative relationships with self-rated health. Thus, there is a positive correlation for path b for those with cultural displacement scores 2.25 or higher, indicating a differential effect of community cohesion on health by level of cultural displacement. In other words, when cultural displacement scores are 2.25 or higher, community cohesion has a protective effect on health.

Hypothesis 3. Mediation

Due to the significant relationships found between cultural displacement, community cohesion, and self-rated health for people with cultural displacement scores 2.25 or higher, the following analyses were performed on this subset of the data.

First, adjusting for depression and anxiety, age, gender, language preference, and country of birth, separately, there were negative effects of cultural displacement on self-rated health (path c_0), and between cultural displacement and community cohesion (path a), and a positive effect of community cohesion on self-rated health (path b). Second, adjusting for the same variables, there were joint effects of the interaction terms of cultural displacement and community cohesion (path $a*b$) on self-rated health. See Table 6 for path coefficient values and related parameters. Comparing the standardized regression coefficients of the direct path between cultural displacement and community cohesion and the mediated model when community cohesion was added, there was not only a change in the degree of the slope but also the direction of the slope in favor of the relationship between community cohesion and health.

Table 6

Regression coefficients by path of influence

Path	<i>B</i>	<i>SE B</i>	95% <i>CI</i>	β
a_{hi} : cultural displacement—cohesion	-0.52***	0.14	[-0.79, -0.25]	-0.31
b_{hi} : cohesion—health	0.25*	0.12	[0.02, 0.49]	0.19
c_{0-hi} : cultural displacement—health	-0.46*	0.20	[-0.85, -0.07]	-0.20
c_{m-hi} : cultural displacement—cohesion—health	0.27	0.84	[-1.39, 1.94]	0.12
c_{0-full} : cultural displacement—health	-0.20***	0.06	[-0.31, -0.09]	-0.22
c_{m-full} : cultural displacement—cohesion—health	-0.37	0.20	[-0.77, 0.04]	-0.15

Note: Paths with “hi” subscripts were analyzed on the subset of the data with cultural displacement scores 2.25 and above. Paths with the “full” subscripts were from analyses on the full dataset with all values of cultural displacement. $p < 0.05 = *$, $p < 0.0001 = ***$

Hypothesis 4. Effectiveness

Although 53 pre-intervention surveys were collected, due to many constraints, mainly time, personnel, and the fact that the majority of participants did not attend the last session when post-intervention data collection took place, post-intervention data were collected on 17 of the 55 attendees of the *Stories of Us - Chuyện Kể Nhau Nghe* storytelling sessions. Two of the 17 post-intervention measurements did not have the corresponding pre-intervention measurements.

Therefore, the final sample size for analysis was 15, with five participants from the 60 or older

age group and ten younger than 60. Table 7 presents the means and standard deviations of the primary and adjustment variables for the whole intervention group (N=53) and by language preference. *Figure 6* illustrates the weight and spread of these variables by age group.

Table 7

Phase II - Descriptive statistics of primary and adjustment variables pre-intervention for the whole sample and by language preference

<u>Variable</u>	mean (std.dev)		
	<u>Vietnamese</u> (n = 22)	<u>English</u> (n = 31)	<u>All</u> (N = 53)
Age in years	73.06 (11.45)	29.48 (9.23)	47.36 (23.93)
Cultural Displacement	2.32 (0.79)	2.47 (0.58)	2.51 (0.69)
Community Cohesion	4.42 (0.56)	3.83 (0.61)	4.07 (0.65)
Self-rated Health	3.31 (0.95)	3.96 (0.71)	3.69 (0.86)
Depression and Anxiety	2.94 (2.69)	1.61 (2.04)	2.15 (2.39)
Number of Sessions	2.38 (1.09)	1.48 (0.85)	1.85 (1.04)

