

Pathways of cancer care burdens:

The experiences of Asian American immigrant cancer patients
and their family carers

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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Abstract

Background: The burden of cancer embodies the lived experiences and perspectives of people who have dealt with the challenges and difficulties of cancer. The landscape of cancer care in the United States has transitioned to a predominantly outpatient care system, so cancer care has become increasingly burdensome on the patient and family.

Aim: The thesis describes the cancer care burden experiences of Chinese, Filipino and Indian American cancer-diagnosed immigrants and their family carers as well as explores the factors associated with their cancer care burdens.

Method: Interpretivist and constructivist qualitative approaches were used to gather and analyse data from 9 cancer-diagnosed individuals and 9 family carers. Purposive and snowball sampling methods were employed. A semi-structured interview format was used for data collection.

Results: The analysis generated three main themes that reflect cancer care burden experiences of the sample population: psychosocial burdens, burdens related to healthcare, and competing priorities. Several factors related to social, economic, cultural, and institutional context were found to have a relationship with the cancer care burdens.

Conclusion: The findings illustrate that Asian American immigrant families deal with complex and multifaceted cancer care burdens that are connected to the social, economic and cultural conditions that shape their lives. Insight from the thesis is a critical first step for understanding the pathways of cancer care burdens amongst immigrant families.

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Chapter 1 | Introduction

1.1 An autobiographical introduction

My deep personal connection with immigrant and refugee communities is rooted from my family's arrival in the United States (U.S.) and the friends who welcomed me as part of their home. Since childhood, I have observed that assimilating into American life was important for many people from these communities. Part of that assimilation was having secure housing, steady employment, healthcare access, and education. For many, these were more than ordinary essentials - they were life securities that were once limited or beyond their reach. The stories from immigrant friends and neighbours about establishing American life often included lacking critical resources or knowledge, facing double standards, and having limited support. These perspectives influenced how I sought to understand the challenges immigrant populations faced with illness and healthcare.

Several years ago, I attended a talk given by Dr. Anthony Iton regarding the analysis of racial group health status according to the socioeconomic status of neighbourhoods. His quantitative data analysis of mortality rates indicated there was no socioeconomic gradient amongst Asians and Hispanics in Alameda County, California (2006, Iton). Dr. Iton suggested this was due to the "healthy-migrant theory" in which first-generation immigrants are healthier than their American-born counterparts as a result of healthier behaviours (e.g. food choices). I felt this rationale diverted attention away from the other potential factors that affect the health of immigrant populations. Research on disease incidence, mortality and risk patterns has influenced my work in minority health and cancer. However, it also limited the understanding of other problems with illness and care that I have learned about

through healthcare and community setting experiences. Epidemiology data made it difficult to recognise how other crosscutting areas such as healthcare access, communication, and decision-making impacted cancer related outcomes. These experiences shaped my exploratory qualitative approach to redefine knowledge about the burden of disease in sub-population health research.

1.2 Thesis structure

The thesis is organised into ten chapters, supported by appendices that present the questions used for the interviews, the informed consent forms, table of characteristics about the sample population, pen portraits of individual study participants, and the key elements for conducting the literature review. In addition to acknowledging my personal connection to the study, Chapter 1 introduces the background of cancer burden as it relates to cancer research, patient care and caregiving in the U.S. It underlines the rationale for the study and specifies the research question and objectives, thereby setting the context for the study. The chapter concludes with a list of key terminology.

Chapter 2 examines the current research literature relevant to the study's question and purpose. The literature review draws upon three main subject matters found in the published research work that the study aimed to explore: the importance of family in dealing with cancer care; the burdens related to cancer care; and the social determinants associated with cancer care burdens. This chapter also recognises the strengths, limitations, and gaps in the research literature.

Chapter 3 discusses the theoretical underpinnings of the study's approach for assessing and understanding cancer care burdens. The chapter explains the relevance

for using the social determinants of health theories and Pierre Bourdieu's (1986) social, economic and cultural capital theory in guiding the research.

Chapter 4 explains the research methodology and methods employed in the study. An overview is provided why principals of interpretivism and constructionism were chosen as epistemology influences for this research. Various aspects of the research methods employed are covered which include research design, population sampling, data collection and analysis, approach to study reliability and validity, and the ethical considerations and protocols for research.

Chapter 5 describes the sample population characteristics in order to provide an understanding about the social and economic conditions of the study participants' lives. It includes brief profiles to introduce a personal background of each study participant.

Chapter 6, 7 and 8 presents the study findings regarding burdens in cancer care. Chapter 6 explains what cancer care means to the study participants and the psychological burdens they experienced. The findings are discussed within the categories of self-efficacy, concealment, and the unknown and uncertain. Chapter 7 describes the findings related to the burdens that the study participants experienced with healthcare. These findings are presented under healthcare access, communication, and decision-making. Chapter 8 illustrates the issue of competing priorities through the cases of four study participants. The specific factors impacting the lives of these study participants are highlighted in order to illustrate the social and economic conditions surrounding the competing priorities.

Chapter 9 discusses the analysis of the study results as it pertains to the research question and the theoretical frameworks. The core of the analysis is

demonstrated within the three main cancer care burden themes, the social determinants of health framework, and Bourdieu's (1986) social, economic and cultural capital theory. It discusses the significance of the study's findings on immigrant populations and how the findings compare to prior published research literature. Also discussed are the study's limitations, concerning issues, and strengths.

Chapter 10 is the final chapter of the thesis which draws together the important aspects of the study's purpose, the implications of the knowledge gained from the study findings, and final reflections about the significance of the study's overall contribution to the field of cancer research and further work to be explored.

1.3 Conceptualisation of cancer burden in research

This section will highlight how cancer burden is predominantly portrayed through cancer research. Reducing the burden of cancer in the U.S. became a federal mandate through the National Cancer Act of 1937 and a priority undertaken by the National Cancer Institute (NCI) through cancer control research (National Cancer Institute, 2015). Cancer control research is defined by the NCI as "...the conduct of basic and applied research in the behavioral, social, and population sciences that, independently, or in combination with biomedical approaches, reduces cancer risk, incidence, morbidity, and mortality and improves quality-of-life" (Hiatt & Rimer 1999: p.957). This definition corresponds with how 'cancer burden' has been conceptualised by research in the U.S.

Knowledge about cancer burden in the U.S. has been primarily constructed by epidemiology, in which the problem is often characterised by population outcomes in disease incidence, prevalence and mortality (Polite et al. 2017). Cancer epidemiology

stems from a positivist model of assessing the quantifiable effects of disease on populations. The position of the positivist paradigm is that an objective reality can be observed and measured through the scientific method (Alvesson & Sköldberg 2018), thus quantitative methods are often applied to research with a positivist rationale (Bowling, 2009). Measures of cancer burden such as disease surveillance outcomes (Siegel et al. 2016), economic cost (Ahmed et al. 2015; Yabroff et al. 2011), and disparities between groups (Lortet-Tieulent et al. 2016 and 2017) have helped justify the large-scale policies and funding aimed at decreasing cancer rates (Neta et al. 2015; Peto 2001).

Whilst social epidemiology has expanded the context of cancer burden with the understanding of how social factors correlate with disease surveillance outcomes (Krieger, 2001), disciplines such as psychology, sociology, and medical anthropology have paved the way for knowledge about the problems that patients, carers, and families face with cancer. Published research literature under these disciplines have not explicitly labeled these problems as ‘cancer burdens’. The literature review in the next chapter will showcase research knowledge produced from these disciplines including those with an interpretivist approach to understanding the burdens of cancer. Interpretivism addresses research questions under the premise that the reality is multifaceted, relative, and socially constructed (Ritchie & Lewis, 2003). Although the use of interpretivist inquiry has not been widely associated with conceptualising cancer burden within cancer control research, this approach may be critical for capturing how the burdens of cancer is also about the meanings and experiences of those affected by cancer and how it fundamentally reflects personal adversities.

1.4 Summary of research purpose, question and objectives

With the advancement in cancer medicine and disease management, care for adult cancer patients in the U.S. has largely shifted from long term hospitalisation to outpatient services (Brédart et al. 2014; Jacobson & Mulvey 2012; Williamson 2008). This contemporary healthcare model often requires more resources from patients, because the support system extends into the patient's home and local community, such as assistance with coordinating appointments, errands, daily tasks, cancer support group attendance, and meeting physical demands (Benoot et. al 2015; Given et al. 2001; Harrison et al. 2009; Mor et al. 1992; Sherman et al. 2008). Outpatient care can also create obstacles for patients and their carers to comply with the care plan, manage treatment side effects, maintain general well being, and communicate about problems or needs (Sanson-Fisher et al. 2000; Longman et al. 1992).

For many individuals diagnosed with cancer, family members become an essential and ongoing resource for their care. Support from family can enhance a cancer patient's capacity to manage multiple components of care. For example, some cancer patients have reported more favourable outpatient clinical care experiences when they received assistance with commuting to the medical facility (Payne et al., 2000) or being accompanied during clinical visits (Veach & Nicholas, 1998). On the other hand, the demands of caring for a patient can have negative effects on the carer's psychological, economic and other aspects of personal well-being (Lapid et al. 2016; Porter & Dionne-Odom 2017). These demands can be exacerbated when cancer patients are further apart from their family members and/or social networks.

Learning from cancer experiences in families can provide understanding of how the collective and individual ‘being’ are impacted by illness, including the meanings they discover from those encounters. Research knowledge is limited about Asian American family challenges with cancer. My study seeks to produce new knowledge regarding the burden of cancer care experienced by Asian American families. The terminology, ‘cancer care burden’, refers to the obstacles, hardships and load of responsibilities in dealing with a cancer patient’s care. Through qualitative approaches, I identified key factors that had a critical relationship with the cancer care burdens experienced by Chinese, Indian and Filipino American immigrant cancer patients and their family carers. Findings from the study also illustrate: 1) what cancer care is regarded as constituting from the viewpoint of cancer patients and their carers; 2) how expectations, choices, and barriers shape their encounters with cancer care; and 3) the main burdens in cancer care experienced by the study participants, and the determinants affecting these burdens. New knowledge from this research is expected to further develop other investigative topic areas as well as inform interventions for improving the care experiences and outcomes of Asian American immigrant cancer patients and families.

1.5 Rationale for studying Asians in the San Francisco Bay Area

Asians represent a quarter of the San Francisco Bay Area’s population and make up the largest percentage of immigrants in the region (PolicyLink & PERE, 2017). Historically, most of the Asian population have resided in densely populated urban and suburb regions due to employment opportunities and the existence of ethnic enclave neighbourhoods (Allen & Turner 1996; White & Biddlecom 1993; Yu &

Myers 2007). Four large counties in the San Francisco Bay Area are heavily concentrated with Asian populations (Asian American Center for Advancing Justice, 2013). There has been a growing trend of long distance relationships for racial-minority families (Walker & Schafran, 2015), because the further outlying regions offer a way for some families to adapt to the challenging housing and economic climate (Pamuk 2004; Walker & Schafran 2015). Many immigrant families members who live in the U.S. also function as ‘transnational immigrant families’, in which they “...maintain emotional and economic connections...” (Falicov 2007: p.159) with their family members abroad. These connections include ongoing communication, shared decision making, and income support. Family distance and transnational family connections may have important implications for how immigrants and their family members perceive and experience care for illness.

In regard to the health status of the Asian American population, current cancer surveillance reveals that when compared to racial groups in the U.S., Asians (combined with Pacific Islanders) have the lowest cancer incidence and mortality rates overall (Siegel et al. 2016). Thus the burden of cancer in Asian populations is reported as low in comparison to other groups such as African Americans and Hispanics. In reference to how epidemiology defines cancer burden, this type of reported outcome can perpetuate the ‘model minority’ stereotype amongst Asian Americans in which they are considered to have more advantages with health, education and socioeconomic status (Ibaraki et al., 2014). Kiang et al. (2017) asserts that this stereotype has created assumptions that Asian Americans do not have a need to further benefit from additional resources, representation in research, and interventions that address health and social well-being. Part of this argument was

supported by Ibaraki's et al. (2014: p.75) finding that "...a search of the terms "African American" and "health disparity" in PubMed yields 974 results. A search for "Asian American" and "health disparity" yields 124." Although this appears to be a speculative observation about the way Asian Americans are underrepresented in health research, it is a powerful suggestion that the research available on health disparities in Asian American populations is very limited.

1.6 Definitions of key terminology

The following terms are used frequently throughout the thesis, and are defined as follows:

- **Burdens:** The challenges, difficulties, and/or shouldering of a 'load'. This term is frequently used in conjunction with cancer or cancer care.
- **Capital theory:** This is an umbrella term for a theoretical framework originating from the work of Pierre Bourdieu. In his research commentary, *The Forms of Capital* (1986), Bourdieu addressed the characteristics of social, cultural and economic capital. He further explains that these capital resources and assets are acquired, accumulated and reproduced on individual and group levels.
- **Cancer care:** The ways in which cancer patients are supported, looked after and receive medical or health-related attention.
- **Clinical care:** Medical care and services received in a hospital or clinical setting of a healthcare institution.

