Cultural Considerations among Family Caregivers in Palliative and Hospice Care

Soojeong Han

A dissertation submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy

University of Washington
2019

Reading Committee:
Anne Hirsch, Co-Chair
JoAnne Whitney, Co-Chair
George Demiris
Susanne May
Arnold de Castro

Program Authorized to Offer Degree:
School of Nursing

University of Washington

Abstract

Cultural Considerations among Family Caregivers in Palliative and Hospice Care

Soojeong Han

Co-Chairs of the Supervisory Committee:
Professor Anne Hirsch, Psychosocial and Community Health Nursing
Professor JoAnne Whitney, Biobehavioral Nursing and Health Informatics

Persisting caregiving burden causes health problems among family caregivers. In this diverse, global society, culturally sensitive care for both patients and their family has been emphasized. Exploring interactions of race/ethnicity and other cultural components with caregiving patterns and coping styles is important. Furthermore, cultural values interacted with race/ethnicity shape different patterns of using social support and coping styles, and thereby explain differing mental health outcomes among family caregivers. Examining the influence of cultural factors is important to develop culturally sensitive interventions targeting potentially modifiable social and cultural factors that delineate coping mechanisms and resilience. This dissertation consists of the introduction (Chapter 1), three manuscripts regarding family caregiving in palliative and hospice care that are presented in three chapters (Chapters 2, 3, and 4) and the conclusion (Chapter 5).

Chapter 2 is a quantitative secondary analysis study and examines the effect of the interaction between race/ethnicity and other cultural factors on mental health among family caregivers. The findings of this study suggested that we can refine culturally tailored interventions focusing on modifiable cultural predictors such as family functioning and trust in providers interacted with race/ethnicity for improving mental health among ethnically diverse family caregivers of pediatric patients in intensive care units.

Chapter 3 is a qualitative secondary analysis study and aims to identify challenges, possible solutions that are resources for resilience, and expected consequences from hospice dementia caregivers' perspectives. The findings of this study suggested that there are several resources for enhancing resilience among family caregivers of hospice geriatric patients with dementia.

Chapter 4 is a systematic narrative review. This review identified the studies reporting on the interconnected relationships among cultural components and social determinants of health including race/ethnicity, and the impact of these relationships on resilience and coping mechanisms among family caregivers of older adults in palliative and hospice care settings.

Overall, my dissertation examines resilience and coping mechanisms, which are differently shaped by potentially modifiable social and cultural factors that are closely related to race/ethnicity among family caregivers. My research will provide guidance for developing culturally tailored interventions to support the patient-family caregiver dyads in palliative and hospice care.

TABLE OF CONTENTS

CHAPTER 4. RELATIONSHIPS AMONG RACE, ETHNICITY, OTHER SOCIAL AND CULTURAL COMPONENTS, AND RESILIENCE IN FAMILY CAREGIVING IN THE CONTEXT OF PALLIATIVE AND HOSPICE CARE: A SYSTEMATICALLY CONDUCTED NARRATIVE REVIEW

CHAPTER 5. CONCLUSION

APPENDICES

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

AA	African American
AAHPM	American Academy of Hospice and Palliative Medicine
ADRD	Alzheimer’s Disease and Related Dementias
ANOVA	Analysis of Variance
CINAHL	Cumulative Index of Nursing and Allied Health Literature
EMBASE	Excerpta Medica database
GAD-7	General Anxiety Disorder
GEE	Generalized Estimating Equations
HPNA	Hospice and Palliative Nurses Association
ICU	Intensive Care Unit
IRB	Institutional Review Board
MMAT	Mixed Methods Appraisal Tool
MSPSS	Multidimensional Scale of Perceived Social Support
NA or AN	Native American or Alaskan Native
NHOPI	Native Hawaiians or Pacific Islanders
PHQ-9	Patient Health Questionnaire
PRISMA	Preferred Reporting Items for Systematic Reviews and Metal-analysis
RCT	Randomized Controlled Trial
SSCM	Sociocultural Stress and Coping Model
US	United States
WFTS	Wake Forest Trust Scale

ACKNOWLEDGMENT

I would like to gratefully acknowledge several people who helped and supported me for the completion of this dissertation. This dissertation is the result of many experiences with plenty of ups and downs throughout the Ph.D. program at the University of Washington, and it would have been impossible without the help and support of those people.

Much thanks to my chairs, Professors Anne Hirsch and Joie Whitney, for their guidance, enthusiasm, and supervision during my long-standing Ph.D. journey. I would like to thank Professors Helene Starks, Susanne May, Butch de Castro, and George Demiris. Thanks to them for supporting me in the pursuit of my studies.

I would like to express my sincere gratitude to the entire staff in Academic and Student Services at the School of Nursing. Graduate Program Advisor, Betsy Mau.

This dissertation would not have been possible without my mentors' and friends' encouragements and support. All their kind support, love and care were received. Sincere thanks go to my beloved James Lee and my family for providing continuous support and encouragement throughout my entire life.

I hope that people will find a better way to better health. I will continue my commitment to the future of palliative and hospice care by conducting research and practicing as a healthcare provider. May future generations live in an interculturally understanding world.

Acknowledgment of material arising from this dissertation

Manuscripts published

- **Han S**, Chi NC, Han C, Parker Oliver D, Washington K, Demiris G. Adapting the resilience framework for family caregivers of hospice patients with dementia. *American Journal of Alzheimer's disease and other dementias.* 2019; 34(6): 339-411 [Epub ahead of print].

I would like to dedicate this Ph.D. dissertation

to all patients and their family members all over the world

as well as

my beloved, James Lee,

family, mentors, and friends

who have helped me to become the person I am today.

And…

Thank you, Lord.

CHAPTER 1.

INTRODUCTION

Importance of Cultural Consideration among Family Caregivers across Lifespan in Palliative and Hospice Care

Individuals and families receiving palliative care are increasingly culturally diverse. Palliative care is a supportive approach to minimize pain and other symptoms and improve quality of life for patients and their families. Palliative care can be received by patients at any time whether the stage of illness is terminal or not, unlike hospice offered only for people with a terminal illness. Providing palliative care to all populations regardless of their race and ethnicity is important. Culturally sensitive palliative care is needed to help address the ethnic disparities in health care. When other factors such as age, income, insurance status, and the severity of illness are comparable, minorities experience more negative health outcomes and a higher death rate (Betancourt, 2006; Nelson, 2002). Little research has focused on understanding the mechanisms that lead to disparities in health outcomes by race and ethnicity in palliative care and raising awareness about the importance of cultural values and influences on palliative care (Adames, Chavez-Duenas, Fuentes, Salas, & Perez-Chavez, 2014). A culturally competent care approach, considering the differences in health outcomes by race and ethnicity, should be implemented. Some research exploring influences of cultural and racial aspects on pediatric palliative care has been conducted. It may be useful to consider whether any of the insights from previous research are transferable to populations with dementia having the same cultural and racial backgrounds.

According to the World Alzheimer Report (2015), the prevalence of persons with dementia is estimated at 46.8 million people worldwide and expected to rise up to 74.7 million by 2030. Despite the high prevalence of dementia, the need for palliative and hospice care for dementia has been overlooked.

Older adults with dementia were sometimes not recognized as patients who need to receive palliative and hospice care because of patients' declined communication abilities, great variability in predicted expectancy of dementia, difficulty in nonverbal assessment and management for pain and other behavioral and psychological symptoms, lack of recognition of dementia as an terminal illness or a cause of death, and difficulty in decision-making for end-of-life care among family members (Sachs, Shega, & Cox-Hayley, 2004; Sampson, 2010). Researchers are starting to focus on identifying challenges that persons with dementia and their caregiver's experience in accessing palliative care, but little attention has been given to cultural sensitivity (Birch & Draper, 2008). Growing recognition of cultural and racial factors should be considered in providing palliative care to persons with dementia.

Pediatric palliative and hospice care is specialized care for children with serious illnesses and has had a long successful history for over the last two decades of supporting pediatric patients and their family caregivers (American Academy of Pediatrics, 2013; Liben, Papadatou, & Wolfe, 2008). Pediatric palliative care is family-centered, as most pediatric patients are dependent on family members, primarily parents. Research exploring cultural aspects in pediatric palliative and hospice care has provided guidance to comprehensively and holistically support pediatric patients and their families. Researchers who are involved in pediatric palliative and hospice care underlined the importance of evidence-based practice along with cultural and religious/spiritual consideration (American Academy of Pediatrics, 2013; Liben et al., 2008). Some of those cultural and religious principles have been discovered in pediatric palliative care (Wiener, McConnell, Latella, & Ludi, 2013). To be specific, the quality of communication between family members and providers, which is influenced by providers' respect for pediatric patients and their family's religion and culture as well as language barriers, affected the quality or direction of pediatric end-of-life care (Marsac, Kindler, Weiss, & Ragsdale, 2018). Effective communication and trusting relationships between parents and providers improved parents' emotional status and increased their satisfaction with the quality of care (Marsac et al., 2018). As another example of cultural context that affects family caregiving for pediatric patients, parents asserted their right to control their child and took away their child's right to consent to life-saving treatments because of the influence of the paternal authoritarianism and filial submissiveness (Hui, 2008). The parents' role and family functioning were also considered key factors in decision-making in pediatric care (Doorenbos et al., 2012; Michelson et al., 2009). Michelson et al. (2009) presented how parents perceive death and view afterlife and whether they trust in healthcare providers influenced parents to consider withdrawing life-sustaining therapies. Cultural understanding may improve communication patterns and trusting relationships between family members and providers and balance between supporting the right to the pediatric patient's own lives and respecting their parents. As such, healthcare research has shown that culture operates at pediatric care, provided the implications for better care, and enlightened healthcare providers to consider the importance of cultural factors in pediatric palliative and hospice care.

Catlin and Carter (2002) have served as a primary source for the pediatric palliative care protocol and emphasized culturally sensitive care. Families may wish to meet other families with the same diagnosis, need time to inform other family members and prepare for emotional and spiritual support, and funeral or memorial services (Catlin & Carter, 2002). The provisions of linguistically appropriate care by hospital-trained and certified translators, culture-specific practices such as eye contact and touch, education to help families consider palliative care as providing comfort, and grief counseling were considered to provide culturally sensitive care (Catlin & Carter, 2002). The culturally sensitive care, including the aforementioned components, should be applied to all patients and their families.

Although pediatric patients have unique characteristics (Ullrich & Morrison, 2013), cultural elements of family caregivers of pediatric patients are comparable to those of older adults with dementia. These cultural aspects also influence dementia palliative care for culturally diverse persons with dementia and their family caregivers. In cases of disabled newborns, families may abandon treatments to decrease their burden (Beauchamp & Childress, 2013). This logic can be applied to other populations of feeble, debilitated, and seriously ill patients who are a burden on their family and society (Beauchamp & Childress, 2013). Persons with dementia can be one of those population categories. We can take lessons from pediatric family caregiving in palliative care and apply those lessons to dementia by identifying sharable cultural factors across the lifespan (see Figure 1). This approach would be optimal for developing more efficient and effective dementia palliative care practices with limited resources.

Research on dementia in palliative care is a relatively new area (Harris, 2007). A widely used clear definition or standards of palliative care in dementia have not been established (van der Steen et al., 2014) because dementia patients were often not considered candidates for palliative and hospice care (Sachs et al., 2004; Sampson, 2010). However, pediatric and dementia palliative care provide common challenges and opportunities. Every young and cognitively old disabled person requires the help of a caregiver. Challenges in caring for a patient-caregiver dyad include: involving and supporting family/friend caregivers, difficulty in assessing and monitoring patients' symptoms, and the need for individual and family approaches that consider cultural issues (Harris, 2007; Ullrich & Morrison, 2013; van der Steen et al., 2014). Persons with dementia need their family members' support and involvement to make decisions just as pediatric patients need their parent's support and involvement. This decision-making process is central to quality palliative care for both pediatric and geriatric patients with dementia. Those two populations rely on family and may be considered to have less decision-making capacity. As the pediatric patient and geriatric patient with dementia need support for having the right of self-determination, healthcare providers should have the ethical principle of autonomy and consider higher demands for successful palliative and hospice care with respects for the patient's rights.

Healthcare providers should adopt ethical principles of autonomy within the unique provider-family-patient relationship. Both pediatric and dementia patients might be not generally deemed to be fully autonomous or be the final decision-maker at the end. Cultural sensitivity within a family context is therefore necessary across these two care areas.

According to the review of Nápoles, Chadiha, Eversley, and Moreno-John (2010), there was remarkably little evidence of culturally tailored interventions for dementia caregivers with ethnocultural differences. This gap in knowledge and practice of cultural considerations in dementia palliative care has great implications for healthcare providers and researchers to set their priorities for developing culturally sensitive dementia palliative caregiving research. Family dynamics, including family cohesion, communication, and functioning, were associated with dementia family caregivers' mental health and may impact the quality of dementia care (Sutter et al., 2014).

Familism has had an important role in East Asian and Latin American cultures (Santos, Sousa, Ganem, Silva, & Dourado, 2013). East Asians strongly adhere to Confucianism, which emphasizes filial piety (Chee & Levkoff, 2001). These cultural elements were significantly associated with dementia caregiving experience (Santos et al., 2013). To be specific, East Asians influenced by Confucian familism had strong filial obligations and pressure to fulfill their duty to prolong a patient's life and to make end-of-life decisions on behalf of the patient (Ho, Radha Krishna, & Yee, 2010; Kwok, Twinn, & Yan, 2007). Hence, palliative and hospice dementia caregiving may be supported by similar models of family-centered care that have been implemented in pediatric palliative and hospice care because caregivers from the same culture where the community emphasizes family obligations for caregiving to other family members may show similar caregiving experience or patterns based on the same culture.

It is important to identify sharable and transferable cultural elements to establish standards of culturally appropriate practice. Healthcare researchers need to apply methods from earlier research for integrating cultural considerations from pediatric care to dementia care. The findings from studies about culturally congruent palliative and hospice care for pediatric patients and their family can provide guidance to develop the quality of care for older adults with dementia and their family.

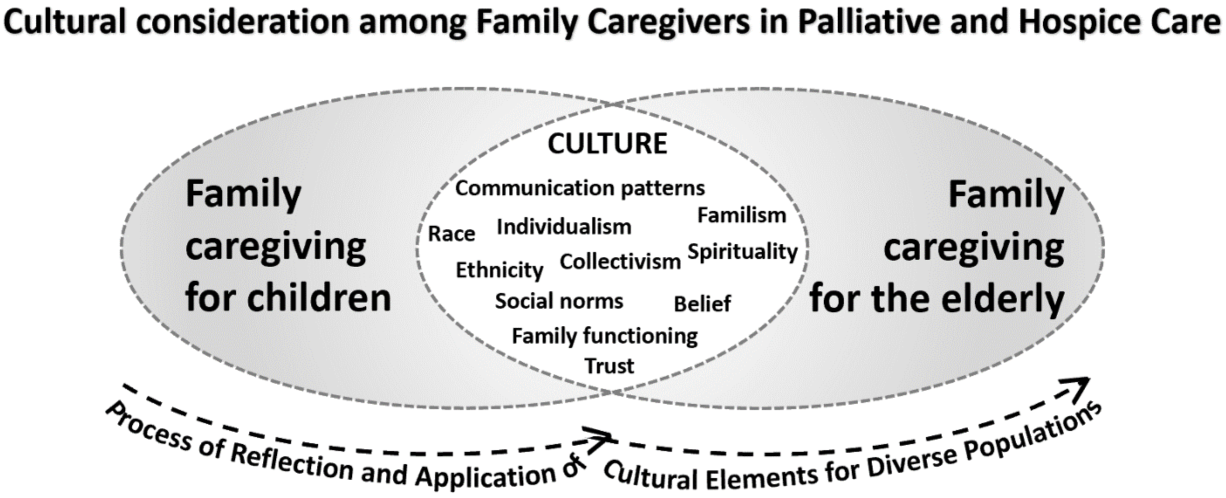


Figure 1. Conceptual model of cultural consideration among family caregivers in palliative and hospice care

References

Adames, H. Y., Chavez-Duenas, N. Y., Fuentes, M. A., Salas, S. P., & Perez-Chavez, J. G. (2014). Integration of Latino/a cultural values into palliative health care: A culture centered model. *Palliative and Supportive Care, 12*(2), 149-157. doi:10.1017/s147895151300028x

Alzheimer's Disease International. World Alzheimer report 2015: The global impact of dementia. London, UK: Alzheimer's Disease International, 2015. Available from: https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf. Accessed February 15, 2018.

American Academy of Pediatrics. (2013). Policy statement. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics, 132*(5), 966-972. doi:10.1542/peds.2013-2731

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics*. New York, NY: Oxford University Press.

Betancourt, J. (2006). Eliminating racial and ethnic disparities in health care: What is the role of academic medicine? A*cademic Medicine, 81*(9), 788-792.

Birch, D., & Draper, J. (2008). A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *J Clin Nurs, 17*(9), 1144-1163. doi:10.1111/j.1365-2702.2007.02220.x

Catlin, A., & Carter, B. (2002). Creation of a neonatal end-of-life palliative care protocol. *Journal of Perinatology, 22*(3), 184-195. doi:10.1038/sj.jp.7210687

Chee, Y. K., & Levkoff, S. E. (2001). Culture and dementia: Accounts by family caregivers and health professionals for dementia-affected elders in South Korea. *J Cross Cult Gerontol, 16*(2), 111-125.

Doorenbos, A., Lindhorst, T., Starks, H., Aisenberg, E., Curtis, J. R., & Hays, R. (2012). Palliative care in the pediatric ICU: Challenges and opportunities for family-centered practice. *J Soc Work End Life Palliat Care, 8*(4), 297-315. doi:10.1080/15524256.2012.732461

Harris, D. (2007). Forget me not: Palliative care for people with dementia. *Postgraduate Medical Journal, 83*(980), 362-366. doi:10.1136/pgmj.2006.052936

Ho, Z. J., Radha Krishna, L. K., & Yee, C. P. (2010). Chinese familial tradition and Western influence: A case study in Singapore on decision making at the end of life. *J Pain Symptom Manage, 40*(6), 932-937. doi:10.1016/j.jpainsymman.2010.06.010

Hui, E. (2008). Parental refusal of life-saving treatments for adolescents: Chinese familism in medical decision-making re-visited. *Bioethics, 22*(5), 286-295. doi:10.1111/j.1467-8519.2008.00607.x

Kwok, T., Twinn, S., & Yan, E. (2007). The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments. *J Adv Nurs, 58*(3), 256-262. doi:10.1111/j.1365-2648.2007.04230.x

Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas. *The Lancet, 371*(9615), 852-864. doi:10.1016/s0140-6736(07)61203-3

Marsac, M. L., Kindler, C., Weiss, D., & Ragsdale, L. (2018). Let's talk about it: Supporting family communication during end-of-life care of pediatric patients. *J Palliat Med, 21*(6), 862-878. doi:10.1089/jpm.2017.0307

Michelson, K. N., Koogler, T., Sullivan, C., Ortega Mdel, P., Hall, E., & Frader, J. (2009). Parental views on withdrawing life-sustaining therapies in critically ill children. *Archives of Pediatrics & Adolescent Medicine, 163*(11), 986-992. doi:10.1001/archpediatrics.2009.180

Nápoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer's Disease & Other Dementias, 25*(5), 389-406. doi:10.1177/1533317510370957

Nelson, A. (2002). Unequal treatment: Confronting racial and ethnic disparities in health care. *Journal of the National Medical Association, 94*(8), 666-668.

Sachs, G. A., Shega, J. W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med, 19*(10), 1057-1063. doi:10.1111/j.1525-1497.2004.30329.x

Sampson, E. L. (2010). Palliative care for people with dementia. *British Medical Bulletin, 96*, 159-174. doi:10.1093/bmb/ldq024

Santos, R. L., Sousa, M. F., Ganem, A. C., Silva, T. V., & Dourado, M. C. (2013). Cultural aspects in dementia: Differences in the awareness of Brazilian caregivers. *Trends in Psychiatry and Psychotherapy, 35*(3), 191-197.

Sutter, M., Perrin, P. B., Chang, Y. P., Hoyos, G. R., Buraye, J. A., & Arango-Lasprilla, J. C. (2014). Linking family dynamics and the mental health of Colombian dementia caregivers. *American Journal of Alzheimer's Disease & Other Dementias, 29*(1), 67-75. doi:10.1177/1533317513505128

Ullrich, C., & Morrison, R. S. (2013). Pediatric palliative care research comes of age: What we stand to learn from children with life-threatening illness. *J Palliat Med, 16*(4), 334-336. doi:10.1089/jpm.2013.9518

van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., . . . European Association for Palliative, C. (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med, 28*(3), 197-209. doi:10.1177/0269216313493685

Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative and Supportive Care, 11*(1), 47-67. doi:10.1017/s1478951511001027

THEORY AND CONCEPTUAL FRAMEWORKS

There are four theoretical or conceptual frameworks that can be applied to caregiving research and explain the coping mechanisms interacted with social and cultural factors including race/ethnicity or supported by the factors at multiple levels among family caregivers.

1. The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984)

The Transactional Model of Stress and Coping underlies the mutually reciprocal, bidirectional relationship between the persona and the environment in a specific context (Lazarus & Folkman, 1984). The stress process is constantly changing, depending on the relationships among the stress stimulus, individual's response, and reaction. This interactive stress process is continuous until the condition is considered stressful no longer (Schuster, Hammitt, & Moore, 2003). As Figure 2 indicates, the transactional model includes steps from influencing factors, appraisals, coping, and outcomes (Schuster et al., 2003). Psychological stress is created from the relationship between the individual and the environment that is appraised by the individual as increasing or decreasing the individual's resources and jeopardize the individual's well-being (Lazarus & Folkman, 1984). Coping is a process of rationally or empirically classified responses of the individual to stressful situations. Cognitive strategies are categorized into problem-focused (actions that change the relationship between the person and the environment) and emotion-focused (actions that change the meaning of that relationship such as avoidance, distraction, and minimization) (Lazarus & Folkman, 1984). Each step of the problem-solving process can be moderated by the standards of one's own culture because different cognitive coping styles can be shaped by cultural influences (Strohschneider & Güss, 1998). Cultural and social structural variables are interrelated, and the cultural components of a social system influence the individual's emotional life (Lazarus & Folkman, 1984). The responses to a certain challenge such as pain could be differently demonstrated based on cultural differences, which is even more obvious when the emotion is responding to stimuli in interpersonal transactions (e.g., interpersonal processes in the context of family caregiving) (Lazarus & Folkman, 1984). The transactional stress and coping framework has been applied to research about family caregiving in a palliative care setting (Hudson, 2003).

2. The Sociocultural Stress and Coping Model Aranda and Knight (1997)

The Sociocultural Stress and Coping Model (SSCM) was originally proposed by Aranda and Knight (1997). Individuals' beliefs, values, and even coping behaviors may be shaped by culture (Aranda and Knight, 1997). Specifically, coping styles may be agglomerated by previous coping experiences from the individual or group (Aranda and Knight, 1997). Aranda and Knight (1997) study underlined the role of ethnicity and culture in explaining different coping strategies when other factors such as age, income, and education are controlled (Aranda and Knight, 1997). Cultural differences shape different caregiving experiences because caregiving experiences, including reactions to stressful situations, vary depending on cultural factors such as ethnicity (Aranda & Knight, 1997; M. G. Cherry et al., 2013; Cohen & Lee, 2007; Hansen, Hodgson, Budhathoki, & Gitlin, 2018). Ethnicity as a culture and as a structural status variable, which is confounded with socioeconomic status, affects each step of the stress and coping model. The steps in the SSCM include coping strategies and emotional/psychological distress (Aranda and Knight, 1997). Furthermore, cultural resources build a reserve capacity linked with caregivers' coping management styles and social support. The reserve capacity that is shaped by culture moderates and mediates the impact of stresses over time and the effect on health outcomes among family caregivers (Peggye Dilworth-Anderson, Goodwin, & Williams, 2004; Gallo & Matthews, 2003). For example, the results of a study by Knight, Silvertein, McCallum & Fox (2000) revealed that the effects of African American ethnicity were mediated through the appraisal of stress and coping styles among family caregivers, which confirmed the SSCM (Figure 3). In spite of other confounders such as age and health status, African American caregivers perceived caregiving as less stressful, which was related to lower levels of mental health problems such as anxiety, depression, and other psychological problems (Knight, Silverstein, McCallum, & Fox, 2000). In addition, the influences on coping resources for caregivers, such as receptiveness to formal care services (e.g., home care, health care facility), differed based on cultural values (Aranda & Knight, 1997; Knight & Sayegh, 2010).

3. The Reciprocal and Recursive Lifespan Meta-Model (Myers, 2009)

According to the Reciprocal and Recursive Lifespan Meta-Model (Figure 4), psychosocial reserve capacity acting as a mediator is a primary factor in the association between race/ethnicity interacting with socioeconomic status, and the exposure to psychosocial adversities (Myers, 2009). Stressors linked with social and cultural factors such as ethnic minority and low socioeconomic status confer risk for health problems through health behaviors and create ethnic health disparities over the lifespan and across generations (Myers, 2009). As a matter of fact, the race/ethnicity- and socioeconomic status-related stressors may limit the access to reserve resources for coping. Individuals may develop context-specific coping resources. The coping resources are tangible (e.g., income, childcare, transportation), interpersonal (e.g., supportive social relationships), intrapersonal (e.g., optimistic future orientation), socio-cultural (e.g., familismo, biculturalism, strong ethnic identity), and health care-related (e.g., access to quality care) (Myers, 2009). The resources create a psychosocial reserve capacity (Myers, 2009). Mindfulness-based interventions have been beneficial to racial and ethnic minority caregivers with a lower socioeconomic status (Waldron, Hong, Moskowitz, & Burnett-Zeigler, 2018). Mindfulness-based interventions for those caregivers reflected the Reciprocal and

Recursive Lifespan Metal-Model by Myers (2009) in that the interaction between racial and ethnic minority and lower socioeconomic statuses results in health problems (Waldron et al., 2018).

4. The Resilience Framework for caregivers (Windle & Bennett, 2011)

As Figure 5 displays, this framework supports the thesis that resilience can be enhanced with various resources at the individual, society, and community levels (Bennett, Reyes-Rodriguez, Altamar, & Soulsby, 2016). The use of this ecological framework can provide a better exploration of understanding caregivers' resilience and coping mechanisms by capturing caregiving challenges, solutions (resilience resources) and expected consequences (Bennett & Windle, 2015; Donnellan, Bennett, & Soulsby, 2015). First, resources at the individual level include psychological resources, such as mastery, personal control, competence, self-esteem, and appraisal. Second, resources at the community level include geographically immediate community resources, which are located in or near the caregivers' neighborhood areas such as social support (e.g., formal and informal social support from friends and family relations). Lastly, resources at the societal level such as laws, policies, national associations or organizations, culture, and religion can be linked to caregivers' ability to deal with stressful caregiving situations (Bennett et al., 2016). The resilience framework has been applied to family caregiving research in hospice (Han et al., 2019).

Taken together, the aforementioned four frameworks demonstrate that family caregivers can handle stress in a certain way formed by ethnocultural factors. It is important to identify interconnected relationships among race/ethnicity, other cultural components, and coping strategies operated through the complex stress and coping pathway within a cultural context.

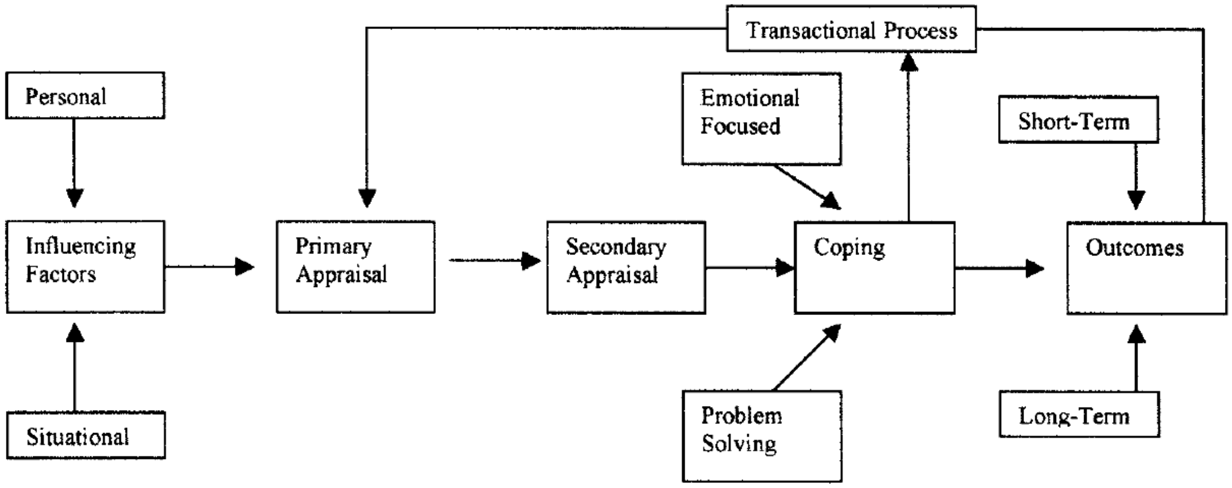


Figure 2. Transactional stress/coping model based on the theory developed by Lazarus and Folkman (1984). From “A theoretical model to measure the appraisal and coping response to hassles in outdoor recreation settings” by Schuster, Hammitt, and Moore (2003), 25(2-3), 277-299. p. 279.