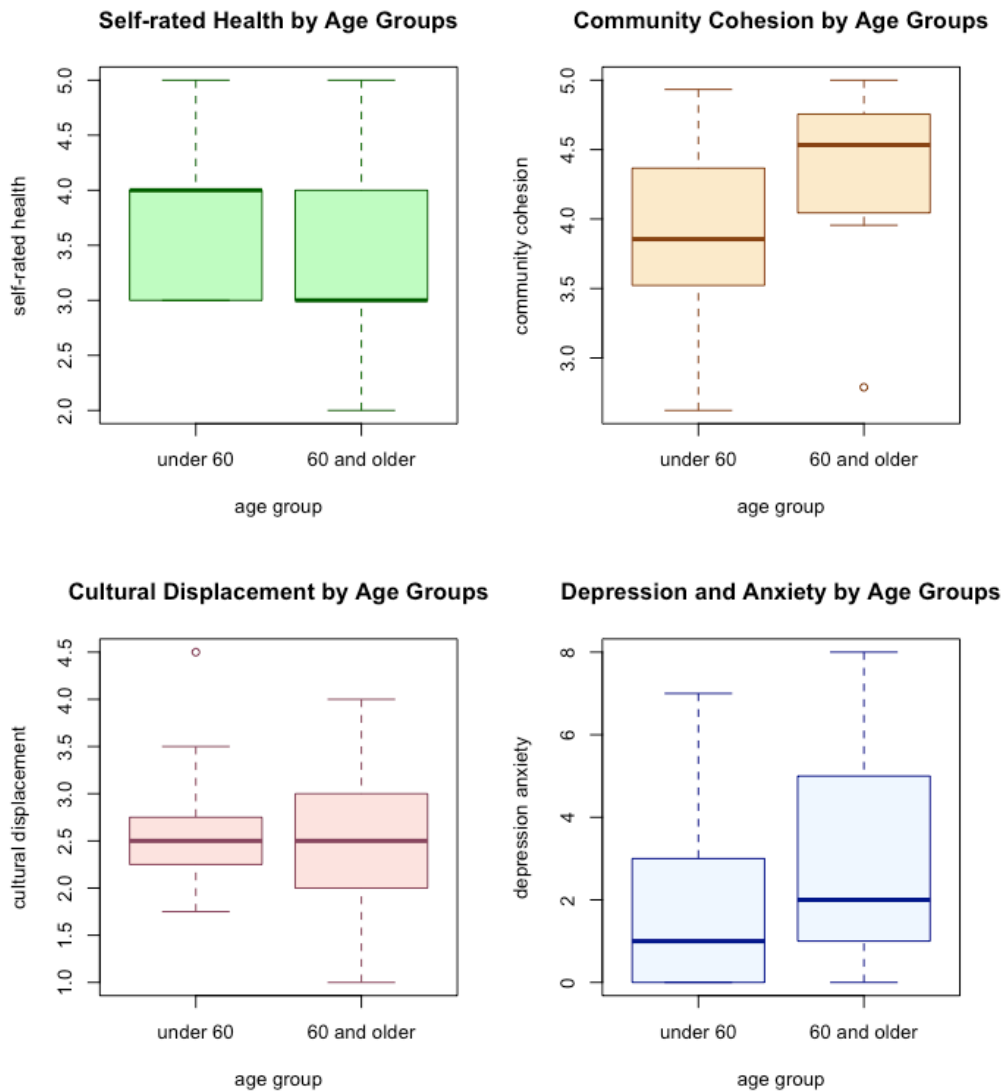


Figure 6. Selected variables by age groups for the whole intervention group.

Means, quartiles, and ranges for self-rated health, community cohesion, cultural displacement, and depression and anxiety at baseline for the whole intervention group.

$N = 53$, $n_{\text{under 60}} = 22$, $n_{\text{60 and older}} = 31$.

Paired-t test results for self-rated health, cultural displacement, and community cohesion to compare pre- and post-intervention measurements showed no significant change from baseline. Due to the small sample size ($n=15$), Wilcoxon signed-rank tests were also performed with similar results. The null hypotheses could not be rejected with 95% confidence. Therefore,

it could not be concluded that the *Stories of Us - Chuyện Kể Nhau Nghe* intervention affected changes in health, cultural displacement, or community cohesion in the sample for which post-intervention data exist.

Application of the functions `cohen.d`, `cohen.d.by`, and `d.ci` in the statistical program R provided the results for effect sizes and their 95% CI for the whole sample and for different age groups presented in Table 8. For a one-group pre-post design with a small sample, these figures approximate the differences between group means post-intervention and pre-intervention divided by the standard deviations of the means at pre-intervention (Durlak, 2009). Durlak cautioned against common usage of Cohen's original and cautious recommendations for interpreting effect sizes, i.e. $d = 0.20$ is small, 0.5 is medium, and 0.8 is large, but rather to consider the clinical and practical significance of effect sizes. For this study, it is worthy to note that these effect sizes are not statistically significant and that *Stories of Us – Chuyện Kể Nhau Nghe* life review sessions affected different age groups differently.

Table 8

Effects size Cohen's d (95% ci) of intergenerational life review on cultural displacement, community cohesion, and self-rated health by age group and for the whole sample

	<u>Cultural displacement</u>	<u>Community cohesion</u>	<u>Self-rated health</u>
60 and older	-0.07 (-0.60, 0.46)	0.14 (-0.39, 0.67)	-0.40 (-0.93, 0.14)
Under 60	-0.20 (-0.73, 0.33)	0.51 (-0.03, 1.05)	-0.06 (-0.59, 0.47)
Whole sample	-0.15 (-0.74, 0.43)	0.43 (-0.16, 1.02)	-0.33 (-0.91, 0.26)