- **Family carer:** Study participant identified by the cancer patients as a family member who provided cancer care. This term is also referred to as ‘carer’.
- **HIPAA (Health Insurance Portability and Accountability Act):** A U.S. legislation that protects medical information through regulations related to data security and privacy (U.S. Department of Health & Human Services, 2018).
- **Immigrant:** An individual who chooses to reside in another country and becomes a permanent or long-term residence.
- **Individual(s) diagnosed with cancer:** Study participant who was or is currently a cancer patient. This term interchangeably is referred to as ‘cancer-diagnosed individual(s)’ and ‘cancer patient(s)’.
- **Social determinants of health:** The factors and circumstances shaping the health perspectives, experiences and outcomes of individuals or populations. General categories of determinants include individual behaviours, social, economic, and environmental. This term is also referred to as ‘determinants of health’.
- **Nativity status in the United States:** Nativity refers to the place and circumstances of a person's birth. Thus in relation to nativity status in the U.S., this term refers to being a U.S. native born or foreign-born. U.S. native born individuals had U.S. citizenship status at birth, whilst foreign-born individuals did not have U.S. citizen status at birth. Foreign-born residents in the U.S. are also recognised as immigrants.

Chapter 2 | Review of the literature

2.1 Introduction

The purpose of this chapter is to examine and discuss research literature relevant to family and Asian population experiences with cancer care as well as the theoretical background supporting the study's data analysis. A narrative overview approach (Green, Johnson & Adams, 2006) is used to review literature relevant to three fundamental areas addressed in the study: the significance of family caring for relatives with health problems, the burden of cancer care, and the determinants of cancer care burdens. The aim for this type of literature review is to assess a wide range of issues regarding family experiences with care, to help outline how knowledge in this topic area has developed in health research, and to justify the importance of further examining concepts that are inadequately studied in research (Green, Johnson & Adams, 2006). The frequently used terms in the literature review (burden, cancer care, determinants of health, health determinants, and carer) refer to the same meanings previously defined in Chapter 1. Lastly, the chapter will conclude with a summary of the strengths and limitations amongst the research literature reviewed, particularly revealing where there are gaps in knowledge regarding the key concepts and research population being examined in this study.

2.2 The narrative review approach

The following describes the key components of how a narrative review approach was carried out for this literature review, which are guided by papers written by Green, Johnson and Adams (2006) and Ferrari (2015). First a literature search was conducted, which the method and criteria is described in the next section of this

chapter. A more narrow selection of the literature was evaluated for how it addresses the question: What are the care related needs, challenges, and burdens of care recipients and family carers, as well as the factors associated with them? The selected literature for the review was grouped by primary topic area. These topics were established based on the cancer care, caregiving, and cancer burden issues. For each primary topic section, the essential findings and knowledge gained from the research literature are discussed and evaluated in relation to how it addresses the key question guiding the literature review as well as contributes research knowledge to the topic area.

Briefly mentioned in Chapter 1, the issues of transnational family relationships are pertinent to the concerns related to immigrant and ethnic minority experiences with health and healthcare. There is a growing body of research on transnationalism and health, which Villa-Torres et al. (2017) provide a systematic review of the literature that illustrates how and why migrants shift between their country of origin and the country of relocation in order to seek health needs and services. The concept of medical pluralism is also examined with transnationalism because it relates to people having simultaneous beliefs and use of separate medical systems or health approaches (Green et al. 2006, Raffaetà et al. 2017). These topic areas were not included as part of the literature review in order to narrow the scope of the narrative overview and highlight attention on the current research topics that are more closely associated with burdens in cancer care.

2.3 Literature search methods and criteria

A systematised literature search and appraisal framework was used for the literature review. The literature search began with a brief ‘scoping study’ using the *Academic Search Complete*, *Web of Science* and *PubMed* databases to help determine: the breadth of literature available, additional topic areas, and terms associated with the research question. Davis, Drey, and Gould (2009: p. 1387) describe a scoping study as the “... preliminary investigative processes that identify the range and nature of existing evidence...”. This exploratory stage developed this study’s structured approach for identifying a specific range of research publications and selection criteria for literature to review. Medical Subject Headings (MeSH) terms from the U.S. National Library of Medicine were also applied to the research literature searches. Appendix B provides a listing of scoping and MeSH terms used within the title, abstract and keyword search fields. The searches were conducted in multiple databases and online journals relevant to health, social and psychology research (Appendix B). Lastly, the citations referenced by or linked with the publications were inspected to identify additional publications that were not previously found from the database search results.

Using both ‘scoping’ and in-depth search strategies helped locate a large range of health research literature that was applicable in addressing the circumstances and experiences of cancer care dealt by families, cancer patients, carers, and Asian populations. The research publications selected for this literature review were limited to journal articles, books and institutional reports in the English language that were published between 1990 and 2018. Table 2.1 on the next page, lists the following inclusion and exclusion criteria used to guide the selection of publications for the

literature review. In addition to reviewing research implemented in Asian and European countries, studies that were conducted in the U.S., Canada, Australia, and United Kingdom (U.K.) were particularly selected because of the migration and settlement patterns of Chinese, Indians and Filipinos in these regions (Castles & Miller, 2009). The papers relating to non-cancer health conditions were included

Table 2.1 Literature review inclusion and exclusion criteria

	Inclusion	Exclusion
Publication type	journal articles, books, institutional reports	dissertations, conference papers, unpublished reports
Publication language	English	non-English
Publication year	1990 - 2018	Prior to 1990
Country of study	U.S., Canada, Australia, U.K., Europe, Asia	-
Health condition	cancer, chronic conditions, elderly care	-
Study population	adult, cancer patients, family carers, informal carers, Asian care recipients, immigrants, immigrant family members	paediatric, adolescent, and young adult patients or carers

based on the extent of how much the study findings, literature review, or expert-based opinions filled gaps in knowledge concerning the purpose of this literature review and thesis. By incorporating publications from other kinds of health and social research areas, it expanded representation and depth of key issues relevant to the sample population of this thesis. Paediatric, adolescent and young adult patient populations were excluded since this thesis focuses on older adult cancer patients over the age of 50 years old.

Of the 373 research literature that initially met the search criteria, a subset of 92 publications were integrated as part of the literature review chapter because of their strong relevance to the study's purpose as well as ability to promote a robust

understanding of the subject areas most pertinent to the study. The first set of publications that satisfied the search criteria were appraised for the topics areas primarily addressed in the study or commentary. Each topic area was assigned a categorical name (Appendix B) which served two purposes: 1) used to code the publication according to the key issues identified in the study, commentary or literature review; and 2) provided a way to group the publications that shared similarities by subject matter and/or sample populations. More defined categories were generated for the subsequent set of publications reviewed in this chapter.

Table 2.2 and Figure 2.1 characterise the research literature reviewed and discussed in this chapter. Table 2.2 indicates the number of publications that are research-based studies, commentary or expert-based evaluation writing, and general or literature review publications. The table further enumerates the type of research

Table 2.2: Reviewed literature by publication type and research methods

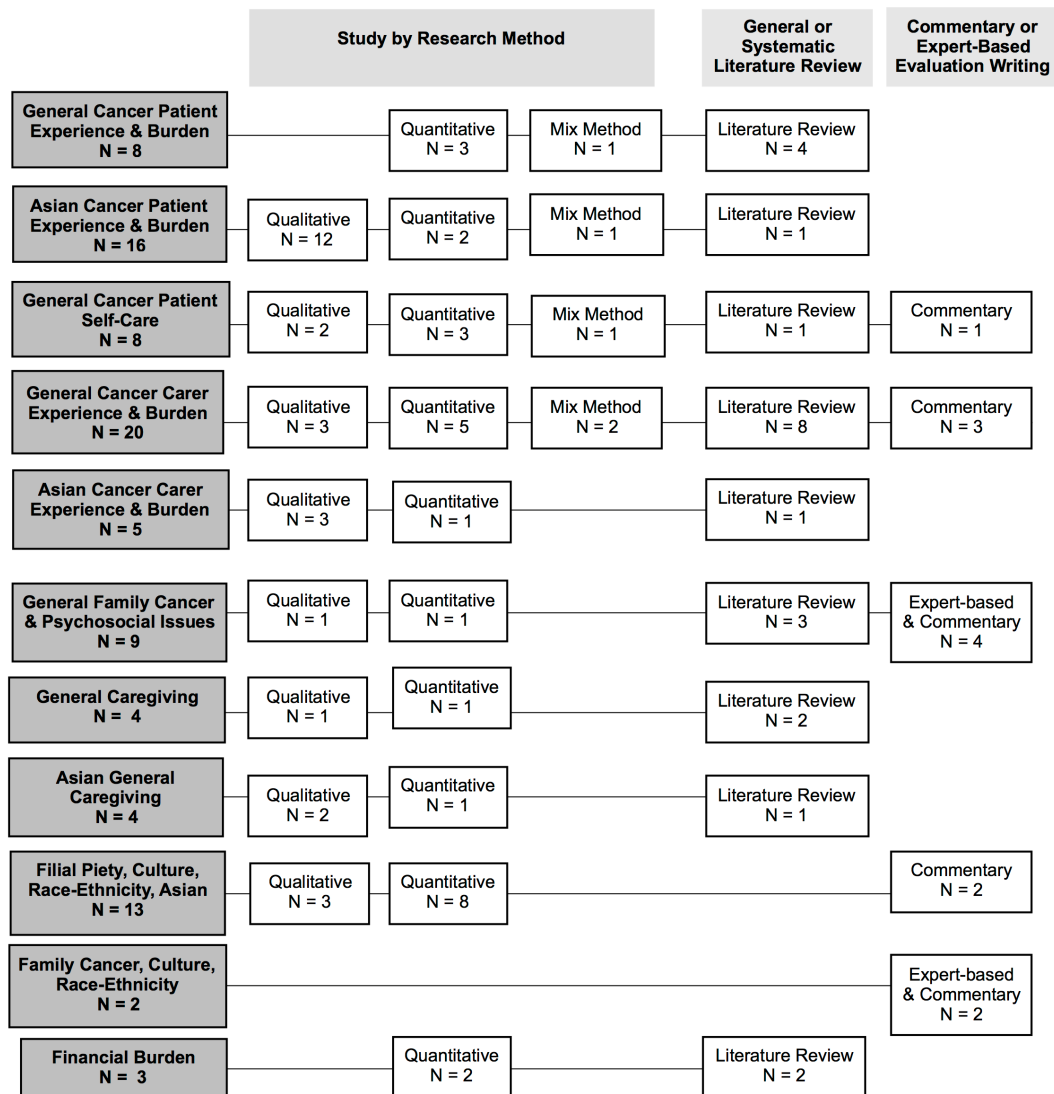
	No Methods (not applicable)	Qualitative Methods	Quantitative Methods	Mix or All Methods
Research-Based Studies	-	27	27	4
Commentary, Expert-Based Evaluation Writing	12	-	-	-
General, Systematic Literature Review	-	3	5	15

method used in a study or analysed for a general/literature review. On the following page, Figure 2.1 exhibits the main categories of this chapter’s reviewed publications, which were generated from the categories of the preliminary search and review phase.

The evaluation of the literature by topic area was followed by an assessment of the publication’s overall value towards enhancing the knowledge and understanding about the subject areas most important for the study as well as its

usefulness for a qualitative data analysis and discussion of findings. There was no judgement of quality on a study's research methodology, method or data reporting,

Figure 2.1: Key topic areas of reviewed literature with corresponding research method or scholarly review/writing



but the publication was evaluated for the study's type of research method or the research writing used. The approach that was used for this research literature review was able to draw out the pertinent and critical publications addressing family carer and cancer patient issues and burdens, especially those relating to Asian populations. In Appendix C, Table 2.3 list each publication in the literature review with relevant findings, study location, sample population, authorship, and publication details.

2.4 Significance of family in cancer care

The responsibility of care is likely to be inevitable for families with a relative experiencing health problems. There has been a growing presence of various family support topics in cancer research literature over the last three decades. Historically, as suggested by Thomas and Morris (2002), knowledge of how cancer care impacts families and carers was largely shaped by the psychology field also known as 'psycho-oncology'. The scope of family cancer research during the 1970s through the 1980s evolved tremendously since its initial focus on spouses as carers (Lewis, 1986). Kristjanson's and Ashcroft's (1994) literature review of over two hundred papers published from 1970 to 1991 identified four main concepts regarding family experiences with cancer: the family life cycle, communication, family transitions, and the behavioural responses towards cancer. These broad concepts remain relevant for current research, which incorporates more contemporary topic areas for understanding how families are impacted by the cancer patient's treatment process and outcomes, supportive care needs, quality of life, and cultural values.