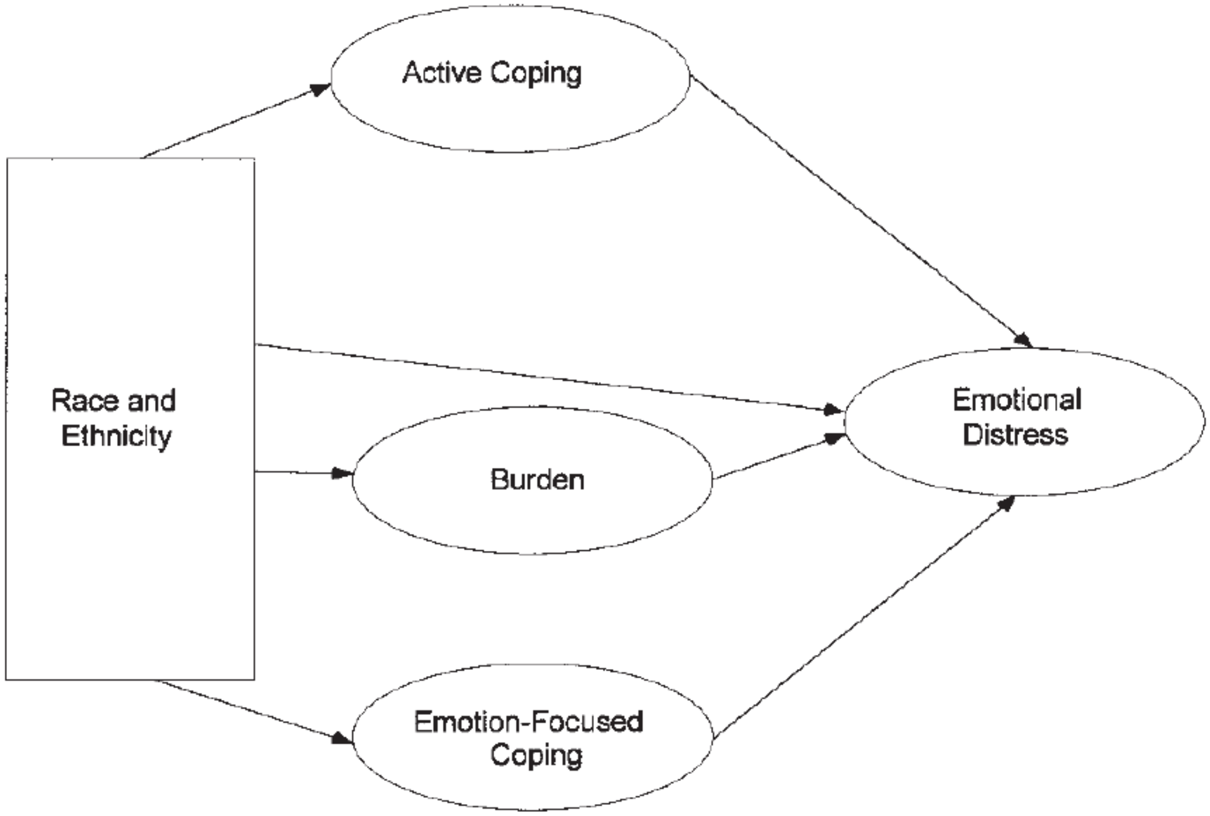


Figure 3. Conceptual stress-coping model: Race/ethnicity and its mediators. From “A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California” by Knight, Silverstein, McCallum, and Fox (2000), 55B(3): 142-150. p. 143

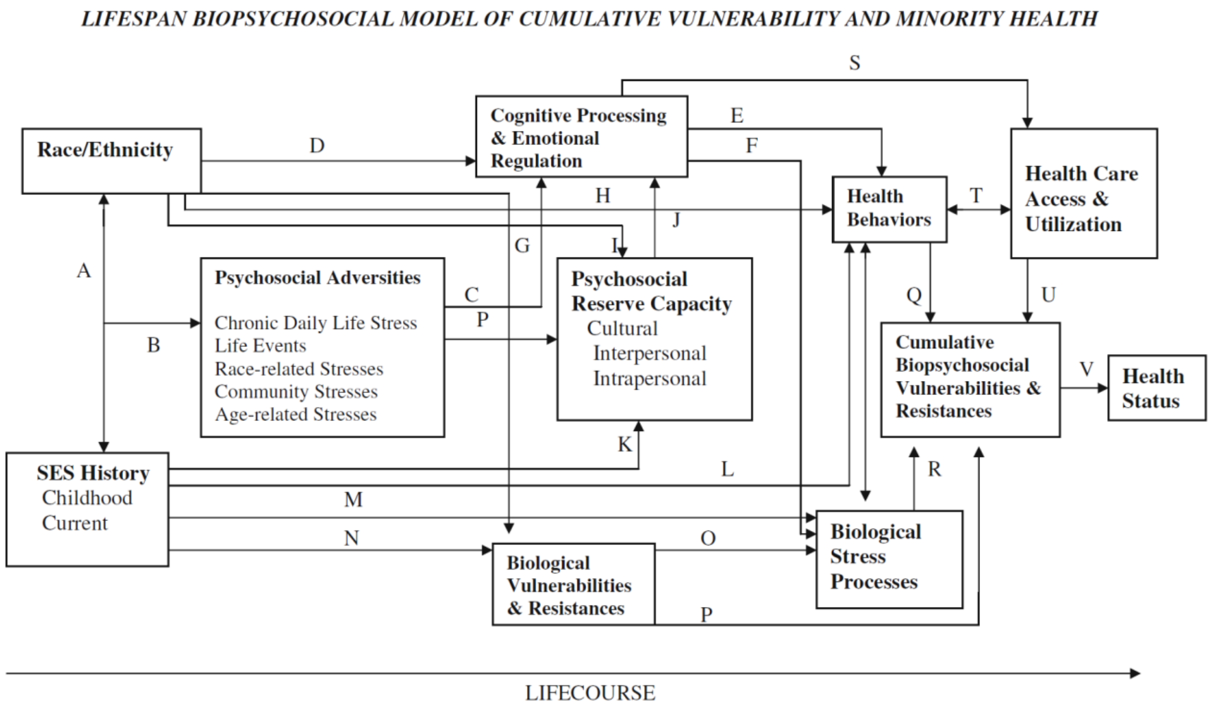


Figure 4. A reciprocal and recursive model of the complex relationships between race/ethnicity and socio-economic status on psychosocial adversities, reserve capacity and cumulative vulnerabilities in predicting health status over the lifespan. From “Ethnicity- and socio-economic status-related stresses in context: An integrative review and conceptual model” by Myers (2009), 32:9-19. p. 13.

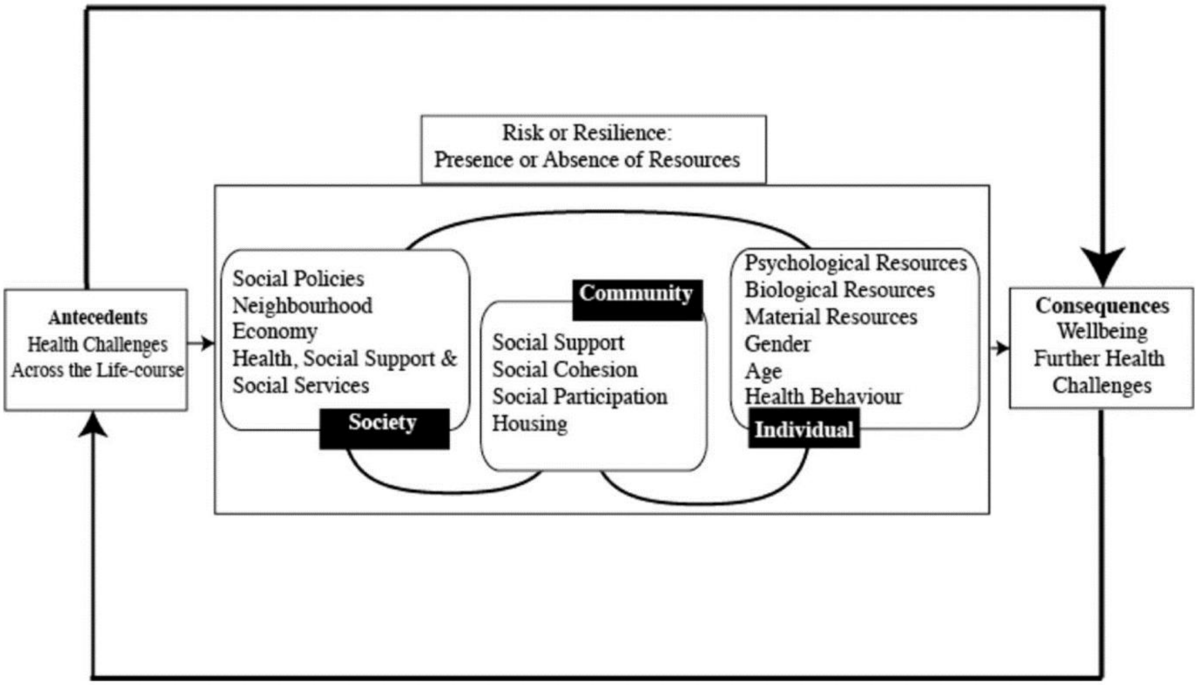


Figure 5. Ecological model of resilience. From “Resilience amongst older Colombians living in poverty: An ecological approach” by Bennett, Reyes-Rodriguez, Altamar, and Soulsby (2016), 31: 385-407. p. 387.

References

Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist, 37*(3), 342-354. doi:10.1093/geront/37.3.342

Bennett, K. M., Reyes-Rodriguez, M. F., Altamar, P., & Soulsby, L. K. (2016). Resilience amongst older Colombians living in poverty: An ecological approach. *Journal of Cross-Cultural Gerontology, 31*(4), 385-407. doi:10.1007/s10823-016-9303-3

Bennett, K. M., & Windle, G. (2015). The importance of not only individual, but also community and society factors in resilience in later life. *Behavioral and Brain Sciences, 38*, e94. doi:10.1017/S0140525X14001459

Cherry, M. G., Salmon, P., Dickson, J. M., Powell, D., Sikdar, S., & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology, 23*(04), 251-266. doi:10.1017/s0959259813000130

Cohen, H. L., & Lee, Y. (2007). Dementia caregivers: Rewards in multicultural perspectives. *Journal of Human Behavior in the Social Environment, 14*(1), 299-324.

Dilworth-Anderson, P., Goodwin, P. Y., & Williams, S. W. (2004). Can culture help explain the physical health effects of caregiving over time among African American caregivers? *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 59*(3), S138-S145. doi:10.1093/geronb/59.3.S138

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health, 19*(10), 932-939. doi:10.1080/13607863.2014.977771

Gallo, L. C., & Matthews, K. A. (2003). Understanding the association between socioeconomic status and physical health: Do negative emotions play a role? *Psychological Bulletin, 129*(1), 10-51. doi:10.1037/0033-2909.129.1.10

Han, S., Chi, N.-C., Han, C., Oliver, D. P., Washington, K., & Demiris, G. (2019). Adapting the resilience framework for family caregivers of hospice patients with dementia. *American Journal of Alzheimer's Disease & Other Dementias, 34*(6), 399-411. doi:10.1177/1533317519862095

Hansen, B. R., Hodgson, N. A., Budhathoki, C., & Gitlin, L. N. (2018). Caregiver reactions to aggressive behaviors in persons with dementia in a diverse, community-dwelling sample. *J Appl Gerontol*, 733464818756999. doi:10.1177/0733464818756999

Hudson, P. (2003). A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. *Palliat Support Care, 1*(4), 353-365. doi:10.10170S1478951503030426

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: the updated sociocultural stress and coping model. *J Gerontol B Psychol Sci Soc Sci, 65B*(1), 5-13. doi:10.1093/geronb/gbp096

Knight, B. G., Silverstein, M., McCallum, T. J., & Fox, L. S. (2000). A sociocultural stress and coping model for mental health outcomes Among African American caregivers in Southern California. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 55*(3), P142-P150. doi:10.1093/geronb/55.3.P142

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer Publishing Company.

Myers, H. F. (2009). Ethnicity- and socio-economic status-related stresses in context: an integrative review and conceptual model. *J Behav Med, 32*(1), 9-19. doi:10.1007/s10865-008-9181-4

Schuster, R. M., Hammitt, W. E., & Moore, D. (2003). A theoretical model to measure the appraisal and coping response to hassles in outdoor recreation settings. *Leisure Sciences, 25*(2-3), 277-299. doi:10.1080/01490400306568

Strohschneider, S., & Güss, D. (1998). Planning and problem solving: Differences between Brazilian and German students. *Journal of Cross-Cultural Psychology, 29*(6), 695-716. doi:10.1177/0022022198296002

Waldron, E. M., Hong, S., Moskowitz, J. T., & Burnett-Zeigler, I. (2018). A systematic review of the demographic characteristics of participants in US-based randomized controlled trials of mindfulness-based Interventions. *Mindfulness, 9*(6), 1671-1692. doi:10.1007/s12671-018-0920-5

CHAPTER 2

Effects of Interactions of Psychosocial Factors and Race/ethnicity on Anxiety among Families in Pediatric Intensive Care Units

Aim: This study examined factors associated with anxiety symptoms in a sample of family members whose children had intensive care unit stays longer than 8 days, and whether there are interaction effects between race/ethnicity and psychosocial factors such as family functioning, perceived social support, and trust in providers.

Background: Minority family caregivers of their pediatric patient in intensive care units are at increased risk for mental health problems, but the mechanism of racial and ethnic disparities has not been fully explored.

Design and Methods: Secondary analysis utilizing the baseline data from a cluster randomized clinical trial for parents in the ICUs (n=333, collected from July 2010 to March 2014). Generalized Estimating Equations and Wald tests were used to determine whether there are interaction effects between psychosocial factors and race/ethnicity on anxiety.

Findings: We found statistically significant interaction effects between perceived social support and race/ethnicity and between trust in providers and race/ethnicity on anxiety, but no interaction effects between family functioning and race/ethnicity on anxiety.

Conclusions: Interventions, with a consideration of the influence of social support, or trust in providers, may reduce the risk for anxiety among family caregivers. Further studies about the mechanism of racial and ethnic disparities with other potential factors are warranted.

Impact: Psychosocial factors, such as perceived social support and trust in providers, may serve as cultural factors that interact with race and ethnicity and impact a family member’s mental health. This study underlines that the quality of pediatric intensive care and mental health outcomes among family caregivers can be improved through culturally tailored interventions, focusing on establishing trusting relationships among providers, pediatric patients, and their families and encouraging patients and their family to utilize social supports across race/ethnicity.

Key words: family caregiving, pediatric intensive care, anxiety, race/ethnicity, family functioning, perceived social support, trust in provider

INTRODUCTION

Having a child in the Intensive Care Unit (ICU) is a stressful event, and it causes parental mental health problems such as posttraumatic stress disorder, anxiety, and depression (Alkozei, McMahon, & Lahav, 2014; Rodriguez-Rey & Alonso-Tapia, 2017; Rodriguez-Rey, Alonso-Tapia, & Colville, 2018). More importantly, data about anxiety was fewer than those about stress/trauma or depression, and there have been inconsistent findings regarding anxiety (Roque, Lasiuk, Radunz, & Hegadoren, 2017). However, some parents are more resilient and recover from this extremely difficult situation. They report posttraumatic growth, experiencing the unexpected positive outcomes from traumatic events, and not denying experiencing difficulties (Rodriguez-Rey & Alonso-Tapia, 2017; Rodriguez-Rey, Alonso-Tapia, & Colville, 2018). However, how parents' resilience functions at this extremely difficult situation, if resilience operates similarly across different racial and ethnic groups, and how it is associated with psychopathology symptoms have still not been found (Rodriguez-Rey, Alonso-Tapia, & Colville, 2018).

Nursing and other health-related disciplines have emphasized research aimed at improving the quality of practice and reducing health disparities (Painter & Lavizzo-Mourey, 2008). There is a huge disparity in healthcare based on race and ethnicity comparable to that of on age, income, insurance status, and severity of illness. However, the existence of this racial/ethnic disparity in health outcomes was sometimes overlooked (Nelson, 2002). Ethnic minorities presented more negative health outcomes and a higher death rate than Whites (J. Betancourt, 2006; Nelson, 2002). Among patients diagnosed with major depressive disorder in the US, Asian Americans reported higher levels of anxiety and emotional distress compared to other racial groups (Rao, Poland, & Lin, 2012). This suggests that the trend of anxiety may be different depending on race/ethnicity. A racial and ethnic group that comes from a particular cultural background may show different cultural dimensions (H. Betancourt & Lopez, 1993).

Cultural elements such as spirituality, collectivism, individualism, family functioning, trust, belief, and emotional aspects contribute to positive and negative stress responses, and these vary by ethnic groups (Leininger & McFarland, 2002).

Above all, family functioning, perceived social support, and trust in healthcare professionals, as psychosocial factors are crucial cultural elements that are associated with socio-demographic characteristics such as race and ethnicity. These factors may influence the mechanism of stress responses to mental and emotional distress due to caregiving burden and stress. Prior research points to possible associations between some aspects of family functioning, social support, and trust in providers influenced by race/ethnicity and health (Han et al., 2014; Ilowite, Cronin, Kang, & Mack, 2017; Morrison & Meier, 2004; Plant & Sachs-Ericsson, 2004; Welch, Teno, & Mor, 2005). First, the style of decision-making among family members may determine the degree of a successful family coping and adaptation because families who value collectivism may be more influenced by family dynamics. Hispanics and African Americans valued collective decision-making as a family for advance care planning, unlike White counterparts who valued individual decision-making (Morrison & Meier, 2004). The success of coping and adaptation occurs within families with positive dynamics representing high cohesiveness and expressiveness, and low conflict (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). Second, coping styles of caregivers are related to social support (Han et al., 2014). Specifically, the emotion-focused coping style was positively associated with social support, depression, and maladaptive coping style among Chinese family caregivers (Han et al., 2014). The availability or effects of social support may shape caregivers' coping mechanisms and may differ across cultures. Third, establishing trusting relationships with patients and their family should be accompanied by a cultural understanding of each individual's perceptions by race/ethnicity. African Americans were less likely to trust healthcare professionals than non-Hispanic Whites (Guffey & Yang, 2012). Family members of African American decedents were less likely to report that the decedent had a good quality of care than those of Whites decedents (Welch et al., 2005). Furthermore, physicians tended to believe that African American and Hispanic family caregivers are less interested in hearing prognostic information in-depth than White caregivers, even though most family caregivers, regardless of race, wanted to hear about as much information as possible (Ilowite et al., 2017). Culturally appropriate interventions that help reduce anxiety among racially minority parents of infants in the ICU have been emphasized (Roque, Lasiuk, Radunz, & Hegadoren, 2017). Thus, it is necessary to examine whether there are interacting relationships between each of these three factors – family functioning, perceived social support, and trust in provider – and race/ethnicity among caregivers who are at risk for mental and emotional challenges.

METHODS

This study examined whether: 1) socio-demographic characteristics differ by race and ethnicity, and 2) there are interaction effects between race/ethnicity and a) family functioning, b) perceived social support, and c) trust in providers on anxiety symptoms among family members of a pediatric ICU patient.

Study Design, Participants and Data Source

This study utilized the baseline data from a cluster randomized clinical trial for parents in the ICUs (Starks et al., 2016). The purpose of the original study was to examine the effect of adding an extra layer of support upfront to reduce anxiety and depression symptoms among family members experiencing their child's extensive ICU stay. The original study included 380 family members of 220 children admitted to the ICUs. Study enrollment started with identifying eligible children who were required to meet the following criteria: 1) no prior ICU stay of more than 48 hours during the current admission and 2) no prior involvement by the study interventionists. Family members had to be: 1) aged 18 years or older; 2) involved in decision-making for the patient's care; and 3) fluent in English or Spanish. Family members included parents, step-parents, foster parents, grandparents, siblings, cousins, aunts, uncles, or close family friends in this study. The sample for this analysis included the 333 of 380 family members who reported their race/ethnicity. The National Institutes of Health criteria for race/ethnicity were used. We categorized participants into five groups based on their self-report about race and ethnicity. Four groups included non-Hispanic: 1) White, 2) African American (AA), 3) Native American or Alaskan Native (NA or AN), or 4) Asians and Native Hawaiians or Pacific Islanders (NHOPI), and the fifth group included all who identified as Hispanic across all racial categories.

Measures

The baseline data were collected from families at approximately one week after the child's admission to the ICU. To understand the characteristics of these study participants, we collected the following demographic information: age, gender, language, education, and income. Psychosocial information was also collected, including measures of anxiety and depression symptoms, family functioning, perceived social support, and trust in healthcare providers. Paper-based questionnaires were completed by family members (either on their own or with help from study staff); questionnaires were available in English or Spanish based on participants' preferences.

Anxiety. The General Anxiety Disorder (GAD-7) scale is a 7-item measure with a total score ranging from 0 to 21, with higher scores indicating greater severity of anxiety. A GAD-7 score of 10 or higher indicates clinical symptoms: scores of 10 to14 represent moderate anxiety symptoms, and scores of 15 or higher represent severe anxiety (Spitzer, Kroenke, Williams, & Lowe, 2006). The scale has been used to assess family caregivers' severity of anxiety (Ullrich et al., 2017). The tool demonstrated excellent reliability and validity in both English (Spitzer et al., 2006) and Spanish (Garcia-Campayo et al., 2010).

Depression. The Patient Health Questionnaire (PHQ-9) scale is a 9-item global self-assessment of depressive symptom severity. Each item can be scored from 0 to 3, and the PHQ-9 scale ranges in score from 0 to 27, with higher scores indicating greater severity of depressive symptoms. Similar to the GAD7, PHQ-9 scores of 10 to 14 represent moderate depression symptoms, scores of 15 to 19 represent moderately severe symptoms, and scores of 20 or higher represent severe symptoms (Spitzer, Kroenke, & Williams, 1999). The scale has widely been used with people from a variety of ethnic backgrounds (Friedemann, Buckwalter, Newman, & Mauro, 2013; Huang, Chung, Kroenke, Delucchi, & Spitzer, 2006), and with family caregivers of patients (Ullrich et al., 2017) and has demonstrated good internal reliability for each racial and ethnic group with Cronbach's α from 0.79 to 0.89 (Huang et al., 2006). Both English and Spanish versions are available (Wulsin, Somoza, & Heck, 2002).

Family functioning. The Family Relationship Index (FRI) ranges from 3 to 12 and is used to assess relationship cohesiveness, expressiveness, and conflict. Higher scores indicate better family functioning (Hoge, Andrews, Faulkner, & Robinson, 1989). There are three subscales: family cohesiveness, expressiveness, and family conflict. This scale has been shown good validity and reliability (Hoge et al., 1989; Moos & Moos, 1986).

Social support. The Multidimensional Scale of Perceived Social Support (MSPSS) demonstrates good reliability and validity and includes 12-items measured on a 7-point Likert-type scale to assess perceived social support from family, friends, and a significant other (Dahlem, Zimet, & Walker, 1991; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Total and subscale scores range from 1 to 7, with higher scores indicating greater levels of perceived social support. A Spanish version is available (Edwards, 2016).

Trust in providers. We included 10 items from the Wake Forest Trust Scale (WFTS) to assess a family's perceptions toward physicians and nurses caring for their child (Hall, Camacho, Dugan, & Balkrishnan, 2002). Scores range from 10 to 50, with higher scores indicating greater trust. The scale demonstrates good reliability (Hall et al., 2002).

Ethical Considerations

The original study was approved by the Institutional Review Board (IRB) of Seattle Children's Hospital. The written informed consent forms, including the description of the purpose, procedure, risks, and benefits of the original study, were received by study participants. This analysis used de-identified data from the original study, thus the University of Washington Human Subjects Division determined that this analysis is an exemption from further IRB review.

Data Analysis

Descriptive analyses were performed to describe family caregivers' characteristics, including age, gender, language, education, and income as a whole and by the five racial/ethnic groups. Analysis of Variance (ANOVA) and regressions were used to examine whether socio-demographic characteristics differed by race and ethnicity.

We used the Generalized Estimating Equations (GEE) because of their capacity to estimate population-averaged effects (Dupont, 2009; Hubbard et al., 2010; Shen & Chen, 2013) and their use in family studies (Homish, Edwards, Eiden, & Leonard, 2010) that accounts for intrafamilial correlation for data clustered at the level of the family. We examined the effects of the interaction between subjects using the GEE with an exchangeable correlation structure (Liang & Zeger, 1986; Wang, Kong, Li, & Zhang, 2016) and used Wald tests to assess the statistical significance of the interaction effects in the

GEE models because GEE is a quasi-likelihood method, which the likelihood-ratio tests cannot be applied to (Wang et al., 2016). We tested interactions between three psychosocial variables (family functioning; perceived social support; and trust in providers) and race/ethnicity and their effect on anxiety after controlling for depression. The tables with model results for each of the GEE models in Appendices A-C.

The counts and proportion of missing values for each variable were checked. The missing values were about 10% for regressions, so complete case analysis, also called listwise deletion, was employed (Graham, 2009; Schulz & Grimes, 2002). A p-value of less than .05 was accepted as significant. Statistical analyses were conducted using R version 3.4.1, which was run in the RStudio interface, RStudio version 1.1.463; R Studio Inc. 2009-2018 (R Foundation for Statistical Computing). The main R codes for the models are added (see Appendix D).

RESULTS

Demographic and Psychosocial Characteristics of Study Participants

The baseline characteristics of 333 family caregivers are summarized in Table 1. The means of age ($p < 0.001$), language ($p < 0.001$), highest education ($p < 0.001$), household income ($p < 0.001$), family functioning (FRI scores) ($p < 0.05$), and perceived social support (MSPSS scores) ($p < 0.05$) were significantly different based on race and ethnicity. Hispanic family caregivers, with a mean age of 27.8±7.9 years, were younger than the other four racial/ethnic groups. The majority of Hispanics reported that they speak in Spanish (54.8%), while other racial/ethnic groups reported that they do not speak in Spanish. The levels of education and income were relatively lower for both non-Hispanic NA or AN and Hispanic caregivers than for other racial and ethnic groups (Table 1).

Table 1. Demographic characteristics comparisons of different racial/ethnic groups at baseline

	Total	Subgroups Based on Race/Ethnicity					
Characteristics	(N=333)	Non-Hispanic White (n=241)	Non-Hispanic AA (n=17)	Non-Hispanic NA or AN (n=18)	Non-Hispanic Asian/ NHOPI (n=15)	Hispanic (n=42)	Missing data (n)
N families	200	145	12	14	10	35	0
Ageǂ ***	34.3±10.5	35.0±10.2	37.6±9.4	34.6±16.2	38.5±7.8	27.8±7.9	28
Female	220/333	156/241	13/17	14/18	9/15	28/42	0
Languageǂ***							1
English	296	238	13	18	11	16	
Spanish	23	0	0	0	0	23	
Other	13	2	4	0	4	3	
Highest educationǂ ***							9
High school or lower	117	71	7	11	3	25	
College/Associate	95	71	4	6	3	11	
Bachelors	73	62	5	1	4	1	
Graduate/Professional	39	31	1	0	5	2	
Household incomeǂ ***							40
less than $25,000	76	41	3	9	1	22	
$25,000-$75,000	128	99	5	6	5	13	
$75,000-$25,000	57	47	2	1	6	1	
$125,000-$175,000	15	15	0	0	0	0	
$175,000 or higher	17	13	2	0	1	1	
FRIǂ *	10 (4, 12)	10 (4, 12)	10 (8, 11)	9 (5, 12)	10 (6, 12)	9 (4, 12)	28
MSPSS *	6.4 (1.3, 7)	6.6 (1.3, 7)	6.3 (2, 7)	6.3 (3.2, 7)	6.3 (4.8, 7)	6.1 (2.1, 7)	0
WFTS ǂ	33 (10, 39)	33 (10, 38)	32 (10, 39)	33 (14, 35)	32 (28, 35)	32 (22, 38)	4

Abbreviations: AA, African American; NA or AN, Native American or Alaskan Native; NHOPI, Native Hawaiians or Pacific Islanders; FRI, Family Relationship Index; MSPSS, Multidimensional Scale of Perceived Social Support; WFTS, Wake Forest Trust Scale.

Bold indicates variable is statistically significant as follows: *** $p<0.001$,** $p<0.01$, * $p<0.05$.

Age was presented as the mean and standard deviation, FRI, MSPSS, and WFTS as the median and range (minimum, maximum).

ANOVAs for categorical variables and linear regressions for continuous variables (e.g., age, FRI, MSPSS, WFTS) were used.

ǂ: Missing data were excluded from the table.

Interaction Effects of Race/Ethnicity and Psychosocial Factors on Anxiety

There were no significant interaction effects between race/ethnicity and family functioning on anxiety symptoms, after controlling for depression ($p = 0.130$). There were for perceived social support ($p < 0.001$) and trust in provider ($p = 0.022$), after controlling for depression. However, Figures 6-8 show the interaction effects without controlling for depression.

Figures 6-8 show the results from the estimation of interaction effects between race/ethnicity and family functioning (Figure 6), perceived social support (Figure 7), and trust in providers (Figure 8) on anxiety symptoms without controlling for depression. A GAD-7 score of 10 or less represents mild anxiety symptoms; scores of 10-15 represent moderate anxiety symptoms and scores 15-20 and above represent moderate-severe and severe anxiety symptoms. Overall, anxiety symptoms were mild to moderate for each of these analyses.

Figure 7 shows that non-Hispanic AA, non-Hispanic Asian and NHOPI, and Hispanics tend to show higher levels of anxiety when their perceived social support is greater, while non-Hispanic Whites and non-Hispanic NA or AN show higher levels of anxiety when their perceived social support is lesser (Figure 7). Regarding trust in providers, in general, greater trust was associated with slightly increased anxiety symptoms, but still below the clinical threshold. Only non-Hispanic Whites demonstrate the associations between greater trust in providers and lower anxiety (Figure 8).

The line graphs from Figures 6-8 are mapped into scatter plots and line graphs in Appendices E-S using GEE models for cluster data without controlling for depression.

Figures 6-8. Interaction effects between race/ethnicity and psychosocial factors on anxiety

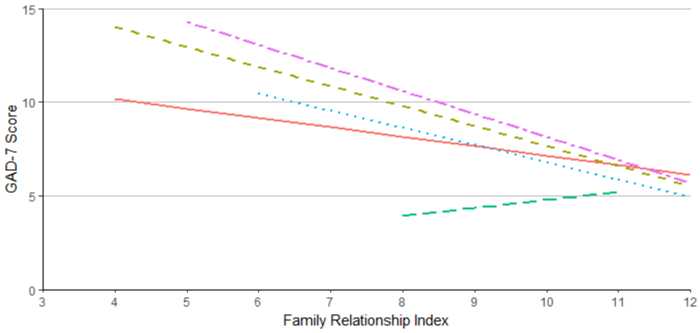


Figure 6. Family functioning (Maximum score on FRI = 12)

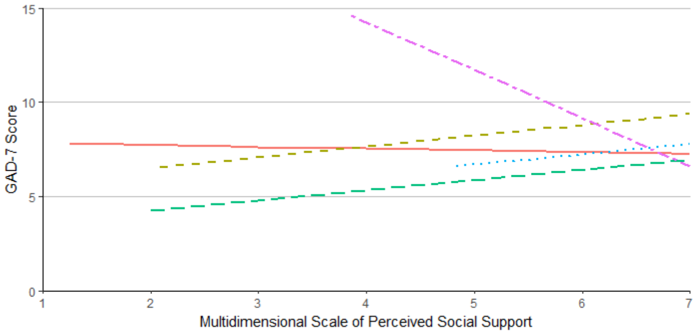


Figure 7. Perceived social support (Maximum score on MSPSS = 7)

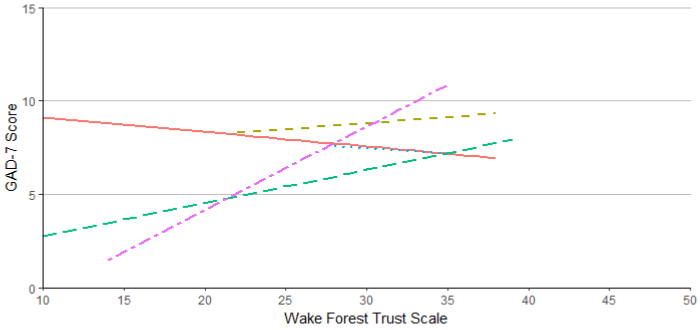


Figure 8. Trust in providers (Maximum score on WFTS = 50)

Abbreviations: AA, African American; NA or AN, Native American or Alaskan Native; NHOPI, Native Hawaiians or Pacific Islanders; FRI, Family Relationship Index; MSPSS, Multidimensional Scale of Perceived Social Support; WFTS, Wake Forest Trust Scale.