Feasibility and Acceptability

In post-intervention questionnaires, participants were asked to select from a list of words describing feelings to indicate how they felt about the storytelling sessions. Nearly 65% participants selected feeling touched (11/17), 53% having fun (9/17), 35% being glad and reflective (6/17 each). Sadness, melancholy, and frustration each received two selections (12%). No one picked disturbed, furious, or angry. Since participants were encouraged to select as many of the emotions as they felt, those who selected sadness, melancholy, or frustration also

chose other more positive emotions as well. Focus group discussions immediately after confirmed the above sentiments. Comment from a male participant in his thirties summed up the overall feelings, “I’m so happy to have come to this gathering. I got to share my stories, listen to many fascinating stories, and learn so much from everyone.” A female elder received nods from her peers with, “Compliments to the young people who are understanding and willing to learn.” A woman in her 70s said, “I never thought I had anything to offer anyone other than my family. You young people make me feel like I am worth listening to. Look at you. You go to the university. You are lawyers and engineers. Me? Zero education. You make me feel proud.”

For the question about which parts of the sessions to keep the same, warm-up activity, prepared stories, small group discussions, and closing activity received the highest endorsement (11 keep votes). The two parts that received the least number of keep votes also had the highest number of change votes—asking clarifying questions (4 keep and 3 change votes) and reframing (2 keep and 2 change votes). Six participants suggested keeping all parts of the sessions as they were.

In focus group discussions, participants expressed overwhelming support for the sessions. There was one general theme: the need to continue with more sessions. One man in his 60s lamented, “Four sessions are too few. They went by too quickly. When can we have more?” One community leader who attended the session asked, “When can you train more people to conduct similar sessions throughout our community? We have been needing something like this for a long time.” One man in his early 30s was emphatic, “Whenever you’re ready to have more of these, please let me know. I’m ready for more anytime.” In short, the intergenerational life review sessions conducted by *Stories of Us - Chuyện Kể Nhau Nghe* were acceptable and feasible with the Vietnamese-American community in the Greater Seattle area.

Discussion

In Phase I, the first purpose of this study was to examine the relationships between cultural displacement, community cohesion, and self-rated health. Results from this sample showed some expected effects and two unexpected findings. As expected, the negative relationships between cultural displacement and community cohesion and between cultural displacement and self-rated health were clear in bivariate regressions as well as after adjusting for covariates.

The first unexpected finding was the differential effects of cultural displacement on health by level of cultural displacement. At low-level cultural displacement, the regression line was flat. In other words, when a person felt at home in the mainstream culture, assured in their identity, not feeling like an outsider, and feeling connected to the other generations in their family, then cultural displacement had no effect on their self-rated health. With a cultural displacement score of 2.25 or higher on a 1 - 5 scale, a clear negative relationship with self-rated health emerged.

The second unexpected finding was the small and non-significant relationship in this sample between community cohesion and self-rated health in bivariate regression. Closer inspection of the locally weighted scatterplot smoothing (LOWESS) line showed a clear positive relationship between community cohesion and health up until community cohesion score of 3.75, where the line levels out. In other words, when a person felt well connected to their ethnic community, increasing community cohesion did not impact their self-rated health. As noted in Table 3, the mean cohesion for the community survey sample in Phase I was 4.26 (sd 0.62) on a scale of 1 to 5. Likewise, for the intervention group as a whole at pre-intervention, the mean for

cohesion was 4.07 (sd 0.65) (see Table 8). The high mean in community cohesion before the intervention might partially explain the null effect of the intervention in this small pilot sample.

Furthermore, when regressions were performed separately for subsets of the community sample with the cutoff of cultural displacement at 2.25, community cohesion showed a significant positive relationship with health for the high cultural displacement subset. The implications for interventions would be to concentrate on those with higher cultural displacement to mitigate the negative effects of cultural displacement on health. To date, the investigator has not found other studies that examined the relationship between cultural displacement, community cohesion, and health to compare the results of this study. Hence, it is difficult to interpret whether the effect sizes found have practical or clinical significance.

The next purpose of Phase I was to test whether community cohesion mediated the effects of cultural displacement on self-rated health. Results from this study showed not only a reduction in the regression coefficient when community cohesion and the interaction term were introduced into the equation of the effects of cultural displacement on health, but also a change in direction from negative to positive. Baron and Kenny (1986) suggested that such change represented inconsistent mediation. In this case, since cultural displacement has a negative effect on health and community cohesion has a positive effect on health, perhaps this effect is so strong as to nullify the effects of cultural displacement and the positive effect seen is the residual effect of community cohesion on health, after taking into account cultural displacement. More research with a large and representative sample may help tease out this relationship. Furthermore, although the data suggested a causal process, since there was no manipulation of variables in Phase I, causality cannot be concluded definitively.