This literature review was followed by Baider, Cooper and De-Nour's book (1996) which featured emerging psycho-oncology concepts in family cancer research. In their book, Gotay's (1996) work is highlighted to bring attention on the cultural context of family social support and what it means to different groups. Cultural beliefs and values have been an area of focus in cancer research pertaining to Asian populations. Currently, there are several studies on Asian family and carer experiences with cancer, which are discussed later in this chapter. Lewis' (2006, p.20) commentary highlighted evidence-based reasons why "...family-focused research in cancer survivorship..." is essential: 1) cancer brings high levels of stress in the

family; 2) family members are unaware or unresponsive towards another family member's cancer experience; 3) attempts are made to cope with the tension and effects of cancer on the family; and finally, 4) family members face difficulty with continuing their family functions.

More recently, researchers have brought greater attention to the supportive care systems (Gaugler et al. 2008; Grant et al. 2013; Northfield et al. 2010), the quality of life for both cancer patients and family members (Kitrungrote & Cohen 2006; Li et al. 2013; Mellon et al. 2006; Mukwato et al. 2010; Rolland 2005; Young et al. 2016), the psychosocial burden on carers, partners and family members (Ge & Mordiffi 2017; Pitceathly & Maguire 2003; Stenberg et al. 2010; Thomas & Morris 2002; Ussher et al. 2013; van Ryn et al. 2011), and the interventions to improve caregiving outcomes for informal carers (Frambes et al., 2017). As research continually evolves in the area of supportive care, the family experiences examined primarily from the psychosocial context remain prevalent in cancer care research.

Family members as carers

It is widely depicted in the health research literature that family members often function as the main support throughout a person's illness. Although a small range of studies illustrate patient self-care due to limited or absence of family support, researchers often concentrate on the family members as the primary giver of care or the family as the cancer patient's preferred source of support. In a questionnaire study with male (N = 14) and female (N = 50) adult cancer patient respondents, family members were identified as the most desired source for 'tangible aid' (e.g. providing food, obtaining transportation needs) (Rose, 1990). Forms of emotional support (i.e.

reassurance, intimacy and esteem) were also crucial needs sought from family members (Rose, 1990).

As indicated in Rose's (1990) paper, there are values, beliefs, and expectations regarding support that can influence the way the family carer role is formed. A study based on key informant interviews with southern White American adult children (N = 43) of elderly parents, illustrated the effects of how their roles as carers emerged (Piercy & Chapman, 2001). The authors identified five core themes for how the family carer role manifested: fulfilment of expectations, family norms, religious instruction and beliefs, serving as a good family example, and shifts in family roles (Piercy & Chapman, 2001). The themes identified by Piercy and Chapman (2001) are crosscutting with the findings in Asian health research regarding 'filial piety'.

Filial piety and other similar forms of this concept also referred to as 'filial responsibility', 'filial obligation', 'communalism', and 'familism', are values usually defined by shared cultural norms and considered as a key influence on the expectations and choices for providing care to family and friends (Santoro et al. 2016; Schwartz et al. 2010). Filial piety is a concept that particularly applies to the Asian family responsibility of caring for elder family members such as parents (Funk et al. 2013; Santoro et al. 2016). The next section reviews Asian family caregiving research publications, several of which have cited 'filial piety' as an important part of Asian cultural beliefs that either motivates or obliges family members to become carers (Chou et al. 2010; Funk et al. 2014; Miyawaki 2015; Nichols 2013; Sun et al. 2012).

Family carers in Asian families

Filial piety is a cultural norm commonly referred to as an East Asian and South Asian cultural value that binds the family responsibility with caring for ageing parents (Schwartz et al., 2010). Earlier discussed in Chapter 1, the study's objectives include the exploration of meanings and expectations about cancer care. This objective can help to identify how certain psychosocial factors, such as beliefs influenced by cultural norms, may have a relationship with the burden of care. Filial piety is frequently emphasised as an underlying factor for why adult children in Chinese and Indian immigrant families commit to caring for their parents regardless of their circumstances (Baldwin et al 2017; Diwan et al. 2011; Dong et al. 2014; Gupta et al. 2000; Gupta et al. 2005; Lan 2002; Parveen et al. 2009; Sun 2012; Wong et al. 2006). There is lack of current research literature assessing this cultural norm in Filipino populations in the context of cancer or illness. Research papers highlighting the opinions of Chinese Americans, Chinese Australians and Punjabi Canadian immigrant family members, indicated that providing support to the patient with cancer was part of their duty (Lan 2002; Tsai et al. 2011), "natural" (Lui, Ip & Chui, 2009), or traditionally learned as a way of showing respect (Balneaves et al., 2007). Although filial piety specifically pertains to reciprocating care for their parents' family virtues, this principle is part of the broader Asian family values towards caring for a relative experiencing illness or health decline.

The studies of Chinese, Indian, and Filipino cancer patient populations in the U.S., Canada, and Australia, demonstrate that family members were considered a critical part of the cancer care. Several qualitative studies indicate that Asian cancer patients or cancer survivors recognise family support as the main aspect in helping

them deal or cope with their illness (Ashing et al. 2003; Ashing-Giwa 2004; Balneaves et al. 2007; Burke et al. 2011; Gurm et al. 2008; Harle et al. 2007; Howard et al. 2007; Lee et al. 2013; Lui, Ip & Chui 2009; Patel et al. 2014; Singh–Carlson et al. 2013; Tsai et al. 2011; Wong-Kim et al. 2005). Amongst the studies that interviewed Asian immigrant cancer patient populations, they described their family members as supportive around financial and practical needs, physical care, sympathy, emotional coping, and/or physical presence (Balneaves et al. 2007; Gurm et al. 2008; Harle et al. 2007; Howard et al. 2007; Lee & Bell 2011). These findings run parallel to the perspectives of cancer-diagnosed Chinese sample populations in China, who also acknowledged their family members as the main source of support (Liu et al. 2005; You & Lu 2014).

Frequently, authors of family care research papers label family members as ‘caregivers’, ‘carers’ or ‘informal carers’. However, an ethnographic study by Burke, Villero and Guerra (2012) demonstrated a cultural difference in how Filipino cancer patients define the role of their family members. Most of the Filipina breast cancer study participants (N = 51) rejected the idea of having a ‘caregiver’ (Burke, Villero & Guerra, 2012). Instead, they acknowledged their family members as being helpful with financial and practical matters, which was differentiated from a ‘caregiver’ who is expected to be fully involved in every aspect of their care (Burke, Villero & Guerra, 2012). This particular finding identified by Burke et al. (2012), indicates the need to investigate what cancer care means to patients and carers as well as their expectations for caregiving or the carer role. By doing so, the research can bring greater understanding to how care experiences and perceived burdens are influenced by opinions, beliefs, and meanings.

2.5 Burdens in cancer care

In cancer care research, the notion of ‘burden in cancer’ is primarily interpreted by family members and carers as the difficulties and obligations related to caring for a family member. Given et al. (2001) emphasise that the burden experienced by carers is correlated with the demands of caring for the cancer patient. There are studies that provide some insights into how cancer patients perceive the burden of their care, but knowledge in this area remains limited. The burden of cancer care in families is multi-dimensional, because there are social, financial, physical, and psychological implications associated with the individual and collective needs of providing or receiving care (Bevans & Sternberg 2012; Sternberg et al. 2010; Yabroff et al. 2004). The studies in this literature review demonstrate the different ways in which care burden is perceived by family members, carers and individuals experiencing illness.

Types of family perceived burdens

The majority of the research literature assessing the burden of cancer care in families is concerned with how providing support to the care recipient has a negative effect on carers (Bastawrous, 2013). This is frequently described as ‘caregiver burden’ (Kramer, 1997) in American health research, but the term ‘carer burden’ is used in this chapter. There are two types of carer burden described in the literature: objective burden results from the physical functions and resources of caring that can change or impede the carer’s life; and the subjective burden comes from psychological, emotional or attitudinal responses towards the objective burden (Bastawrous, 2013, Hunt 2003). In other literature, these burdens are also identified as unmet needs.

Glajchen's (2004: p. 147) commentary on cancer care literature indicated that the types of unmet needs carers often recognise include those that are "...physical, psychosocial, economic, and instrumental...". When support or resources are not adequate enough to fulfil certain needs, these unmet needs become compounded into more complex or increasing levels of burden (Glajchen 2004; Grunfeld et al. 2004; Siegel et al. 1991). In regard to the prior reviewed literature in this chapter that examined how family members evolve into their role, other researchers have found that the psychological impact of fulfilling the caregiving role was particularly associated with the unexpected and unfamiliar nature of adapting towards being a carer for the cancer patient (Schubart et al. 2008). Through a mixed methods approach, a study of bereaved family members (N = 105) identified multiple "sources of strain" as a result of providing direct and indirect cancer care: the demanding presence of caring, the physical deprivation, the unpredictability of daily routine, and the obligation towards last minute change in planning (Yates, 1999: para. 8).

Another study on carers, referred to as 'informal carers' and 'companions' by the authors, demonstrated varying circumstances that place a burden on their role as carers for a person with cancer (Thomas, Morris & Harman, 2002). The interview findings (N = 32 carers) revealed several objective burdens (e.g. physical, daily tasks, childcare, and transportation demands) that intersected with emotional challenges, which Thomas, Morris and Harman (2002: p. 537) regarded as the "management of emotion" and "...a crucial aspect of what informal carers do in cancer contexts...". Stenberg's et al. (2010) literature review of publications regarding the effects of cancer care on family or carers, identified over 200 kinds of burdens within the 192 publications. The primary concerns were the emotional (subjective burden) and social

(objective burden) problems with care (Stenberg et al., 2010). Together these three papers establish cancer care as heavily demanding on the carers and that subjective burdens occur alongside the objective burdens of cancer care.

Cancer patient and cancer survivor perceived burdens

Although many of the research studies regarding cancer care burden are mainly concerned with how it affects the individuals caring for the ill patient, some of the literature demonstrates cancer care burden from the patient perspective. Knowledge in this area is limited especially for Asian populations. Harrison's et al. (2009) systematic review of the literature revealed that cancer patients experienced the burden of unmet needs relating to emotional and social support, daily tasks, physical needs, and information. McPherson's, Wilson's and Murray's (2007) review of the literature demonstrated that cancer patients who received end-of-life care perceived themselves as a burden on others. The social supportive care during the end of life stage was a major source of this self-perceived burden (McPherson, Wilson & Murray, 2007). In a survey sampling cancer survivors, forty-nine percent reported unmet needs that were 'non-medical' and fifty-three percent "...[agreed] that the practical and emotional consequences with cancer were often harder than the medical issues" (Wolff, 2007: p. 8). These observations correlate with some of the following research findings regarding Asian family care for ageing parents and cancer patients.

In a study of Chinese and Korean speaking immigrants over the age of sixty, study subjects shared their views on family support in a focus group interview (N = 8 focus groups) (Wong, Yoo & Stewart, 2006). Prevailing themes in this study were: 1) the cancer patient's self perception as a heavy burden on their children; 2) their

struggles to establish independence; and 3) their feelings of pressure to adopt or accept American cultural norms (Wong, Yoo & Stewart, 2006). Cancer studies in other Chinese communities echo this same sentiment as well. Qualitative findings from several studies assessing female Asian cancer patients, demonstrated that these women acknowledged themselves as a burden on their family members (Ashing et al., 2003; Kagawa-Singer et al. 2003; Fu et al. 2008; Lui, Ip & Chui, 2009; & Wen et al. 2014). These studies along with the research conducted by Harle et al. (2007), also found that family members distressed the cancer patients because they (the cancer patients) were expected to be self-reliant despite the hardships of cancer therapy. Some of these women perceived that they were required to be self-reliant because of their role (e.g. mother, wife) and function (e.g. household caretaker) within the family structure.

The pressure of sustaining self-dependency and accountability towards maintaining a 'normal' functioning household, are examples of the psychosocial component that manifests from family experiences with cancer care. Gurm's et al. (2006) paper on Canadian Punjabi-speaking South Asian breast cancer patients exhibited findings on the lack of family support with their condition. Several women described it as "...unbending role expectations" (Gurm et al. 2006: 272) in which they were expected to carry on fulfilling the duties of caring for the family household and children. This may also be considered as unspoken burdens which are not communicated with the family.

The topic of self-care has a growing presence in recently published cancer research papers (Fann et al. 2017; Hasanpour-Dehkordi 2016; Hughes et al. 2016; O'Regan et al. 2017; Ose et al. 2017; Taylor 2015; Zhang et al. 2015), in order to

address the issues of patients who must self-manage their cancer care and to also demonstrate a different view of what cancer care is like for some patients who self-manage. These findings in the literature refer to the psychosocial nature of what it means to experience disease or ill health as a family. In summary, the burden of cancer care experienced by cancer patients is another area of research that is critical to expand where evidence is limited.

2.6 Social determinants related to cancer care burdens

As discussed earlier, understanding how social determinants impact health is an important approach for researchers to consider when asking why and how populations face certain burdens with illness. The studies in this literature review do not use a social determinants framework in their methodology, but focus on a narrow subset of factors such as social demographics and culture. Despite the limited scope of research literature regarding how social determinant factors influence or are associated with cancer care burdens, the factors recognised in these publications are important for making comparisons with the study findings as well as identifying the areas of gaps in cancer research. This section will begin highlighting key findings from a small number of general and systematic literature reviews conducted on published studies that identified social factors associated with burdens in cancer care.