LEGEND for Figures 6-8

Racial/Ethnic Groups

— Non-Hispanic white

- - Hispanic

– – Non-Hispanic AA

····· Non-Hispanic Asian and NHOPI

-·- Non-Hispanic NA or AN

DISCUSSION

The findings of this study provide insights into the mechanisms of health disparities on the basis of race and ethnicity. This study showed that socio-demographic and psychosocial factors such as age, language, education level, household income, family functioning, and perceived social support differed by race and ethnicity, and that there can be effects of the interactions between race/ethnicity and perceived social support and between race/ethnicity and trust in providers on anxiety among family caregivers. This can help us to develop culturally tailored interventions based on an advanced understanding of racial and ethnic difference as well as psychosocial factors' influence on mental health outcomes in family caregivers.

Overall, the information about demographic characteristics based on race and ethnicity is consistent with the existing literature (Table 1). The support for female mental health status is critical because the gender of family caregivers is predominantly female across race and ethnicity. Our study also supports the notions of existing literature that education and income levels tend to be lower in racial and ethnic minorities compared to non-Hispanic White and non-Hispanic Asian and NHOPI counterparts (Guarnaccia & Parra, 1996). Non-Hispanic AAs have strong familism (Dilworth-Anderson et al., 2005), and our study supports this claim, finding that the highest levels of family functioning were observed in African Americans. In addition, our study expands upon existing knowledge of non-Hispanic Whites being more likely to trust providers than non-Hispanic African Americans (Guffey & Yang, 2012) because our study showed a tendency of Whites' higher scores of WFTS even though there was no statistical significance.

Race/ethnicity is not a modifiable variable, but perceived social support and trust in providers are modifiable and manageable through interventions aimed at improving anxiety for racially and ethnically diverse family caregivers of a child in the ICUs. It was challenging to find possible explanations from scientific literature for the relationships between better family functioning and lower levels of anxiety among non-Hispanic AAs and the relationship between higher levels of anxiety and greater perceived social support among non-Hispanic AA, non-Hispanic Asian and NHOPI, and Hispanics (Figures 6 and 7). The mechanism should be further investigated in future studies. Healthcare professionals should acknowledge that racial and ethnic minority families may be vulnerable to anxiety because minority families reported higher levels of anxiety even with greater trust in healthcare professionals. Only non-Hispanic Whites reported a tendency to a positive relationship between greater trust and less anxiety (Figure 8). One possible explanation for this is that racial and ethnic minorities may have other factors exacerbating anxiety, beyond trust in providers. Nonetheless, emotional connection and trust in healthcare professionals are considered a crucial factor for a better medical decision process for their patient (Thelen, 2005). Providers should be competent in establishing trusting relationships with families and provide psychosocial support for mental well-being (Kuo et al., 2012) because building trusting relationships between family caregivers and providers is one of the most important components of culturally sensitive patient- and family-centered care (Kuhlthau et al., 2011; Kuo et al., 2012). Healthcare professionals need to be culturally competent in understanding of how family caregivers' cultural backgrounds and psychosocial characteristics such as perceived social support and trust in providers relate to mental health across racial/ethnic groups.

Limitations

Limitations of this exploratory, hypothesis-generating study should be considered in interpreting the findings and in taking into consideration for future studies. One of the greatest limitations of this secondary analysis of existing data is that we had smaller sample sizes for minority groups compared to that of the non-Hispanic White group. This imbalance in the number of subjects allocated to the minority groups may weaken statistical power. Initially, there were seven different non-Hispanic racial groups: 1) White, 2) African American or Black, 3) Native American or Alaska Native, 4) Asian, 5) Native Hawaiian or Pacific Islander, 6) Other, and 7) Mixed. After extensive discussions and consultation with a statistician in consideration of the characteristics of each racial/ethnic group and sample sizes, we ended up dividing into five racial/ethnic groups, after excluding subjects who reported that their race is ‘other’ or ‘mixed’, or not reported. We were not able to include many variables in a single regression model because of the small sample size. This created another limitation of not being able to control for education and economic status in the models. In addition, complete case analysis has drawbacks. This approach might have caused a greater loss of participant numbers, especially in minority racial/ethnic groups with small sample sizes. Future studies can consider larger sample sizes for minority groups and ensure fairly equal allocation across groups for greater statistical power to check if the findings of our study are generalizable. Also, cultural aspects are intertwined. Other than psychosocial variables such as family functioning, perceived social support, and trust in providers, further studies need to consider the influence of variations in economic, social and health services, and legal contexts.

With regard to cultural difference influenced by race/ethnicity, there is another limitation. The race of individuals can be different within a single-family. For example, families having two or more different racial composition may have mixed cultures, which means that they might not have a specific single culture based on racial/ethnic backgrounds. This quantitative secondary analysis is limited to capturing the effects of the heterogeneous mixture of races or ethnicities within a family. This mixed culture can affect the results of the study results.

Furthermore, each family caregiver in the same family group might have subjective, different perceptions towards their family functioning. To be specific, one family member can report that his/her family has fewer conflicts and has effective communication, but another family member can report negative perception towards family functioning. In this example, family functioning may not be a family culture, but an individual culture.

Moreover, our study used the data collected in a single center in the Seattle metropolitan area, and the findings of our study can be generalizable, only to those family members whose English or Spanish is fluent in similar environments such as big cities. Future studies can consider multiple geographic locations, use measures in other languages, and can cast a wider net of sampling to recruit more diverse populations because it is important to focus on sampling heavily from racially and ethnically minority groups to capture the perspectives from many, diverse cultures.

In addition, this study did not consider matching race/ethnicity between providers and care-recipients. The discordance of race/ethnicity between patients, families, and providers may cause less opened communication and providers' control over the care and responsibilities for patients' own decisions (Neubauer, Dixon, Corona, & Bodurtha, 2016). This can affect the levels of trust in providers, and this point needs to be considered in future studies.

Nevertheless, learning differences in health outcomes that are influenced by ethnocultural factors can help healthcare professionals to evolve care for culturally diverse and multi-linguistic pediatric patients and their families. The major findings of this study will contribute to the development of culturally tailored interventions for diverse populations and the improvement of quality care. Although this secondary analysis did not show the interaction effects between family functioning and race/ethnicity on anxiety, family functioning was considered to be a modifiable predictor of psychosocial morbidity (Yoon, Kim, Jung, Kim, & Kim, 2014). Thus, interventions that target on improving family functioning may bring more favorable health outcomes in anxiety among family caregivers from all cultures in a diverse, multicultural environment. Additionally, raising awareness about the inequality and inequity due to ethnocultural differences among policymakers can help decrease the gap between patient expectations and the current care services and can establish policies to advocate for pediatric patients and their family members regardless of race, ethnicity, or cultural identity.

CONCLUSION

This study is informative for providers to identify and pay attention to families who are at risk for anxiety based on their race/ethnicity and psychosocial factors. The findings of this study will increase awareness of the importance of better family functioning between family members, having social support, and establishing trusting relationships between providers and family members with a child in ICU settings. This study can enable healthcare professionals to implement culturally sensitive care and maximize the effects of quality care that will ultimately meet the needs of the patient-parent dyads.

Conflict of Interest

No conflict of interest has been declared by the authors.

Funding Statement

This study was supported by the National Institutes of Health [Grant Number. R01NR011179; Program PI: Ross Hays and Co PI: Helene Starks].

References

Alkozei, A., McMahon, E., & Lahav, A. (2014). Stress levels and depressive symptoms in NICU mothers in the early postpartum period. *J Matern Fetal Neonatal Med, 27*(17), 1738-1743. doi:10.3109/14767058.2014.942626

Angus, D. C., Barnato, A. E., Linde-Zwirble, W. T., Weissfeld, L. A., Watson, R. S., Rickert, T., . . . Grp, R. W. J. F. E.-o.-L. P. (2004). Use of intensive care at the end of life in the United States: An epidemiologic study. *Critical Care Medicine, 32*(3), 638-643. doi:10.1097/01.Ccm.0000114816.62331.08

Betancourt, H., & Lopez, S. R. (1993). The study of culture, ethnicity, and race in American psychology. *American Psychologist, 48*(6), 629-637. doi:Doi 10.1037/0003-066x.48.6.629

Betancourt, J. (2006). Eliminating racial and ethnic disparities in health care: What is the role of academic medicine? A*cademic Medicine, 81*(9), 788-792.

Dahlem, N. W., Zimet, G. D., & Walker, R. R. (1991). The multidimensional scale of perceived social support: A confirmation study. *Journal of Clinical Psychology, 47*(6), 756-761. doi:10.1002/1097-4679(199111)47:6<756::aid-jclp2270470605>3.0.co;2-l

Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *The Journals of Gerontology: Series B, 60*(5), S257-S262. doi:10.1093/geronb/60.5.S257

Dupont, W. D. (2009). *Statistical modeling for biomedical researchers: A simple introduction to the analysis of complex data* (Second ed.): Cambridge, UK: Cambridge University Press.

Edwards, L. M. (2016). Measuring perceived social support in Mexican American youth: Psychometric properties of the multidimensional scale of perceived social support.

Hispanic Journal of Behavioral Sciences, 26(2), 187-194. doi:10.1177/0739986304264374

Friedemann, M. L., Buckwalter, K. C., Newman, F. L., & Mauro, A. C. (2013). Patterns of caregiving of Cuban, other Hispanic, Caribbean Black, and White elders in South Florida. *Journal of Cross-Cultural Gerontology, 28*(2), 137-152. doi:10.1007/s10823-013-9193-6

Garcia-Campayo, J., Zamorano, E., Ruiz, M. A., Pardo, A., Perez-Paramo, M., Lopez-Gomez, V., . . . Rejas, J. (2010). Cultural adaptation into Spanish of the generalized anxiety disorder-7 (GAD-7) scale as a screening tool. *Health and Quality of Life Outcomes, 8*, 8. doi:10.1186/1477-7525-8-8

Graham, J. W. (2009). Missing data analysis: Making it work in the real world. *Annual Review Psychology, 60*, 549-576. doi:10.1146/annurev.psych.58.110405.085530

Guarnaccia, P. J., & Parra, P. (1996). Ethnicity, social status, and families' experiences of caring for a mentally ill family member. *Community Ment Health J, 32*(3), 243-260.

Guffey, T., & Yang, P. Q. (2012). Trust in doctors: Are African Americans less likely to trust their doctors than white Americans? *SAGE Open, 2*(4). doi:10.1177/2158244012466092

Hall, M. A., Camacho, F., Dugan, E., & Balkrishnan, R. (2002). Trust in the medical profession: Conceptual and measurement issues. *Health Services Research, 37*(5), 1419-1439.

Han, Y., Hu, D., Liu, Y., Caihong, L., Luo, Z., Zhao, J., . . . Mao, J. (2014). Coping styles and social support among depressed Chinese family caregivers of patients with esophageal cancer. *Eur J Oncol Nurs, 18*(6), 571-577. doi:10.1016/j.ejon.2014.07.002

Hoge, R. D., Andrews, D. A., Faulkner, P., & Robinson, D. (1989). The family relationship index: Validity data. *Journal of Clinical Psychology, 45*(6), 897-903.

Homish, G. G., Edwards, E. P., Eiden, R. D., & Leonard, K. E. (2010). Analyzing family data: A GEE approach for substance use researchers. *Addictive Behaviors, 35*(6), 558-563. doi:10.1016/j.addbeh.2010.01.002

Huang, F. Y., Chung, H., Kroenke, K., Delucchi, K. L., & Spitzer, R. L. (2006). Using the patient health questionnaire-9 to measure depression among racially and ethnically diverse primary care patients. *Journal of General Internal Medicine, 21*(6), 547-552. doi:10.1111/j.1525-1497.2006.00409.x

Hubbard, A. E., Ahern, J., Fleischer, N. L., Van der Laan, M., Lippman, S. A., Jewell, N., . . . Satariano, W. A. (2010). To GEE or not to GEE: comparing population average and mixed models for estimating the associations between neighborhood risk factors and health. *Epidemiology, 21*(4), 467-474. doi:10.1097/EDE.0b013e3181caeb90

Ilowite, M. F., Cronin, A. M., Kang, T. I., & Mack, J. W. (2017). Disparities in prognosis communication among parents of children with cancer: The impact of race and ethnicity. *Cancer, 123*(20), 3995-4003. doi:10.1002/cncr.30960

Kross, E. K., Engelberg, R. A., Gries, C. J., Nielsen, E. L., Zatzick, D., & Curtis, J. R. (2011). ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. *Chest, 139*(4), 795-801. doi:10.1378/chest.10-0652

Kuhlthau, K. A., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., . . . Perrin, J. M. (2011). Evidence for family-centered care for children with special health care needs: a systematic review. *Acad Pediatr, 11*(2), 136-143. doi:10.1016/j.acap.2010.12.014

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: current applications and future directions in pediatric health care. *Matern Child Health J, 16*(2), 297-305. doi:10.1007/s10995-011-0751-7

Leininger, M., & McFarland M. R. (2002). *Transcultural nursing: Concepts, theories, research, and practice.* New York: McGraw-Hill.

Lewandowski, A. S., Palermo, T. M., Stinson, J., Handley, S., & Chambers, C. T. (2010). Systematic review of family functioning in families of children and adolescents with chronic pain. *J Pain, 11*(11), 1027-1038. doi:10.1016/j.jpain.2010.04.005

Liang, K.-Y., & Zeger, S. L. (1986). Longitudinal data analysis using generalized linear models. *Biometrika, 73*(1), 13-22. doi:10.1093/biomet/73.1.13

Moos, R. H., & Moos, B. S. (1986). *Family environment scale manual*. Palo Alto, California: Consulting Psychologists Press.

Morrison, R. S., & Meier, D. E. (2004). High rates of advance care planning in New York City's elderly population. *Arch Intern Med, 164*(22), 2421-2426. doi:10.1001/archinte.164.22.2421

Nelson, A. (2002). Unequal treatment: Confronting racial and ethnic disparities in health care. *Journal of the National Medical Association, 94*(8), 666-668.

Neubauer, K., Dixon, W., Corona, R., & Bodurtha, J. (2016). Chapter 11: Cultural humility. In E. Wittenberg, B. R. Ferrell, J. Goldsmith, T. Goldsmith, S. L. Ragan, M. Glajchen, & T. R. G. F. Handzo (Eds.), *Textbook of palliative care communication* (pp. 79-89). New York: Oxford University Press.

O'Mahony, S., McHenry, J., Blank, A. E., Snow, D., Eti Karakas, S., Santoro, G., . . . Kvetan, V. (2010). Preliminary report of the integration of a palliative care team into an intensive care unit. *Palliat Med, 24*(2), 154-165. doi:10.1177/0269216309346540

Olagunju, A. T., Sarimiye, F. O., Olagunju, T. O., Habeebu, M. Y., & Aina, O. F. (2016). Child's symptom burden and depressive symptoms among caregivers of children with cancers: An argument for early integration of pediatric palliative care. *Annals of Palliative Medicine, 5*(3), 157-165. doi:10.21037/apm.2016.04.03

Painter, M. W., & Lavizzo-Mourey, R. (2008). Aligning forces for quality: A program to improve health and health care in communities across the United States. Retrieved from https://www.healthaffairs.org/doi/full/10.1377/hlthaff.27.5.1461

Plant, E. A., & Sachs-Ericsson, N. (2004). Racial and ethnic differences in depression: The roles of social support and meeting basic needs. *Journal of Consulting and Clinical Psychology, 72*(1), 41-52. doi:10.1037/0022-006X.72.1.41

Pochard, F., Azoulay, E., Chevret, S., Lemaire, F., Hubert, P., Canoui, P., . . . French, F. G. (2001). Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capacity. *Critical Care Medicine, 29*(10), 1893-1897.

Rao, U., Poland, R. E., & Lin, K. M. (2012). Comparison of symptoms in African-American, Asian-American, Mexican-American and Non-Hispanic White patients with major depressive disorder. *Asian Journal of Psychiatry, 5*(1), 28-33. doi:10.1016/j.ajp.2012.01.006

Rodriguez-Rey, R., & Alonso-Tapia, J. (2017). Relation between parental psychopathology and posttraumatic growth after a child's admission to intensive care: Two faces of the same coin? *Intensive Crit Care Nurs, 43,* 156-161. doi:10.1016/j.iccn.2017.08.005

Rodriguez-Rey, R., Alonso-Tapia, J., & Colville, G. (2018). Prediction of parental posttraumatic stress, anxiety and depression after a child's critical hospitalization. *J Crit Care, 45,* 149-155. doi:10.1016/j.jcrc.2018.02.006

Roque, A. T. F., Lasiuk, G. C., Radunz, V., & Hegadoren, K. (2017). Scoping review of the mental health of parents of infants in the NICU. *J Obstet Gynecol Neonatal Nurs, 46*(4), 576-587. doi:10.1016/j.jogn.2017.02.005

Schulz, K. F., & Grimes, D. A. (2002). Sample size slippages in randomised trials: exclusions and the lost and wayward. *The Lancet, 359*(9308), 781-785. doi:10.1016/s0140-6736(02)07882-0

Shen, C. W., & Chen, Y. H. (2013). Model selection of generalized estimating equations with multiply imputed longitudinal data. *Biometrical Journal, 55*(6), 899-911. doi:10.1002/bimj.201200236

Spitzer, R. L., Kroenke, K., & Williams, J. B. (1999). Validation and utility of a self-report version of PRIME-MD: The PHQ primary care study. Primary care evaluation of mental disorders. Patient Health Questionnaire. *Jama, 282*(18), 1737-1744. doi:10.1001/jama.282.18.1737

Spitzer, R. L., Kroenke, K., Williams, J. B., & Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder: The GAD-7. *JAMA Internal Medicine, 166*(10), 1092-1097. doi:10.1001/archinte.166.10.1092

Starks, H., Doorenbos, A., Lindhorst, T., Bourget, E., Aisenberg, E., Oman, N., . . . Hays, R. (2016). The family communication study: A randomized trial of prospective pediatric palliative care consultation, study methodology and perceptions of participation burden. *Contemporary Clinical Trials, 49*, 15-20. doi:10.1016/j.cct.2016.05.004

Thelen, M. (2005). End-of-life decision making in intensive care. *Crit Care Nurse, 25*(6), 28-37; quiz 38.

Ullrich, A., Ascherfeld, L., Marx, G., Bokemeyer, C., Bergelt, C., & Oechsle, K. (2017). Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. *BMC Palliative Care, 16*(1), 31. doi:10.1186/s12904-017-0206-z

Wang, M., Kong, L., Li, Z., & Zhang, L. (2016). Covariance estimators for generalized estimating equations (GEE) in longitudinal analysis with small samples. *Stat Med, 35*(10), 1706-1721. doi:10.1002/sim.6817

Welch, L. C., Teno, J. M., & Mor, V. (2005). End-of-life care in black and white: Race matters for medical care of dying patients and their families. *Journal of American Geriatrics Society, 53*(7), 1145-1153. doi:10.1111/j.1532-5415.2005.53357.x

Wulsin, L., Somoza, E., & Heck, J. (2002). The feasibility of using the Spanish PHQ-9 to screen for depression in primary care in Honduras. *Primary Care Companion to the Journal of Clinical Psychiatry, 4*(5), 191-195.

Yoon, S. J., Kim, J. S., Jung, J. G., Kim, S. S., & Kim, S. (2014). Modifiable factors associated with caregiver burden among family caregivers of terminally ill Korean cancer patients. *Support Care Cancer, 22*(5), 1243-1250. doi:10.1007/s00520-013-2077-z

Youngblut, J. M., & Brooten, D. (2012). Perinatal and pediatric issues in palliative and end-of-life care from the 2011 Summit on the science of compassion. *Nurs Outlook, 60*(6), 343-350. doi:10.1016/j.outlook.2012.08.007

Zimet, G. D., Powell, S. S., Farley, G. K., Werkman, S., & Berkoff, K. A. (1990). Psychometric characteristics of the multidimensional scale of perceived social support. *J Pers Assess, 55*(3-4), 610-617. doi:10.1080/00223891.1990.9674095

CHAPTER 3

Adapting the Resilience Framework for Family caregivers of Hospice Patients with Dementia

Background: Family caregivers face continuous stress and formidable caregiving burden. Due to the unpredictable nature and symptoms of dementia, several caregiving challenges may be unique in the context of hospice dementia caregiving. Under the continuous caregiving stress situations, caregivers need more sustainable and steady support by improving their resilience because resilience functions as an adaptation to challenges. Thus, it is necessary to identify hospice dementia family caregivers' challenges compared to general caregiving challenges as well as resilience resources and its consequences in order to improve the quality of life of hospice dementia caregivers.

Objective: This paper aims to identify challenges, possible solutions that are resources for resilience, and expected consequences from hospice dementia caregivers' perspectives.

Methods: A subsample of the 39 dementia caregivers from the primary study was analyzed using thematic analysis for this secondary analysis paper. The Resilience Framework was used to analyze qualitative data.

Results: We identified challenges, resilience resources, and expected consequences from the interview data. Resilience resources for dementia-related challenges are classified, taking into account the ecological levels: the individual, community, and societal levels. We also identified general caregiving challenges and resources that may not be considered only dementia-related ones as well as the absence of resilience resources that caregivers wish to have.

Discussion: Further studies can enlighten the importance of developing interventions for enhancing hospice dementia caregivers' positive adaptation to the unique challenges by filling

the absence of resources and bolstering the existing resources for resilience. Support for resources at societal and community levels may be realized through policy, law, or regulation on communities.

INTRODUCTION

Alzheimer’s disease as the most common type of dementia is the sixth leading cause of death in the United States, and its mortality rate has dramatically increased from 1980 to 2014 (Kochanek, Murphy, Xu, & Tejada-Vera, 2016). According to data from 2016, dementia is one of the top three diagnoses that progress to terminal among Medicare hospice patients (National Hospice and Palliative Care Organization, 2018). Among hospice patients, those with dementia account for the most days of care and the largest amount of Medicare spending (National Hospice and Palliative Care Organization, 2018). The number of persons with dementia is projected to reach 65.7 million in 2030 and rise to 115.4 million in 2050 (Prince et al., 2013). This increase is expected to lead to a proportionate rise in the use and costs of hospice care for persons with dementia (Alzheimer's Association, 2016). The healthcare costs for persons with dementia, including hospice services, are projected to increase from $259 billion in 2017 to $1.1 trillion in 2050 (Alzheimer's Association, 2017).

Dementia Caregiving in Hospice Care

Hospice provides the gold standard of care for patients with Alzheimer’s Disease and Related Dementias (ADRD) at the end of life, facilitating much needed assistance to family caregivers who have long provided care often in the absence of tailored support. The role of caregivers can be a fulfilling one but often with adverse effects on caregivers themselves (Haley, LaMonde, Han, Narramore, & Schonwetter, 2000). Stress and caregiving burden can negatively impact caregivers’ morbidity and mortality (Schulz & Beach, 1999). Caregivers of persons with ADRD face particularly stressful demands associated with the extended length of care, potential behavioral problems common in late-stage dementia, and the extreme impairment and debilitation of patients with end-stage Alzheimer's disease (Hurley & Volicer, 2002). Caregivers of a hospice patient with dementia have to grapple with continuous, stressful situations while assisting with basic and higher order activities of daily living of their patient such as personal hygiene, medication management, household chores, and transportation (Emanuel et al., 1999; R. Schulz et al., 2003). Family caregivers experience chronic stress, depression, deteriorating physical health, tenuous financial conditions, and premature death because of caregiving burden and stress (Langa et al., 2001; Pruchno, Kleban, Michaels, & Dempsey, 1990). Support for meeting caregivers' health and emotional needs to mitigate health risks should be provided to avoid such catastrophic consequences of stressful hospice dementia caregiving. Compared to patients with other kinds of diseases or disorders, dementia patients demonstrate unique needs and require substantial support. These unique needs among family caregivers include physical, psychological, emotional, and spiritual needs. Caregivers need both the knowledge to make informed decisions for patients who lack decision-making capacity and the ability to cope with patients' behavior challenges. Caregivers often have emotional strain due to the changes in cognition, mood, and behaviors of patients with ADRD. Moreover, family caregivers experience *dementia grief* associated with the disruption in communication and memory, which is perceived as many small and large losses throughout the disease progression before physical death (Blandin & Pepin, 2015; McCabe, You, & Tatangelo, 2016; Thompson & Roger, 2014). Toward the end of the patient's life, caregivers may face difficulties and need specific resources at various points in the disease trajectory. They may have to cope with intense intellectual and emotional conflicts because caregivers reckon with uncertainty about continued unpredictable losses and when to expect the death of their patient (Hurley & Volicer, 2002; Sanders & Adams, 2005). It is imperative that hospice care develops support services for caregivers tailored to those who care for patients with ADRD (Sachs, Shega, & Cox-Hayley, 2004).

Resilience Resources for the Challenges of Hospice Dementia Caregiving

In response to persistent caregiving stress, healthcare professionals are called upon to provide sustainable, continuous support throughout the entirety of the disease trajectory and even after. Caregivers should be able to restore balance and harmony, which may be achieved by enhancing inherent adaptation, also known as caregiving resilience (Deist & Greeff, 2015; Gaugler, Kane, & Newcomer, 2007). Fostering resilience enables dementia caregivers to overcome challenges of negative circumstances and continual stress with strength and positivity (Gaugler et al., 2007). Not every caregiving experience is negative. Caregiving itself can be positive or become positive over time. Caregivers' responses to challenges could be influenced by their own experience, knowledge, and environmental factors. Caregivers are more likely to be resilient when they are knowledgeable, supported by family members, and able to have access to support services such as respite care (Donnellan, Bennett, & Soulsby, 2015). In addition, personal mastery, self-efficacy and coping strategies are considered resilience domains that have a protective effect on health outcomes (Harmell, Chattillion, Roepke, & Mausbach, 2011). To maximize positive aspects of caregiving and improve caregiver health, it is important to provide and support the resources for resilience from the perspectives of caregivers. Although many researchers have studied about general caregiving challenges in hospice care, family caregivers' responses to their hospice dementia caregiving challenges and possible solutions for improving their resilience have yet to be fully understood due to the paucity of research studies in hospice adopting the resilience lens. Acknowledging resources can help to develop patient- and family-centered interventions. Healthcare professionals, administrators and policymakers can set up an infrastructure and appropriate policies to provide supportive resources to the patient-caregiver dyad. The aim of this study was to identify challenges, possible resources for resilience, and associated benefits for family caregivers of hospice patients with dementia.

METHODS

A theory-driven, deductive content analysis of secondary data obtained from a clinical trial [Grant Number: NIH/NINR, R01NR012213, PI: Demiris] was carried out to explore family caregivers' experience in taking care of hospice patients with ADRD. The parent study was designed to test the efficacy of a problem-solving therapy intervention for hospice caregivers with the goal to improve their capacity to handle challenges. The parent study recruited 514 hospice caregivers who were 18 years or older, completed a six-grade education at least, could speak and read English, and received home hospice services for their patient. A more detailed description of the parent study can be found elsewhere (Demiris et al., 2012). For our study, we conducted a secondary analysis on baseline interviews of a subsample of 39 caregivers of a hospice patient who had a primary hospice diagnosis of dementia to understand caregivers' barriers and facilitators to resilience in the context of dementia care in depth.

Conceptual framework

This study used an existing framework to analyze the interview data. The Resilience Framework for caregivers was developed by Windle and Bennett (2011) and it has been used in several studies (Bennett, Reyes-Rodriguez, Altamar, & Soulsby, 2016; Bennett & Windle, 2015; Donnellan et al., 2015). The use of the Windle and Bennett's Resilience Framework enabled us to explore a deeper understanding of caregivers' adaptation by capturing caregiving challenges, solutions (resilience resources) and expected consequences. We categorized various resources into the individual, community, and societal levels (Bennett et al., 2016). First, resources at the individual level include psychological resources, such as mastery, personal control, competence, self-esteem, and appraisal. Examples of individual-level resources are: caregivers' own abilities to maintain normal functioning, manage stress, stay positive, and have a sense of humor; biological factors such as gender and age; material factors such as income and financial capacity; and internal traits and personal characteristics such as health behavior. Second, resources at the community level include geographically immediate community resources which are located in or near the caregivers' neighborhood areas. Formal and informal social support from friends and other family members are considered resources at the community level. Social participation and cohesion (e.g., dementia support groups or religious groups) and housing are also included. Lastly, resources at the societal level are associated with laws, policies, national associations or organizations. These resources at the societal levels are structures that are usually not geographically close to the area where the individuals reside. Social policies, welfare and respite services, including home help, day and respite care, innovative services (e.g., DVDs), culture, and religion can be intertwined with these structures. Medicare hotline service can be an example of the resources at the societal level.

Data Analysis

Using the Resilience Framework, a deductive content analysis was carried out (Hsieh & Shannon, 2005). Four members of the team served as coders and had either in-person meetings or email communications to match each coder's coding results, discuss inconsistencies to find agreements, and develop the comprehensive coding framework. Professional transcriptionists transcribed interviews verbatim. Thirty-nine transcripts were independently analyzed by three authors (SH, NC, and CH). Initially, they coded line by line for content that fit the components and dimensions of the Resilience Framework, and categorized resilience resources into three levels. The first three transcripts were coded individually and compared. For any cases where there were differences in coding, a consensus was reached after discussion, and the rest of transcripts was coded. The intercoder agreement was 89.23% and the Cohen's Kappa value was 0.78, indicating solid agreement between coders (Burla et al., 2008). To enhance the trustworthiness of our results, we used peer debriefing on a regular basis to discuss the process (Gunawan, 2015).

RESULTS

Characteristics of Study Participants

Descriptive statistics are detailed in Table 2. We studied 39 caregivers (30 females 76.9%; 9 males 23.1%), with a mean age of 62 (Standard Deviation 7.4) years. The relationships of caregivers to hospice patients were: adult child (82%), spouse/partner (7.7%), niece (5.1%) and friend (5.1%). Hospice patients consisted of 31 women (79.5%) and 8 men (20.5%). The 39 patients had an average age of 90.2 (SD 7.3) years. Primary diagnosis of 37 patients (94.9%) was dementia and the other two hospice patients had a secondary diagnosis of dementia. The primary diagnoses of those two patients were cardiovascular and 'other'.