In Phase II, the purpose of the study was to test the effectiveness of *Stories of Us - Chuyện Kể Nhau Nghe* intergenerational life review sessions on cultural displacement, community cohesion, and health. The results did not show significant effects on any of the primary variables, most likely due to the small sample size. The other explanation might be the floor/ceiling effect. At baseline, the intervention sample had high means at baseline for self-rated health and community cohesion, and low mean for cultural displacement, which was marginally above the low cultural displacement cutoff, 2.25, below which cultural displacement did not have an effect on self-rated health.

Finally, this study demonstrated that intergenerational life review sessions are not only feasible and acceptable with the Vietnamese-American community in the Greater Seattle area. They are desirable. Although the study did not find statistically significant effects on any primary variables, quantitative and qualitative evaluation data showed the participants' appreciation for the opportunity to share stories across generations and eagerness to continue with similar sessions in the future. This finding is congruent with the proliferation of projects to tell stories of the Vietnamese-American experiences in the area and nationally. This study hopes to contribute to that trend.

Implications for Future Research

Findings from this study demonstrated that cultural displacement has a negative influence on self-rated health and that community cohesion may mitigate this effect. However, studies on ethnic minorities tend to focus on acculturation, which measures the behaviors of individuals against the mainstream culture as a reference. Cultural displacement, however, considers culture from the point of view of the minority population and is a measure of the impact of the social environment on the individuals. More studies with stronger designs and with other minority

populations may help unpack the immigrant health paradox, where immigrants were observed to have better health than U.S. born counterparts despite lower socioeconomic status (John et al., 2012).

In contrast, there has been substantial scholarship on the effect of life review on health, particularly depression, and, to a lesser extent, on people's relationship with each other and with the society. Studies on intergenerational reminiscence among mainstream participants have found increased understanding and better positive perceptions of the other generation. Since culturally displaced populations may experience more pronounced generational gaps due to cultural and language barriers, more studies on the effects of intergenerational reminiscence on cultural displacement, community cohesion, and self-rated health among minority populations may provide another tool to affect the social environment and promote the health of disadvantaged populations. Replicating the intervention in this study with a larger sample and more matched pre- and post- data may be helpful in detecting the effects of the intervention, if any.

Limitations

This study has several limitations. First, the samples for both Phase I and Phase II were not representative of the Vietnamese-American population in the Puget Sound. Although there were a few individual from ethnic minorities, such as ethnic Chẵm, Chinese, and Khmer from Việt Nam, they were under-represented in both samples. More efforts should be spent to reach out to these groups in future research among this population. Second, in Phase II, the one-group pre-post design can be improved in the future with a comparison group. Therefore, even if there were significant effects on the primary variables, no definitive conclusion can be made to attribute such effects to intergenerational life review. Third, the low completion rate resulting in

the small final sample in Phase II severely limited the power to detect any effects. Fourth, the instruments for this study could be reduced and refined further to be more relevant to the Vietnamese-American population.

Conclusion

In summary, although exploratory, the findings of the *Stories of Us - Chuyện Kể Nhau Nghe* study suggest dimensions of deleterious and protective factors on the health of immigrants and refugees that are under-studied. Although changing a feeling of cultural displacement requires alterations in societal norms, which may feel out of reach to these vulnerable populations, improving community cohesion through sharing life stories across generations is not. Such intervention is desirable by the community, is feasible and economical to implement, and is built on community traditions, which makes the intervention culturally relevant.

Stories of Us - Chuyện Kể Nhau Nghe contributes to the current literature on health research in several ways. First, the study examined a health promotion intervention among refugees and immigrants from the point of view of the participants. The intervention utilized existing under-utilized community assets—community elders and their life stories. Second, the study revealed further complexity in the impact of the social environment on the health of refugees and immigrants. Third, the study confirmed the feasibility of conducting community participatory action research among the Vietnamese-American community and the implementation of structured intergenerational life review intervention with this community to promote health. The study holds promise to add one more tool to the toolbox of health promotion research in the community.

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BUILDING COMMUNITY FOR HEALTH THROUGH STORIES

Appendices. Research Documents



Project Information Statement – Phase I Cross-sectional Survey

English

Stories of Us– Chuyện Kể Nhau Nghe is a community health research project by a PhD candidate at the University of Washington. The study is about the connection of Vietnamese Americans to each other and to the Vietnamese communities.

Our goals:

- 1) Promote connections and understanding across generations of Vietnamese Americans through stories
- 2) Build community capacity on action research among Vietnamese Americans

Please help us by completing the attached survey. It is voluntary. You can skip any question. You can stop at any time. It takes about 15 minutes to complete the questionnaire.

Please **do not write your name** on the survey. The data are anonymous. By completing the survey, you voluntarily agree to participate in the survey.

You **will not gain any direct benefit and may suffer some discomfort** by completing the survey. You will **not suffer any adverse effect** if you do not participate. The information you provide will help us understand our community better.