Findings from the general and systematic literature reviews

The general and systematic research literature review papers discussed in this section identified a limited set of factors associated with the emotional, psychological, and financial burdens of cancer care amongst family carers and patients. These papers reviewed studies with either a cancer patient or a carer sample population. The term

‘social determinants’ was not used in any of the literature review publications, but ‘factors’ was used as an umbrella term for the social demographics (gender, age, socioeconomic status, marital status) found associated with cancer care burdens. Pitceathly and Maguire (2003) reviewed various research literature assessing the factors related to the carers’ psychological health problems. The authors recognised that general caregiving research has found young age, the female gender, and socioeconomic status as the factors most associated with depression in carers (Pitceathly & Maguire, 2003). However, Pitceathly and Maguire (2003) considered the findings in the reviewed publications to be inconsistent in cancer research. In a more recent systematic review of the literature, Ge and Mordiffi (2017) confirmed there was ‘moderate evidence’ of younger family carers having higher levels of emotional burdens when caring for an elderly cancer patient.

Studies have also assessed the social demographics related to cancer patient burdens. In a literature review of research on loneliness in cancer patient populations, Deckx et al. (2015) found that the cancer patients’ marital status (never-been married, widowed or divorced) and the lack of psychological or social support were the social factors linked to loneliness. From the systematic review by Cook et al. (2018), only nineteen of the thirty-nine papers assessed the relationship of social demographic factors with emotional distress and depression in patients after being diagnosed with cancer for a year or more. Furthermore, the findings were not consistent amongst the studies that measured social demographic factors. A few papers demonstrated that emotional distress or depression had a significant relationship with age and gender. Also from a limited number of studies, only three other social demographics were considered ‘significant predictors’: income, education and socioeconomic status

(Cook et al., 2018). From the studies systematically reviewed for factors related to financial burden in cancer patient populations, the female gender, younger age, and low-income status were identified as the most commonly reported social factors related to financial burden (Gordon et al., 2017). Some of these studies included in the review were those conducted in low-income countries. Therefore some of the findings must be reconsidered for relevance in high-income countries.

The literature reviews papers discussed in this section demonstrate the challenge of identifying consistent data across studies that measure and analyse social demographic factors from a cancer care perspective. The authors suggested that in addition to the limited amount of published work in this area, it was challenging to compare findings amongst the varied approaches for measuring and analysing how social demographic factors have a causal relationship with a burden in cancer care. The remaining section of this chapter examines individual studies that evaluate the factors associated with family care burdens experienced by both general and Asian populations.

Factors related to care burdens in general populations

In studies pertaining to the general population or multiple racial-ethnic samples, the factors of income, gender, race-ethnicity and marital status, were found to be most associated with the financial and care burden found in the illness experiences of families. The care burdens assessed in these papers were those of family carers. Pinqart's and Sørensen's (2005) meta-analysis of family care compared racial differences (between Whites, African Americans, Asian Americans and Hispanics) regarding resources, mental well being, and stress. Amongst the

findings relevant to Asian Americans and the associated burden in caregiving, the authors observed that Asian Americans as compared to Whites had more caregiving duties, lower relationship quality and were more depressed (Pinquart & Sörensen, 2005).

Another paper looking at work and gender impact on stress levels from a sample of 183 main carers of cancer patients, revealed that employed women reported more “care-related fatigue” than men (Gaugler et al. 2008: p. 351). Also for women with or without jobs, they were more likely to be heavily relied upon as the support for the daily routine of the cancer patient when compared to men (Gaugler et al. 2008). These findings are supported by Marshall’s et al. (2011) review of the literature in which the authors established that females especially experienced a great deal of burden with providing care. Papers assessing stress on family finances revealed that the carers who provided “high intensity care” (Gardiner et al. 2014: p. 377): 1) had a lower socioeconomic status or income; 2) were from an ethnic minority group; or 3) were more likely to experience either financial burden or greater levels of this problem (Arozullah et al. 2004; Gardiner et al. 2014; Lahaie et al. 2012; Yun et al. 2005). Although the studies on the general sample populations identified different types of social determinants factors, these studies focused solely on family carer populations. The literature review on Asian populations will report study findings pertaining to elder relatives, cancer patients, and family carers. Unlike the general population studies, the research on Asian populations primarily evaluates the cultural beliefs and norms related to care.

Factors related to care burdens in Asian families

Many of the studies reviewed in this section largely focused on how cultural beliefs, values, and norms correlate with the emotional or psychosocial burdens in cancer care. Subtle inferences can be made about the other types of social determinants related to the cancer care burdens of Asian populations. In this research literature review, three main types of social determinants emerged from the literature regarding the burden in cancer care experienced by Asian families: values, beliefs, and social support. Language, acculturation, and economic status were other factors associated with cancer care burden findings. These studies were mostly qualitative and assessed Chinese, Taiwanese, Indian, South Asian, and Korean populations. A few studies with multiple racial-ethnic sample populations are included in this review to understand some of the comparisons made between the groups.

Values and beliefs were found to impact the perceived burden in caring for a relative. In two studies that interviewed immigrant cancer patients and caregivers from South Asian or Chinese families, there were research participants who believed that the family would be judged negatively by others due to the cancer (Balneaves et al. 2007; Lui, Ip & Chui 2009). Caregiving was a way of upholding honour in the family, because it protected the patient's well-being and exposing of family member's cancer diagnosis. Connected to the belief of upholding family honour is also the value of reciprocating the duty of family care between parents and children. Findings related to family duty and reciprocity is prominent in research conducted on family care in Asian populations, indicating both positive and challenging outcomes related to this important family value.

The Asian care studies display a strong emphasis on the relationship between family carer values and their experience or perceptions of care burden. Youn's et al. (1999) paper reported that Koreans valued the highest degree of familism (i.e. family needs over individual needs) towards caregiving, followed by Korean Americans and then White Americans. With the higher levels of familism, the burden of caregiving perceived by Korean Americans ($M = 33.4$, $SD = 8.2$) and Koreans ($M = 31.5$, $SD = 7.2$) were found to be higher than White Americans ($M = 26.9$, $SD = 10.5$) (Youn et al., 1999). This finding relates to Lan's (2002) work on learning about filial piety values amongst the children and carers of ageing Chinese immigrant parents. The data relating to the adult children's experiences and feelings towards elderly care revealed that securing and ensuring care for their parents was their duty regardless of the hardships (Lan, 2002). This author's paper on filial norms outlines the cultural meanings and behaviours of Chinese American immigrant families dealing with elderly care in California. The key informant interviews revealed that both the adult children and the paid care workers (who eventually become extended family members) felt obligated to fulfil the responsibility of caring for the ageing parent in a family home (Lan, 2002). Although there were varied circumstances of caregiving between the four families, each family's sense of burden was intertwined with cultural beliefs that the family reciprocity of care for elders was crucial, necessary and binding (Lan 2002).

Between two studies with South Asian family carer populations, the findings differed on how the presence of cultural norms impacted the care burden. Although not specific to cancer care, Gupta and Pillai's (2005) interview questionnaire study with immigrant family carers of South Asian parents in Texas revealed the importance

of cultural norms. The authors reported that those who greatly valued carrying out filial norms were less likely to experience burden compared to the people who did not believe in fulfilling filial norms (beta = 0.182; p = 0.05) (Gupta & Pillai, 2005). This study implies that the carers' attitude towards caregiving norms may have an effect on the extent of the burden experienced by carers. This finding contrasts with an earlier published paper assessing family members who cared for a Punjabi breast cancer patient residing in Canada (Balneaves et al., 2007). The level of care burden was not measured quantitatively, but the researchers found that the family members reported moderate levels of distress as well as pressure to safeguard their family member's condition and circumstances from other Punjabi community members. Although the family members dealt with various challenges (e.g. leaving a job, difficulty with sustaining physical and supportive presence, dealing with the stigma of cancer), the carers' description of their supportive roles to maintain the family member's optimism and strength had a positive tone (Balneaves et al., 2007). The family structural support around caregiving which is guided by beliefs and cultural norms, appears to play an important role in sustaining the cancer support that patient's may need.

Other social determinants that were observed to have an impact on care burdens on Asian cancer patients and family carers included language, acculturation, and economic status. Yun's et al. (2005) Korean population study (N = 704) reported that carers who were married, provided prolonged care, and cared for patients with poor functioning, were more likely to be associated with the loss of family income as a burden in cancer care. Han et al. (2008: p. 520) found that Korean American immigrant family members were struggling with 'competing priorities', in which the

long hours of employment shifted their attitudes towards elderly care as an obligatory burden. Language and acculturation, two important aspects for assimilating into mainstream social access and structure, were both found to have an effect with the immigrant family cancer care experiences. The limited or lack of ability to speak English proficiently was related to the cancer patient's and carer's feelings of burden in dealing with cancer care (Ashing et al. 2003; Lui, Ip & Chui 2009; Tsai et al. 2011). For example, a family member of a cancer patient described bringing his father to his medical appointment as "...definitely [making his] work harder..." since neither his father or mother spoke English well enough (Lui, Ip & Chui 2009). In addition to immigrants who faced language barriers, others felt the burden in cancer care from the difficulty of assimilating in their new home country (Wong-Kim et al., 2005), their limited resources and social support (Balneaves et al. 2007; Tsai et al. 2011), and the social isolation of being apart from the family or friends they left in their home country (Tsai et al., 2011). In South Asian (Gupta & Pillai, 2005) and Taiwanese families (Shieh et al., 2012), those with greater social support or networks were found to have less burden with cancer care. These findings indicate that cultural, social and economic factors appear to have a critical impact on the cancer experiences of immigrant families.

2.7 Strengths, limitations, and identified gaps of the reviewed literature

This literature review has demonstrated diverse knowledge about the experiences of patients and family members dealing with the challenges of care, particularly relating to cancer. Research related to cultural influences, caregiving and psycho-oncology, have a strong subject matter presence amongst the publications

reviewed in this chapter. In order to review a wider scope of research relevant to the care experiences of Asian populations, studies that were not specific to cancer were included in the review. The findings from the literature review establishes that family obligations and expectations together with the individual opinions of patients and carers, are often integrated aspects of dealing with cancer care. Across several studies and expert commentaries, there was a strong consensus that family members have a critical role, relationship, and influence on the care for their family members and their well being. As a result, the majority of studies examined the perspective of family carers compared to cancer patients viewpoints. Since cancer care experiences in the family involve both family members and the cancer patient, the study's research method of gaining perspectives from both sides can bring a more cohesive understanding of family cancer experiences. There is a limited volume of cancer research publications that demonstrate the experiences of patients self-caring for themselves at any point of the cancer care trajectory. This may be a critical area to investigate when evaluating the factors contributing to cancer care burden, because family carers may weave in and out of the patient's care and support needs.

The research pertaining to Asian populations provided distinct cultural or ethnic-specific knowledge on how the provision of care and its burden have shaped the lives of Asian families and their perceptions. Although several of the Asian studies had small sample populations, these studies produced some critical in-depth findings that may have not been achievable through large-scale research. There were a small number of studies available on Asian populations about family experiences related to cancer care burden and determinants of health. Chinese were the most frequently studied Asian ethnic group in the literature review. There were fewer studies

involving Filipino and Indian research participants. Amongst the studies with Indian immigrant populations, these groups resided either in Canada or the United Kingdom. Despite the large numbers of Filipinos and Indians that live in the U.S., the limited research literature relating to these two ethnic groups confirms that they remain underrepresented in family cancer care research (Chen 2005; Shavers 2007). In addition to the limited ethnic-specific cancer research literature, the concepts of social determinants and immigrant health was not explicitly discussed in the body of literature reviewed on family cancer care and its burdens. Other aspects of immigration such as the length of residency, acquiring resources or assets in the adopted country, and establishing priorities, are also critical factors to consider when assessing the burden of cancer care in immigrant families.

The body of research literature identified and reviewed in this chapter exemplifies the multi-faceted nature of: 1) how families experience dealing with care for individuals with cancer whose health status is in a vulnerable state; and 2) what it means for carers and individuals in poor health to shoulder the burden of caring for illness as a family. This literature review revealed that knowledge about family cancer care remains limited in the areas of Asian American immigrant populations and determinants of health research. Therefore, the thesis addresses this gap in knowledge by constructing evidence to understand the following in Chinese, Indian and Filipino immigrant populations: the meanings of cancer care; the circumstances influencing the experiences with cancer; the types of burdens experienced in cancer care; and the key factors influencing the determinants of the cancer care burden. The ways in which the research question and objectives are addressed in this study is further examined in the next chapter.

Chapter 3 | Theoretical framework

3.1 Introduction and background

In parallel with epidemiological health disparities research that seeks to understand disease with the use of social demographic variables, a social theoretical framework is applied in this thesis to evaluate the fundamental factors associated with the burdens in cancer care. The social determinants of health theories (Dahlgren & Whitehead 1991; Berkman et al. 2000) were particularly influential in shaping the thesis' research objectives and interview questions. Together with the theory on social, economic and cultural capital (Bourdieu, 1986), the integrated theoretical framework helps facilitate the analysis and interpretation of research findings. Refraining from making social category comparisons and contrasts, the aim for using a social theoretical framework is to recognise and comprehend the interplaying social elements related to cancer care burdens.