Challenges and Resources in Hospice Dementia Caregiving

We used the existing Resilience Framework and identified resilience resources from our interview data (Figure 9). We conceptualized caregivers' challenges, desirable resources for resilience, and expected consequences by exploring the perspectives of caregivers. Resilience resources are broken into the individual, community, and societal levels.

Dementia-related Challenges and Resilience Resources

We identified dementia-related challenges as expressed by caregivers. We did not include all challenges here in order to elaborate the most frequently addressed challenges; to see all challenges, refer to Tables 2, 3, and 4. Resources at multiple levels were identified as follows:

Individual Level

1) Knowledge Support for Contributing to Self-appraisal

There were several dementia-related challenges that could be resolved by using resilience resources at the individual level (Table 3). First, six caregivers addressed lack of knowledge in how to manage anxiety elevated by the unpredictable nature and symptoms of dementia such as paranoia, confusion, change in cognition, combativeness, and depression, how to deal with emotional stress, and how to provide appropriate care to a patient. Caregivers added that assessing and managing the care needs for a hospice dementia patient who display changes in independence and abilities is challenging. Patients with ADRD may show confusion and mood instability, impeding communication. Additionally, feelings of guilt, irritability, agitation, anxiety, and fatigue exacerbate those difficulties. One caregiver said that feeling 'tied down' because of obligations that force the caregiver to go and see the care-recipient every single week leads to the loss of happiness. In spite of those particular dementia-related issues, caregivers were able to identify individual strategies and tactics such as mastery and mind control to let things go and accept the unpredictable nature and symptoms of dementia as one of the examples of individual level-resilience resources. In addition, another caregiver stated that he/she appraised himself/herself and believed in himself/herself. The caregiver added that the personal appraisal of oneself is helpful to alleviate a feeling of guilt and increase self-confidence in one's own worth or abilities. Again, another caregiver also used self-talk or writing mental preparation to manage frustration, guilt, and anger.

2) *Strategies for Overcoming Communication Issues with a Patient*

Several caregivers reported having communication issues with their patient because of the patients' progressive deterioration along with pain, agitation, and hearing impairment, especially when the patient is reluctant to wear a hearing aid, uncooperative, and irritable or confused. Caregivers having such issues developed effective communication methods by using visual materials as an individual resource to promote improved listening and comprehension. The following quotes present how caregivers solved communication issues by themselves.

"We got her a pocket ear which she absolutely refuses to put on – the headphones on. . . . She had a $5,000 pair of fancy hearing aids which she has worn probably a total of five days. She lost one of them. . . . I got a replacement. She refused to wear them for a while. . . . The next time she got them in her ears, and when they came out we couldn't find one of them. And then we found that the dog had chewed it. . . . what I am doing is when I wanna talk to her about something, I turn off the radio. I turn off the TV. I even close the whole door."

"I tried twice. [NAME] is getting, you know, blah, blah, blah – and she just would look at me and it was just not getting in there. And so finally, I just took – I have a little, a little spiral notebook. A little notepad thing in my purse, just a small one. And I just wrote: [NAME] and

> [NAME] are getting married. And I turned it around and I showed it to her. And she read it and then she started smiling and goes: somehow she was showing her approval."

3) *Self-care Management and Activities*

One caregiver expressed exhaustion related to pressure during the decision-making process and wished to maintain a normal, routine life. According to several caregivers, sometimes they wanted the patient to die and be free from suffering, yet still wanted to see and spend time with the patient; this can cause great difficulty when making decisions. Another caregiver maintained self-care strategies such as exercise to boost their level of energy. Identifying strategies to overcome emotional challenges is also one of the important individual resilience resources. Another caregiver explicitly described that besides emotional self-care, following good health practice and maintaining well-being were indispensable. This caregiver stated that maintaining and managing health is necessary even when the care-recipient's status declines:

> "I worry about that, usually every time I have to go to the doctor. You know, I told you I also have a head injury. And I've noticed that I'm more dizzy that I used to be. I don't know if I need to go back to therapy again. . . . My goals would be to try and keep myself from worrying so much. Worrying about her decline, my decline, the relationship between the two and to try and stay healthy. I do healthy things. I eat fairly healthy. . . . There's nothing I can do about my mother's decline. It's going to happen. It's just how I manage myself when she declines."

Community Level

1) *Utilizing the Facility: Home-like Environments*

Next, we identified resilience resources at the community level (Table 4). Concerns about choosing the right facility were predominantly addressed by many caregivers. Some caregivers had positive experiences and others had negative experiences regarding the facility that they had used. One hospice dementia patient said that she was very happy because the facility is very similar to her own home. Some caregivers emphasized that the facility should equip home furniture that is more appropriate for people with ADRD.

2) *Utilizing the Facility: Dementia-friendly Environments and Building Trusting Relationships*

One caregiver pointed out that patients with dementia need larger rooms because they would wander, and talked about the residential environment needing to be adaptable to the symptoms of dementia. One caregiver reported difficulty when attempting to have a phone or in-person conversations with hospice nurses about their family member, stating that shift change and nurses' busy schedules interfered with their availability. However, another caregiver felt that high-quality hospice nurses provided constant quality care despite shift changes. Two caregivers addressed the critical components of good care, which includes staff members' ability to deal with an impending crisis, ability to tightly coordinate in a timely manner and ability to build a good, trusting relationship with patients and their family, created through effective communication.

3) *Utilizing the Facility: Providers and staff members' Communication Skills and Attitudes*

Communication impacts the quality of a facility. Five out of seven caregivers emphasized the importance of communication. Because the progression of dementia can be complicated, communication is very critical to caregivers. Caregivers want to be informed about the unstable and complicated progress and stage of dementia on a regular basis. Based on their experience, healthcare providers sometimes did not provide specific information on a patient's changing condition, which is important information to caregivers, even if not considered clinically important for providers. Not surprisingly, our study participants also argued that providers should have opportunities to improve their communication skills through continuing education or increased compensation. One caregiver had a negative experience when a member of the staff treated the patient as a child without respect. She added that moving a patient to another facility was not an easy decision because it can make the patient more confused. Five caregivers experienced emotional challenges such as anxiety, frustration, guilt, anger, and low self-confidence and utilized professional support. They specifically stated their wish to get support for these emotional challenges.

Societal Level

Lastly, several challenges can be resolved by using resilience resources at the societal level (Table 5). These resilience resources can be legal, policy or insurance-related, or provided by religious or cultural groups or state, federal or other entities and organizations. One caregiver emphasized legal challenges resulting from the fact that patients with ADRD cannot express themselves:

> "How do you get the law changed so that an Alzheimer's patient can choose to use the death with dignity? . . . Oh, and the other thing is – the other element of the law is that, uh, the person must administer the drugs to themselves. . . . I would like to see the law changed so that it would allow someone who has a disease similar to Alzheimer's, dementia disease, and like – to be able to, in effect, pre-authorize."

This quote illustrates that the caregiver wished for the person with dementia to die with dignity. The caregiver wanted local policymakers consider crafting laws and pointed out that hospice eligibility for dementia patients and treatment decision-making are tough topics due to prolonged caregiving related to the unexpected longevity. One caregiver said that having insurance makes it easier to make treatment decisions because insurance or financial status influences the direction or quality of care.

General Challenges and Resilience Resources

We identified general challenges that caregivers emphasized but are not exclusive to dementia care. Challenges that can be supported by resources at the individual level include (Table 3): 1) personal health issues, 2) communication with other family members or healthcare providers, and 3) financial problems. Those three general challenges can be alleviated by using individual resources. Methods and strategies to improve their own health problems such as physical therapy, healthy diet, exercise, travel, and the use of medications were identified. One caregiver prepared for a family meeting with a specific goal and suggested sharable activities to other family members to have more effective communication. There is an absence of resources for gender-related pressures when it comes to the difficulty in communicating with family members. Female caregivers were expected to serve as a primary caregiver, so the caregiving burden is heavier for women. To solve financial concerns, caregivers gathered information that was helpful for them to choose the best financial option, which is one of the personal strategies

At the community level, there are several general challenges (Table 4). There was a situation of a patient living in the United States, but the patient came from another country. The patient wished to die in his country. However, it is difficult to carry out the patient’s wish where he can be supported by family and friends. Patients may wish to have more intimate supporters such as family at the end of life. The caregiver had conflicts because the care-recipient received both Medicaid and Medicare in the United States. It would be costlier without such government assistance in his country where those supportive systems do not exist. Caregivers also need other family members to help decrease their emotional burden. When caregivers face difficulties in communicating with other family members, they sometimes use professional counselors' support. One caregiver said that all family members have a feeling of guilt. Thus, even if they can share their responsibilities, they all need support from professionals.

There are general challenges that can be supported by resilience resources at the societal level (Table 5). Using social support services, having the strength from religion or politicians can be solutions for emotional challenges, inability to provide home care, and financial problems. One caregiver had full support from family members, but the family support was not enough to support the primary caregiver and decrease the caregiver's burden. The caregiver started considering transcendental power and relied on God. However, the caregiver struggled with religion. She pointed out that the extended praying instead caused internal conflict and doubt about trust in God.

Absence of Resilience Resources

Capturing what resources caregivers wish to have access to is one of the priorities in an aging society. We specifically extracted the resilience resources that do not exist, but caregivers wish to receive, especially for caregivers of hospice dementia patients. Caregivers stated that they do not know how to provide better care to their patient and deal with emotional challenges. Based on this conversation, caregivers need education concerning these topics. Caregivers experience frustrations because dementia patients speak repeated phrases and are not able to remember previous conversations. Some caregivers developed self-strategies (e.g., using communication tools and writing communication) and were engaged in joint activities with their patient.

Many caregivers addressed struggles when they need to choose a facility to send their patient to. Hospice patients with ADRD rely on other systems and, therefore, caregivers inevitably confront formidable challenges when they are not satisfied with the external support system. One caregiver had no choice but to send a patient to a facility. Another caregiver also said that the hope and responsibility to meet a patient's needs created too much pressure and chose a facility to provide better care to meet the patient's care needs. However, finding a satisfying facility is another challenging task. The facility should be an appropriate setting to provide services to meet specific needs. Caregivers want healthcare providers at a facility to provide meaningful and detailed information about the continuously changing status of a hospice patient with ADRD by phone call or in-person follow-ups on a regular basis. Facilities should have an available contact system, enhancing trust in healthcare providers, and provide 24/7 care. Caregivers also want to have an opportunity for a family meeting or a team meeting with providers. Facilities need to be culturally adapted, and more importantly, provide respectful care for multicultural populations. Culture contains several relevant concepts. It is not limited to biological race. It is expanded to ways of life that can be reflected in language, material culture such as clothing and food, religious forms, and cultural products such as music, literature, and art (Palos, 2016). Caregivers in this study stated that facilities should offer a culturally fit environment to dementia patients with an understanding of what kind of music dementia patients are used to enjoying. Caregivers also complained about language barriers between patients and some healthcare staff members in the facility.

Other support that caregivers desire to receive includes: financial support, family or friend support, social support services such as respite care, spiritual support, and political support. Caregivers having a substantial financial burden need our attention. When they cannot reach a consensus in decision-making among family members, it is more challenging. When one caregiver decides, other family members should be able to align with the caregiver's decision. Although the primary caregiver has the support of other family members, the strength of support depends on how much they are aligned with each other. When family support is limited, they tend to lean on spiritual power. Moreover, there is more limited Death with Dignity for dementia populations. Hospice eligibility is still complicated and varies depending on the states. With debating hospice eligibility through research and practice, which is emerging as part of the hospice care development, policymakers may develop the standards and laws for dementia patients and their family.

DISCUSSION

According to the Alzheimer's Association (2017), informal caregivers have experienced special challenges (Royall, Palmer, & Markides, 2017). Recognizing the challenges is essential. Family caregivers deal with care-recipients' loss in judgment, orientation, and ability to communicate and understand, as well as changes in personality and behavior (Royall et al., 2017). This paper employed secondary analysis of data regarding caregivers of persons with dementia admitted to hospice. The utilization of the data from a problem-solving intervention study is profound and proper. Based on the nature of the original study, caregivers were encouraged to identify challenges, helpful resources to gain positive appraisals rather than just explore challenges, and even further, the expected consequences through the interview process.

Hospice dementia caregiving might be more challenging in light of the average age of caregivers. The mean age is 62 in our sample, while the mean age among dementia caregivers is 53.9 according to the national profile (National Alliance for Caregiving and Alzheimer's Association, 2017). Caregivers of dementia are becoming older as our society ages, and older caregivers may be burdened with more concerns compared to younger counterparts. This paper was distinctly focused on resilience resources, rather than challenges. The application of the Resilience Framework helped us to comprehensively present a variety of resources for resilience at multiple levels. We found affluent resilience resources and acknowledged the lack of certain resources. Several caregivers exhibited their capacity to identify available resources and predict positive consequences. Resilient families can set goals and priorities (Walsh, 2003). Some resilient caregivers showed self-directedness, which is an ability to adapt to a situation. Caregivers with a higher level of resilience, one of the personal traits, can rebound. On the other hand, in the case of caregivers who have a lower level of resilience and limited coping mechanisms to fulfill the caregiving duties, we can consider external resources that support their strength because the surrounding environment can also affect the individual's strength. As Borson and Chodosh (2014) proposed, dementia-capable health care systems require the consideration of the uniqueness of dementia, early invitation of partners and accessible information that our participants addressed during the interview. The findings of our paper may help to guide healthcare scientists to tailor interventions for families caring for their hospice patient with dementia. We can be more supportive of them in using the existing resources and providing additional desired resources. This paper provides insights into what resources are not present but can be supplied. Making up for the depletion of resources for resilience can be another profound step to establish a better hospice dementia care. We can target those modifiable and changeable resources.

Enrollment of a loved one with ADRD in hospice can offer substantial benefits to caregivers' perception of the patient's quality of life and death, greater satisfaction with management of terminal pain and shortness of breath, and a marked reduction in perceived unmet needs for knowledge about the dying process and what to do when death occurs, as well as substantial improvements in social support during the dying process (Teno et al., 2011). All participants were recruited through agencies in the Pacific Northwest US. Legal requirements differ by states. Persons with ADRD might not be able to qualify for the Death with Dignity Act depending on the states. One caregiver emphasized that hospice dementia populations might be overlooked for Death with Dignity due to their inability to advocate for themselves. Healthcare providers should recommend the persons diagnosed with dementia and their family to consider the Advance Directives when the persons are in the early stages of dementia. It is important to provide education about the importance of family roles and involvement in this issue including Advance Directives, and maximize positive consequences of their decisions, further preventing questions and complicated grief among families (Starks et al., 2007).

Several caregivers emphasized the need to support patients' autonomy for their respectful death when it comes to the choice of place for care. Dementia patients would like to stay in a home-like facility. Approximately, 70% of palliative care patients wish to be cared for at home at the end of life, although only 25% of them die at home (Wheatley & Baker, 2007). When patients need to transfer to a facility, the place must be a dementia-friendly environment. Cognitively impaired patients have particular characteristics, such as wandering, which require a certain environment to accommodate this symptom. Two caregivers explained that their patients wander, and it gets worse at night. Long-term care facilities with dementia residents should accommodate particular behaviors that dementia patients exhibit. They might need a large space to walk around with environmental stimuli while being exposed to familiar home-like environments (Brooke & Semlyen, 2017).

Caregivers had different opinions regarding the quality of care. The quality may be negatively influenced by staff shifting, but it can be overcome as long as hospice nurses provide a good quality of care. Providing training programs and a training reimbursement system to improve clinicians' ability to deal with unexpected health events and to develop communication skills may also have a positive influence on the quality of care. Literature brings into question the lack of both communication skill training and a reimbursement system to incentivize clinicians (Gabbard & Smith, 2016; Neubauer, Dixon, Corona, & Bodurtha, 2016). Healthcare providers and healthcare staff members should take care of patients with respect in a non-condescending manner to make them calm because patients' personality and emotions remain even in the severe stages of dementia with cognitive loss. Religious considerations were also emphasized. When caregivers were not able to find a way to support themselves even though they rely on their religion, a chaplain's support may be required. As per several caregivers, they had communication difficulties with dementia patients. As dementia progresses, communication problems become more frequent and serious. As older adults become more susceptible to infections such as urinary tract infections that can cause sudden and severe confusion, dementia family caregivers are more likely to have stressful problems, including communication difficulties. Healthcare professionals need to consider how to maximize the effect of family caregivers' communication methods. Furthermore, providing a more supportive communication environment for dementia patient-family caregiver dyads is important (Byrne & Orange, 2009). Several caregivers showed that they have their own coping strategies and self-control. When caregivers properly use positive appraisal through self-monitoring, self-management, and self-evaluation, they can boost their confidence and caregiving skills. Possessing the ability to maintain positive emotions through these coping mechanisms, which is presented as a form of resilience, may mitigate and reduce stress.

Understanding of the process of caregivers' experience lays the groundwork for future research. The next step would be to conduct prospective data collection using theoretical sampling through semi-structured interviews with family caregivers to produce richer and varied data. Analysis of qualitative data by applying policy analysis may evaluate the impact of a policy, law, or regulation on communities regarding several resources at societal and community levels addressed by caregivers in this study. This study will influence health policies and their implementation. Policymakers need to ensure that any other attainable resources can be provided according to their claims. In addition, providing supportive resources for enhancing caregivers' resilience in facilities is important to maintain a good quality of life as well as achieve a good quality of dying and death for the entire elderly friendly-community. Additional studies can explore challenges in improving the quality of a facility and care by healthcare providers or staff members in order to alleviate those challenges. Research is also needed in testing the efficacy and effectiveness of supportive behavioral and coping interventions, designed specifically for caregivers of patients with dementia.

Several limitations in our study have been accounted for. Our data were extracted from a parent larger study designed for another research question. For that reason, several parameters listed in the Resilience Framework (e.g., health behavior or characteristics) were not present in our secondary dataset. The differentiation between societal and community level is obscure due to the ambiguity of the definitions of resources between each level. For example, having a support group can be interpreted as either societal level or community level, or both. We differentiate them based on the geographical standards and tangibility of the resource. If a resource can be obtained in their community or near it, we considered the resource as a community-level resource. If a resource can be provided by a government, policy, or religion that is not tangible, we considered the resource as a society-level resource. A few resources overlap. For example, we included trust in healthcare providers and the healthcare system under the category of resources at the community level in this study. This could be addressed at the societal level because culture is a broader concept, and trust can be considered as one of the cultural elements. Mistrust in healthcare providers can be created by cultural barriers (Gabbard & Smith, 2016). Trust in healthcare providers can be maximized by having effective communication and being assured that hospice team members are competent, communicative and caring, which would be the way we pursue to support hospice dementia patients and their caregivers. Another overlapping resource is gender-related caregiving pressure as a challenge at the individual level in this study because gender is one of the individual components, but can be considered one of the social determinants because gender can be particularly defined and determined by society. As such, differentiating such resources at each level is a little complicated and unclear. The Resilience Framework should be further developed because its obscure standards need to be clearer. Nevertheless, the focus of this study was to comprehensively identify as many resources as possible based on the Resilience Framework at multiple levels, not to divide resources into each level, and not to differentiate them at each level. Another limitation is the use of a single dataset in one geographic location. Notwithstanding these limitations, the findings of this study are important for healthcare providers to consider hospice dementia caregivers' unique challenges and a lack of resilience resources.

Funding Sources

This study was supported by the National Institute of Nursing [Grant Number: NIH/NINR, R01NR012213, PI: Demiris].

Table 2. Characteristics of caregivers and patients

Characteristic	Caregivers (n=39)	Patients (n =39)
Age, mean (SD)	62.0 (7.4)	90.2 (7.3)
Gender		
Female	30 (76.9)	31 (79.5)
Male	9 (23.1)	8 (20.5)
Race		
White	38 (97.4)	38 (97.4)
Asian American	1 (2.6)	1 (2.6)
Relationship to patient		
Adult Child	32 (82.1)	
Spouse or Partner	3 (7.7)	
Other	4 (10.2)	
Marital Status		
Single, never married/partnered	2 (5.1)	
Married/partnered	26 (66.7)	7 (18.0)
Widowed	2 (5.1)	29 (74.3)
Divorced	9 (23.1)	3 (7.7)
Education		
Some College	10 (25.6)	
Associates	3 (7.7)	
Bachelors	14 (35.9)	
Masters	10 (25.6)	
Professional Degree (MD, JD)	2 (5.1)	
Patient Residence Location		
Lives with Patient	6 (15.4)	
Less than one hour away	31 (79.5)	
More than one hour away	2 (5.1)	
Employment		
Employed full or part-time	18 (46.2)	
Not employed	21 (53.8)	
Amount of Care Provided		
< 5 hours per week	8 (20.5)	
5 – 10 hours per week	13 (33.3)	
11 – 20 hours per week	7 (17.9)	
> 20 hours per week	11 (28.2)	
Duration of Caregiving		
< 6 months	1 (2.6)	
6 months – 1 year	1 (2.6)	
1 year – 2 years	2 (5.1)	
2 years – 3 years	3 (7.7)	
≥ 3 years	32 (82.1)	

N, (%) unless otherwise noted.

Table 3. Challenges, presence or absence of resources for resilience, and consequences at the individual level

Challenges (The number of caregivers in our sample who experienced this challenge)		Presence or absence of resilience resources		Consequences
		Specific Themes	Exemplars (Excerpts from transcripts)	
Dementia-specific Challenges	Uncertainty in providing care (2)	Lack of knowledge about caring for a hospice dementia patient	*Taking the great-grandson over to see her often will be one of the ways. I don't know what else to do. I don't know she doesn't accept anyone else.*	To provide better care to a patient with strategies and knowledge, enhance self-confidence and increase self-care
			I always tell her well, I'll see you tomorrow and I'll be here either and I'll say morning or afternoon or after work. But she forgets of course.	
		Developing organizational strategies	*After you prioritize, then come up with a plan of attack to do that and then, calendar of events that actually, like to do every day kind of a list.*	
		Practicing self-care	*The strategies, that I had personally, like, the yoga and the walking and that sort of things, is not happening too much. I would like to do more reading about self-care and meditation.*	
	Lack of knowledge about dealing with emotional challenges (4)	Self-control to accept the nature of dementia	*I would be a happier person if I could just accept all of this a little bit easier.*	To improve the state of mind
		Self-reassurance, appraisal and coping strategies	*Take a deep breath and count to 1,000. And restating, again, reassuring yourself that you're doing the best that you can.*	To promote emotional well-being
		Notetaking/Writing	*Writing at night, sometimes I do.*	
		Having time to engage in joint activities	*I have tried bringing like a little activity for us to do together. I am working on. Knitting or mending something. We write letters together or we talk about pictures of people.*	
	Communication issues (2)	Creating a quiet environment	*What I am doing is when I want to talk to her about something, I turn off the radio. I turn off the TV. I even close the whole door.*	To decrease communication challenges

		Adaptation of using visual materials and learning communication methods	*I have a little spiral notebook. A little notepad thing in my purse, just a small one. And I just wrote: [NAME] and [NAME] are getting married. And I turned it around and I showed it to her. And she read it and then she started smiling and goes: somehow she was showing her approval.*	
	Exhaustion because of the difficulty in decision-making (1)	Self-care strategies and tactics (e.g., exercise)	*Well, I walk them twice a day and that's very helpful. I mean I love to walk them so.*	To facilitate respite
General Challenges	Experiencing personal health issues (2)	Seeking health care services	*And I don't know if I need to go back to therapy again, to just…To do the physical therapy. For a couple of sessions. It helped.*	To better manage caregivers' own health issues and promote physical and emotional health
		Maintaining a healthy diet	*Worrying about her decline, my decline, the relationship between the two and to try and stay healthy. I do healthy things. I eat fairly healthy.*	
		Exercise and travel	*Chi Gung, it helps me focus on things other than me. Chi Gung is the healing art. I do weights, I do something called Nia. And I do Zumba. Oh, and getting away. A trip is great.*	
		Meditation	*Meditations help me.*	
	Noncooperation or poor communication between family members (2)	Gender-related caregiving pressure	*I find it's really sad, especially for women, because they're thrown into this role of well, of course, you're the nurturer.*	To decrease frustration, anxiety, and exhaustion and improve communication with family members
		Strategies (e.g., well-prepared and organized family meeting with a specific agenda)	*A white board like, okay, let's brainstorm this. Do we want it here in [CITY NAME] or here in [CITY NAME]? But again, we need some kind of tactful outline to get down to the nitty-gritty. Well, you know, we're gonna have to face mom's passing. Well, okay. Mom wants to be buried here.*	

		Strategies to maintain self-preservation and to invite other family members	*I'm just asking if he (family member) wants to go for a walk so we have a connection and can talk.*	
	Financial concern (2)	Tactics and strategies to create better financial plans (e.g., gathering information from websites)	*I am currently actively involved in working with my financial advisor on all kinds of financial issues. I would like spending time on the Social Security website to gather information and that kind of thing.*	To reduce financial burden
			I have been doing online searches both for buying and renting.	

Table 4. Challenges, presence or absence of resources for resilience, and consequences at the community level

Challenges (The number of caregivers in our sample who experienced this challenge)		Presence or absence of resilience resources		Consequences
		Specific Themes	Exemplars (Excerpts from transcripts)	
Dementia-specific Challenges	Concern about facility selection (7)	Home-like environment of a facility	*We had to make her apartment look as much like her home as possible. There were some pieces of furniture that really needed to be replaced. She had a couch that was too low. She had a hard time getting out of it.*	To locate appropriate settings of care and decrease emotional burden
		Dementia-friendly facility	*But they had a living situation where mom and dad could live there and have full-time care, but they couldn't be in the same room. It was people that were pretty advanced, and people would wander during the day. They had very small rooms so that that wasn't going to work.*	
		Good relationship with and quality care of healthcare providers and staff Timely care needs	*They're taking good care of her and to just talk to the staff there a lot to see how she's doing and what she's doing. We have a pretty good relationship and when she hits a crisis like when she was hospitalized in February, it's a pretty tight team that works pretty quickly now.*	
			All of the systems out there are designed to deny care or designed to ignore them or designed to obfuscate, to make things a pain, to delay, to postpone.	
		Communication issues	*I'd like to just be informed. If I hadn't have asked, I wouldn't have gotten that information.*	
		Needs for training services and curriculum to health care workers Staffing and provider compensation needs	*I would like to see the curriculum improved so that people are trained.*	
		Trust in hospice team members and system	*To relinquish more trust and care to the hospice team. And then I feel more comfortable because the other*	

		(e.g., available contact system)	*woman would call me every like once, uh, a week and a half or something. And just say, 'Everything OK?', 'Yeah, fine'. Just checking in.*	
		Negative experience and difficulty in switching to another facility because of the worry about the confusion of dementia.	*I'll be there and [NAME] will leave the room, and when she leaves the room, mom turns around and sticks her tongue out at her. And it's not that she isn't nice, you know, but it's just her personality. To move her somewhere else would confuse her even more.*	
		Cultural fit (e.g., language and familiar music)	*Like the cultural spot may mother came from or would be interested in, because they're not familiar with what the music was of her time or the things that…it's hard for them to have a kind of conversation. And I think, you know, again the culture and the language barrier play into it.*	
		Allowability of costs Reasonable costs	*If there a place even closer to where I live that could be good or a place that would be a little less expensive.*	
	Communication difficulties (1)	Moving the patient to a nursing home	*We are planning on putting her in a nursing home in July, so we can do some family reunions and travel a bit.*	To improve the quality of life
	Emotional challenges (5)	Seeking external support (e.g., geriatric physicians, hospice nurses and chaplains)	*A good friend of mine is a geriatric doctor in the clinic that my mom goes to. That actually has helped so that's something that I am currently doing.* *I always feel better when the hospice nurses or the caregiver say, "You sure do take good care of your dad".* *The chaplain was giving me some tips on some reading that I could do. We were talking about meditation and about, um, spiritual reading.*	To promote emotional stability
		Family support	*I have enough support with my siblings. See my grandkids and not feel guilty about the time I spent with them.*	

		Lack of other family members' involvement in care	*I'm not sure how to approach my brother about getting more involved or involved in a different way. He likes to just do what he's always done which isn't very appropriate.*	To decrease frustration, guilt, and anger
		Volunteering	*Make sure that I do things that make me happy, like volunteering and church.*	
	Difficulty in treatment decision-making (1)	Family agreement in end-of-life medical decision making	*I think they (family members) make me feel guilty even though they probably aren't. I'm the one that has to make the decision. I don't want to ask them for permission because I don't want to argue it.*	To make a decision that is validated and reassured by family
	Prolonged caregiving burden (1)	Adult family home providing 24-hour care with certified nursing assistants	*It's hard to watch somebody you love, decline as you know, people would have watched other people die. One thing I just do wanna add is that the adult family home. And it came at the right time and has turned out to be very good.*	To improve caregivers' quality of life
General Challenges	Support a patient's preference for care in the home (1)	Care needs in the care-recipient's country	*He needs more attention, care, support by loved ones, like family members, relatives, friends. And most of our relatives, friends, or family members are in the [COUNTRY]. We're only three here in the family. Besides we cannot afford to hire caregivers to take care of him, like, 24 hours a day.*	To meet patients' wishes
	Emotional exhaustion (5)	Needs for setting up shared roles and responsibilities among family members	*Part of me was angry almost feeling victimized by it because I was not getting any support from my brothers.*	Physical and psychological well-being and satisfaction
			It's like the three of us share responsibility for taking care of my mom. I need to try to redefine my role.	
		Inadequate social support from family and friends	*It would be great if I had someone to help with the groceries*	
	Financial concerns (2)	Professional consultation Legal services	*We got the best attorneys in [CITY], the head of their Estate Planning practice. The law gives special support to those so which would be in perpetuity type of thing. We used the legal system to our benefit. We used the medical system to our benefit to his benefit and we lined it all up.*	Decrease financial burden

	Noncooperation and poor communication among families (2)	Professional family counselors' support	*Respondent: I can meet with a counselor, if he wants to see somebody. I kinda gave up and I think he needs to talk to somebody that's a third party.*	To work harmoniously with other family members

Table 5. Challenges, presence or absence of resources for resilience, and consequences at the societal level

Challenges (The number of caregivers in our sample who experienced this challenge)		Presence or absence of resilience resources		Consequences
		Specific Themes	Exemplars (Excerpts from transcripts)	
Dementia-specific Challenges	Efforts to pursue death with dignity (1)	Legal and policy challenges: Difficulty in applying the existing law to hospice dementia patients who cannot advocate for themselves	*I would like to see the law changed so that it would allow someone who has a disease similar to Alzheimer's, dementia disease. And like to be able to, in effect, pre-authorize. A concurrent goal has to happen. It would be to raise awareness and get public support.*	Recognition of caregivers' perception of quality death for their loved one and the provision of public support
	Lack of public awareness of hospice eligibility (1)	Public awareness	*Most people don't know that somebody with Alzheimer's could be a potential candidate for hospice care. Because with the big question mark as to how long will they live, not being able to be answered so well.*	To increase public awareness of hospice eligibility
		Organization support	*There is this Alzheimer's Association and they do have support groups and it's not to say that everybody who has Alzheimer's would be eligible. You know, there's still their criteria that people have to meet.*	
	Difficulty in treatment decision-making (1)	Insurance	*I'm talking about the hospital and what they provided, and I guess a part of that is her insurance too.*	To make the right treatment decision
General	Emotional challenges (2)	Social support services (e.g., respite services, transportation for care, day care)	*I think, even one day a week for respite care would make a difference. I discovered that it's really more helpful to me if he leaves.*	Physical and psychological well-being