If you think you have a medical problem or illness related to this research, please contact Hoàng t. Diệu-Hiền at (360) 545-3536 right away. She will treat you or refer you for treatment.

If you have questions about your rights as a research subject, you can call the Human Subjects Division at (206) 543-0098 or call collect at (206) 221-5940.

For more information, please contact Hoàng t. Diệu-Hiền at stories-of-us@uw.edu or call (360) 545-3536. Please remember that we cannot guarantee the confidentiality of information sent by email.

If you would like to be involved, please provide your contact information below. Please keep this portion for your information, tear off the portion below the line, and drop it in the box with the *Stories of Us – Chuyện Kể Nhau Nghe* logo.

Please tear here

Thank you for your interest in *Stories of Us – Chuyện Kể Nhau Nghe*. Please provide your contact information and let us know how you would like to be involved.

Name: _____

I am interested in being part of

Phone: _____

_____ the research team

Email: _____

_____ the community advisory group

Facebook: _____

_____ the storytelling sessions



Project Information Statement – Phase I Cross-sectional Survey

Vietnamese

Stories of Us – Chuyện Kể Nhau Nghe là một chương trình nghiên cứu về sức khỏe cộng đồng của một nghiên cứu sinh ở trường Đại học Tiểu bang Washington (UW). Chương trình này nghiên cứu về sự gắn bó giữa người Việt với nhau và với cộng đồng người Việt.

Mục đích:

- 1) Tăng cường sự gắn bó và cảm thông giữa các thế hệ người Việt qua kể chuyện
- 2) Tăng khả năng nghiên cứu đưa đến hành động của cộng đồng người Việt

Xin giúp chúng tôi bằng cách góp ý vào bảng câu hỏi đính kèm. Việc trả lời bảng câu hỏi hoàn toàn tự nguyện. Quý vị có thể bỏ không trả lời bất kỳ câu hỏi nào. Quý vị có thể ngưng tham gia bất kỳ lúc nào. Việc trả lời bảng câu hỏi mất khoảng 15 phút.

Xin quý vị **không ghi tên** mình vào bảng câu hỏi. Các dữ liệu hoàn toàn ẩn danh. Khi trả lời bảng câu hỏi là quý vị tự nguyện đồng ý tham gia vào cuộc thăm dò ý kiến này.

Quý vị sẽ **không được thêm quyền lợi và có thể cảm thấy hơi khó chịu** nếu trả lời bảng câu hỏi. Quý vị sẽ **không bị bất kỳ ảnh hưởng xấu nào** nếu quý vị không tham gia. Thông tin quý vị cung cấp sẽ giúp chúng tôi hiểu rõ hơn về cộng đồng của chúng ta.

Nếu quý vị cảm thấy có vấn đề về sức khỏe hay bệnh tật nào liên quan đến nghiên cứu này, xin liên lạc với cô Hoàng t. Diệu-Hiền tại số (360) 545-3536 ngay lập tức. Cô ấy sẽ điều trị cho quý vị hoặc chuyển quý vị đến nơi để được điều trị.

Nếu quý vị có thắc mắc gì về quyền lợi của mình là người tham gia nghiên cứu, xin gọi Human Subjects Division tại số (206) 543-0098 hay gọi số (206) 221-5940 để người nhận trả tiền.

Để biết thêm chi tiết, xin liên lạc với cô Hoàng t. Diệu-Hiền tại stories-of-us@uw.edu hay gọi số (360) 545-3536. Xin lưu ý rằng chúng tôi không thể bảo đảm tính bảo mật cho những thông tin gửi qua email hay thư tín điện tử.

Nếu quý vị muốn tham gia vào nghiên cứu này, yêu cầu cho chúng tôi biết tên và thông tin để liên lạc với quý vị dưới đây. Yêu cầu quý vị giữ đoạn trên này, xé rời tại lần gạch dưới đây và bỏ phần có tên của quý vị vào thùng có dấu hiệu *Stories of Us – Chuyện Kể Nhau Nghe*.

Please tear here - Vui lòng xé ở lần này

Cám ơn quý vị đã quan tâm đến chương trình *Stories of Us – Chuyện Kể Nhau Nghe*. Yêu cầu quý vị cho chúng tôi biết tên, cách liên lạc với quý vị, và quý vị muốn tham gia trên phương diện nào.

Tên: _____	Tôi muốn tham gia vào
Số điện thoại: _____	_____ nhóm làm nghiên cứu
Email: _____	_____ nhóm cố vấn cộng đồng
Facebook: _____	_____ những buổi kể chuyện



Project Information Statement

Phase II *Stories of Us* Intergenerational Intervention - English

Stories of Us - Chuyện Kể Nhau Nghe is a community health research project by a PhD candidate at the University of Washington. The study is about the connection of Vietnamese Americans to each other and to the Vietnamese communities.