As discussed in Chapter 1, the underlying theory of social determinants in health have been conventionally applied to social epidemiology macro-level research. The study purpose and objectives creates an opportunity for applying this theoretical construct on a micro-level. Through understanding the sample population's background, circumstances, opinions, and experiences, the study can begin to identify factors and reasons why cancer patients and family carers experience burdens with cancer care. The social, financial, and cultural capital theory plays an important, but subtle, role in the study's theoretical construct for generating knowledge about the cancer care burdens. Resources and assets can be influential towards the patient's and family carers perspectives and experiences in dealing with cancer care.

The pathway for identifying how social determinants of health contribute to burdens in cancer care is guided by the research objectives outlined and by key informant interview questions. During the interview, there were several questions asked about the respondent's sociodemographic background (i.e. household income, gender, education, marital/relationship status, zip code, employment, health insurance coverage, language spoken, and age). Whilst the interview questions were centred on meanings of cancer care as well as the experiences and perceptions of cancer care burdens, the interviews collected viewpoints on expectations, choices, barriers and conditions surrounding the cancer care burdens. The conditions and circumstances of the study participants lives (social determinants) are presumed to have an influence on expectations, meanings and opinions (ways of thinking) which result in choices, barriers, and burdens (outcomes) within cancer care.

3.2 Use of theoretical constructs from health and social research

The study's underlying theoretical assumptions regarding cancer care burdens related to Asian American immigrants are guided by the theoretical constructs associated with the social determinants of health framework and Bourdieu's (1986) social, cultural and economic forms of capital. These social theory based, distinctive theoretical constructs have a subtle presence in the cancer literature reviewed in this chapter, yet are critical for understanding disease burden, socioeconomic access, healthcare barriers, and social relationships. The framework for social determinants of health has been applied to current cancer research and therefore research literature associated with this model are discussed more extensively in this chapter. The basic principles of social, economic and cultural capital are introduced in this chapter. This

section reviews the literature on the theoretical constructs which shape the study's methodology and interpretation of the data as it relates to understanding the factors associated with cancer care burdens.

Social determinants of health

The World Health Organization (2018: para.1) defines social determinants of health as "...the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life." Examples of these factors include income, identity, beliefs, and support network. The social determinants of health model has been widely applied to disciplines relating to social epidemiology (Baum 2016; Berkman et al. 2014; Honjo 2004; Marmot & Bell 2016) and socioeconomic structural policy (Baum 2016; Braveman & Gottlieb 2014; Graham 2004; Marmot 2005; Wilkinson & Marmot 2003). These disciplines are often reinforced by quantitative data and therefore qualitative research tends to be a minority amongst the body of research that incorporates the social determinants of health framework in its methodology. Nonetheless, the framework offers a way for research that is exploratory to examine how factors that are socially, economically, and individually embedded in people's lives influence their health experiences and outcomes. Whitehead and Dahlgren's (1991) and Berkman's et al. (2000) theoretical frameworks feature varying types of social determinant categories, upon which the study can build an association between determinants of health and cancer care burdens.

To provide a general understanding about the current scope of health research literature relating to social determinants, this section reviews some of Raphael's

(2006) appraisal of the types of health research related to social determinants as well as recognise how these types of research are applied to the field of cancer. Only “explanatory frameworks” and “life-course perspectives” are discussed in this chapter due to their relevance for the study. Concepts drawn from these two social determinant research themes are further examined later with the study findings.

The explanatory frameworks that have been predominantly used in recent research to primarily demonstrate how socioeconomic inequality affect health outcomes (Raphael, 2006). Utilising an explanatory framework, Marmot and Wilkinson’s (2003, 2005) influential publications on social determinants emphasise how socioeconomic stratification and social inequities are associated with population health disparities. Race-ethnicity, income, education level, neighbourhood poverty levels, and healthcare insurance are the social determinants frequently analysed and correlated with poor outcomes related to cancer screening, incidence, survival and mortality rates in U.S. populations (Ahmed et al. 2015; Damiani et al. 2015; Landrine et al. 2017; Manser et al. 2014; Maskarinec et al. 2011; O’Keefe et al. 2015; Singh et al. 2011; Zahnd et al. 2017). The breadth of social determinants research has extended to the study of other social factors and cancer outcomes relating to: cancer survivorship care (Advani et al. 2014; Coughlin et al. 2015; Wen et al. 2014), psychosocial being (Smith-McLallen et al. 2011; Von Wagner et al. 2011; Wen et al. 2014), treatment decision-making and adherence (Enard et al. 2016; Mead et al. 2013; Wheeler et al. 2013), biological characteristics (Wheeler et al. 2013), and marital status (Aizer et al. 2013).

Life-course factors have also been applied in social determinants research to make sense of how certain factors together with experiences over time have an effect

on an individual's or population's health (Hertzman 2000; Hertzman & Power 2003, 2006; Raphael 2006). There are few cancer research literature outputs relating to social determinants connected to the health effects that are acquired and accumulated during the life course. The paper by Oliffe (2009) serves as an example for assessing experiences, opinions and social determinants of cancer patients from a life-course perspective. Oliffe (2009) described the lives of three Australian men who were diagnosed with prostate cancer. Childhood illness experiences, social class, and cultural norms were some of the social determinants influencing these men's health behaviours associated with perspectives on masculinity acquired from childhood and developed throughout adulthood.

Dahlgren and Whitehead's (1991) and Berkman et al's. (2000) foundational concepts for examining how social determinants impact health have informed the work of other researchers who utilised an explanatory framework or a life-course approach to understand the ways in which social networking (Gordon et al. 2017; Holt-Lunstad et al. 2017;), gender (Östlin et al. 2006; Szreter & Woolcock 2004), socioeconomic status (Lahelma 2001; Ncho & Wright, 2013), and immigrant status (Dong & Chang 2017, Zheng 2017) factors have an effect on a population's health. The subsequent sections briefly review how each model demonstrates the fundamental categories of social determinants relevant to health.

Dahlgren and Whitehead (1991, p.314) conceptualised a model that characterises social determinants as a diverse range of intersecting layers of factors that impact health. In Figure 3.1, there are four main categories for the social determinants of health model: 1) socioeconomic, cultural and environmental conditions; 2) living and working conditions; 3) social and community networks; and

4) individual lifestyle factors. The outermost layer depicts socioeconomic, cultural and environmental conditions as a macro structural level of influence on health. The innermost layer of individual characteristics and lifestyle appear to function as a personal intrinsic core linked to social identities, cognitive behaviours, and biological

Figure 3.1 has been removed due to Copyright restrictions
from Dahlgren & Whitehead, 2001

Figure 3.1: Social determinants of health (Dahlgren & Whitehead, 2001)

characteristics. Although this model does not illustrate mechanisms for how social determinants lead to health pathways or generate health outcomes, it provides an initial overview of determinants of health as a complex range of social conditions, networks and individual factors (Dahlgren & Whitehead 2001, p. 314).

Berkman et al's. (2000, p. 847) model, which is regarded as the 'Social Networks of Health', demonstrates an overview of social determinant categories that are connected to health pathways. The authors categorised the determinants as 'macro', 'mezzo', and 'micro' to depict the varying degrees of influence on health. Berkman and colleagues (2000, p. 847) also linked these categories to 'pathways',

which can be viewed as trajectories that lead to behavioural, psychological and physiological health outcomes. Shown in Figure 3.2, the categories of health determinants range from social structural to social networks to psychosocial factors.

Figure 3.2 has been removed due to Copyright restrictions from Berkman et al., 2000

Figure 3.2: Social networks of health (Berkman et al., 2000)

Similarly to Dahlgren and Whitehead's (1991) work, this model is reflective of socio-economic, public policy and sociological disciplines. A distinct aspect of Berkman et al's. (2000, p. 847) theoretical framework is the explicit recognition of psychosocial factors (micro) that lead to individual health pathways. This brings awareness that populations are made up of individuals who each have their own personal set of behaviours, emotions, and biological being.

The models developed by Berkman et al. (2000) and Whitehead and Dahlgren (1991) offer a broad framework to identify and understand from a diverse range of categories, macro to micro levels, the factors that are associated with health and the

burdens of illness. Although the current landscape of social determinants research is dominated by studies measuring the health outcomes affected by socioeconomic differences and inequality, there are opportunities for exploratory, qualitative, and sub-population research to evolve the use of this theoretical framework for producing novel findings where there are gaps in research. Capital theory, which is discussed in the next section, has a complementary role in understanding how social factors impact health.

Social, economic and cultural capital

Some of the general principals from the social determinants of health framework have an important connection with Pierre Bourdieu's (1986) contemporary approach to understanding capital theory. Both the social determinants of health and capital theories regard specific sets of social factors as influential sources for shaping the outcome of people's status in society. In correspondence with the social determinants framework's focus on the relationship of social conditions with health status, Bourdieu highlighted three fundamental types of capital which he viewed as influencing the progress of socioeconomic gains and status: social, cultural and economic capital (1986). This section introduces the basis of social, economic and cultural capital theory in order to highlight aspects of the study's philosophical approach to understanding the burdens of cancer care in an immigrant sample population. Connections are made with the social determinants of health framework, in order to comprehend how the scope of capital theory relates to this contemporary sociology public health research area. Later, Chapter 9 provides more discussion of

the literature review and perspectives of the capital theory as they relate to the study's data analysis and discussion of findings.

Bourdieu identified three main kinds of capital in his essay, "The Different Forms of Capital" (1986): social, cultural and economic. Other sociological researchers, including Coleman (1988) and Putnam et al. (1993), have further developed the theoretical constructs of capital by assessing the dimensions of attaining and using capital, social stratification, and social mobility (i.e. movement within the social hierarchy). For example, Coleman explicitly stated that social capital "...all consist of some aspect of social structure, and they facilitate certain actions of individuals who are within the structure" (1988: p. 302). Other recent publications provide a more global definition of capital and perspectives regarding how the varying forms of capital impact the social, economic and health welfare of populations. The following definitions provide a general background on what is meant by social, cultural and economic capital.

Cultural capital may come in diverse forms primarily recognised in the embodied state (e.g. skills, knowledge, language, identity), objectified state (e.g. writings, artistic works, inventions), and institutionalised state (e.g. credentials and titles in reference to authority or competence) (Abel 2008; Bourdieu 1986; Davies and Rizk 2017). Social capital can be defined as collective social resources, including shared norms and the previously described cultural assets, which are gained through connections and networks (Bourdieu 1986; Keeley 2007; Rocco & Suhrcke 2012). Lastly, economic capital refers to the varying forms of and connection to economic and financial assets such as employment income and benefits, financial assistance, and personal property (Bourdieu 1986; McQueen et al., 2007). Although there are

various perspectives on the meanings of social, cultural and economic capital, a mutually shared concept of the capital theory is that the lives of people are often affected by the availability, accessibility and accumulation of social, cultural and economic resources. Bourdieu's 'capital theory' alludes to the idea that individuals and groups must allocate capital, including certain types and amounts of capital, in order to make socioeconomic progress which he labels as 'profits' in his paper.

In the book, "Social Capital and Health", the authors provide views on both the potential benefits and harmful effects of social capital (Kawachi, Subramanian & Kim, 2008). The chapter discussing research results on ageing populations reported that older groups exposed to positive or higher levels of social networks had "...lower risk of all-cause mortality..." and better quality of life (Cagney & Wen, 2008: p. 241). On the other hand, other studies reveal that social capital can create excessive expectations for individuals to provide support to members of their group as well as to comply with group norms in ways that differ from independent preferences or choices (Baum 2016; Kawachi, Subramanian & Kim 2008). The social determinants of health framework has a correlative implication to Bourdieu's work, but it approaches the evaluation of social strata from a reverse approach. The theoretical framework typically focuses on the detrimental health effects of social inequalities, particularly the outcomes resulting from poor economic status or conditions (Ahnquist et al. 2012; Marmot 2005; McQueen et al., 2007; Scheffler et al. 2010). Although this concept of social inequalities is not meant to imply that all health outcomes is solely based on economic status or that health status is the same for populations with similar per capita (average) income.

Marmot (2005) alludes to this point by noting in his paper that poor populations in China and in the State of Kerala, India were observed to have better health status compared to other corresponding groups of similar socioeconomic status. Later research papers comparing groups from the same per capita income status exhibit how other factors may have a role in population health disparities. The State of Kerala, which has a poor per capita income status, was found to have differences in life expectancy outcomes by social indicators of populations and households. The study found that life expectancy was 2 to 3 years longer for those who went to college in comparison to people who were illiterate (Sauvalet et al., 2011). Also households that were small, “materially privileged”, or had higher income with “good housing conditions”, had better life expectancy (Sauvalet et al., 2011: p. 479).