		Spirituality	*I’ve always had a large value on spirituality that never quite could find a place that felt comfortable to practice. I’m finding that within the Buddhist practice, it’s feeling more comfortable.*	
	Inability to provide home care (2)	Culture and religion	*It’s also a great relief to me to be with family, relatives, you know, you’re Christian. This past week, I say, “If I am being contempt to think, I doubt God’s faithfulness”. We’ve been praying for God’s mercy to be together.*	To decrease burden to take care of a patient and provide better care
		Organization support	*We’re so glad that the [organization] is here. All the folks, like, that they made that the joint resolution to request, particularly to help my dad’s family.*	
		Political support in a care-recipient’s country with different payment structures	*In the [COUNTRY], there is no free medical care. I don’t’ think with his present medications, they’re available. You know, he can…only available, especially the medication that are only available in the Department of Health.*	
		Government support (e.g., Medicaid and Medicare) in the United States	*He is under Medicaid and Medicare, supported by the government, if we bring him home it’s also financial.*	To decrease caregiving burden
		Hospice service	*Most of her meds are taken care of by hospice. All of her incontinent products are taken care of by hospice. I don’t have to do that anymore. And they do her laundry.*	
	Financial concerns (2)	Insurance	*I have health insurance but it’s expensive.* *Hey, if I’m gonna pay 500 bucks a month for health insurance, and the penalty is $25? It’s like: I’ll just pay the $25.*	To reduce financial burden
		Medicare or Medicaid	*This one kind of Social Security is that it does come with an automatic Medicare or Medicaid. You’re not allowed to have any more than $2,000 in assets.*	
		Selection of a facility with limited financial support	*But they needed to move her financially that it would just make better sense for them to have Medicaid patients in a location that was less costly to administer the health.*	

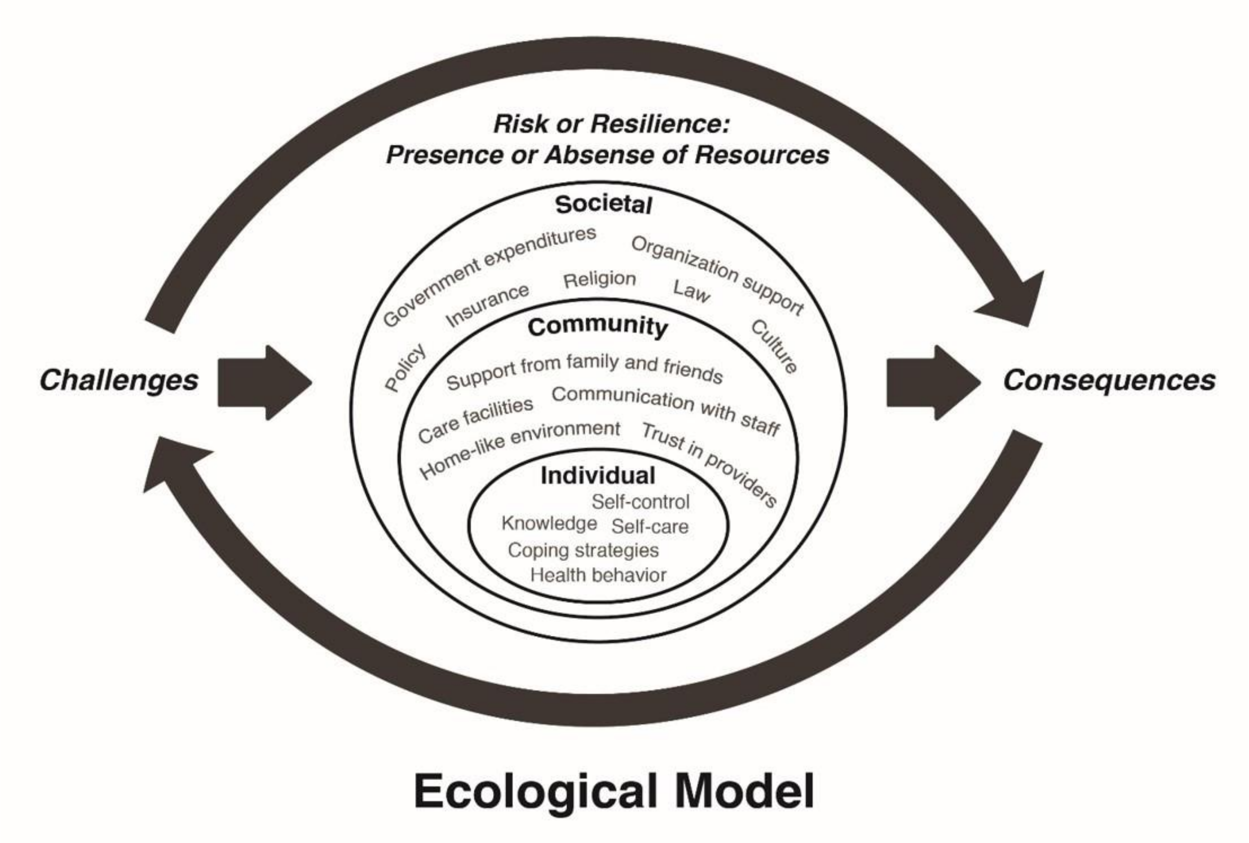


Figure 9. Conceptual framework of resilience resources (adapted from Windle and Bennett (2011) and reproduced with permission of the authors) for hospice dementia family caregivers

References

Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 12*(4), 459-509. doi:10.1016/j.jalz.2016.03.001

Alzheimer's Association. (2017). Alzheimer's Association Report: 2017 Alzheimer's disease facts and figures. Retrieved from https://www.alzheimersanddementia.com/article/S1552-5260(17)30051-1/pdf

Bennett, K. M., Reyes-Rodriguez, M. F., Altamar, P., & Soulsby, L. K. (2016). Resilience amongst older Colombians living in poverty: An ecological approach. *Journal of Cross-Cultural Gerontology, 31*(4), 385-407. doi:10.1007/s10823-016-9303-3

Bennett, K. M., & Windle, G. (2015). The importance of not only individual, but also community and society factors in resilience in later life. *Behavioral and Brain Sciences, 38*, e94. doi:10.1017/S0140525X14001459

Blandin, K., & Pepin, R. (2015). Dementia grief: A theoretical model of a unique grief experience. *Dementia (London)*. doi:10.1177/1471301215581081

Borson, S., & Chodosh, J. (2014). Developing dementia-capable health care systems: A 12-step program. *Clinics in Geriatric Medicine, 30*(3), 395-420. doi:10.1016/j.cger.2014.05.001

Brooke, J., & Semlyen, J. (2017). Exploring the impact of dementia-friendly ward environments on the provision of care: A qualitative thematic analysis. *Dementia (London)*. doi:10.1177/1471301216689402

Burla, L., Knierim, B., Barth, J., Liewald, K., Duetz, M., & Abel, T. (2008). From text to codings: Intercoder reliability assessment in qualitative content analysis. *Nursing Research, 57*(2), 113-117. doi:10.1097/01.NNR.0000313482.33917.7d

Byrne, K., & Orange, J. B. (2009). Conceptualizing communication enhancement in dementia for family caregivers using the WHO-ICFframework. *Advances in Speech Language Pathology, 7*(4), 187-202. doi:10.1080/14417040500337062

Deist, M., & Greeff, A. P. (2015). Living with a parent with dementia: A family resilience study. *Dementia (London), 16*(1), 126-141. doi:10.1177/1471301215621853

Demiris, G., Parker Oliver, D., Wittenberg-Lyles, E., Washington, K., Doorenbos, A., Rue, T., & Berry, D. (2012). A noninferiority trial of a problem-solving intervention for hospice caregivers: In person versus videophone. *Journal of Palliative Medicine, 15*(6), 653-660. doi:10.1089/jpm.2011.0488

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health, 19*(10), 932-939. doi:10.1080/13607863.2014.977771

Emanuel, E. J., Fairclough, D. L., Slutsman, J., Alpert, H., Baldwin, D., & Emanuel, L. L. (1999). Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine, 341*(13), 956-963. doi:10.1056/NEJM199909233411306

Gabbard, J., & Smith, T. (2016). Chapter 7: Communication in palliative medicine. In E. Wittenberg, B. R. Ferrell, J. Goldsmith, T. Goldsmith, S. L. Ragan, M. Glajchen, & T. R. G. F. Handzo (Eds.), *Textbook of Palliative Care Communication*. New York: Oxford University Press.

Gaugler, J. E., Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *Journal of Gerontology, Series B: Psychological Sciences and Social Sciences, 62*(1), P38-44.

Gunawan, J. (2015). Ensuring trustworthiness in qualitative research. *Belitung Nursing Journal, 1*(1), 10-11. doi:10.33546/bnj.4

Haley, W. E., LaMonde, L. A., Han, B., Narramore, S., & Schonwetter, R. (2000). Family caregiving in hospice: Effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hospice Journal, 15*(4), 1-18. doi:10.1080/0742-969x.2000.11882959

Harmell, A. L., Chattillion, E. A., Roepke, S. K., & Mausbach, B. T. (2011). A review of the psychobiology of dementia caregiving: A focus on resilience factors. *Current Psychiatry Reports, 13*(3), 219-224. doi:10.1007/s11920-011-0187-1

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. doi:10.1177/1049732305276687

Hurley, A. C., & Volicer, L. (2002). Alzheimer disease: "It's okay, Mama, if you want to go, it's okay". *JAMA, 288*(18). doi:10.1001/jama.288.18.2324

Kochanek, K. D., Murphy, S. L., Xu, J. Q., & Tejada-Vera, B. (2016). *Deaths: Final data for 2014. National Vital Statistics Reports; vol 65 no 4. Hyattsville, MD: National Center for Health Statistics*.

Langa, K. M., Chernew, M. E., Kabeto, M. U., Herzog, A. R., Ofstedal, M. B., Willis, R. J., . . . Fendrick, A. M. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *Journal of General Internal Medicine, 16*(11), 770-778. doi:10.1111/j.1525-1497.2001.10123.x

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *Gerontologist, 56*(5), e70-88. doi:10.1093/geront/gnw078

National Alliance for Caregiving and Alzheimer's Association. (2017, February 2017). Dementia caregiving in the U.S. Retrieved from http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf

National Hospice and Palliative Care Organization. (2018). NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, April 2018. Available from https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf.

Neubauer, K., Dixon, W., Corona, R., & Bodurtha, J. (2016). Chapter 11: Cultural humility. In E. Wittenberg, B. R. Ferrell, J. Goldsmith, T. Goldsmith, S. L. Ragan, M. Glajchen, & T. R. G. F. Handzo (Eds.), *Textbook of Palliative Care Communication*. New York: Oxford University Press.

Palos, G. R. (2016). Chapter 12: Cultural considerations in palliative care and seriou sillness. In E. Wittenberg, B. R. Ferrell, J. Goldsmith, T. Goldsmith, S. L. Ragan, M. Glajchen, & T. R. G. F. Handzo (Eds.), *Textbook of Palliative Care Communication*. New York: Oxford University Press.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia, 9*(1), 63-75. doi:10.1016/j.jalz.2012.11.007

Pruchno, R. A., Kleban, M. H., Michaels, J. E., & Dempsey, N. P. (1990). Mental and physical health of caregiving spouses: Development of a causal model. *Journal of Gerontology, 45*(5), P192-199. doi:10.1093/geronj/45.5.P192

Royall, D. R., Palmer, R. F., & Markides, K. S. (2017). Exportation and validation of latent constructs for dementia case finding in a Mexican American population-based cohort. *Journal of Gerontology, Series B: Psychological Sciences and Social Sciences, 72*(6), 947-955. doi:10.1093/geronb/gbw004

Sachs, G. A., Shega, J. W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine, 19*(10), 1057-1063. doi:10.1111/j.1525-1497.2004.30329.x

Sanders, S., & Adams, K. B. (2005). Grief reactions and depression in caregivers of individuals with Alzheimer's disease: Results from a pilot study in an urban setting. *Health & Social Work, 30*(4), 287-295. doi:10.1093/hsw/30.4.287

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA, 282*(23), 2215-2219. doi:10.1001/jama.282.23.2215

Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., . . . Resources for Enhancing Alzheimer's Caregiver Health, I. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*(20), 1936-1942. doi:10.1056/NEJMsa035373

Starks, H., Back, A. L., Pearlman, R. A., Koenig, B. A., Hsu, C., Gordon, J. R., & Bharucha, A. J. (2007). Family member involvement in hastened death. *Death Studies, 31*(2), 105-130. doi:10.1080/07481180601100483

Teno, J. M., Gozalo, P. L., Lee, I. C., Kuo, S., Spence, C., Connor, S. R., & Casarett, D. J. (2011). Does hospice improve quality of care for persons dying from dementia? *Journal of the American Geriatrics Society, 59*(8), 1531-1536. doi:10.1111/j.1532-5415.2011.03505.x

Thompson, G. N., & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. *Palliative and Supportive Care, 12*(3), 223-231. doi:10.1017/S1478951513000461

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*(1), 1-18.

Wheatley, V. J., & Baker, J. I. (2007). ‘‘Please, I want to go home’’: Ethical issues raised when considering choice of place of care in palliative care. *Postgraduate Medical Journal, 83*(984), 643-648. doi:10.1136/pgmj.2007.058487

Windle, G., & Bennett, K. M. (2011). *Resilience and caring relationships*. New York, NY: Springer.

CHAPTER 4

Relationships among Race, Ethnicity, Other Social and Cultural Components, and Resilience

in Family Caregiving in the Context of Palliative and Hospice Care:

A Systematically Conducted Narrative Review

Backgrounds: Older adults and their family have complex needs because older adults experience multiple health problems, and they primarily rely on their family in palliative care and hospice settings. The influences of race/ethnicity, social, and cultural factors delineate different caregiving patterns and coping strategies such as using social support, thereby explaining different levels of resilience and health outcomes among family caregivers.

Aim: To explore the influences of race/ethnicity and other social and cultural factors on caregiving patterns and coping styles among family caregivers of older adults in palliative care and hospice.

Design: This review synthesized identified articles in narrative form to describe the literature on a broad, complex topic related to race/ethnicity, social and cultural factors as well as different caregiving patterns, coping strategies, and resilience.

Data Source: Databases searched for this review included CINAHL, PsycINFO, Medline, and EMBASE. Of 498 published papers, 6 met inclusion criteria and included in this review.

Results: The influences of race/ethnicity, social and cultural factors, and coping styles, as well as the interacted relationships between those factors, were identified in palliative care and hospice. Relevant factors included race, ethnicity, family tradition and structure, familiarity with the healthcare system, employment, occupation, financial status, social and political support, perceptions toward external services, geography, gender, and personal belief system.

Conclusions: The findings of this systematically conducted narrative review suggest that not many studies addressed racial and ethnic disparities among family caregivers in palliative care and hospice. The interconnected relationships among race, ethnicity, and other social and cultural factors need to be considered to enhance resilience and develop coping strategies among family caregivers.

Keywords: culture, diversity, race, and ethnicity, social and cultural factors, palliative care, hospice, family caregivers, older adults

INTRODUCTION

The US populations have been influenced by a multitude of cultures and are projected to grow rapidly in linguistic, and ethnic and cultural diversity. In this globalized and culturally diverse, aging American society, culturally sensitive care for family caregivers of older adults has been underlined, both empirically and theoretically. Older adults and their family members have complex needs because older adults experience multiple chronic conditions and disabilities. Family caregivers sometimes have to provide constant care for older adults. Persistent caregiving burden escalates the levels of stress and strain among family caregivers of older adults, and even worse, their efforts are often unappreciated (Feinberg, 2014; Janevic & Connell, 2001; V. E. Richardson et al., 2017). As a result of caregiving burden and stress, family caregivers are at risk for physical and mental health problems (Epstein-Lubow, Davis, Miller, & Tremont, 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; T. J. Richardson, Lee, Berg-Weger, & Grossberg, 2013).

In addition, older adults and their family have had less access to palliative and hospice care and their needs for end-of-life care have not been met due to underassessment and undertreatment of older adults' health problems (Davies, Higginson, & World Health Organization, 2004). However, the movements to emphasize the need for palliative and hospice care for older adults and their family have been growing, and the focus of palliative care has been expanded from individual-centered care to individual- and family-centered care across settings including hospital, long-term care, and community-based settings (Ornstein, Schulz, & Meier, 2017).

As family caregivers are not homogeneous, caregiving experiences vary. Cultural values operate at a high level in palliative and hospice care (van der Steen et al., 2014; World Health

Organization, 2011). Culture-specific care increases client satisfaction, expedites recovery, and helps clients to cooperate with healthcare providers because clients see that their values and beliefs are incorporated into their care (Leininger & McFarland, 2002). It is important to understand cultural factors such as language, relationships, roles, interaction patterns, values, beliefs, and cultural norms (Leininger & McFarland, 2002). For example, some caregivers have stronger reliance on religion and spirituality as a coping method in a certain cultural context. In addition, language barriers affect caregiving experience and burden. In certain racial/ethnic groups, caregivers hold different attitudes about caring due to the influence of filial piety. In relation to familism, filial obligation may result in a reluctance to utilize formal support services (Scharlach et al., 2006). Moreover, the effects of age and gender on familism have been inconsistent, so the influence of ethnicity on familism, as a third important factor, was emphasized (Parveen & Morrison, 2009). This argument was supported by the ideas that: 1) the peak age that shows strongest filial norms was different when other factors such as parental deaths were controlled; 2) there have been mixed results about the relationships between gender and filial obligations; and 3) filial obligations differed by race and ethnicity, and filial obligations were exacerbated with other stressors due to a minority status among family caregivers (Parveen & Morrison, 2009). Parveen and Morrison (2009) also found that among Asian caregivers, age, gender, and ethnicity contributed to the variance in familism and that familism has an association with coping styles. Specifically, when Asian caregivers have religious affiliation, they have different ways to cope (Parveen & Morrison, 2009). As another example that supports the argument that cultural factors, as well as race and ethnicity, affect caregiving experiences, daughters-in-law are the most common caregivers in South Korea, representing about 60 % of caregivers (Lim, Ahn, & Ahn, 2016). This phenomenon that they were reluctant to use institutional and community-based services and rather provided hands-on care to their husbands' parents may be explained by strong filial obligations among Korean Americans and Chinese Americans (P. Dilworth-Anderson & Gibson, 2002).

Cultural factors should be considered with social determinants of health in the pursuit for reducing health disparities because determinants of health represent a mix of the biological, behavioral, cultural, social, economic, and political factors (e.g., healthcare and education systems, housing, employment, safety of neighborhoods, and food) (Patrick et al., 2006). For example, some caregivers assume caregiving tasks and do not rely on external services because of obligations from filial piety. As another example, other racial groups, even without such familial obligations, also do not utilize external services due to social determinants of health such as lack of available healthcare service and barriers to transportation in rural areas. These examples demonstrate that caregiving patterns and coping mechanisms among family caregivers can be influenced by family, cultural dynamics, and other social determinants of health (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007). Thus, there is a need for expanding views on the influence of cultural factors to that of social determinants of health as these factors contribute to caregiving patterns and the utilization of coping mechanisms (social determinants of health are referred to as "social and cultural factors" in this paper).

Along with coping mechanisms, the concept of resilience is also important because resilience is a modifiable personality characteristic that is influenced by coping mechanisms (Spangler, Koesten, Fox, & Radel, 2012; Wu et al., 2013). Resilience is defined as the ability to deal with stressful situations and rebound from life challenges. Resilience involves processes that foster positive adaptation from significant adversities (Walsh, 2003). Considering the concepts of coping and resilience, an individual may be more likely to have an ability to withstand challenges when the individual is equipped with better coping mechanisms. In fact, the relationship between coping and resilience was addressed in Cohen and Lee’s study (2007). To be specific, when caregivers took a proactive coping style, they tended to be more resilient (Cohen & Lee, 2007).

A list of ten consensus indicators for hospice and palliative care has been established for US settings (Dy et al., 2015) by the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA) and is relevant when considering caregiving of older adults. The list of indicators consists of 8 domains: 1) structure and process of care, 2) physical aspects of care, 3) psychological and psychiatric aspects of care, 4) social aspects of care, 5) spiritual, religious, and existential aspects of care, 6) cultural aspects of care, 7) care of the patient at the end of life, and 8) ethical and legal aspects of care. However, there are no indicators for social aspects of care, cultural aspects of care, and care of the patient at the end of life (Dy et al., 2015). AAHPM and HPNA were not able to determine the indicators for those aspects due to the lack of scientific evidence and insufficient documentation in the record. This shows a need for studies about palliative and end-of-life care in regard to social and cultural aspects. To capture the social and cultural aspects, it is important to consider the inclusion of potential indicators such as race, ethnicity, social determinants of health, and cultural aspects and dynamics at multiple levels including individual, family, society, and community levels. It is worth noting that health care providers need to assess patients’ and their family’s culture, customs, and faith within in a culturally sensitive approach for better end-of-life care in a culturally sensitive way based on care-recipients’ culture, customs, and faith (Seow et al., 2016). Establishing standardized sets of indicators for enhancing resilience, ultimately for better palliative and hospice care, by exploring multiple levels based on characteristics of individual, family, society, and community can be a future solution for reducing negative aspects of caregiving within their cultural context.

Thus, it is crucial to raise awareness about the importance and influences of cultural values on palliative care among family caregivers based on their cultural backgrounds (Adames, Chavez-Duenas, Fuentes, Salas, & Perez-Chavez, 2014). By doing so, healthcare providers can provide better assistance for family caregivers based on cultural understanding about coping strategies or mechanisms, which can improve caregivers' physical and mental health outcomes. This can eventually lead to reduced health disparities for family caregivers based on race/ethnicity and other social and cultural factors.

The purpose of this systemic narrative review is to identify studies reporting on interconnected relationships among race/ethnicity and other social and cultural factors, and the impact of these relationships on resilience and coping mechanisms among family caregivers of older adults in palliative and hospice care. The findings of this review will ultimately contribute to caregiving research to enhance health outcomes among family caregivers by improving their caregiving coping and resilience.

METHODS

Design

Systematic reviews must follow systematic review principles such as the Preferred Reporting Items for Systematic Reviews and Metal-analysis (PRISMA) guidelines, requiring the inclusion of two or more independent reviewers for accuracy (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). In this paper, the term *narrative review* is used because the reviews were synthesized in a narrative form to describe the literature on a broad topic and to interconnect cultural components in a wide variety of studies. Screening and data extraction were performed by one reviewer even though relevant papers were systematically searched and appraised (Bowling et al., 2015; Smith & Estefan, 2014). The results were analyzed based on the associations between race/ethnicity, and other social and cultural components as well as the impact of cultural components and those associations on mental health outcomes such as anxiety and depression.

Data Sources and Search Strategy

Recent literature over the last 14 years (2006-2019) was reviewed using electronic databases of CINAHL, PsycINFO, Medline, and EMBASE, because hospice and palliative medicine was officially recognized by the American Board of Medical Specialties in 2006. Both quantitative and qualitative studies regarding the associations among race, ethnicity, and other social and cultural factors, health or the impacts of those factors on resilience and coping strategies among family caregivers of older adults were searched. Articles were searched on 1/27/2019. With assistance in finalizing search terms from a librarian, a combination of key terms, including race, ethnicity, and other social and cultural factors, resilience, and palliative and hospice care, was used (Table 6).

Inclusion and Exclusion Criteria

Studies were included if they 1) were published in English; 2) were observational or intervention studies; 3) included information about the influences of race, ethnicity, and other social and cultural factors on coping strategies, resilience or health outcomes among family caregivers; 4) targeted family caregivers of older adults; 5) settings were palliative or hospice care; and 6) published between 2006 and 2019. Studies were excluded if the care-recipients were not older adults for the following two reasons. First, filial obligations, as one of the cultural factors shaping different caregiving patterns and coping strategies across race and ethnicity, were the expected caregiving duties towards adult children caregivers for their aging parents (Parveen & Morrison, 2009). Second, caregiving experiences and needs as well as some aspects of palliative care and hospice can be different depending on the relationship between care-recipients and caregivers, the care-recipients' age or disease trajectory (Conway, Jones, & Speakes-Lewis, 2011; Steadman, Tremont, & Davis, 2007; Thompson & Roger, 2014). Therefore, the population of care-recipients was limited to older adults in order to identify the unique nature or characteristics of family caregiving within the realm of palliative care or hospice. In addition, studies were excluded if they were dissertations, conference abstracts, reports, and unpublished documents, and did not address associations among race, ethnicity, or other social and cultural factors. Of 498 articles, six articles were finally selected for this review after applying the inclusion/exclusion criteria (Figure 10).

Data Analysis and Synthesis

Titles and abstracts were screened first, and then full-text papers were screened based on the pre-specified criteria. Six articles met the inclusion criteria. Summaries of the included studies are presented in Table 7. Findings were synthesized into two main domains (palliative care and hospice) because these two terms refer to different types of care. While hospice is applied to patients who need to prepare for a good death, palliative care is for individuals with serious illness and focuses on providing relief from pain and symptoms or relieving stress for patients and their family (Buss, Rock, & McCarthy, 2017).

Quality Assessment

Methodological quality was assessed using the Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012). It was developed in 2006, and the most recent version was launched in 2018 (Hong et al., 2018). The MMAT has been used as an effective and reliable tool to evaluate quantitative, qualitative, and mixed methods designs. The appraisal tool was also used for a systematic review, focusing on older adults and their caregivers (Thordardottir, Malmgren Fange, Lethin, Rodriguez Gatta, & Chiatti, 2019). According to the version 2018 of the MMAT, excluding studies that reported low quality, and presenting the overall scores of qualitative assessments, is discouraged. Thus, all identified studies were included for this review. Also, providing more detailed information about the quality of papers as well as each criterion of the papers will enable researchers to perform a sensitivity analysis (Hong et al., 2018; Thordardottir et al., 2019).

RESULTS

Palliative Care

1. Race and Ethnicity

Race/ethnicity and other cultural components have been addressed in research focused on palliative and hospice care. Ejem, Bauldry, Bakitas, and Drentea (2018) examined the effects of interaction between social exchange and race on care-recipient depression, and the association between caregiver burden and care-recipient depression. No relationship was found between care-recipient's race and the exchange of psychological and physical services such as making the caregiver feel useful or helping with household chores. However, this study found that while

African American care-recipients benefit from the exchange of the social good of ‘helpful company’ for less depressive symptoms, non-African American care-recipients showed increased depressive symptoms, even with social exchange (Ejem et al., 2018). This supports the idea that social exchange is an important factor to improve mental health among African American patients and their families in palliative care settings (Ejem et al., 2018).

The Portuguese, even those of younger generations, continue to practice the cultural tradition of caring for older people in the family and women, especially, assume more caregiving duties as primary caregivers (Fonseca, Gonçalves, & Pereira, 2010). Yet, caregivers have their own lives and often need to work. Palliative care teams need to help caregivers balance daily employment with caregiving roles, and facilitate the distribution of caregiving roles between men and women in the family because women are usually expected to be caregivers and hold multiple roles in the household beyond caregiving (Fonseca et al., 2010). A female family caregiver in Fonseca, Gonçalves, and Pereira’s study expressed feelings of being overwhelmed and vulnerability as well as limited ability to cope with emotional tension, due to the expectations of women having multiple roles (2010).

2. Other Social and Cultural Factors

1) Family Tradition and Structure

In the life-course stage, if caregivers do not have any other dependents such as children, the context of not having to care for anyone else is supportive of the caregivers’ resilience because they can fully devote themselves to support care-recipients without conflicts from multiple other responsibilities (Giesbrecht, Wolse, Crooks, & Stajduhar, 2015). Also, using other external services such as home care nursing services or having support from other family members allows caregivers to have a capacity for resilience (Giesbrecht et al., 2015). Support from other family members affects the process of decision making about care provision (Clemmer, Ward-Griffin, & Forbes, 2008). Some caregivers prioritized that their care-recipient is not alone at home. The pressure of not leaving their care-recipients alone at home does not disappear even if there is another family member present. However, having another person present can still ease their pressure, enabling the caregivers to leave their home (Clemmer et al., 2008).

2) Familiarity with Healthcare System

Socio-Environmental Factors, such as familiarity with the healthcare system, also influence coping strategies. According to a case study with two English-speaking Canadian citizens, who are the majority in their cultural context, Canadian citizenship was linked with having more access to the Canadian healthcare system and having more knowledge of how the system works (Giesbrecht et al., 2015).

3) Employment and Financial Status

If caregivers are flexible with time and are not financially pressured, they can fulfill their caregiving duties. This shows that employment and financial status are also important factors for increased resilience (Giesbrecht et al., 2015). The financial factor may be linked to housing status because secure housing stability can play a supportive part in carrying out caregiving roles with freedom from caregiving stress and responsibilities (Giesbrecht et al., 2015).

4) Social and Political Support and Perceptions toward External Services

In Portugal, public services were very limited because the services were provided during day time, and not during weekends or night time (Fonseca et al., 2010). Due to limited support, caregivers did not have the personal freedom to fulfill all the needs of care-recipients. Even worse, when they utilized external services such as a nursing home, there was a stigma towards them for having their care-recipients institutionalized. This was considered an abandonment of their care-recipient and was considered morally unethical (Fonseca et al., 2010). The negative perceptions directed toward using such services exacerbated caregivers' feeling of vulnerability (Fonseca et al., 2010).

In Canada, caregivers had more positive caregiving experiences when they had a support system. Social support from close friends or visiting nurses, as well as from other family members, helped caregivers experience feelings of fulfillment (Clemmer et al., 2008). With social support, caregivers were able to improve challenging relationships with the care-recipient by understanding one another, sharing feelings, and getting closer (Clemmer et al., 2008).

5) Geography

Being part of the majority group in a certain geographical area (e.g., English-speaking Canadians in Canada) is accompanied by knowledge of the healthcare system (Giesbrecht et al., 2015). Also, depending on the location of residence within a country, accessibility to healthcare is different. Caregivers who lived in large urban areas had more access to formal home care nursing support, community-based hospice services, pharmacies, or nearby grocery stores (Giesbrecht et al., 2015).