Our goals:

- 1) Promote connections and understanding across generations of Vietnamese Americans through stories
- 2) Build community capacity on action research among Vietnamese Americans

Please help us by answering the attached questionnaire. Completing the questionnaire is **voluntary and confidential**. Your name will not be associated with your answers. You can skip any question. You can stop at any time. The questionnaire takes about 15 minutes.

We appreciate your willingness to take part in the storytelling sessions. There will be four inter-generational storytelling sessions. Each session lasts approximately four hours. Participants will listen to elders reading stories from their life experiences. Then all will discuss the stories within their historical, cultural, and social contexts. We request that participants commit to attending all four sessions.

During the first session, we will establish ground rules that all will commit to follow. All who participate must commit to keeping the information gained through these sessions confidential and not letting it get outside the group. By attending the storytelling sessions, you voluntarily agree to participate in the study.

You **will not gain any direct benefit** by completing the survey or taking part in the storytelling sessions. You **will not suffer any adverse effect** if you do **not** complete the survey or do **not** participate in the storytelling sessions. The information you provide by completing the survey will help us understand our community better. You **may have some emotional distress** during the storytelling sessions.

Please share only what you are comfortable to tell this group. Unless you have signed permissions otherwise, your stories and any recording of your stories are yours to keep. Even if you have signed permissions for us to use your stories outside of this group, you may withdraw it at anytime. We will keep data for future analysis and study after removing all personal information.

If everyone agrees, we will video record these sessions for training and research purposes only. If even one person objects, we will not video record the sessions. We will take notes during the sessions. By attending the sessions, you agree to participate in *Stories of Us* study.

If you think you have a medical problem or illness related to this research, please contact Hoàng t. Diệu-Hiền at (360) 545-3536 right away. She will treat you or refer you for treatment.

If you have questions about your rights as a research subject, you can call the Human Subjects Division at (206) 543-0098 or call collect at (206) 221-5940.

Thank you for taking part in this study to heal our community. Please feel free to ask any question at any time.

For more information, please contact Hoàng t. Diệu-Hiền at stories-of-us@uw.edu or call (360) 545-3536. Please remember that we cannot guarantee the confidentiality of information sent by email.



Project Information Statement

Phase II *Stories of Us* Intergenerational Intervention - Vietnamese

Stories of Us - Chuyện Kể Nhau Nghe là một chương trình nghiên cứu về sức khỏe cộng đồng của một nghiên cứu sinh ở trường Đại học Tiểu bang Washington (UW). Chương trình này nghiên cứu về sự gắn bó giữa người Việt với nhau và với cộng đồng người Việt.

Mục đích:

- 1) Tăng cường sự gắn bó và cảm thông giữa các thế hệ người Việt qua kể chuyện
- 2) Tăng khả năng nghiên cứu tìm giải pháp của cộng đồng người Việt

Xin giúp chúng tôi bằng cách góp ý vào bảng câu hỏi đính kèm. Việc trả lời bảng câu hỏi là **tự nguyện và được giữ kín**. Tên của quý vị sẽ không gắn liền với câu trả lời của quý vị. Quý vị có thể bỏ qua bất kỳ câu hỏi nào. Quý vị có thể ngưng bất kỳ lúc nào. Việc trả lời bảng câu hỏi mất khoảng 15 phút.

Chúng tôi cảm ơn quý vị sẵn lòng tham gia vào các buổi kể chuyện. Sẽ có bốn buổi kể chuyện với sự tham gia của những thế hệ khác nhau. Mỗi buổi kể chuyện sẽ kéo dài bốn tiếng. Những người tham gia sẽ nghe quý vị cao niên đọc lại chuyện từ cuộc sống của mình. Sau đó, tất cả sẽ thảo luận những mẫu chuyện đó trong bối cảnh lịch sử, văn hoá, và xã hội của nó. Chúng tôi yêu cầu những người tham gia cam kết sẽ dự đủ bốn buổi kể chuyện.

Trong buổi kể chuyện đầu tiên, chúng ta sẽ cùng lập ra nội quy mà tất cả những người tham gia sẽ cam kết tuân theo. Tất cả những ai tham gia phải cam kết giữ kín thông tin nhận được từ các buổi kể chuyện để không thoát ra ngoài nhóm kể chuyện. Khi tham gia buổi kể chuyện là quý vị tự nguyện đồng ý tham gia nghiên cứu này.

Quý vị sẽ **không trực tiếp hưởng quyền lợi gì** khi trả lời bảng câu hỏi hay tham gia vào các buổi kể chuyện. Quý vị sẽ **không bị bất kỳ ảnh hưởng xấu nào** nếu quý vị **không** trả lời bảng câu hỏi hay **không** tham gia các buổi kể chuyện. Thông tin quý vị cung cấp qua việc trả lời bảng câu hỏi sẽ giúp chúng tôi hiểu rõ hơn về cộng đồng của chúng ta. Quý vị **có thể sẽ cảm thấy đau buồn** trong các buổi kể chuyện.