In a study comparing racial groups, Wilson, Thorpe and LaVeist (2017) found differences of health behaviours and outcomes amongst racial groups in the U.S. with ‘very high income’ status (\$175,000 or more). The study’s odds ratio analyses revealed that in comparison to Whites, Blacks and Asians had lower odds of self-rating their physical health as ‘excellent’ or ‘very good’ (Wilson, Thorpe & LaVeist, 2017). Furthermore, Asians had the highest odds of reporting a high cholesterol diagnosis, whilst Blacks had the highest odds of reporting a diagnosis of diabetes and of hypertension (Wilson, Thorpe & LaVeist, 2017). In this study, it shows that there are racial differences in the self-rating of overall health and self-reporting of chronic conditions despite the sample population having ‘very high income’ status.

Thus there are multiple factors, which Bourdieu (1986) and intervening references have suggested, that can have an effect on the individual’s or population’s social and economic conditions. Bourdieu does not specify types of conditions nor

expand this theory under the context of evaluating socioeconomic status and health outcomes. Rather, the capital theory focuses on the sociological dynamics of how social, cultural and economic assets or resources are acquired, reproduced, and accumulated. Bourdieu's philosophical perspective has particular importance in the later chapters that report and discuss the study findings.

3.3 Concluding Summary

The theoretical framework for this thesis provides the context for me to examine how social determinants and the different forms of capital are relevant to the study population's perspectives of the cancer care burdens they experienced. The theories of Dahlgren and Whitehead (1991), Berkman et al. (2000), and Bourdieu (1986) lay conceptual groundwork that inform how social factors shape the stratification, conditions and norms in populations, which in turn affect the life-course of individuals. In addition to producing study findings to help narrow the gaps knowledge about Asian immigrant experiences and outcomes with cancer care burdens, the thesis explores a new approach for incorporating social theories in cancer care research. This theoretical approach can promote understanding about how the diverse, fluid and intersecting nature of social factors can affect cancer burden. The next chapter will describe the research methodology and methods applied in my study and how they complement the theoretical framework.

Chapter 4 | Research methodology & methods

4.1 Introduction

Earlier in Chapter 1, it was briefly discussed how the concept of ‘cancer burden’ was established through positivist inquiry. Alongside a social theoretical framework, my research draws upon interpretivist and constructionist positions to reshape the way cancer burden is understood. This chapter will describe the epistemological foundation that guides the research. Also discussed are the research design and methods which explain: 1) the research strategies applied towards collecting, analysing and interpreting the qualitative data; and 2) the ethical considerations and protocols implemented for the study. The limitations and strengths of the study are explained in this chapter in order to recognise the extent to which the selected methodology and methods can examine and interpret cancer care burdens of Chinese, Indian and Filipino American immigrant families.

4.2 The research methodology

The thesis addresses the study question and objectives through interpretivist and constructionist approaches. It also leverages on sociology theory frameworks to help identify and further comprehend the factors associated with the burdens of cancer care. Defined earlier in Chapter 1, the burdens in cancer care are viewed here as the personal challenges and difficulties in dealing with the care of the disease. The thesis draws upon an interpretivist and constructionist stance to generate in-depth understanding about cancer burden as it relates to the personal experiences with cancer care and the circumstances surrounding these adversities. Two key sets of realities for explaining the types of burdens that exist with cancer care, as well as the

factors contributing to these burdens, are examined. The realities come in the form of viewpoints, meanings and lived experiences as perceived by those affected by the disease (i.e. cancer patients and carers) as well as the conditions (e.g. social, economic, environmental) that surround the lives of these individuals.

Although the social and economic conditions associated with cancer burden have been mostly assessed from a positivist approach used in social epidemiology, my study will incorporate social theory frameworks used in social epidemiology as a way to guide a multi-layered understanding about pathways to cancer care burdens. “Meaning and human agency” (Ritchie & Lewis, 2003: p.17) together with social research theories can redefine the way the burden in cancer is conceptualised in the thesis. The following sections illustrate the role of interpretivism, constructivism, the social determinants of health framework, and the capital theory as a basis for the qualitative research methods used to form new knowledge about the cancer care burdens.

Depth through interpretivism

As previously stated in Chapter 1, the intent of the study is to explore the factors that have crucial relevance for illustrating the cancer care burdens experienced by Chinese, Indian and Filipinos immigrants diagnosed with cancer, and their family carers. Interpretivism, as a basis for the research objectives and methods, allows me to consider several aspects of the research question being studied. The research objectives and methods lead to what might be described as subjective knowledge, yet provides greater depth of insight into experiences, populations, and subjects matters, particularly those that have not been well studied in the domain of research (Alvesson

& Sköldbberg, 2018). The subjective knowledge includes meanings and interpretations about living with cancer, as well as accessing the social and cultural nature of the sample's circumstances (Rubin & Rubin, 2005). This should fulfil the research objectives of the study: how cancer patients and family carers perceive cancer care; the way experiences and meanings of cancer care burden are influenced by their expectations, choices and obstacles in cancer care; and the social determinants that are related to the burdens of cancer care. This study will present some novel findings drawn from the experiences of Asian American immigrant families and the use of social theories together with qualitative methods to understand the factors of cancer burdens.

Another particular strength of the interpretivist approach for addressing the research question is that it can facilitate greater comprehension about the social processes involved. That is, it explores the relationships between individuals or groups as well as how their social identity, position, status or culture may play a role in the way burdens are perceived and experienced. The familial context of the study can potentially inform how "...the broader domains sometimes labeled as society and culture have a profound influence on what happens in private relationships, and private relationships undoubtedly play into larger discourses of societies and cultures" (Manning & Kunkel, 2013: p.16). Examples of family and caregiving research with an interpretivist approach have been discussed in the literature review.

Engaging in interpretivist inquiry to identify and understand the social determinants related to the cancer burdens findings from this study is an innovative approach to further promote in health research. Social epidemiology (i.e. study of social structures such as race, economic status, and gender) has been frequently

selected as the research approach to understand the social determinants of disease and how it impacts specific population health outcomes (Haynes & Smedley 1999). Wuest et al. (2002), Schulz et al. (2002), and Ornelas et al. (2009) have explicitly structured their research on social determinants with an interpretivist lens. Their work enabled a deeper understanding of varying social contexts and factors that are present in the effects of harmful health circumstances on individuals and groups. Research knowledge about the burdens in cancer care can be represented by people's realities and constructs as well as how I interpret the data using social theoretical frameworks to guide research analysis and discussion.

Multiple realities through constructivism

The concept of 'constructivism' is part of the data collection approach, because 'meanings' are rooted and constructed from the sample population and the investigator to produce findings (Silverman, 2011). The "multiple constructed realities" (Ritchie & Lewis, 2003: p.12) employed by the constructivist model has an important role in building the comprehension of and explanation for cancer care burdens in immigrant families. The research question in this study brings a level of complexity that can benefit from the integration of my use of social theory and interpretation of data with the lived realities of individuals diagnosed with cancer and their family carers. Both the research literature reviewed in Chapter 2 and the research conducted for this thesis take on the assumption that some families share the burden of cancer care, because they collectively deal with the illness in a certain way or form that may be reflective of their relationships, beliefs, experiences and the conditions they live in.

Based on Lee's (2012) observation between social and radical constructionism, the study takes on a more social constructionism side for data collection. Lee (2012: p.405) explains that social constructionism "...focuses on collective generation of meaning..." and radical constructivism is centred on applying the individual cognition to solely participate "...in the meaning-making activity." In this thesis, the various realities merged to answer the research question are: 1) the knowledge of the individuals diagnosed with cancer; 2) the knowledge of the family carer; 3) my worldview of research and social realities; 4) the findings from the literature reviewed; and 6) how the I interpret the research data alongside with the methodology and social theories.

4.3 Research Design

The qualitative research design was cross-sectional for the purpose of studying the burdens in cancer care in a sample population that is able to communicate about their lived experiences, conditions, and viewpoints during a period in their life in which they dealt with familial circumstances of cancer care. In line with the methodology discussed earlier, the research design sought to gather multiple realities to form an interpretative understanding about family cancer care experiences. Key informant interviews were conducted with a multi-ethnic Asian American immigrant cancer patient and carer population samples.

The findings from the data collection were examined using a pragmatic qualitative approach of thematic analysis. This way of constructing knowledge through identified collective experiences, meanings, and perspectives which formulate the themes, was employed in order to methodically establish and structure

themes as well as interpret the patterns within and across themes (Aronson 1995; Braun & Clarke 2012; Riger & Sigurvinsdottir 2015). Sub-thematic categories were derived from the themes to bring out other attributes, which exhibit the multi-dimensionality of the overarching theme. A deductive process with the data coding and analysis (Braun & Clarke, 2012) was implemented in order to incorporate the theoretical framework that shapes the research objectives and thesis. Although the employed research methods do not provide findings that can be statistically generalised for Asian American groups, the research strategies were instrumental in exploring Asian American immigrant family cancer care issues at greater depth.

4.4 Research setting, strategy, and criteria for sample selection

The study was conducted in the San Francisco Bay Area to recruit a sample population that reflects the growing immigrant community living in the region. The population was sampled from Chinese, Indian and Filipino groups living in the counties of San Francisco, San Mateo, Santa Clara, Alameda, and Contra Costa. The study's sample population encompasses a total of nine cancer-diagnosed adults (from different ethnic groups) and nine corresponding family adult carers. Chapter 4 will provide additional details about the ethnic representation of the sample population. Structuring the sampling by pairs within families enabled me to gain knowledge from two distinct sides and learn from a collective view of family experiences and dynamics with illness. Although the sample size was small, it is reasonable for achieving the intended number of people who fit the sample population criteria and could provide in-depth perspectives (Braun & Clarke, 2013).

The research aimed to study the scope of Asian American immigrant cancer care experiences rather than put forth a set of findings to be statistically generalised for each Asian ethnic group in the sample population. So another important strategy for the sampling was to have a level of heterogeneity regarding immigrant diversity. Diversity in the sample population can reflect the range of people's life experiences, social conditions, beliefs, and constructs (Luborsky & Rubinstein, 1995). These aspects include the rationale for immigrating to the U.S., the infrastructures in place for enabling immigration, the time of immigration, the length of residence in the U.S., the adaptation or acculturation into American society, and the social and economic conditions of resettlement (Berry 1997; Fawcett & Arnold, 1987; Jasso et al. 2004; Viruell-Fuentes et al. 2012). These features may help explain how certain determinants of health and social cognition factors are associated with the way lives as an immigrant, or being part of an immigration family, impacts cancer care. The fluctuating patterns of immigrant families who currently live in the San Francisco Bay Area made it more challenging to achieve immigrant diversity within one Asian ethnic group. Thus, the three major Asian ethnic groups were part of the sampling strategy to make attaining immigrant diversity more feasible.

The study inclusion criteria for study participants who were diagnosed with cancer were as follows: 1) had a first-time diagnosis of cancer within the last 10 years at the age of 50 years old or older; self-identified as Chinese, Filipino or Indian; 2) immigrated to the U.S. at 25 years old or older; 3) spoke English Mandarin, Cantonese, Hindi, Punjabi, Tagalog or Ilocano; 4) received the cancer treatment in the U.S.; and 5) lived in the U.S. as a permanent resident. The exclusion criteria were: 1) having more than one cancer diagnosis; 2) inability to speak a language spoken by me

or the interpreter; 3) not residing in the U.S. permanently; 4) did not receive cancer care or treatment in the U.S.; and 5) did not meet the age criteria.

The rationale for recruiting a cancer patient population of 50 years old and older is that cancer is largely attributed as an ageing disease. The age-adjusted cancer incidence rates in the U.S. are about six times higher amongst those aged 50 through 64 years old than populations who are between 20 to 49 years old (SEER Program, 2014). By restricting the cancer patient sample population to a certain age range for cancer diagnosis and U.S. immigration, it enables me to learn from a group of people who are more likely to share similarities in cancer risks, stage of life-course, immigration experiences, and assimilation patterns (Berry 1997; Clark et al. 2009; Lynch & Smith 2005; Rumbaut, 2004; Wingens et al. 2011). The sample were expected to be permanent U.S. residents to demonstrate that the cancer care, social conditions, and environmental factors encountered by the study participants were associated with immigrant family lives in the U.S. The sample population inclusion criteria helped produce a baseline level of homogeneity for conducting comparative analysis.

Another important inclusion specification was for the cancer patient's to select a family carer to participate in the study. The study participants with a cancer diagnosis were asked to identify and recommend a family carer for the interview. The established criteria for the family carer was that she or he was involved with the cancer patient participant's cancer care at the age of 25 years old or older. The guideline for this age criteria was established due to potential significant differences between youth and adult carer experiences with caring for a loved one who is ill (Lackey & Gates 2001; Pakenham et al. 2007). There were no requirements for the

family carer to have the same ethnic identity as the cancer patient participant nor have biological or marital family relations. I relied on the cancer patient's judgement on who was considered her or his appropriate family carer to participate in the study.