6) Gender

When family caregivers were faced with the expectation to assume the caregiver role, their response to the expectation was different depending on gender (Clemmer et al., 2008). Female caregivers tended to autonomously adopt caregiving roles, while male caregivers considered being a caregiver unusual or unfamiliar (Clemmer et al., 2008). In Portugal, women were expected to be a primary caregiver, even when they were employed in full-time (Fonseca et al., 2010). Thus, women had multiple roles as a worker, housekeeper, mother, spouse, and sometimes caregiver for care-recipients (Fonseca et al., 2010). They were most likely to be more burdened due to gender inequality in the distribution of responsibility within a family (Fonseca et al., 2010).

7) Personal Belief System

Clemmer et al. (2008) in their study showed that one of the caregivers expressed the benefits of providing care for her own health. The caregiver was advised to reduce physical care because the intensity of providing physical care to her care-recipient would be burdening. However, the caregiver did not decrease her caregiving duties to provide physical care to her care-recipient. In fact, the act of providing care helped the caregiver take care of her own health and experienced reduced fatigue and emotional benefits. This indicates that caregivers' personal health can, in certain circumstances, be maintained based on their health values and beliefs (Clemmer et al., 2008).

Hospice Care

1. Race and Ethnicity

Japanese and Chinese groups tended to care about how others in their community perceive their caregiving responsibility (Anngela-Cole & Busch, 2011). This social perception affected more than a filial obligation among Japanese and Chinese groups. Contrarily, Native Hawaiians were more likely to follow their traditional custom of the family system (Anngela-Cole & Busch, 2011).

Coping with anticipatory mourning is also different across race. The Native Hawaiians, Japanese, and Chinese caregivers valued the recognition of anticipatory mourning with comfort and traditional food, while The European Americans did not focus on food issues (Anngela-Cole & Busch, 2011). Chinese and Japanese caregivers felt comfortable in expressing their sadness to their spouse, but they were not comfortable in sharing their sadness with anyone else because it could be seen as a weakness (Anngela-Cole & Busch, 2011). Also, the Native Hawaiians expressed that they rely on all types of support, including social and monetary support, spiritual power, religious belief, and respite care (Anngela-Cole & Busch, 2011). As such, race/ethnicity may be related to the use of coping mechanisms.

Caregiving justifications are also different across racial and ethnic groups. In literature, Chinese and Japanese cared about how their community perceives them (Anngela-Cole & Busch, 2011). In this sense, caregivers expressed less emotion in groups. Chinese caregivers tended to provide care due to filial piety and social perception (Anngela-Cole & Busch, 2011). Japanese caregivers were usually the oldest child in the family, and if the caregiving duty was assigned to the son, who is married, the daughter-in-law was usually designated as the caregiver (Anngela-Cole & Busch, 2011). Native Hawaiians provided care because of their traditional customs and they believed that everyone is involved in caregiving (Anngela-Cole & Busch, 2011). For the Hawaiian caregivers, it was natural to provide care if someone is ill or frail as they are taught to care for anyone who is in need from a young age (Anngela-Cole & Busch, 2011). European American caregivers tended to provide care if they are living close to their care-recipients or if they are financially secured to provide care (Anngela-Cole & Busch, 2011).

2. Other Social and Cultural Factors

1) Occupation or Employment and Financial Status

Beside race/ethnicity and its relationship with other cultural components, individual characteristics, such as occupation, affect caregiving patterns among family members. In a qualitative study about grandchildren caregivers taking care of a dying grandparent, one of the grandchildren caregivers said that she was a health care provider. Although another family member was supposed to assume the caregiving role, she was preferred as the primary caregiver by her other family members due to her previous occupation (Boquet, Oliver, Wittenberg-Lyles, Doorenbos, & Demiris, 2011). Caregiving experience can also be more challenging, depending on employment and financial status (Boquet et al., 2011).

2) Family Tradition and Structure

Family tradition and structure also determines caregiving patterns in the family. If caregivers are grandchildren, they may have multiple roles as a grandchild, child, and mother/father, assuming caregiving roles for a grandparent(s), parent(s), spouse, and child (Boquet et al., 2011). To reduce the caregiving burden from multiple roles as a grandchild caregiver, one caregiver utilized a memo system, a guestbook, as her coping strategy to keep other family members updated (Boquet et al., 2011). In addition, a recent divorce and other family situations can make caregiving experiences more difficult in a hospice setting (Boquet et al., 2011). If caregivers did not have support from other family members, were not appreciated by others, and had overwhelming expectations from other family members, caregivers felt guilty for feeling frustrated and obliged to care (Boquet et al., 2011).

3) Geography

The geographic proximity was a critical factor in assuming the primary caregiver's role, especially among European Americans (Anngela-Cole & Busch, 2011). This was a unique factor for determining who provides care (Anngela-Cole & Busch, 2011). The study conducted by Giesbrecht et al. (2005) also mentioned geographical factor as one of the predictors for quality of hospice as well as palliative care. Access to hospice services without much travel enabled family caregivers to promptly receive care (Giesbrecht et al., 2015). Other family members preferred that if one family member lives close to the care-recipient, the individual should assume the primary caregiving roles (Boquet et al., 2011).

DISCUSSION

The findings of this review suggest that race/ethnicity, and other social and cultural factors such as family culture and tradition, financial status, geographical location, environment, and familiarity with healthcare system shape caregiving patterns, determine who is more obligated to provide care as a primary caregiver, and affect decisions about how to cope with caregiving situations in palliative and hospice care. The need for understanding the mechanisms of different caregiving experiences across race and ethnicity, beyond presumed cultural differences, has been emphasized (Haley et al., 1995). In light of the complexity of the influence of cultural factors, using an intersectionality approach presented by Giesbrecht et al. (2015) is one of the optimal approaches. The intersectionality approach examines the joint and simultaneous influences of race/ethnicity and other factors on health and health trajectories across the life course (Read & Gorman, 2006; Warner & Brown, 2011). The importance of intersectionality in research has been growing. This information about-the interrelationships among race/ethnicity and other social and cultural components can better guide culturally tailored interventions for diverse patients and their family caregivers.

Some of the social factors that were found in this review are geographical and financial status. This supports the argument of existing research that urban, adult children were likely to show more frequent support for their adult parents, financially and physically, by frequently meeting and calling adult parents, and providing monetary support, compared to rural, adult children (A. Hu & Chen, 2018). As (Boquet et al., 2011) demonstrated, family tradition and structure, as social and cultural factors, also affected caregiving patterns of grandchildren caregivers who had more duties. Grandchildren caregivers may be more vulnerable in falling to burden and losing resilience to carry out caregiving roles. Urban, adult children who had advantaged socioeconomic status may be related to higher levels of capacity to carry out caregiving duties because they had more time and money that is required for providing care. Thus, grandchildren caregivers may need additional financial support and access to services to save their time and fulfill all duties (Anning Hu, 2017).

Receiving social support from others can help caregivers have positive caregiving experiences (Clemmer et al., 2008). Furthermore, having social connectedness with others was also associated with emotional well-being among older adults (Ermer & Proulx, 2018). It is important to expand the availability of social support for the older adult-family caregiver dyads. One of the findings of this review is that the positive influence of having a helpful company with a caregiver on care-recipients' depressive symptoms was stronger among Black caregivers compared to non-Black caregivers (Ejem et al., 2018). However, Ejem et al. (2018) did not capture the information about racial/ethnic backgrounds among caregivers. Different racial and ethnic backgrounds between care-recipients and caregivers, as well as their immigration status, may create different levels of mixed culture. In this sense, caregiving research requires information about age, social connectedness, social support, and race/ethnicity from both patients and their family.

As Anngela-Cole and Busch (2011) pointed out, some caregivers may feel reluctant to disclose true feelings of weakness. In focus group cases, it is important to create a non-judgmental and accepting atmosphere to make caregivers feel comfortable sharing their true emotions and opinions. All caregivers come from different cultural backgrounds and the community, which may lead to endurable and undeniable expectations and duties towards the caregivers.

The results of this review show that there is a scarcity of studies related to the influences of cultural values from Eastern countries on caregiving experience in the US even though diverse populations including those who came from the Eastern communities reside in the US. Thus, we need to expand our understanding by comparing family caregivers residing in the western part of the world such as USA, Canada, and Portugal, which were discussed in this review, to those in Eastern countries, to identify influential factors of the effects of interventions. Further investigation into possible alternative interventions or treatments, congruent with Eastern culture, is warranted for diverse populations in the US.

The quality of each included article is presented in Table 7. The detailed quality assessment of all included studies is presented in Table 8. The quality score ranges from 60 to 100%. Two studies met 60%, and four studies met 100%. Four out of 6 are qualitative secondary analysis studies (Boquet et al., 2011; Clemmer et al., 2008; Ejem et al., 2018; Giesbrecht et al., 2015). These four studies described fewer than 5 cases. Although these are qualitative studies, the sample sizes are still small. The results of the case studies are less generalizable. However, case studies, which are deep and narrow, are sometimes welcomed because the case studies can still have generalizability, especially for studies about complex systems. Large-N studies can be too broad and shallow, which attempts to provide merely a hypothesis (Steinberg, 2015). For example, the purpose of the study by Giesbrecht et al. (2015) was to identify multiple factors that enhance resilience among family caregivers in palliative care. In this study, using a qualitative case study approach was optimal to profoundly capture complex and multidimensional, lived experiences of resilience among caregivers. In spite of limiting articles published from 2006 for this review, one study used old data collected in 2004 (Ejem et al., 2018). The results of this review show that there were no longitudinal studies identified. This implies that there is a lack of longitudinal studies or other types of studies with a more rigorous method in literature. The longitudinal studies, however, can provide a better understanding of the changes in social connectedness over time, and furthermore, the causal relationships among multiple factors in a mixed cultural context (Ejem et al., 2018).

The search terms that were developed after consultation with a librarian included palliative and hospice care (Table 6). However, a relatively scarce amount of literature about racial/ethnic minority older adults and their family in palliative care and hospice was included in this review (Figure 10). One possible explanation is that the search terms may limit published studies. Researchers may have used a different terminology such as supportive care even though there is no general consensus whether supportive care is the same as palliative care (Hui et al., 2013). Also, some articles may not have used the term, palliative care or hospice, because there is a great deal of stigma around hospice and palliative care. Using the terminology, palliative care, provokes more anxiety compared to supportive care (Hui et al., 2013). Furthermore, some authors considered hospice care to be under palliative care, which could be because palliative care has evolved from the philosophy of care for the dying (Hui et al., 2013). Due to discrepancies in the meanings of terminologies, this review may not include some published studies.

Additionally, the number of racial/ethnic minority older adults who enroll in palliative care and hospice programs may be very limited. This may in part explain why only a few studies were selected in this review. One of the possible reasons why only few minority groups in the US enrolled in palliative care or hospice is that they may not be qualified for Medicare or Medicaid, which covers palliative care and hospice. In 2016 the majority of Medicare hospice patients in the US were Caucasian (86.5%), followed by African American (8.3%), Hispanic

(2.1%), Asian (1.2%), other (1.0%), Native American (0.4%), and unknown (0.4%) in the US (National Hospice and Palliative Care Organization, 2018). Similar findings to those reported by Johnson (2013) asserted that both data about minority hospice enrollees and research on disparities in the use of nonhospice-based palliative care are limited. Research about racial and ethnic disparities, influenced by other social and cultural factors among older adults and their family, is scarce. Johnson (2013) emphasized the importance of continuous effort in having knowledge about different racial and ethnic groups to fill the gap in knowledge about palliative care and hospice among racial and ethnic minorities in order to reduce disparities in rapidly growing diverse populations of older adults and their family caregivers.

Limitations

The use of two or more independent reviewers reduces errors in systematic reviews (Buscemi, Hartling, Vandermeer, Tjosvold, & Klassen, 2006), but this review was conducted by a single reviewer. However, due to a wide range of heterogeneous studies and the complexity of a topic related to cultural influences, conducting a narrative review provided insights about complex interrelations among multiple factors.

Future research

African Americans and Hispanics have stronger cultural reasons for providing care and obligations to their family than Caucasians (Peggye Dilworth-Anderson et al., 2005). This may account for the longer periods of caregiving compared to Caucasian counterparts. The excessively high pressure and long-term stress of caregiving can lead to health problems for primary family caregivers (Katiria Perez & Cruess, 2014; Merritt, McCallum, & Fritsch, 2011).

Hispanics are less likely to use formal services and report emotional support available to them, compared to Caucasians (Scharlach, Giunta, Chow, & Lehning, 2008). Besides African Americans and Hispanics, there has been much literature concentrating upon familism and filial piety, which is a central value of respect for parents or elders among family caregivers in Asian cultures (Ahn, Youn, Phillips, & Lim, 2011; Chang, Schneider, & Sessanna, 2011; Gardner, 2014; Kim & Kim, 2014; Lim et al., 2016). Attitudes toward using paid services are more negative among Japanese Americans. They tend to rely exclusively on family rather than on nursing homes compared to Caucasian Americans who tend to be cared for by paid providers (McCormick et al., 2002). When family members have fewer conflicts (e.g., problems related to role expectations within families) and have more effective communication, caregiving pressure may be lower. Aranda and Knight (1997) addressed that familism decreases caregiver burden because perceived support from family makes family members more resilient. This shows that familism positively functions as a distress-reducing factor with perceived support from family (Knight & Sayegh, 2010). Concurrent with this argument, one study argues that filial piety is a coping resource because it inspires and motivates family caregivers, even dementia family caregivers (Zhang, Clarke, & Rhynas, 2018). On the other hand, familism can negatively impact familial obligation and lead to caregivers' emotional distress (Knight & Sayegh, 2010). Knight and Sayegh (2010) elaborated on the effect of culture on caregiving using the SSCM model. It was found that cultural values, norms, worldviews, and traditions are the reasons why caregivers provide care to their care-recipient and impact how they provide care. These cultural factors can function positively or negatively (Janevic & Connell, 2001; Liu, Insel, Reed, & Crist, 2012). Cultural beliefs and attitudes about life may also cultivate caregivers' coping mechanisms and may improve their resilience (Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015). Stronger intrinsic motives, afforded by cultural justifications for caregiving, are related to greater resilience (Romero-Moreno, Marquez-Gonzalez, Losada, & Lopez, 2011). In this sense, the inclusion of social support, as one of the resilience resources as well as one of the social and cultural factors for culturally sensitive care, should be considered by healthcare scientists when they conduct future research for patients and their family in an African American, Hispanic, or Asian cultural context (Lee & Choi, 2013). Chinese American caregivers cope with their caregiving stress spiritually or value caregiving itself. The relationship between coping through family support or formal external services and culture has not yet been fully understood, but it is necessary to examine this relationship. This cultural impact that is differently presented based on race/ethnicity would be sharable to be considered among healthcare providers and researchers, regardless of the populations or the settings they target.

Once we better understand how patients and family deal with difficult situations with culturally specific coping strategies determined by cultural backgrounds through qualitative research, we can support these coping strategies for ethnic minorities through a culturally sensitive approach (Sun, Ong, & Burnette, 2012). With a deeper cultural understanding of cultural influences on family caregiving, racial and ethnic disparities among family caregivers who are at risk for health problems due to caregiving stress and burden can be leveled. Conceptually, cultural values such as familism would lead to lower burden and higher appraisals as well as different patterns of social support and coping styles, thereby providing an explanation for differing physical and mental health outcomes. Burden and gain in caregiving are not separate. They sometimes coexist as seemingly opposite aspects of caregiving. Implementing and developing culturally sensitive interventions by highlighting their cultural motivations for providing caregiving and helping caregivers perceive caregiving as positively rewarding is important in reducing feelings of caregiving burden and enhancing caregivers' resilience. Future studies can investigate the connection between variations in caregiving and resilience across racial/ethnic groups, which may then guide culturally tailored interventions for culturally diverse family caregivers of older adults.

CONCLUSION

The findings of this systematically conducted narrative review suggest that the mechanisms of racial and ethnic disparities are complex and influenced by multiple social and cultural factors and interconnected relationships with multiple factors. Furthermore, this study highlights family caregivers demonstrate different coping styles and resilience depending on their social and cultural backgrounds in palliative care and hospice. In addition to helping caregivers enhance their resilience and develop coping strategies, we need to consider advanced approaches, including the intersectionality approach to understand the complexities of social and cultural contexts.

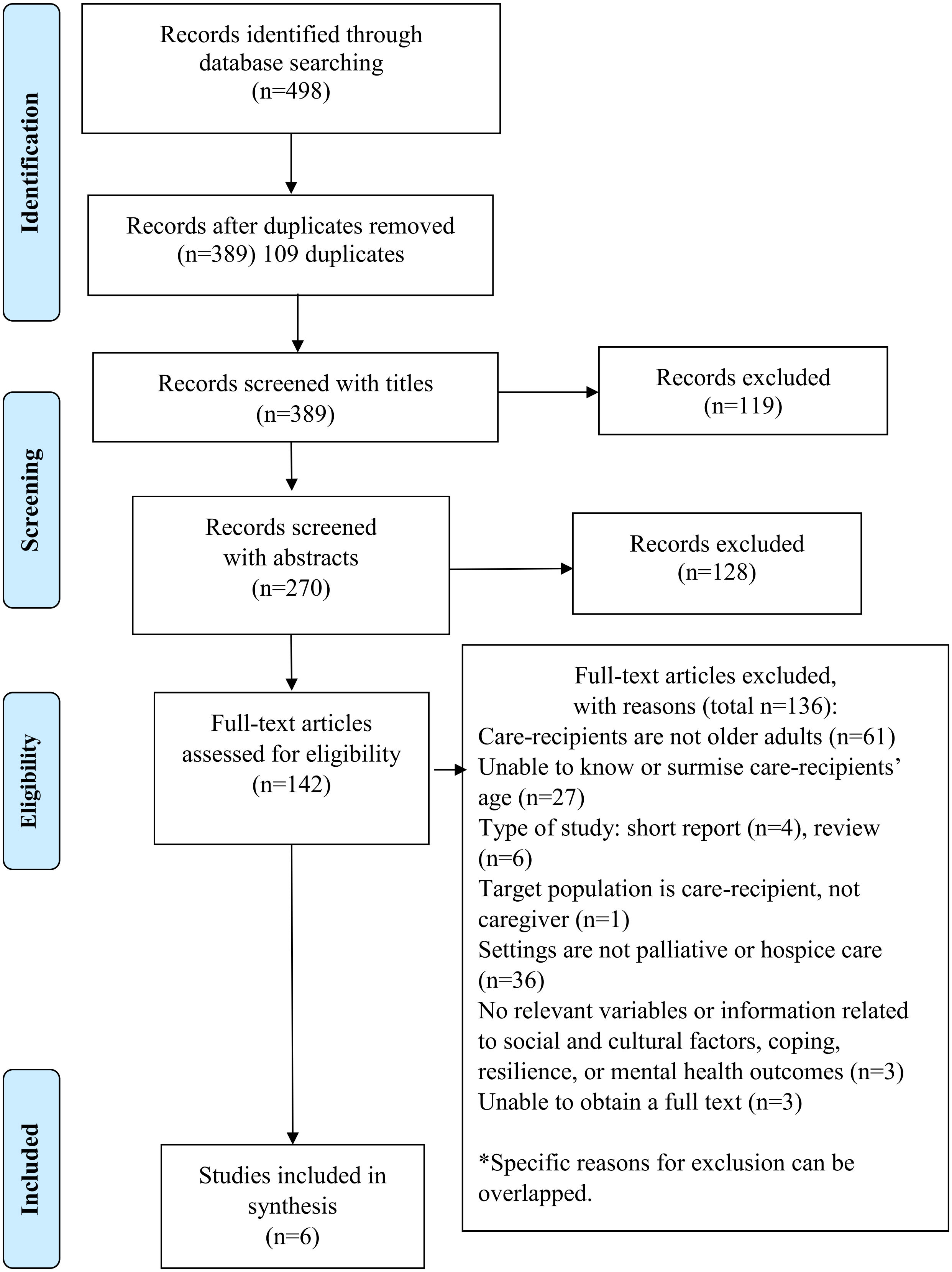


Figure 10. Search and selection process.

Table 6. Search terms

PubMed (MeSH)	**CINAHL Complete (CINAHL Subject Headings)**	**PsycINFO (Thesaurus)**	**EMBASE (Emtree)**
(“family caregivers” OR “family caregiver” OR “informal caregiver” OR “informal caregivers” OR Family[mh] OR Caregivers[mh]) AND	(“family caregivers” OR “family caregiver” OR “informal caregiver” OR “informal caregivers” OR (MH "Family+") OR (MH "Caregivers")) AND	(“family caregivers” OR “family caregiver” OR “informal caregiver” OR “informal caregivers” OR DE "Family" OR DE "Biological Family" OR DE "Extended Family" OR DE "Family of Origin" OR DE "Interethnic Family" OR DE "Interracial Family" OR DE "Military Families" OR DE "Nuclear Family" OR DE "Schizophrenogenic Family" OR DE "Stepfamily" OR DE "Caregivers") AND	(“family caregivers” OR “family caregiver” OR “informal caregiver” OR “informal caregivers” OR 'family'/exp OR 'caregiver'/exp) AND
(cultur* OR diversity OR “social determinants of health” OR race OR racial OR ethnicity OR ethnic OR Cultural Diversity[mh] OR Culture[mh] OR Anthropology, Cultural[mh] OR Social Determinants of Health[mh] OR Race Relations[mh] OR Race Factors[mh] OR Ethnic Groups[mh] OR Minority Groups[mh]) AND	(cultur* OR diversity OR “social determinants of health” OR race OR racial OR ethnicity OR ethnic OR (MH "Cultural Diversity") OR (MH "Culture") OR (MH "Anthropology, Cultural") OR (MH "Cultural Sensitivity") OR (MH "Social Determinants of Health") OR (MH "Race Factors") OR (MH "Race Relations") OR (MH "Ethnic Groups+") OR (MH "Minority Groups"))	(cultur* OR diversity OR “social determinants of health” OR race OR racial OR ethnicity OR ethnic OR DE "Cultural Sensitivity" OR DE "Ethnic Identity" OR DE "Ethnic Values" OR DE "Minority Groups" OR DE "Racial and Ethnic Differences" OR DE "Culture (Anthropological)" OR DE "Racial and Ethnic Groups" OR DE "African Cultural Groups" OR DE "Arabs" OR	(cultur* OR diversity OR “social determinants of health” OR race OR racial OR ethnicity OR ethnic OR 'cultural diversity'/exp OR 'cultural sensitivity'/exp OR 'cultural anthropology'/exp OR 'social determinants of health'/exp OR 'race'/exp OR 'race relation'/de OR 'ethnic or racial aspects'/exp OR 'ethnic group'/exp OR 'minority group'/exp) AND

	AND	DE "Asians" OR DE "Blacks" OR DE "European Cultural Groups" OR DE "Indigenous Populations" OR DE "Latinos/Latinas" OR DE "Romanies" OR DE "Whites" OR DE "Racial and Ethnic Relations" OR DE "Minority Groups") AND	
(end-of-life OR “end of life” OR hospice OR palliative OR Terminal Care[mh] OR Palliative Care[mh] OR Hospice Care[mh]) AND	(end-of-life OR “end of life” OR hospice OR palliative OR (MH “Terminal Care”) OR (MH “Palliative Care”) OR (MH “Hospice Care”)) AND	(end-of-life OR “end of life” OR hospice OR palliative OR DE "Terminally Ill Patients" OR DE "Hospice" OR DE "Palliative Care") AND	(end-of-life OR “end of life” OR hospice OR palliative OR 'terminal care'/de OR 'palliative therapy'/exp OR 'hospice care'/exp) AND
(resilience OR resiliency OR coping OR hardiness OR Resilience, Psychological[mh] OR Adaptation, Psychological[mh])	(resilience OR resiliency OR coping OR hardiness OR (MH “Coping”) OR (MH “Family Coping’) OR (MH “Adaptation, Psychological”) OR (MH “Hardiness”))	(resilience OR resiliency OR coping OR hardiness OR DE "Coping Behavior" OR DE "Resilience (Psychological)" OR DE "Adaptive Behavior" OR DE "Adaptability (Personality)")	(resilience OR resiliency OR coping OR hardiness OR 'coping behavior'/exp OR 'psychological resilience'/exp OR 'family coping'/exp OR 'adaptive behavior'/exp)

Table 7. Characteristics of all identified studies

Author, Year, Country	Purpose of Study	Sample	Design and Methods	Findings	Limitations	Study Quality
Ejem et al. (2018), USA	To examine relationships among caregiver burden, care-recipient depressive symptomology, and race	Physically disabled Medicare recipients aged 65 years or older (total n=1279: non-Black=1167 and Black=112) and their family caregivers	Quantitative descriptive. Cross-sectional study and secondary analysis using the most recent wave (2004) of the National Long Term Care Survey.	Care-recipients' depressive symptoms were associated with objective caregiver burden, not subjective caregiver burden. The interaction between objective burden and more depressive symptoms is more significant among Blacks compared to non-Blacks. Having 'helpful company' has a positive association with depressive symptoms. For Blacks, care-recipients having 'helpful company' with their caregiver was associated with reduced depressive symptoms.	The data were collected over 10 years ago. The data did not have information about caregivers' depressive symptoms and race. Because it is a cross-sectional study, the causality cannot be explained.	60%

Author, Year, Country	Purpose of Study	Sample	Design and Methods	Findings	Limitations	Study Quality
Giesbrecht et al. (2015), Canada	To identify socio-environmental factors that enhance family caregivers' resilience	Two cases were selected. Semi-structured interviews with all three participant groups (homecare nurses, family caregivers, and care-recipients) were conducted (n=2).	Qualitative secondary analysis. Two cases were selected and reviewed using an 'intersectionality lens'.	In the first case, caregiving experience was exacerbated when there was no family support and other family members have different opinions regarding how care should be provided. In the second case, a family caregiver stated that living in an urban area where they can walk to many services is beneficial, and they wanted to take care of the care-recipient with support from other family, not from a social worker. All family members provided care and met the care-recipient's needs, which led to a	As secondary analysis, the purpose of the secondary analysis is different from that of the primary study. The study did not catch all aspects of diversity, which requires further studies to expand the knowledge about socio-environmental influences on caregivers' resilience.	100%

Author, Year, Country	Purpose of Study	Sample	Design and Methods	Findings	Limitations	Study Quality
				peaceful death of the care-recipient and a meaningful moment for family caregivers.		
Anngela-Cole et al. (2011), USA	To compare how family caregivers emotionally respond to their caregiving role based on their ethnocultural backgrounds	Family caregivers of older adults with cancer. 8 focus groups. Each focus group consists of 6 through 8 participants (n=56)	Exploratory study with a qualitative phenomenological approach through focus group interviews. Thematic analysis was guided by three categories (stress, anticipatory mourning, and culture).	Even though strong feelings about stress and sadness are similar across cultural groups, the perceptions and attributions of their feelings as well as coping strategies, varied between ethnocultural groups.	There is a selection bias because only participants who were in support group were recruited. Some caregivers may be reluctant to disclose their feelings. Participants expressed their true feelings more easily when others felt the same way.	100%
Bouquet et al. (2011), USA	To provide insight about the role of grandchildren as caregivers in hospice	Grandchildren as hospice caregivers who care for a grandparent (n=4)	Qualitative secondary analysis. 4 case studies.	Fatigue, stress, guilt, and loss of the “grandchild” identity were identified as several themes of problems or challenges during hospice	Not explicitly stated.	100%

Author, Year, Country	Purpose of Study	Sample	Design and Methods	Findings	Limitations	Study Quality
				caregiving. Grandchildren care for 3 generations and need to simultaneously manage a household, career, family, and caregiving roles in some cases.		
Fonseca et al. (2010), Portugal	To explore some traits of caregiving for older adults in Portugal	45-year-old female caregiver of her 88-year-old father with dementia (n=1)	Single case study. Specific methods not explicitly stated.	Palliative home care teams should consider several traits of caregiving found in a vulnerable condition: emotional tension between caregiving obligation and burden, lack of balance between men and women where women have more duties, limited social service hours, stigma towards using external services, and no	Not explicitly stated.	60%

Author, Year, Country	Purpose of Study	Sample	Design and Methods	Findings	Limitations	Study Quality
				personal social life. By emphasizing the solutions to the challenges, caregivers can feel secured about their caregiving role, which leads to better quality of life among care-recipients and their family caregivers.		
Clemmer et al. (2008), Canada	To explore multiple roles and health experiences of family caregivers of seniors with advanced cancer in a home-based palliative care setting	Family members of seniors with advanced cancer (n=4). Care-recipients' average age was 70, ranging from 67 to 75 years.	Qualitative secondary analysis. Supra analysis of qualitative data (Heaton) was used.	Three interrelated themes about the enactment of multiple roles were balancing, prioritizing, and evolving. Family-centered care should be imbedded in home-based palliative care.	The interpretation of findings might not be flawless because there is a distance between the purpose of the data collection for the original study and that of the current secondary analysis.	100%

Abbreviations: USA, United States of America.