Yêu cầu quý vị chỉ chia sẻ những gì quý vị cảm thấy thoải mái để chia sẻ trong nhóm này. Trừ khi quý vị đã ký tên cho phép làm khác, quý vị có toàn quyền giữ câu chuyện và những hình thức ghi lại câu chuyện của quý vị. Kể cả khi quý vị đã ký tên cho phép chúng tôi sử dụng chuyện của quý vị ngoài nhóm này, quý vị có thể rút lại việc cho phép bất kỳ lúc nào. Chúng tôi sẽ lưu lại dữ kiện để phân tích và nghiên cứu thêm sau này sau khi đã xoá các thông tin cá nhân.

Nếu tất cả mọi người cho phép, chúng tôi sẽ thu hình các buổi kể chuyện cho mục đích huấn luyện và nghiên cứu mà thôi. Nếu chỉ có một người không đồng ý, chúng tôi sẽ không thu hình buổi kể chuyện. Chúng tôi sẽ ghi chép trong buổi kể chuyện. Khi quý vị dự buổi kể chuyện là quý vị đồng ý tham gia vào nghiên cứu *Chuyện Kể Nhau Nghe*.

Nếu quý vị cảm thấy có vấn đề về sức khỏe hay bệnh tật liên quan đến nghiên cứu này, xin liên lạc với cô Hoàng t. Diệu-Hiên tại số (360) 545-3536 ngay lập tức. Cô ấy sẽ điều trị cho quý vị hay chuyển quý vị đến nơi để được điều trị.

Nếu quý vị có thắc mắc gì về quyền lợi của mình là người tham gia nghiên cứu, xin gọi Human Subjects Division tại số (206) 543-0098 hay gọi số (206) 221-5940 để người nhận trả tiền.

Xin cảm ơn quý vị đã tham gia chương trình nghiên cứu này để hàn gắn cộng đồng chúng ta. Xin quý vị tự nhiên đặt câu hỏi bất kỳ lúc nào.

Để biết thêm chi tiết, xin liên lạc với cô Hoàng t. Diệu-Hiền tại stories-of-us@uw.edu hay gọi số (360) 545-3536. Xin lưu ý rằng chúng tôi không thể bảo đảm tính bảo mật cho những thông tin gửi qua email hay thư tín điện tử.

BUILDING COMMUNITY FOR HEALTH THROUGH STORIES

General Plan for the *Stories of Us* – *Chuyện Kể Nhau Nghe* Intervention Sessions 2017

There may be up to 10 older adults participating in the group, but only 5 persons reading their stories. The others may participate in the discussions but will not read their stories during the sessions.

1. There will be 4 intergenerational storytelling sessions
 - a. Saturday mornings, every other week
 - b. 9:00 am to 12:30 pm
 - c. There will be tea and coffee served in the morning, before 9:00 am
 - d. There will be some refreshment after 12:30 pm
 - e. **It is best that participants attend all 4 sessions, unless unforeseen problems happened**
2. The preliminary plan of each session as follow
 - a. 8:45 am, before the program begins: tea, coffee, chatting
 - b. Main program:
 - i. Warm up activity
 - ii. Story reading / listening
 - iii. Clarifying questions to storytellers
 - iv. Discussions on the social, historical, and cultural context of the stories
 - v. Evaluation or reframing events, as appropriate
 - vi. Exchange of thoughts, feelings, impressions about the stories
 - vii. Closing: lessons learned and planning for next session
 - c. After the main program ends: 12:30-1:00 pm: refreshments, chatting
3. Topics for storytelling sessions:
 - a. Please retell a **memorable experience in your youth before you got married**. If you have never married, please retell a memorable experience when you were **between 15 to 30 years old**.
 - b. Please retell a story **during the time** you/your spouse were **in the armed forces** that has had a **significant impact** on you or your family at the time.
 - c. Please retell an experience that has become a **significant marker in your life**.
 - d. Please retell a memorable event that has **touched you after you arrived in the U.S.**