Whilst there was not a specific income or economic class inclusion criteria established for the sample population, the sampling research strategy aimed to recruit study participants from the range of 3 middle income household classes defined by the U.S. Census: second quintile (\$20,593 to \$39,735), third quintile (\$39,736 to \$64,553), and fourth quintile (\$64,554 to \$104,086) (DeNavas-Walt & Proctor, 2014). The income range was determined based on Pew Research Center's (2012) report that Asian Americans have a median yearly household income of \$66,000 base on 2010 U.S. Census data.

4.5 Sampling methods

There were three phases for recruiting the sample population into the study: promotion of the study through purposive and snowball sampling techniques, the collection of study participation inquiries through email and a telephone message line, and the study eligibility screening process conducted over the telephone. Interested study participants had the option of sending an email or leaving a telephone message about their inquiry to participate in the study. Before a study participant was considered for enrolment into the study, the study eligibility screening process was conducted over the telephone or in person if a private meeting space was available.

Multiple languages in verbal and written form (English, Chinese, Tagalog, Ilocano, Hindi, and Punjabi) were incorporated throughout various aspects of recruitment, primarily by leveraging on professional interpretation and translation

services. Recruitment materials for the study were created with the use of lay language in various languages including English. The telephone line for the study had recorded greetings in multiple languages to make it language accessible for potential study participants to leave a message. Certified interpreters provided interpretation services for voicemail messages, eligibility screening calls, and other telephone calls with potential study participants. Due to my limited resources and inability to speak in the Asian languages, during face-to-face study recruitment, I relied on my community partner colleagues to interpret on my behalf about the overview of my study and next steps for enrolling into the study. For study recruitment emails to community and health organisation contacts, I communicated in English, but included the translated recruitment flyers.

The multilingual approach for sampling was essential in building awareness about the study amongst immigrant populations who have limited English speaking capacity or speak their native language/dialect in their home life (U.S. Census, 2013 & 2014). This cultivated the opportunity to make the sample population a diverse representation of Asian immigrant communities and to make a social justice component integrated as part of the research methods. In health research, there has been long-time discrimination or exclusion of populations who have limitations with the English language (Frayne et al, 1996). Without the voices of historically marginalised and underserved communities in research, there are limits to what researchers can assert as knowledge representing the social realities of certain populations. Correlated with the principles of constructivism discussed in the research methodology section, employing sampling methods that facilitate greater sample

population diversity, can join multiple realities together into understanding the range of burdens in cancer care that occur in Asian American immigrant families.

Within the parameters of the sampling criteria, the sampling methods allowed me to recruit study participants who were relevant for providing knowledge to help answer the research question (Bryman, 2008) and address the range of issues being studied in the thesis (Bowling, 2009). In addition, the purposive and snowball sampling approaches helped achieve the targeted sample sizes, specific ethnic groups, and range of backgrounds that was described earlier as part of the research strategy for the sample selection. I applied two main strategies for recruiting study participants which involved the leverage of organisational relationships and my professional work in community settings. These strategies are similar to Sadler's et al. (2010: p.370) snowball sampling recommendations for "...hard-to-reach target group in a more pragmatic and culturally competent way" and Spring's et. al (2003) effective purposive sampling in their study recruitment of African refugees and immigrants.

My engagement with community members through my professional work in community settings help me generate opportunities for recruitment. The initial recruitment occurred at community, educational and support group meetings and events that were both large and small scale. These gatherings were largely attended by Chinese, Indian or Filipino groups. The recruitment settings included those that were cancer, health, social services, and cultural social networking oriented. I was able to provide a brief overview of the study and disseminate the study information sheet. In some cases, there were several non-English speaking individuals who expressed interest in the study. The need to rely on interpreter services when communicating with non-English speaking individuals made it more challenging for me to address

their inquiries about the study, conduct the eligibility screening process, and make arrangements for the interviews.

The other sampling strategy involved community organisations making referrals as well as through impromptu recruitment opportunities. The snowball sampling involved community organisations working in health or social services domains to promote the study directly to their constituents. The organisations displayed and shared the study information sheet through their various interactions with community members seeking their services and resources. Recruitment through this method resulted in higher rates of the potential study participant communicating to me about their interest in the study. I made extensive efforts to partner with a wide variety of organisations to bring diverse backgrounds into the sample population. For example, recruitment assistance was sought from different Chinese organisations so that English, Mandarin and Cantonese speaking individuals could be potentially represented in the study sample. Some recruitment also occurred through the my random interactions with individuals who fit the sample population criteria or through referrals from community members (independent from the organisations) who were aware about the study through ‘word-of-mouth’.

Originally, the snowball sampling method was not intended to be a main strategy, because I felt the recruitment process could become labour intensive for me. There was a possibility of attracting several individuals who did not meet the criteria for the study if the study requirements were not communicated correctly by the referring organisation or individual. I also anticipated that some individuals ineligible for the study would be compelled to contact me as a way to share their story and seek support from me. Purposive and snowball sampling at certain community activities or

through community organisations may lead to a sampling bias by mainly recruiting certain types of study participants or social demographic segment of the population (Benoit's et al., 2005). For instance, my sampling method led to study participants who participated in an organisational activity (e.g. attended an event) or had an affiliation with the organisation (e.g. service client). An assumption can be made that the sample population were those with the means or willingness to access the activities and services of the community organisations. Therefore, the main sampling methods led to a greater likelihood of indirectly excluding people who did not attend the activities nor associate with the community.

The recruitment that took place through the my random encounters with individuals and community 'word-of-mouth' referrals incorporated some population sampling of people who were not affiliated with the organisations assisting with recruitment. Nevertheless, these procedures did not remove the bias of conveniently sampling from a research population. Another sample method limitation resulted from the face-to-face study recruitment encounters. Although I sometimes received assistance from community organisation staff who spoke the language/dialect of the research population, my inability to speak in Asian languages or be representative of a sample population ethnic group may have deterred some individuals from wanting to participate in the study. Despite certain biases resulting from the sampling methods outlined, the purposive and snowball sampling strategies allowed for me to collect evidence that had greater prospects of generating "...a coherent and illuminating description of and perspective on a situation..." (Ward-Schofield 1993: p.227) as well as strengthened existing community partnerships interested in supporting communist-academic research (Benoit's et al., 2005).

4.6 Data collection procedures

I collected the data primarily through single semi-structured key informant interviews with individuals who met the sample population criteria and consented to participate in the study. The interviews took place for approximately one hour in private meeting rooms located in libraries, professional offices, and community/non-profit spaces. The cancer patient and family carer were interviewed separately to maximise privacy and to avoid influences on responses. Most cancer-diagnosed study participants had a family carer partake in the study, with the exception of one participant who later declined to have a family carer interviewed. In addition, a cancer-diagnosed person did not enrol in the study, but invited a family carer to participate. Therefore data collected from Marie (cancer-diagnosed) and Meng (family carer) did not have corresponding family study participant data for the analysis.

An interview script was used to guide the questions and probing (Appendix D). The sample population responses gained during the semi-structured interview influenced how I probed with certain additional questions or made inquiries for clarifications. The nature of bridging social constructs during collection procedures reflects the constructivist paradigm (Lee, 2012) discussed earlier in the methodology section. The script also included general questions related to ethnicity, nativity status, immigration, language(s) spoken, age, employment, marriage status, household income, education, primary mode of transportation, and healthcare access. These social and economic factors were used in this study because they are considered to be measures for social determinants of health (World Health Organization, 2008), which

the research literature reviewed in Chapter 2 have demonstrated as factors associated with minority and immigrant health outcomes. Each interview was audio recorded and transcribed through a professional service to ensure a more accurate documentation of the dialogue between the study participant, myself, and the research interpreter (if present).

Later in this chapter, the research ethics section will elaborate on the protocols in place that ensured the ethical and research protection of the study participants who received interpretation for the interview. Since language accessibility was an important feature for the study's sampling strategy, all study participants were given the opportunity to have a research interpreter available so that the interview could be conducted in their preferred language. Cantonese, Mandarin, Hindi, Punjabi, Tagalog, and Ilocano are most widely spoken amongst the three sample population ethnic groups. The study required that the study participant could communicate in English or the language of the interpreter for the interview.

For the audio transcription of the interviews, only the English dialogue from the recording was transcribed by a professional service. I specified to not transcribe any non-English language in the recording, which was the dialogue spoken by the non-English speaking study participant. This way, only my dialogue and the English interpretation that the interpreter provided me during the interview would be part of the research data collected. I did not want a re-interpretation of the non-English spoken dialogue, because it would create conflict for what was communicated, interpreted, and understood during the interview. So essentially, the interview transcripts only contained what the interpreters and I said in English.

After the interview, I encouraged the interviewees to provide additional information or clarification as part of the data collection. There was one occasion when I followed up with a study participant after the interview to gain further clarification on certain details discussed during the interview. I documented the post-interview data through detailed quotes and notes made during and after the conversation. Each study participant was given my email and telephone contact information so that I could be contacted for any reason at any time.

4.7 Data analysis, reliability, and validity

The findings from the data collection were examined using deductive thematic analysis to generate categorical meanings and patterns linked to the theoretical frameworks to help explain some of the factors that are associated with cancer care burdens. The thematic analysis approach enables this exploratory study to: 1) generate “conceptual labels” (Corbin & Strauss, 1990: p. 7) that will promote an understanding of collective experiences, perceptions, and meanings (Aronson 1995; Braun & Clarke 2012); 2) develop conceptualised meanings into categories and themes with the intent to identify thematic patterns (Aronson 1995; Braun & Clarke 2012) as well as determine if and how themes relate with each other (Corbin & Strauss 1990; Creswell 2014); and 3) expand the application of a theoretical framework with the literature review and data (Creswell, 2014) in order to make a connection with other published research. Despite a wide range of interpretations that can result during the data analysis, conceptual and thematic coding can be useful for merging key attributes of a data set (Creswell, 2014) as well as contribute to the development of questions to address in future research.

In line with the use of qualitative methods, the study did not make ethnic group comparisons numerically, nor create generalisations about specific cultures or ethnicities. Although the cancer burden findings reflect the individual lives of Chinese, Indian and Filipino American immigrant cancer patients and their carers, the goal of the data analysis is to demonstrate the overarching factors affecting the burdens in cancer care experienced by Asian American immigrant families. In reference to the section about conceptualisation of cancer burden in Chapter 1, this goal deviates from cancer epidemiology's concentration on the disparities between racial groups.

A systematic approach was applied to the data analysis process. During my initial reading and highlighting of an interview transcript, an initial list of conceptual codes were generated. The transcript was reviewed again on the Nvivo software where data analysis notations which included conceptual coding (Appendix F). NVivo enabled me to conduct quick word and code searches within the transcripts and notations. After completing data analysis on the transcripts with NVivo, data analysis tables were produced on a word processing program for each category pertaining to a general cancer care burden. These tables were later organised by overarching cancer burden themes.

Each categorical table was designed to group the study participants who had findings affiliated with the burden category as well as analyse the study findings according to study participant. For each study participant, a subcategory was created for their social determinants characteristics, quote(s) relevant to the burden category, and my expanded data analysis related to these subcategories and corresponding findings from their family member who participated in the study.

During the data collection and data analysis process, I carried out specific tasks to ensure the reliability and validity of the data and study findings. A semi-structured interview script was used during all interviews to generate responses from a set of questions that were consistently asked during each interview. After the study participant answered the interview questions, I summarised the main discussion points in which the study participant was given the opportunity to confirm and/or correct the discussion points. I also clarified any areas that were not properly understood or required more explanation from the study participant. All of the audio interview files were professionally transcribed into transcripts, which I reviewed for errors and corrected prior to data analysis. Cancer and community organisation representatives were part of the community participatory process to provide feedback regarding the main study findings from the anonymised data findings. These were representatives who identified as and served Chinese, Indian or Filipino patients. Their feedback on the major themes and cultural-social references helped verify the understanding of concepts derived from the data analysis.

Lastly, practicing reflexivity as part of my research played an integral role in helping to minimise some of the influences such as my social position, beliefs, assumptions, and other experiences encountered before and during research. Engaging in reflexivity has become a key feature of qualitative research (D’Cruz et al. 2007; Finlay 2002), which incorporates “...careful interpretation and reflection” as two key elements (Alvesson & Sköldbberg, 2018: p.11). Attia and Edge (2017) as well as Berger (2015) highlight reflexivity growth and capacity building approaches for researchers to consider taking on, such as such as recognising the values that shape the research purpose, being mindful of interactions with the study participations, and

reflecting on choices made on data collection and analysis. My application of reflexivity included: maintaining a research diary that incorporated self-reflection notes and accounts; self-supervising my concerns, feelings, and judgements; reviewing with the study participants what I understood from the interview; and involving community stakeholders to review my interpretation of the study findings.

4.8 Research ethics

This study received approval and oversight from Lancaster University Faculty of Health and Medicine Research Ethics Committee and Stanford University Institutional Review Board (IRB). ‘Human subject research protection’ practices were applied throughout various aspects of the study and writing of the thesis. I abided by the HIPAA regulations which include health information protection practices. I maintained current human subjects protection training and certification through the Collaborative Institutional Training Initiative (CITI) Program. These are required elements for the Stanford University IRB to approve and renew the research protocol, which permits the implementation and continuation of the research study.