Table 8. Quality assessment of the included studies

Author (Year), Country	Category of study design	Methodological quality criteria	Responses		
			Yes	No	Cannot tell
Ejem et al. (2018), USA	Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?		✓	
		4.2. Is the sample representative of the target population?	✓		
		4.3. Are the measurements appropriate?	✓		
		4.4. Is the risk of nonresponse bias low?			✓
		4.5. Is the statistical analysis appropriate to answer the research question?	✓		
Giesbrecht et al. (2015), Canada	Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	✓		
		1.2. Are the qualitative data collection methods adequate to address the research question?	✓		
		1.3. Are the findings adequately derived from the data?	✓		
		1.4. Is the interpretation of results sufficiently substantiated by data?	✓		
		1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	✓		
Anngela-Cole et al. (2011), USA	Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	✓		
		1.2. Are the qualitative data collection methods adequate to address the research question?	✓		
		1.3. Are the findings adequately derived from the data?	✓		
		1.4. Is the interpretation of results sufficiently substantiated by data?	✓		
		1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	✓		
Bouquet et al. (2011), USA	Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	✓		
		1.2. Are the qualitative data collection methods adequate to address the research question?	✓		
		1.3. Are the findings adequately derived from the data?	✓		
		1.4. Is the interpretation of results sufficiently substantiated by data?	✓		
		1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	✓		

Author (Year), Country	Category of study design	Methodological quality criteria	Responses		
			Yes	No	Cannot tell
Fonseca et al. (2010), Portugal	Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	✓		
		1.2. Are the qualitative data collection methods adequate to address the research question?			✓
		1.3. Are the findings adequately derived from the data?	✓		
		1.4. Is the interpretation of results sufficiently substantiated by data?	✓		
		1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?			✓
Clemmer et al. (2008), Canada	Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	✓		
		1.2. Are the qualitative data collection methods adequate to address the research question?	✓		
		1.3. Are the findings adequately derived from the data?	✓		
		1.4. Is the interpretation of results sufficiently substantiated by data?	✓		
		1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	✓		

References

Adames, H. Y., Chavez-Duenas, N. Y., Fuentes, M. A., Salas, S. P., & Perez-Chavez, J. G. (2014). Integration of Latino/a cultural values into palliative health care: a culture centered model. *Palliat Support Care, 12*(2), 149-157. doi:10.1017/s147895151300028x

Ahn, Y. H., Youn, G., Phillips, L., & Lim, Y. M. (2011). Translation and validation of the Korean version of family scale. *Journal of Nursing Measurement, 19*(3), 179-195. doi:10.1891/1061-3749.19.3.179

Anngela-Cole, L., & Busch, M. (2011). Stress and grief among family caregivers of older adults with cancer: A multicultural comparison from Hawai'i. *Journal of Social Work in End-of-Life and Palliative Care, 7*(4), 318-337. doi:10.1080/15524256.2011.623460

Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist, 37*(3), 342-354. doi:10.1093/geront/37.3.342

Boquet, J. R., Oliver, D. P., Wittenberg-Lyles, E., Doorenbos, A. Z., & Demiris, G. (2011). Taking care of a dying grandparent: Case studies of grandchildren in the hospice caregiver role. *American Journal of Hospice & Palliative Medicine, 28*(8), 564-568. doi:10.1177/1049909111405644

Bowling, A., Rowe, G., Adams, S., Sands, P., Samsi, K., Crane, M., . . . Manthorpe, J. (2015). Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging Ment Health, 19*(1), 13-31. doi:10.1080/13607863.2014.915923

Buscemi, N., Hartling, L., Vandermeer, B., Tjosvold, L., & Klassen, T. P. (2006). Single data extraction generated more errors than double data extraction in systematic reviews. *J Clin Epidemiol, 59*(7), 697-703. doi:10.1016/j.jclinepi.2005.11.010

Buss, M. K., Rock, L. K., & McCarthy, E. P. (2017). Understanding Palliative Care and Hospice: A review for primary care providers. *Mayo Clin Proc, 92*(2), 280-286. doi:10.1016/j.mayocp.2016.11.007

Chang, Y.-P., Schneider, J. K., & Sessanna, L. (2011). Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *Journal of Aging Studies, 25*(4), 436-444. doi:10.1016/j.jaging.2011.05.001

Cherry, K. E., Walker, E. J., Brown, J. S., Volaufova, J., LaMotte, L. R., Welsh, D. A., . . . Frisard, M. I. (2013). Social engagement and health in younger, older, and oldest-old adults in the Louisiana Healthy Aging Study. *J Appl Gerontol, 32*(1), 51-75. doi:10.1177/0733464811409034

Clemmer, S. J., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: the enactment of multiple roles. *Can J Aging, 27*(3), 267-283.

Cohen, H. L., & Lee, Y. (2007). Dementia caregivers: Rewards in multicultural perspectives. *Journal of Human Behavior in the Social Environment, 14*(1), 299-324.

Conway, F., Jones, S., & Speakes-Lewis, A. (2011). Emotional strain in caregiving among African American grandmothers raising their grandchildren. *J Women Aging, 23*(2), 113-128. doi:10.1080/08952841.2011.561142

Davies, E., Higginson, I. J., & World Health Organization. (2004). Better palliative care for older people. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0009/98235/E82933.pdf

Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *The Journals of Gerontology: Series B, 60*(5), S257-S262. doi:10.1093/geronb/60.5.S257

Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Dis Assoc Disord, 16 Suppl 2*, S56-63. doi:10.1097/01.WAD.0000025541.17499.04

Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., McMillan, S. C., . . . Casarett, D. J. (2015). Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *J Pain Symptom Manage, 49*(4), 773-781. doi:10.1016/j.jpainsymman.2015.01.012

Ejem, D., Bauldry, S., Bakitas, M., & Drentea, P. (2018). Caregiver burden, care recipient depressive symptomology, and social exchange: Does race matter? *Journal of palliative care, 33*(2), 100-108. doi:10.1177/0825859718758120

Epstein-Lubow, G., Davis, J. D., Miller, I. W., & Tremont, G. (2008). Persisting burden predicts depressive symptoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology, 21*(3), 198-203. doi:10.1177/0891988708320972

Ermer, A. E., & Proulx, C. M. (2018). Associations between social connectedness, emotional well-being, and self-rated health among older adults: Difference by relationship status. *Res Aging*, 164027518815260. doi:10.1177/0164027518815260

Feinberg, L. F. (2014). Recognizing and supporting family caregivers: The time has come. *Public Policy & Aging Report, 24*(2), 65-69. doi:10.1093/ppar/pru007

Fonseca, A. M., Gonçalves, D. C., & Pereira, S. M. (2010). Working family carers in Portugal: Between the duty and the burden of caring for old vulnerable people. *International Journal of Palliative Nursing, 16*(10), 476-480.

Gardner, D. K. (2014). *Confucianism: a very short introduction*. New York: Oxford University Press.

Giesbrecht, M., Wolse, F., Crooks, V. A., & Stajduhar, K. (2015). Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: a qualitative case study. *Palliative & Supportive Care, 13*(3), 555-565.

Haley, W. E., West, C. A., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., . . . Roth, D. L. (1995). Psychological, social, and health impact of caregiving: a comparison of black and white dementia family caregivers and noncaregivers. *Psychol Aging, 10*(4), 540-552. doi:10.1037/0882-7974.10.4.540

Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., . . . Vedel, I. (2018). Mixed methods appraisal tool (MMAT), version 2018. Registration of Copyright (#1148552). Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf

Hu, A. (2017). Providing more but receiving less: Daughters in intergenerational exchange in mainland China. *Journal of Marriage and Family, 79*(3), 739-757. doi:10.1111/jomf.12391

Hu, A., & Chen, F. (2018). Which child is parents' preferred caregiver/listener in China? *Res Aging*, 164027518813654. doi:10.1177/0164027518813654

Hui, D., De La Cruz, M., Mori, M., Parson, H. A., Kwon, J. H., Torres-Vigil, I., . . . Bruera, E. (2013). Concepts and definitions for "supportive care," best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Support Care Cancer, 21*(3), 659-685. doi:10.1007/s00520-012-1564-y

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *Gerontologist, 41*(3), 334-347.

Johnson, K. S. (2013). Racial and ethnic disparities in palliative care. *J Palliat Med, 16*(11), 1329-1334. doi:10.1089/jpm.2013.9468

Katiria Perez, G., & Cruess, D. (2014). The impact of familism on physical and mental health among Hispanics in the United States. *Health Psychol Rev, 8*(1), 95-127. doi:10.1080/17437199.2011.569936

Kim, J.-K., & Kim, Y.-o. (2014). *Great equal society : Confucianism, China and the 21st century*. New Jersey: World Scientific Publishing.

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: the updated sociocultural stress and coping model. *J Gerontol B Psychol Sci Soc Sci, 65B*(1), 5-13. doi:10.1093/geronb/gbp096

Kosberg, J. I., Kaufman, A. V., Burgio, L. D., Leeper, J. D., & Sun, F. (2007). Family caregiving to those with dementia in rural Alabama: racial similarities and differences. *J Aging Health, 19*(1), 3-21. doi:10.1177/0898264306293604

Lee, Y., & Choi, S. (2013). Korean American dementia caregivers' attitudes toward caregiving: the role of social network versus satisfaction with social support. *J Appl Gerontol, 32*(4), 422-442. doi:10.1177/0733464811431163

Leininger, M., & McFarland, M. R. (2002). *Transcultural nursing: Concepts, theories, research, and practice*. New York: McGraw-Hill.

Lim, Y. M., Ahn, Y. H., & Ahn, J. Y. (2016). Multidimensional caregiving burden of female family caregivers in Korea. *Clinical Nursing Research, 25*(6), 665-682. doi:10.1177/1054773815591472

Liu, Y., Insel, K. C., Reed, P. G., & Crist, J. D. (2012). Family caregiving of older Chinese people with dementia: testing a model. *Nurs Res, 61*(1), 39-50. doi:10.1097/NNR.0b013e31823bc451

McCormick, W. C., Ohata, C. Y., Uomoto, J., Young, H. M., Graves, A. B., Kukull, W., . . . Larson, E. B. (2002). Similarities and differences in attitudes toward long-term care between Japanese Americans and Caucasian Americans. *Journal of the American Geriatrics Society, 50*(6), 1149-1155. doi:DOI 10.1046/j.1532-5415.2002.50275.x

Merritt, M. M., McCallum, T. J., & Fritsch, T. (2011). How much striving is too much? John Henryism active coping predicts worse daily cortisol responses for African American but not white female dementia family caregivers. *Am J Geriatr Psychiatry, 19*(5), 451-460. doi:10.1097/JGP.0b013e3181eaffa4

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, P. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med, 6*(7), e1000097. doi:10.1371/journal.pmed.1000097

National Hospice and Palliative Care Organization. (2018). NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization. Retrieved from https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf

Ornstein, K. A., Schulz, R., & Meier, D. E. (2017). Families caring for an aging America need palliative care. *Journal of the American Geriatrics Society, 65*(4), 877-878. doi:10.1111/jgs.14785

Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot mixed methods appraisal tool (MMAT) for systematic mixed studies review. *Int J Nurs Stud, 49*(1), 47-53. doi:10.1016/j.ijnurstu.2011.07.002

Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing, 58*(5), 446-457. doi:10.1111/j.1365-2648.2007.04250.x

Parveen, S., & Morrison, V. (2009). Predictors of familism in the caregiver role: A pilot study. *Journal of Health Psychology, 14*(8), 1135-1143.

Patrick, D. L., Lee, R. S., Nucci, M., Grembowski, D., Jolles, C. Z., & Milgrom, P. (2006). Reducing oral health disparities: A focus on social and cultural determinants. *BMC Oral Health, 6 Suppl 1,* S4. doi:10.1186/1472-6831-6-S1-S4

Read, J. G., & Gorman, B. K. (2006). Gender inequalities in US adult health: the interplay of race and ethnicity. *Soc Sci Med, 62*(5), 1045-1065. doi:10.1016/j.socscimed.2005.07.009

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: Health of caregivers of Alzheimer's and other dementia patients. *Current Psychiatry Reports, 15*(7), 367. doi:10.1007/s11920-013-0367-2

Richardson, V. E., Fields, N., Won, S., Bradley, E., Gibson, A., Rivera, G., & Holmes, S. D. (2017). At the intersection of culture: Ethnically diverse dementia caregivers' service use. *Dementia (London)*, 1471301217721304. doi:10.1177/1471301217721304

Romero-Moreno, R., Marquez-Gonzalez, M., Losada, A., & Lopez, J. (2011). Motives for caring: relationship to stress and coping dimensions. *Int Psychogeriatr, 23*(4), 573-582. doi:10.1017/S1041610210001821

Roth, D. L., Dilworth-Anderson, P., Huang, J., Gross, A. L., & Gitlin, L. N. (2015). Positive aspects of family caregiving for dementia: Differential item functioning by race. *J Gerontol B Psychol Sci Soc Sci, 70*(6), 813-819. doi:10.1093/geronb/gbv034

Scharlach, A. E., Giunta, N., Chow, J. C., & Lehning, A. (2008). Racial and ethnic variations in caregiver service use. *J Aging Health, 20*(3), 326-346. doi:10.1177/0898264308315426

Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. *J Gerontol Soc Work, 47*(1-2), 133-156. doi:10.1300/J083v47n01_09

Seow, H., Bainbridge, D., Bryant, D., Guthrie, D., Urowitz, S., Zwicker, V., & Marshall, D. (2016). The caregivervoice survey: A pilot study surveying bereaved caregivers to measure the caregiver and patient experience at end of life. *J Palliat Med, 19*(7), 712-719. doi:10.1089/jpm.2015.0366

Smith, J. M., & Estefan, A. (2014). Families parenting adolescents with substance abuse--recovering the mother's voice: a narrative literature review. *J Fam Nurs, 20*(4), 415-441. doi:10.1177/1074840714554397

Spangler, N. W., Koesten, J., Fox, M. H., & Radel, J. (2012). Employer perceptions of stress and resilience intervention. *J Occup Environ Med, 54*(11), 1421-1429. doi:10.1097/JOM.0b013e3182619038

Steadman, P. L., Tremont, G., & Davis, J. D. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *J Geriatr Psychiatry Neurol, 20*(2), 115-119. doi:10.1177/0891988706298624

Steinberg, P. F. (2015). Can we generalize from case studies? *Global Environmental Politics, 15*(3), 152-175. doi:10.1162/GLEP_a_00316

Sun, F., Ong, R., & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: a review of empirical studies on Chinese Americans. *Am J Alzheimers Dis Other Demen, 27*(1), 13-22. doi:10.1177/1533317512438224

Thompson, G. N., & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. *Palliat Support Care, 12*(3), 223-231. doi:10.1017/S1478951513000461

Thordardottir, B., Malmgren Fange, A., Lethin, C., Rodriguez Gatta, D., & Chiatti, C. (2019). Acceptance and use of innovative assistive technologies among people with cognitive impairment and their caregivers: A systematic review. *Biomed Res Int, 2019*, 9196729. doi:10.1155/2019/9196729

van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., . . . European Association for Palliative, C. (2014). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine, 28*(3), 197-209. doi:10.1177/0269216313493685

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*(1), 1-18. doi:10.1111/j.1545-5300.2003.00001.x

Warner, D. F., & Brown, T. H. (2011). Understanding how race/ethnicity and gender define age-trajectories of disability: an intersectionality approach. *Soc Sci Med, 72*(8), 1236-1248. doi:10.1016/j.socscimed.2011.02.034

Windle, G., & Bennett, K. M. (2011). *Resilience and caring relationships*. New York, NY: Springer.

World Health Organization. (2011). Palliative care for older people: Better practices 2011, Copenhagen, Denmark:World Health Organization, Regional Office for Europe. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf

Zhang, X., Clarke, C. L., & Rhynas, S. J. (2018). What is the meaning of filial piety for people with dementia and their family caregivers in China under the current social transitions? An interpretative phenomenological analysis. *Dementia (London)*, 1471301217753775. doi:10.1177/1471301217753775

CHAPTER 5

CONCLUSION

Findings and Discussions of Chapters 2-4

Through my two secondary analysis studies and one review study from Chapters 2-4 of my dissertation, I have found that culture affects caregivers' experience across the care-recipients' lifespan.

First, my secondary analysis study, using quantitative baseline data from a randomized clinical trial, examined the interaction effects between race/ethnicity and psychosocial factors on anxiety among family caregivers of pediatric patients in the ICU. The original study was a randomized clinical trial and it examined if there were significant differences between caregivers who received palliative care interventions and caregivers who did not, regarding the effects of palliative care interventions on mental health outcomes such as anxiety, depression, and post-traumatic stress disorder [Grant Number. R01NR011179; Program PI: Ross Hays and Co PI: Helene Starks]. This data included potentially relevant social and cultural factors such as family functioning, perceived social support, and trust in providers. Thus, the data fit one of my hypotheses that there are interaction effects between race/ethnicity and psychosocial factors such as family functioning, perceived social support, and trust in providers in the context of palliative care. The findings of this study show that the means of age, language, highest education, household income, family functioning, and perceived social support were different based on race and ethnicity. The existence of the interaction effects between race/ethnicity and psychosocial factors such as perceived social support and trust in provider was found to be possible. However, as secondary analysis has its limitation, these findings were discovered from the data of only family members of pediatric patients in the ICU. It is necessary to conduct studies aimed at examining the interaction effects between race/ethnicity and other factors with larger sample sizes among family caregivers of older adults in order to advance health science for the aging society. In addition, while race and ethnicity are not modifiable, psychosocial factors can be modified. The interventions targeting these modifiable variables may help decrease anxiety in ethnic minority family caregivers. This exploration of interactions with modifiable factors proposes directions for future research by understanding interacted relationships with race and ethnicity and raises awareness of the importance of cultural sensitivity. In order to increase statistical power, future studies with a larger sample or with only specific minority groups can consider controlling for potential confounding factors such as education and income and dividing Asians and NHOPI into two separate groups because NHOPI report lower education and income and worse health outcomes compared to Asians do.

Second, in my qualitative secondary analysis, challenges, resilience resources, and consequences were identified at multiple levels, including individual, community, and societal levels among family caregivers of hospice patients with dementia. The original study provided the problem-solving intervention to help caregivers to improve their problem-solving skills in hospice settings [Grant Number: NIH/NINR, R01NR012213, PI: Demiris]. The data was useful in exploring resources that improve resilience in the context of hospice. Study participants addressed factors, some being social and cultural factors, that increase or decrease their resilience at multiple levels. For example, seven out of 39 family caregivers expressed their concerns about selecting a good facility for their care-recipient. As dementia comes with biobehavioral and psychological symptoms (e.g., agitation, aberrant motor behavior, anxiety, depression, delusions, hallucinations, and sleep or appetite changes) as well as cognitive symptoms irrespective of its subtype of dementia, it is very important to choose the best or most suitable facility for hospice dementia patients among family caregivers. Caregivers stated that their dementia patients need to enjoy familiar music, foods, or other activities in the facility and not face cultural and language barriers with facility staff. Thus, the findings of this secondary analysis are informative in discovering some social and cultural resources that improve resilience from the perspectives of family caregivers in hospice. This secondary analysis has a limitation that only one care-recipient was not America-born, which may limit rich findings of cultural components among family caregivers. Future studies can consider recruiting more diverse populations, which can be more representative of racially diverse populations. To recruit racially minority groups, purposeful sampling selecting participants based on specific characteristics may be helpful. Furthermore, longitudinal qualitative study is a good approach to obtain different perspectives on processes, which can capture acculturation. Depending on the immigrant generations of caregivers, their needs and approaches to caregiving may differ. Whether caregivers' experience differ based on the timing of immigration can be determined using longitudinal studies.

Third, social and cultural factors, as well as race and ethnicity in palliative care and hospice settings, were identified in a review study. Family tradition and structure, familiarity with healthcare system, employment and financial status, social and political support, social norms about the use of external services, geographical factor, gender, and personal belief system affect family caregivers' experience and caregiving patterns. Based on the findings of this review, the interrelationships between race/ethnicity and other social and cultural factors should be considered in designing and improving culturally sensitive care. As recent research has emphasized, future studies need to adapt the intersectionality approach to examine the joint and simultaneous influences of race/ethnicity and other factors on health and health trajectories to obtain a better understanding of racial and ethnic differences among family caregivers.

Directions for Future Research

In this globalized and aging American society, culturally sensitive care for family caregivers of older adults has been emphasized, both empirically and theoretically because family caregivers of older adults experience high levels of caregiving stress and strain (Feinberg, 2014; Janevic & Connell, 2001; V. E. Richardson et al., 2017). As a result of caregiving stress and burden, family caregivers are at risk for physical and mental health problems (Epstein-Lubow, Davis, Miller, & Tremont, 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; T. J. Richardson, Lee, Berg-Weger, & Grossberg, 2013).

Cultural values play a main role in shaping caregiving experience and coping mechanisms in caregiving situations (van der Steen et al., 2014; World Health Organization, 2011). The influences on coping resources for caregivers such as receptiveness to formal care services (e.g., home care, health care facility) differ based on cultural values (Aranda & Knight, 1997; Knight & Sayegh, 2010). For example, some caregivers hold different attitudes about caring due to the influence of filial piety or filial obligation, resulting in a reluctance to utilize formal support services (Scharlach et al., 2006). When family caregivers have less pressure from caregiving obligation, they may be more likely to seek and utilize external supportive services, which leads to decreased caregiving burden and improved resilience. To be specific, Hispanics have strong familism as their core cultural value (Katiria Perez & Cruess, 2014). This results in stronger cultural reasons for providing care, and Hispanics are obligated to provide caregiving to their family than whites, which may account for the longer periods of caregiving (Dilworth-Anderson et al., 2005). This excessively high pressure and long-term stress of caregiving can lead to health problems for primary family caregivers (Katiria Perez & Cruess, 2014; Merritt, McCallum, & Fritsch, 2011).

Caregivers’ responsibilities, expectations, roles, and obligations are built and shaped by different cultural components interacted with racial/ethnic backgrounds (Cherry et al., 2013). This demonstrates that both cultural justifications for providing care and family functioning may interact with race/ethnicity, and thereby explain differing resilience among family caregivers. Resilience refers to “a dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar, Cicchetti, & Becker, 2000). Caregivers experiencing challenges should be supported by promoting their positive adaptation to cope with. Exploring caregivers’ modifiable social and cultural factors to enhance their adaptation can be a significant footstep in improving caregivers’ resilience.

In spite of the importance of the influence of cultural factors interacted with race/ethnicity for caregivers’ resilience, there is still a lack of acknowledgment of the impacts of cultural factors or cultural justifications for caregiving on the patterns of coping styles and resilience. The objective of this study is to explore the influences of social and cultural factors on family caregiving and family caregivers’ resilience within an ethnocultural context. Future studies can consider examining the effects of predictors such as race/ethnicity, family functioning, perceived social support, trust in providers, and cultural justifications for caregiving on resilience and the interactions between these factors with a more rigorous study design such as a mixed methods approach. Mixed methods studies will fill the gap in literature about comparisons with other racial/ethnic groups because the study will purposely select the participants from each racial/ethnic group to further understand their experience. In light of the complexity of culture, a further qualitative approach would support the evidence from the quantitative data. By doing so, the results of this study will contribute to the development of culturally adapted interventions. Healthcare providers can provide better assistance for family caregivers with cultural understanding about their coping strategies (i.e., different help-seeking patterns influenced by cultural factors interacted with race and ethnicity), which can improve caregivers' physical and mental health outcomes. This can eventually lead to a better quality of caregiving and improved health outcomes among care-recipients.

References

Aranda, M. P., & Knight, B. G. (1997). The Influence of Ethnicity and Culture on the Caregiver Stress and Coping Process: A Sociocultural Review and Analysis. *The Gerontologist, 37*(3), 342-354. doi:10.1093/geront/37.3.342

Cherry, M. G., Salmon, P., Dickson, J. M., Powell, D., Sikdar, S., & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology, 23*(04), 251-266. doi:10.1017/s0959259813000130

Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of Race on Cultural Justifications for Caregiving. *The Journals of Gerontology: Series B, 60*(5), S257-S262. doi:10.1093/geronb/60.5.S257

Epstein-Lubow, G., Davis, J. D., Miller, I. W., & Tremont, G. (2008). Persisting burden predicts depressive symptoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology, 21*(3), 198-203. doi:10.1177/0891988708320972

Feinberg, L. F. (2014). Recognizing and Supporting Family Caregivers: The Time Has Come. *Public Policy & Aging Report, 24*(2), 65-69. doi:10.1093/ppar/pru007

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *Gerontologist, 41*(3), 334-347.

Katiria Perez, G., & Cruess, D. (2014). The impact of familism on physical and mental health among Hispanics in the United States. *Health Psychol Rev, 8*(1), 95-127. doi:10.1080/17437199.2011.569936

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: the updated sociocultural stress and coping model. *J Gerontol B Psychol Sci Soc Sci, 65B*(1), 5-13. doi:10.1093/geronb/gbp096

Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work. *Child Development, 71*(3), 543-562. doi:10.1111/1467-8624.00164

Merritt, M. M., McCallum, T. J., & Fritsch, T. (2011). How much striving is too much? John Henryism active coping predicts worse daily cortisol responses for African American but not white female dementia family caregivers. *Am J Geriatr Psychiatry, 19*(5), 451-460. doi:10.1097/JGP.0b013e3181eaffa4

Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing, 58*(5), 446-457. doi:10.1111/j.1365-2648.2007.04250.x

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: Health of caregivers of Alzheimer's and other dementia patients. *Current Psychiatry Reports, 15*(7), 367. doi:10.1007/s11920-013-0367-2

Richardson, V. E., Fields, N., Won, S., Bradley, E., Gibson, A., Rivera, G., & Holmes, S. D. (2017). At the intersection of culture: Ethnically diverse dementia caregivers' service use. *Dementia (London)*, 1471301217721304. doi:10.1177/1471301217721304

Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. *J Gerontol Soc Work, 47*(1-2), 133-156. doi:10.1300/J083v47n01_09

van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., . . . European Association for Palliative, C. (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the

European Association for Palliative Care. *Palliat Med, 28*(3), 197-209. doi:10.1177/0269216313493685

World Health Organization. (2011). Palliative Care for Older People: Better Practices 2011, Copenhagen, Denmark:World Health Organization, Regional Office for Europe. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf

APPENDICES

Appendix A. Generalized Estimating Equations on Interaction Effects between Race/Ethnicity and Family Functioning on Anxiety

Parameter	Estimate	SE	Wald x^2	*p*
(Intercept)	0.6970	1.0780	0.42	0.518
Hispanic	2.2324	2.7845	0.64	0.423
Non-Hispanic AA	6.0533	3.7021	2.67	0.102
Non-Hispanic Asian NHOPI	-2.1536	2.1207	1.03	0.310
Non-Hispanic NA or AN	7.0010	4.0797	2.94	0.086
FRI	0.0357	0.1029	0.12	0.729
PHQ-9	0.8290	0.0264	983.60	<0.001***
Hispanic X FRI	-0.2214	0.3072	0.52	0.471
Non-Hispanic AA X FRI	-0.6427	0.4131	2.42	0.120
Non-Hispanic Asian NHOPI X FRI	0.1343	0.2170	0.38	0.536
Non-Hispanic NA or AN X FRI	-07406	0.3925	3.56	0.059

Bold indicates variable is statistically significant as follows: *** $p<0.001$,** $p<0.01$, * $p<0.05$.

Degrees of freedom: 298 total; 287 residual.

Number of clusters: 187.

Maximum cluster size: 3.

Reference group: Non-Hispanic white.

Dependent variable: GAD-7.

Confounding variable: PHQ-9.

Abbreviations: GEE, Generalized Estimating Equations; SE, Standard Error; FRI, Family Relationship Index; AA, African American; NA or AN, Native American or Alaskan Native; NHOPI, Native Hawaiian or Other Pacific Islander; GAD-7, General Anxiety Disorder; PHQ-9, Patient Health Questionnaire.

Appendix B. Generalized Estimating Equations on Interaction Effects between Race/Ethnicity and Perceived Social Support on Anxiety

Parameter	Estimate	SE	Wald x^2	*p*
(Intercept)	-0.7725	1.3242	0.34	0.560
Hispanic	1.9255	2.6143	0.54	0.461
Non-Hispanic AA	0.1306	2.6020	0.00	0.960
Non-Hispanic Asian NHOPI	-11.0370	4.4364	6.19	0.013*
Non-Hispanic NA or AN	15.5032	3.6165	18.38	<0.001***
MSPSS	0.2959	0.2067	2.05	0.152
PHQ-9	0.8233	0.0241	1171.06	<0.001***
Hispanic X MSPSS	-0.2239	0.4500	0.25	0.619
Non-Hispanic AA X MSPSS	-0.0102	0.4618	0.00	0.982
Non-Hispanic Asian NHOPI X MSPSS	1.7172	0.7719	4.95	0.026*
Non-Hispanic NA or AN X MSPSS	-2.5841	0.6098	17.96	<0.001***

Bold indicates variable is statistically significant as follows: *** $p<0.001$,** $p<0.01$, * $p<0.05$.

Degrees of freedom: 324 total; 313 residual.

Number of clusters: 197.

Maximum cluster size: 3.

Reference group: Non-Hispanic white.

Dependent variable: GAD-7.

Confounding variable: PHQ-9.

Abbreviations: GEE, Generalized Estimating Equations; SE, Standard Error; MSPSS, Multidimensional Scale of Perceived Social Support; AA, African American; NA or AN, Native American or Alaskan Native; NHOPI, Native Hawaiian or Other Pacific Islander; GAD-7, General Anxiety Disorder; PHQ-9, Patient Health Questionnaire.

Appendix C. Generalized Estimating Equations on Interaction Effects between Race/Ethnicity and Trust in Provider on Anxiety

Parameter	Estimate	SE	Wald x^2	*p*
(Intercept)	1.6313	1.5964	1.04	0.307
Hispanic	-4.5396	4.7221	0.92	0.336
Non-Hispanic AA	-2.4280	2.3508	1.07	0.302
Non-Hispanic Asian NHOPI	-19.7223	5.6523	12.18	<0.001***
Non-Hispanic NA or AN	-3.8801	4.3650	0.79	0.374
WFTS	-0.0162	0.0488	0.11	0.740
PHQ-9	0.8222	0.0244	1139.81	<0.001***
Hispanic X WFTS	0.1585	0.1547	1.05	0.306
Non-Hispanic AA X WFTS	0.0745	0.0813	0.84	0.359
Non-Hispanic Asian NHOPI X WFTS	0.6088	0.1859	10.73	<0.01**
Non-Hispanic NA or AN X WFTS	0.1249	0.1419	0.77	0.379

Bold indicates variable is statistically significant as follows: *** $p<0.001$,** $p<0.01$, * $p<0.05$.

Degrees of freedom: 320 total; 309 residual.

Number of clusters: 195.

Maximum cluster size: 3.

Reference group: Non-Hispanic white.

Dependent variable: GAD-7.

Confounding variable: PHQ-9.

Abbreviations: GEE, Generalized Estimating Equations; SE, Standard Error; WFTS, Wake Forest Trust Scale; AA, African American; NA or AN, Native American or Alaskan Native; NHOPI, Native Hawaiian or Other Pacific Islander; GAD-7, General Anxiety Disorder; PHQ-9, Patient Health Questionnaire.

Appendix D. Codes for Models in R

1. Creating 5 racial and ethnic groups

```
dataset$5group[dataset$hispanic=="1"] <-4
dataset$5group[dataset$race=="1"& dataset$hispanic=="0"] <-0
dataset$5group[dataset$race=="2"& dataset$hispanic=="0"] <-1
dataset$5group[dataset$race=="3"& dataset$hispanic=="0"] <-2
dataset$5group[dataset$race=="4"&dataset$hispanic=="0"] <-3
dataset$5group[dataset$race=="5"&dataset$hispanic=="0"] <-3
dataset$5group[is.na(dataset$groupnumber)] <-5
```

Note: 5group is 5 racial and ethnic groups. Race is race: 1 (Non-Hispanic European American or White), 2 (Non-Hispanic African American or Black), 3 (Non-Hispanic Native American or Alaska Native), 4 (Non-Hispanic Asian and Native Hawaiian or Pacific Islander), and 5 (Hispanics)

2. Transcribe integers to race/ethnicity names

```
newdata$raceethnicity[newdata$5group=="0"] <-'Non-Hispanic white'
newdata$raceethnicity[newdata$5group=="1"] <-'Non-Hispanic AA'
newdata$raceethnicity[newdata$5group=="2"] <-'Non-Hispanic NA or AN'
newdata$raceethnicity[newdata$5group=="3"] <-'Non-Hispanic Asian and NHOPI'
newdata$raceethnicity[newdata$5group=="4"] <-'Hispanic'
newdata$raceethnicity <-relevel(as.factor(newdata$raceethnicity), ref="Non-Hispanic white")
```

3. Creating a subset using complete case analysis

```
baseline.fri <- baseline[,c("gad7score", "fri","raceethnicity","fam","phq9score")]
baseline.fri <- baseline.fri[complete.cases(baseline.fri),]
```

Note: gad7score is GAD-7 score (anxiety level). fri is Family Relationship Index. raceethnicity is 5 racial and ethnic groups. fam is family number (cluster number). phq9score is PHQ-9 score (depression level).