4. Suggestions for the stories
 - a. The stories can be happy or sad as long as they are memorable to you.
 - b. Please write down the stories on paper, but limit to 2 pages on 8.5 x 11 inches paper. You may write by hand or type.
 - c. Below are suggestions for the stories so that they have rich descriptions, in case you need ideas on what to retell. You do not have to answer all of these questions.
 - i. What year was it? How old were you? What were you doing at the time?
 - ii. When did the story take place? Was it in a village, a town, or a city? Was it in the coastal area, in the jungles, rivers, or rice fields?
 - iii. The event took place outdoor or in the home, or at work, etc.?
 - iv. What was the weather like? Rainy or sunny, or foggy, or pitchblack, or moonlit, etc.?
 - v. The story took place in the morning, midday, afternoon, or at night?
 - vi. When the story took place, what did you hear, see, or smell around you?
 - vii. Who were present at the time? What were they doing?
 - viii. What were you feeling when the event took place?
 - ix. What happened?
 - x. What were your reactions when the event took place?
 - xi. What were the reactions of the people around you when the event took place?
 - xii. What about this event made it memorable to you?
5. If possible, please **bring with you an artifact related to the story** that you will tell. The artifact can be a photo, a handkerchief, a shirt, a pen, a ring, or a book, etc.

Chapter 5. **Conclusion**

In brief, this dissertation research benefited from work on a wide range of topics conducted by researchers from diverse disciplines. The rich literature on social determinants of health, reminiscence, participatory research, and critical theories formed the foundation and conceptualization of this research. The previous chapters summarized this research and consist of three manuscripts.

In Chapter 2, results of an integrative review of 101 studies on the effects of life review reminiscence on social connections and health were presented. The prevention and reduction of depressive symptoms emerged as the strongest evidence of the effects of life review on health among the studies reviewed. Meaning in life, ego integrity, mastery, and positive thoughts were found to mediate those effects. In other words, among study participants, life review enhanced a positive view of oneself and one's life in society, which in turn promoted one's psychological well-being. Studies that examined the effects of life review on the participants' relationships with other people showed promising results of its positive effects on connecting people, particularly by intergenerational interventions. The Model of Intergenerational Life Review and Health was proposed as one suggestion to further study the effects of life review on immigrants and refugees, an area under-studied in this review.

In Chapter 3, the researcher compared and contrasted the experience of conducting *Stories of Us - Chuyện Kể Nhau Nghe*, a community participatory action research project, with the experiences of other researchers in conducting community participatory research with ethnic Vietnamese, a refugee and immigrant population. Lessons learned from the literature and from *Stories of Us - Chuyện Kể Nhau Nghe* included successful strategies to earn mutual trust and respect, build capacity, facilitate empowerment, promote a sense of ownership, and ensure accountability and sustainability. These strategies consist of long-term, consistent, and active

involvement with the community, utilizing and building on community existing assets, and committed investment of time and expertise for sustainable change. The experiences in the literature and from *Stories of Us - Chuyện Kể Nhau Nghe* also remind researchers that each community has its unique characteristics. Guidelines and experiences by other researchers with other communities serve only as general guidelines and not as rigid rules to be substituted for personal relationships with the community.

In Chapter 4, results of *Stories of Us - Chuyện Kể Nhau Nghe* were presented. Findings from Phase I, a cross-sectional community survey, showed that community cohesion mediates the effects of cultural displacement on health, which varied depending on the level of cultural displacement. In Phase II, a one-group pre- post- design, four sessions of weekly intergenerational life stories sharing among Vietnamese-American participants were conducted in English and Vietnamese. A total of 55 Vietnamese-Americans all age groups attended at least one story-sharing session. Fifteen complete pre- post- measurements were collected. Quantitative results did not show significant effects of life review on cultural displacement, community cohesion, or health, possibly due to the small sample size. Qualitative and quantitative evaluation of the intervention demonstrated that intergenerational life stories sharing was feasible and desirable by participants, despite the low completion rate (27%), and that the community would like *Stories of Us - Chuyện Kể Nhau Nghe* to continue and more life stories sharing to take place in the wider community.

As a final point, past research with well-designed studies on life review reminiscence has shown that it is effective in reducing depressive symptoms and it does so by helping to create meaning in life in place of despair, enhancing a sense of self-worth, and improving one's perception of one's place in society, thus reducing the feeling of being displaced and

disconnected from society. In addition, results from past studies have shown that life review has increased communication and promoted relationships between family members and people sharing life stories, connecting people with each other, and promoting a sense of appreciation among participants, particularly intergenerational life review programs. However, past studies took place in small groups focusing on the individuals. Perhaps, given positive results from well-designed past studies, if conducted on a larger scale at the community level, intergenerational life stories sharing may deliver all of the above, affecting change in health, relationships among individuals, and relationships with the society at the population level.

For *Stories of Us - Chuyện Kể Nhau Nghe*, future study with a larger sample, a stronger study design, and more sensitive measurements may enhance community cohesion among Vietnamese-Americans, reduce their sense of being culturally displaced, and improve their holistic sense of well-being. If so, *Stories of Us - Chuyện Kể Nhau Nghe*'s community participatory action research process may be replicated with other culturally displaced populations, including refugees, immigrants, and indigenous peoples, as a culturally relevant tool to promote population health and narrow the health equity gaps.

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VITA

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