4. Using a GEE model and comparing two GEE models using Wald tests

```
library(geepack)

gee.model.gad <- geeglm(gad7score~raceethnicity*fri+phq9score, data=baseline.fri, id=fam, corstr="exchangeable")
gee.model.nointeraction.gad <- geeglm(gad7score~fri+raceethnicity+phq9score, data=baseline.fri, id=fam, corstr="exchangeable")
anova(gee.model.nointeraction.gad, gee.model.gad) #0.130
```

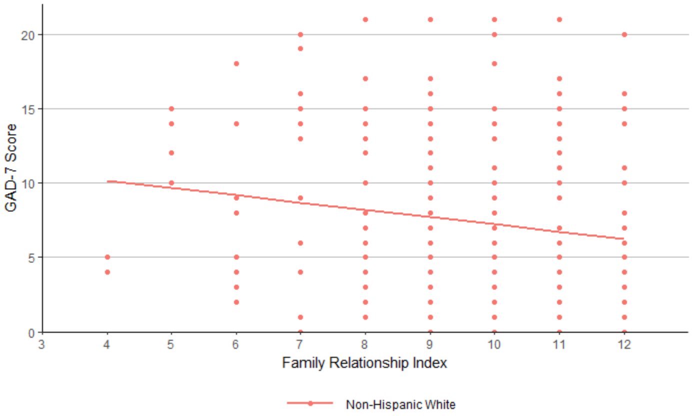
5. Creating a graph

```
g = ggplot(dat, aes(x=fri, dat$gad7scorehat, colour=raceethnicity, linetype=raceethnicity)) +
    geom_line(size=1) +
```

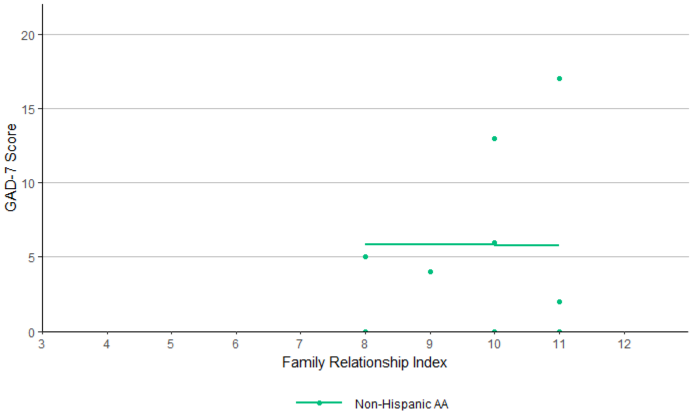
```
    labs(x='Family Relationship Index', y='GAD-7 Score') +
    guides(colour=guide_legend(title='Racial/Ethnic Groups', nrow=3),
         linetype=guide_legend(title='Racial/Ethnic Groups', nrow=3)) +
    theme_classic() +
    theme(panel.grid.major.y = element_line(size=.25, color="gray"),
        legend.position="bottom", legend.key.width = unit(3, "line")) +
 scale_y_continuous(limits = c(0, 15), expand = c(0,0))+
 scale_x_continuous(limits = c(3,12),expand = c(0,0), breaks = 3:12)+
 scale_linetype_manual(values=c("solid", "dashed", "longdash", "dotted", "twodash"));
g;
```

Note: gad7scorehat is fitted values based on GEE models without controlling for depression.

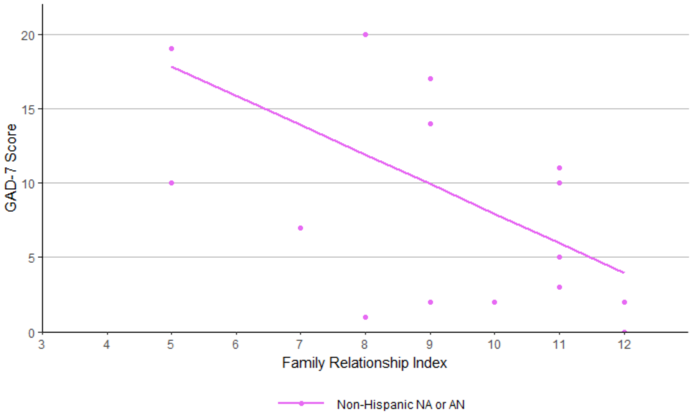
Appendix E. Scatter Plot of Relationship between Family Functioning and Anxiety among Non-Hispanic Whites



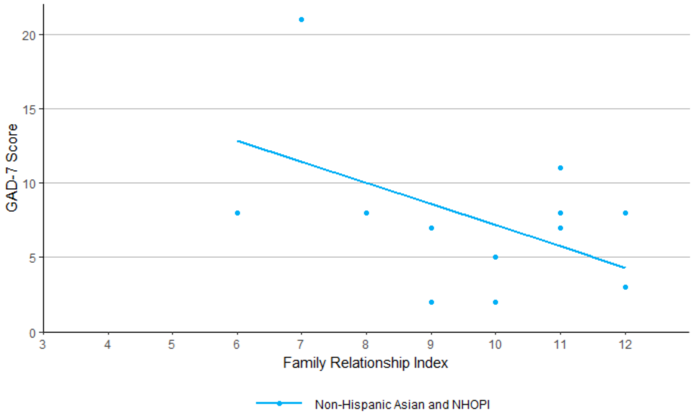
Appendix F. Scatter Plot of Relationship between Family Functioning and Anxiety among Non-Hispanic African Americans



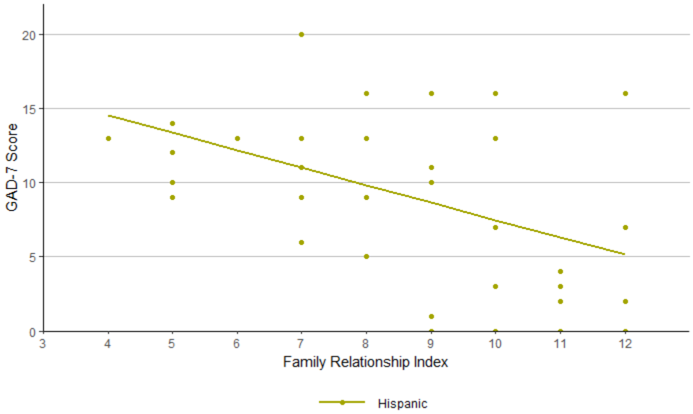
Appendix G. Scatter Plot of Relationship between Family Functioning and Anxiety among Non-Hispanic Native Americans or Alaskan Natives



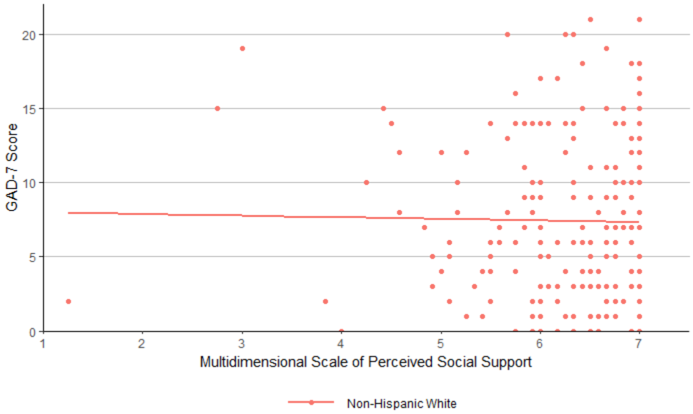
Appendix H. Scatter Plot of Relationship between Family Functioning and Anxiety among Non-Hispanic Asians and Native Hawaiian and Other Pacific Islanders



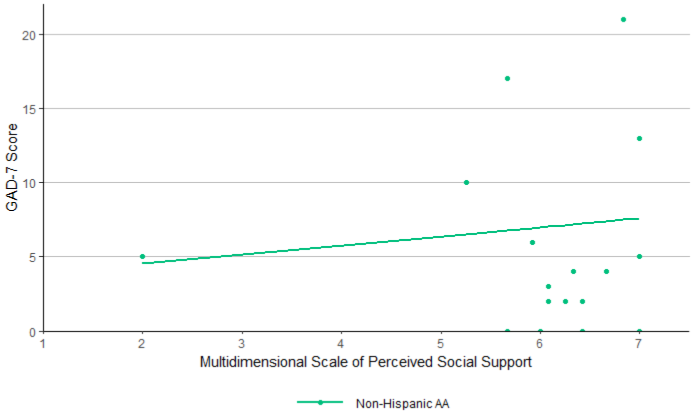
Appendix I. Scatter Plot of Relationship between Family Functioning and Anxiety among Hispanics



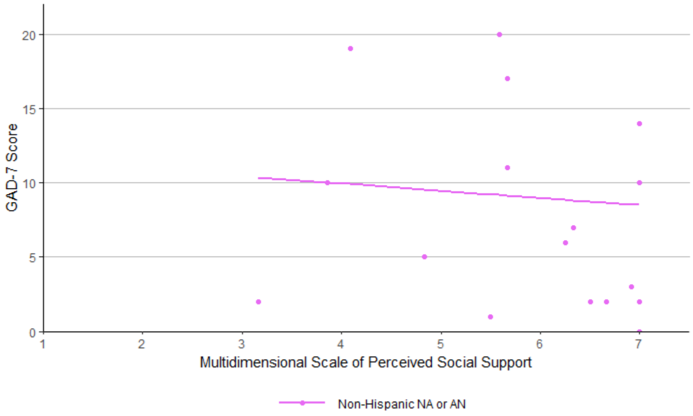
Appendix J. Scatter Plot of Relationship between Perceived Social Support and Anxiety among Non-Hispanic Whites



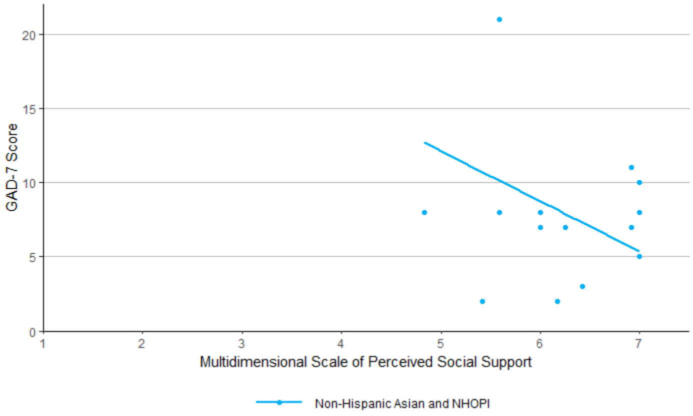
Appendix K. Scatter Plot of Relationship between Perceived Social Support and Anxiety among Non-Hispanic African Americans



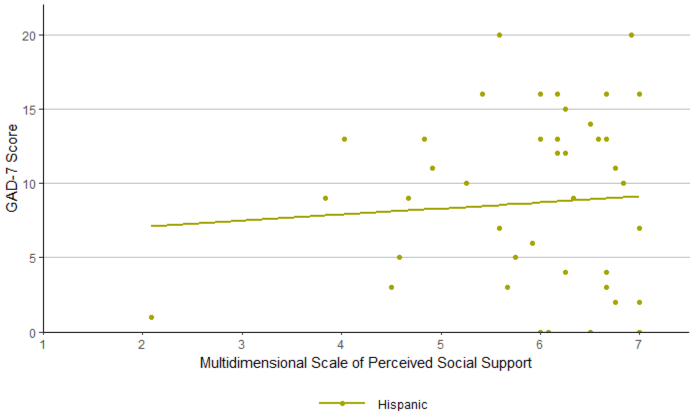
Appendix L. Scatter Plot of Relationship between Perceived Social Support and Anxiety among Non-Hispanic Native Americans or Alaskan Natives



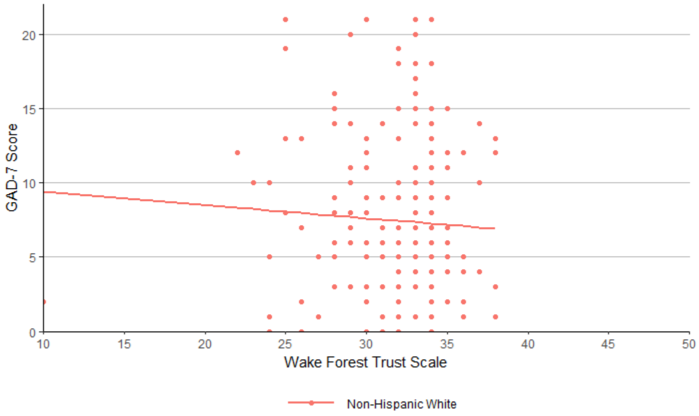
Appendix M. Scatter Plot of Relationship between Perceived Social Support and Anxiety among Non-Hispanic Asians and Native Hawaiian and Other Pacific Islanders



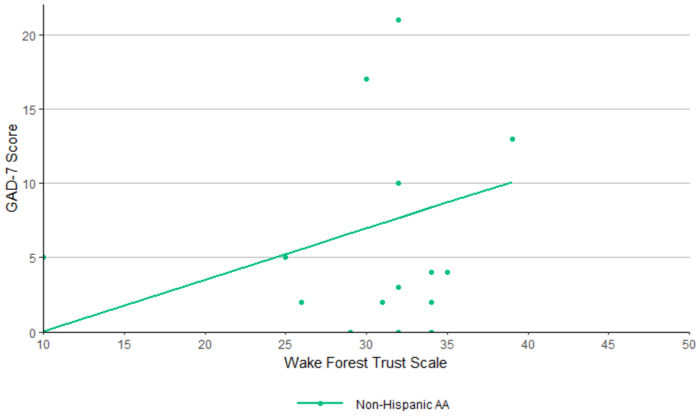
Appendix N. Scatter Plot of Relationship between Perceived Social Support and Anxiety among Hispanics



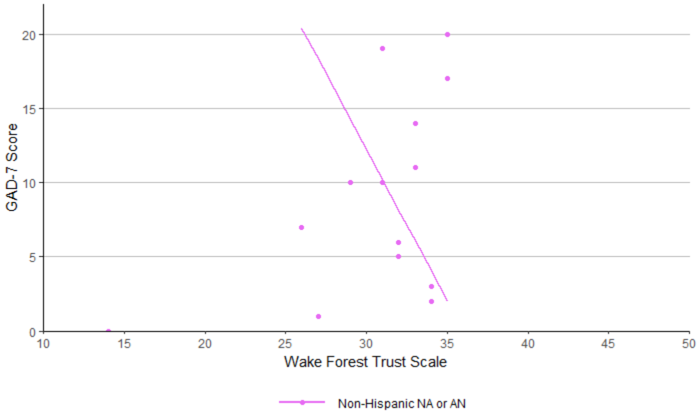
Appendix O. Scatter Plot of Relationship between Trust in Provider and Anxiety among Non-Hispanic Whites



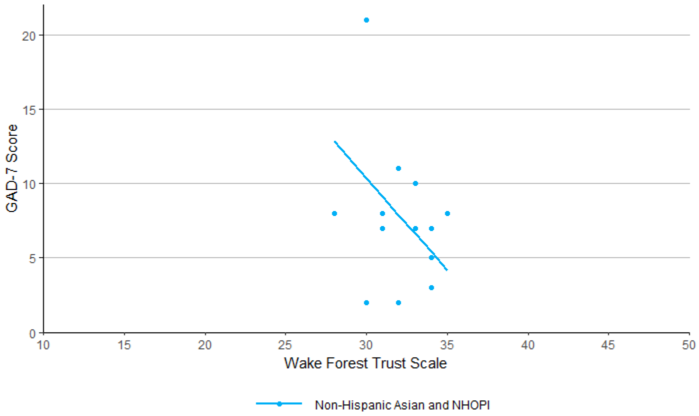
Appendix P. Scatter Plot of Relationship between Trust in Provider and Anxiety among Non-Hispanic African Americans



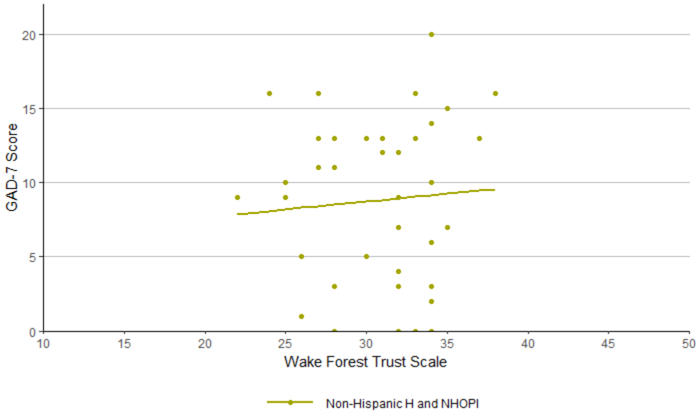
Appendix Q. Scatter Plot of Relationship between Trust in Provider and Anxiety among Non-Hispanic Native Americans or Alaskan Natives



Appendix R. Scatter Plot of Relationship between Trust in Provider and Anxiety among Non-Hispanic Asians and Native Hawaiian and Other Pacific Islanders



Appendix S. Scatter Plot of Relationship between Trust in Provider and Anxiety among Hispanics



Note for Appendices E-S.
Plots of relationships between anxiety and each psychosocial factor for each race using a GEE model for family clustered data with no adjustments for depression.
Abbreviations: AA, African American; NA or AN, Native American or Alaskan Native; NHOPI, Native Hawaiian or Other Pacific Islander; GAD-7, General Anxiety Disorder; GEE, Generalized Estimating Equations.

CURRICULUM VITAE

NAME: SOOJEONG HAN
PhD, AGNP-BC, OCN, RN

WORK ADDRESS: University of Washington School of Nursing
Seattle, WA 98195

EMAIL sh75@uw.edu
sh3351@caa.columbia.edu

EDUCATION

2016-2019 **Ph.D. Nursing Science**
University of Washington, Seattle, WA.
Dissertation Title: "Cultural Considerations among Family Caregivers in Palliative and Hospice Care"
Dissertation Committee: Dr. Anne Hirsch (Chair), Dr. Joie Whitney (Co-Chair), Dr. George Demiris (Committee Member), Dr. Susanne May (Committee Member), Dr. Butch de Castro (Committee Member), Dr. Helene Starks (Graduate School Representative; GSR)

2017-2018 **Graduate Certificate in Palliative Care**
Cambia Palliative Care Center, University of Washington, Seattle, WA.

2014-2016 **M.S. Nursing (Adult Gerontology Nurse Practitioner)**
Columbia University, New York, NY.

2007-2011 **B.S. Nursing**
Hanyang University, Seoul, South Korea.

CERTIFICATION AND LICENSURE

Registered Nurse	Washington State # 60660600 (Expiration June 2020)
Registered Nurse	California State # 95111330 (Expiration July 2020)
Registered Nurse	New York State # 680029 (Expiration May 2022)
Registered Nurse	South Korea # 283111 (Permanent)
ARNP	Washington State # AP60660601 (Expiration June 2021)
ARNP	California State # NP95007324 (Expiration June 2020)
ARNP	New York State # 307599 (Expiration May 2021)
School Nurse	South Korea (Permanent)
AGNP (AANP)	USA # AG0416032 (Expiration April 2021)
BLS Certification	Training Center ID: WA15590 (Expiration June 2021)
OCN (ONCC)	USA (Expiration October 2019)
ONS/ONCC (ONCC)	USA (2016)
IV certification	USA (2016)
Pressure Ulcer	USA (2016)
Infection Control	USA (2015)

Child Abuse	USA (2015)

FUNDED RESEARCH GRANTS

2019	GKNF-USA Scientific Award ($2,000), Global Korean Nursing Foundation, USA

HONORS AND AWARDS

2019	Hester McLaws Nursing Dissertation Scholarship ($3,500), School of Nursing, University of Washington
2019	Travel Scholarship, de Tornyay Center for Healthy Aging ($600), School of Nursing, University of Washington
2019	Poster Finalist at the Western Institute of Nursing (WIN) conference 2019 (San Diego, CA)
2019	King County Nurses Association (KCNA) Scholarship ($3,000), King County Nurses Association
2019	School of Nursing (SoN) Conference Travel Award ($350), School of Nursing, University of Washington
2019	Graduate & Professional Student Senate (GPSS) Travel Grant ($300), University of Washington
2017 – 2019	Teaching Assistantship, School of Nursing, University of Washington
2018 – 2019	Korean Honor Scholarship (KHS) ($1,000), The Embassy of the Republic of Korea
2018 – 2019	Jeanne Beneliol Fellowship, School of Nursing, University of Washington
2018 – 2019	Tripi Scholarship, School of Nursing, University of Washington
2016 – 2017	Top Scholar Awards, Graduate School, University of Washington
2016 – 2017	Nursing Fellowship, School of Nursing, University of Washington
2008 – 2009	Honor Student Scholarship, Hanyang University

PUBLICATIONS

Peer-reviewed Journal Articles (Published/In Press)

1. Teng A, **Han S,** Lin S-Y, Demiris G, Zaslavsky O, Chen AT. Using an innovative discussion platform to give voice to aging-related experiences: A pilot study. *Journal of Gerontological Nursing.* 2019 (In press).

2. **Han S**, Chi NC, Han C, Parker Oliver D, Washington K, Demiris G. Adapting the resilience framework for family caregivers of hospice patients with dementia. *American Journal of Alzheimer's disease and other dementias.* 2019; 34(6): 339-411 [Epub ahead of print].

3. Iwata M, **Han S,** Hays R, Doorenbos A. Predictors of depression and anxiety in family members 3 months after child admission to a pediatric ICU. *American Journal of Hospice and Palliative Medicine.* 2019; 1-10 [Epub ahead of print].

4. Chi NC, **Han S,** Barani E, Parker Oliver D, Washington K, Lewis F, Walker A, Demiris G. Development and preliminary evaluation of a pain management manual for hospice providers to support and educate family caregivers. *American Journal of Hospice and Palliative Medicine.* 2018: 1-9 [Epub ahead of print].

5. Han CJ, Chi NC, **Han S,** Demiris G, Parker-Oliver D, Washington K, Clayton M, Reblin M, Ellington L. Communicating caregivers' challenges with cancer pain management: An analysis of home hospice visits. *Journal of Pain and Symptom Management.* 2018;55(5):1296-1303.

6. Oh E, Hong GS, Lee S, **Han S.** Fear of falling and its predictors among community-living older adults in Korea. *Aging and Mental Health.* 2015;21(4):369-378.

Peer-reviewed Conference Abstracts/Poster Presentations

1. Teng A, **Han S,** Lin S-Y, Demiris G, Zaslavsky O, Chen AT. Virtual online communities for aging life experiences. National Library of Medicine Training Conference, Indianapolis, IN, USA, June 24-25, 2019.

2. **Han S,** Kim S. Moral distress of NICU nurses in end-of-life care. Poster presentation at the 2019 Western Institute of Nursing (WIN) Research Conference, San Diego, CA, April 11, 2019.
   **This poster was awarded as a finalist at the WIN conference 2019.*

3. Zaslavsky O, Chen A, Teng A, Lin S-Y, **Han S,** Demiris G. Virtual online communities for aging life experience (VOCALE). The International Conference on Frailty & Sarcopenia Research (ICFSR), February 20-22, 2019; Miami Beach, FL, USA.

4. Iwata M, **Han S,** Starks H, Hays R, Doorenbos A. Predictors of depression and anxiety in family members 3 months after child admission to pediatric ICUs. Annual Assembly of Hospice and Palliative Care, March 13-16, 2019; Orlando, FL, USA.

5. Chi NC, **Han S,** Barani E, Demiris G, Lewis FM, Walker A, Washington K, Parker Oliver D. Evaluation of the utility of a pain management education tool for hospice care providers. Paper Presentation at the Midwest Nursing Research Society (MNRS) of the 42nd Annual Research Conference, April 12-15, 2018; Cleveland, OH, USA.

6. Chi NC, **Han S**, Demiris G, Lewis FM, Walker A, Washington K, & Parker Oliver D. Testing the utility of a pain management educational tool to support hospice family caregivers. Poster session presented at: Pacific Northwest Palliative Care Conference, 2017; Seattle, WA, USA.

7. Han C, Chi N-C, **Han S**, & Demiris G. Communicating caregivers' challenges with cancer pain management: An analysis of home hospice visits. Poster session presented at: Cambia Palliative Care Center of Excellence, 2017; Seattle, WA, USA.

8. Hong G-R S, LEE Y, Kang H, & **Han S.** Attitudes toward elders among nursing students and nurses in Korea. Poster presented at: Gerontological Society of America, 2012; San Diego, CA, USA.

Manuscripts under Review/Revision

1. Iwata M, **Han S,** Pike K, Ross H, Doorenbos A. Differences in psychosocial outcomes between family members in pediatric, cardiac, and neonatal intensive care units. *Pediatric Critical Care Medicine.* 2019.

2. **Han S,** Chi NC, Choi YK, Demiris G. Technology-based interventions to support persons with dementia and their caregivers: A systematic review. *Informatics for Health and Social Care.* 2019.

Manuscripts in Preparation

1. **Han S,** Kim S. Moral Distress of NICU nurses under the circumstances surrounding the deaths of infants. 2019.

2. **Han S,** Teng A, Lin S-Y, Demiris G, Zaslavsky O, Chen AT. User engagement and experience of online social networking among older adults. 2019.

3. Chi NC, **Han S,** Fu Y, Demiris G. Interventions to enhance resilience among family caregivers: A literature review. 2019.

RESEARCH EXPERIENCE

08/2018 – current **Volunteer Research Assistant**
Virtual Online Communities for Aging Life Experiences (VOCALE) Project:
Principal Investigators: Annie Chen, PhD, and
Oleg Zaslavsky, PhD, MHA, RN
Responsibilities: Recruit study participants; Obtain consent form; Administer questionnaires; Follow up with participants; Update IRB; Collect, manage and analyze data; Processed reimbursements; Present and publish research data
University of Washington, Seattle, WA

06/2018 – current **Volunteer Research Assistant**
Moral distress among NICU nurses in end-of-life settings:

Principal Investigators: Sujeong Kim, PhD, MSN, RN
Responsibilities: Analyze qualitative data;
Present and publish research data
Seattle University, Seattle, WA

07/2019 – 08/2019 **Volunteer Research Assistant**
"Dementia Guide Expert for Families Mobile App" Project:
Principal Investigator: Valerie Gruss, PhD, APRN, CNP-BC, FAAN
Responsibilities: Translate the mobile app contents into Korean
University of Illinois at Chicago, Chicago, IL

08/2018 – 08/2018 **Volunteer Research Assistant**
Pharmacogenomics among children and adolescents with anorexia nervosa:
Principal Investigator: Janiece E. DeSocio, PhD, RN, PMHNP-BC, FAAN
Responsibilities: Analyze quantitative data
Seattle University, Seattle, WA

07/2018 – 08/2018 **Volunteer Research Assistant**
Predictors of health care satisfaction among gay men:
Principal Investigator: Michael Huggins, EdD, APRN, FAANP
Responsibilities: Analyze quantitative data
Seattle University, Seattle, WA

01/2018 – 06/2018 **Volunteer Research Assistant**
Pediatric ICU caregiving project:
Principal Investigator: Ardith Doorenbos, PhD, RN, FAAN
Responsibilities: Analyze quantitative data;
Present and publish research data
University of Washington, Seattle, WA

01/2017 – 12/2017 **Volunteer Research Assistant**
Hospice dementia caregiving and pain management education for providers:
Principal Investigator: George Demiris, PhD
Responsibilities: Analyze qualitative data;
Present and publish research data
University of Washington, Seattle, WA

12/2010 – 09/2015 **Research Assistant**
(Intermittently) Dementia caregiving and policy support:
Principal Investigator: Gwi-Ryung Son Hong, PhD, RN
Responsibilities: Recruit study participants; Administer questionnaires; Collect and manage quantitative data; Present and publish research data
Hanyang University, Seoul, South Korea

TEACHING EXPERIENCE

01/2019 – 03/2019 **Teaching Assistant**
General Anatomy (BSN course)
The Department of Biobehavioral Nursing and Health Informatics
University of Washington
Seattle, WA

10/2018 – 12/2018 **Teaching Assistant**
Comprehensive Health Assessment (DNP course)
The Department of Biobehavioral Nursing and Health Informatics
University of Washington
Seattle, WA

04/2018 – 06/2018 **Teaching Assistant**
Transition to Professional Practice Course (BSN course)
The Department of Family and Child Nursing
University of Washington
Seattle, WA

10/2017 – 03/2018 **Teaching Assistant**
Nursing of Families: Childbearing and Childrearing
(BSN/ABSN course)
The Department of Family and Child Nursing
University of Washington
Seattle, WA

PROFESSIONAL EXPERIENCE

04/2019 – 08/2019 **Student Assistant**
Family and Child Nursing Department
School of Nursing, University of Washington
Seattle, WA

09/2018 **International Liaison**
Visiting Scholars Meeting (University of Washington)
Department of Health Care Policy Research,
Korea Institute for Health and Social Affairs

02/2016 – 07/2016 **Staff Nurse**
Jacobi Medical Center (Oncology)
New York, NY

10/2013 – 04/2014 **School Nurse**
Gyeonggi Academy of Foreign Languages (High School)
Seoul, South Korea

05/2011 – 04/2013 **Staff Nurse**

Asan Medical Center
(Hematology/Oncology and Bone Marrow Transplant)
Seoul, South Korea

12/2010 – 09/2015 **Research Assistant**
Hanyang University
Seoul, South Korea

MEMBERSHIPS

- American Association of Nurse Practitioner (AANP), 2016 to current
- Gerontological Society of America, 2012 to 2013, 2017 to current
- Global Korean Nursing Foundation in USA, 2019 to current
- Oncology Nursing Society (ONS), 2014 to 2017
- Sigma Theta Tau (STT), 2016 to current
- Western Institute of Nursing (WIN), 2016 to current

COMMUNITY INVOLVEMENT

2017 – 2018 Disciple makers (Christian group),
University of Washington, Seattle, WA
Officer

2018 State Board of Health, WA (June 20, 2018 – August 1, 2018),
Health Policy Intern (*Research Volunteer)*

2017 – 2018 Network of Doctoral Students, University of Washington, Seattle, WA
Membership Coordinator (Officer)

2015 Community Outreach and Education Committee,
Columbia University, New York, NY
Subcommittee member

2015 Columbia Student Medical Outreach Program,
Columbia University, New York, NY
Junior Clinician

2008 – 2011 University Medical Volunteer Club ‘AGAPE’
(Medical Group in Christian Organization), Seoul, South Korea
Leader & Mentor