As mentioned earlier, professional interpretation services were used for language translation and interpretation needs for the study. The certified interpreter service company and the independent interpreter contractors signed a form which confirmed the agreement to adhere to research ethics and medical privacy regulations as well as confidentiality compliance. The interpreter service company was contracted to translate and interpret for various communication and material needs primarily for the study’s recruitment phase. The independent interpreter contractors and the translated materials (i.e. forms for informed consent, support resources) were

involved in the interviews of non-English/limited English study participants. The independent interpreter contractors for the study were primarily contracted to provide interpretation for interviews, but they also agreed to interpret for communication needs prior to and after the interview. The three interpreters contracted for this study were certified medical interpreters with current HIPAA and CITI training and certification.

The informed consent process and interviews were conducted individually in a private room with myself and an interpreter (when needed) so that study participants' confidentiality was protected and they felt comfortable throughout the process of research which include: being fully informed about the study and its implications, asking questions, addressing concerns, consenting to participate in the study, being asked questions, sharing information and perspectives, and expressing emotions. All study participants were asked to sign an informed consent form (Appendix E). For study participants with a cancer diagnosis, they were asked to sign a required HIPAA Authorisation form (Appendix E) due to their patient status and potential sharing of health information.

Maximum effort was made to ensure the well being and reduce the risk of harm on the study participants involvement in the study. During the informed consent process, it was acknowledged that the study participant had the option of declining participation or withdrawing from the interview at any time. It was made clear during the informed consent process that if there was indication that the study participant could be harmed in any way or inflict harm on another person, there could be a breach of confidentiality to seek help for the study participant and/or the person at risk of harm. Study participants were made aware that I could not provide advice or answer

questions of medical, psychological, legal and financial nature. I reviewed a list of relevant supportive and informational resources alongside with the option to contact me at any time. When a study participant expressed difficulty with their emotions or exhibited distress during the interview, I paused the interview and inquired if there was a desire to continue with the interview. Study participants were given a copy of the informed consent form and support materials. Due to the emotional nature of the study, I address the needs of my own well being by discussing some of my experiences and feelings with my thesis supervisors. There were also professional support options available through Stanford University.

All data and records were stored and discarded securely according the HIPAA data privacy and security guidelines for safeguarding medical and personal information. The analysed data and reported study findings were de-identified. Each study participant was assigned an appropriate pseudonym. I remained available to speak to the study participants after the data collection and analysis period, in order to maintain a trusting relationship and access to supportive resources.

4.9 Concluding summary

The epistemological models and research methods applied to this study helps to dissect a part of the individual life-course as it relates to the experiences with cancer care burdens and the broader social factors impacting their life circumstances. A qualitative method was selected for this thesis in order to address the research question on Asian American immigrant family cancer experiences from an exploratory and in-depth approach. Individual interviews were conducted with study participants to generate distinctive meanings and perspectives related to cancer care as

well as to identify the personal factors contributing to cancer care burdens. In doing so, the theoretical framework, methodology and methods employed in my study may tackle some of the complexities of cancer care burden that can be distinctively understood by an interpretivist and social theory lens.

Chapter 5 | Description of the sample population

5.1 Introduction

This chapter gives an overview of the sociodemographic and personal characteristics of the sample population. The study participant profiles provide a brief description about each person in order add contextual background to their responses and who they are as individuals. Appendix A contains the pen portraits of each study participant to provide more depth about their background. The description of the sample population enriches the understanding of the social determinants and personal factors that shape their lives as a cancer patient or a family carer.

5.2 Summary of socioeconomic determinants found in the sample population

Tables 5.1, 5.2 in Appendix G summarise the following factors by ethnic group: self-reported gender, English language proficiency, age range, highest education level completed, annual household income, and health insurance. There was a higher representation of the female gender and Chinese ethnicity across the sample population. All of the Chinese participants who had an education less than a Bachelor's degree were found to be both 'non-English' or 'limited English' speaking and low income. Each of the Filipino and Indian participants reported having at least a Bachelor's degree and speaking English well. Also in Appendix G, table 5.3 presents other social and economic variables (e.g. immigration, employment, marriage status) of the sample population according to ethnicity.

Table 5.1 reveals that the majority of cancer-diagnosed individuals reported having either a low or moderate annual household income. Those with low income were recipients of the Medi-Cal insurance for their cancer treatment. Eligibility for

Medi-Cal is based on eligibility criteria which includes poverty level, disability, and legal immigrant status. The study participants who were diagnosed with cancer between the ages of 50 to 64 years old had low incomes and were uninsured or underinsured. Thus meeting the poverty level and legal immigrant status requirements were especially critical for gaining affordable access to medical care. Those who received Medicare coverage, were eligible for the compulsory government health coverage that is available to persons who are 65 years or older and a U.S. citizen, or a permanent legal resident, for a minimum of five years. Whilst publicly funded healthcare insurance in the U.S. is made available as a 'safety-net' for specific populations, the eligibility criteria based on designated social and economic status (e.g. age, immigration, income level, employment) can create barriers for immigrants with limited means of accessing and paying for healthcare. In addition to healthcare access, language interpretation was a crucial requirement for the non or limited English speaking Chinese cancer diagnosed individuals' communication with their healthcare provider.

Table 5.2 demonstrates that the family carer sample population varies by type of family relations (i.e. spouse, child, parent, sister or brother), with ages ranging from 25 to 89 years old. Several family carers were educated with at least a Bachelor's degree and spoke English well. As I shall later discuss in the forthcoming chapters, the education and language capabilities were important factors in caring for cancer patients with a lower level education and poor English language proficiency because they helped facilitate health provider communication and medical decision making. There were varying degrees of education and English proficiency amongst the family carer sample population, suggesting that these factors did not limit them

from fulfilling the caregiving role. Unemployment or retirement were two underlying reasons why some of the family carers had low income. Only one family carer cited income or financial status as a factor affecting their experiences with cancer care. The family carer sample population represents how the caregiving role spans across generations and types of family structure under different social and economic circumstances.

5.3 Study participant profiles

This section briefly describes the background of each study participants, which is further elaborated in the pen portraits found in Appendix A. The profiles and pen portraits are intended to enhance our understanding of the study participants as ‘whole individuals’, beyond categorical constructs. By illustrating a clearer account of who they are, the factors related to cancer care burdens can be better understood.

Cancer-diagnosed sample population

An: An is a 50 to 59-years-old, married Chinese female. She has resided in the U.S. for over 20 years, is limited English speaking, and lives in a moderately low income household. Leila is her daughter and carer.

Angie: Angie is a 70 to 79-years-old widowed Filipina. She has resided in the U.S. for over 40 years, is bilingual English speaking, and retired from her 30-year career with a moderately high income. Sofia is her daughter and carer.

Lian: Lian is a 60 to 69-years-old married Chinese female. As retirees from China, she and her husband are dependent on their son’s moderately low income. She is non-

English speaking and has lived in the U.S. for less than 6 years. Her husband, Bao, is her carer.

Lin: Lin is a 50 to 59 years-old divorced Chinese female. She has resided in the U.S. for over 20 years, is limited English speaking, and lives in a moderately low-income household. Isabel is her daughter and carer.

Luwisa: Luwisa is a 60 to 69-years-old married Filipina. She resided in the U.S. for over 30 years, is bilingual English speaking, and has a moderate household income. Although she retired from her previous employer, she is currently self-employed to supplement her retiree income. Linda is sister and carer.

Marie: Marie is a 50 to 59 years old, divorced Filipina. She resided in the U.S. for over 20 years, is bilingual English speaking, and has low income with transient housing. Prior to her cancer diagnosis, she struggled with postpartum depression.

Meiwen: Miewen is a 50 to 59 years old, divorced Chinese female. She has resided in the U.S. for over 20 years, is bilingual English speaking, and has a moderately high income. She practices traditional Chinese medicine. Ying is her mother and carer.

Rajat: Rajat is a 50 to 59-years-old, married Indian male. He has resided in the U.S. for over 15 years, is bilingual English speaking, and lives in a high income household. Manali is his wife and carer.

Wei: Wei is a 60 to 69-years-old, married Chinese male. Wei has lived in the U.S. for less than 10 years, speaks limited English, and is the sole financial contributor to his

low income household. He relies on his wife and carer, Shen, to provide language interpretation and transportation.

Family carer sample population

Bao: Bao is a 70 to 79-years-old Chinese male, who is the husband and carer of Lian. He has resided in the U.S. for less than 6 years and is non-English speaking. Bao provided physical and emotional care to his wife.

Isabel: Isabel is a 25 to 30-years-old, single Chinese female who is the eldest daughter and carer of her mother Lin. She is U.S. born, bilingual English speaking, and has a Bachelor's degree education.

Leila: Leila is a 25 to 30-years-old, Chinese female who is the eldest daughter and carer of her mother, An. She is U.S. born, bilingual English speaking, and has a Bachelor's degree education.

Linda: Linda is a 60 to 69-years-old married Filipina who is the sister and carer of Luwisa. She has resided in the U.S. for nearly 30 years, is bilingual English speaking, and has a Bachelor's degree education.

Manali: Manali is a 40 to 49-years-old, Indian female who is the wife and carer of Rajat. She has resided in the U.S. for over 15 years, is bilingual English speaking, and has a Master's degree education.

Meng: Meng is a 70 to 79-years-old, married Chinese male was a full time, live-in carer for his brother-in-law with cancer (not a participant of this study). He is non-English speaking and has resided in the U.S. for more than 20 years.

Shan: Shan is a 60 to 69-years-old, married Chinese female who is the wife and carer of Wei. She is a retiree from China and has resided in the U.S. for less than 10 years. She is bilingual English-speaking with a Bachelor's degree education.

Sofia: Sofia is a 30 to 39-years-old married Filipina who is the daughter and carer of Angie. She is U.S. born, only English-speaking, and has a Bachelor's degree education.

Ying: Ying is a 80 to 89-years-old, married Chinese female who is the mother and carer of Meiwen. She is limited English-speaking, has resided in the U.S. for less than 10 years. She has a nursing degree education.

5.4 Concluding summary

This chapter and the supporting appendix presented the sociodemographics and personal characteristics of the sample population composed of Asian American cancer-diagnosed immigrants and family carers. The description of the sample population reveals diversity in sample population, in which there are varied types of social, economic, education, linguistic, healthcare insurance, immigrant, and family factors combined to shape their life circumstances. These factors will be considered when analysing the study findings. The heterogeneity in the sample population allows for consideration of the ways in which burdens in cancer care are associated with different social determinants. The subsequent chapters will present and discuss the research findings regarding the main types of cancer care burdens, the circumstances

surrounding these burdens, and its relationship with social determinants and social, economic and cultural capital.

Chapter 6 | Findings: Cancer care meanings & psychosocial burdens

6.1 Introduction

Three chapters present findings from the study that illustrate the sample population's perceptions of cancer care as well as the main themes of cancer care burdens associated with psychosocial, healthcare, and competing life circumstances. The 'burdens in cancer care' are examined in terms of how cancer-diagnosed individuals and family carers viewed their obligations, hardships and/or struggles with cancer care. Prior to and during the interviews, the 'burdens in cancer care' concept was referred to the sample population as "difficulties or challenges related to dealing with cancer care". The word burden was not used in the interview script (Appendix D) and only referenced if the study participant used this term during the interview.

Together with the description of the sample population, the analysis of these findings is used to support the development of an understanding about the factors related to the cancer care burdens experienced by Asian American immigrants who were diagnosed with cancer and their family carers. This chapter presents the study participants' meanings of cancer care and their psychosocial burdens, which interconnect through the social aspects of emotional well-being and cognitive characteristics such as beliefs, feelings, and reasoning. These study findings also cut across the other main themes of burdens in cancer care, themes explored in the following chapters.

6.2 Meanings of cancer care

Cancer care encompasses different meanings about what is essential and important for the care of health and well-being. Participants were asked to explain

their concept of 'cancer care' in order to incorporate their meanings of cancer care as a part of understanding their experiences and perceptions of burdens in cancer care. The responses were wide ranging, yet shared commonality. Experiences and opinions were described, in various combinations, in the following themes: medical care and treatment; accessible support from family, friends and/or cancer patients; physical and/or emotional care; spirituality; and gaining knowledge about the disease. The emotional and physical aspects of support were predominantly viewed as important components of cancer care by the cancer-diagnosed individuals and family carers.

Several of the study participants diagnosed with cancer emphasised the importance of emotional well-being in cancer care. Alongside this shared perspective, there were some varying opinions regarding the sources and types of emotional care. For example, Wei discussed cancer care within the scope of managing his stress:

First is emotional support because for me, I feel a lot of stress when I first heard and know about my diagnosis of cancer.

I think the most important part is to reduce stress from within from oneself. I think the most relief part that help with my stress is when I believe in God...

So when I felt a lot of stress, I would listen to prayers and read [the] bible...

- Wei, cancer-diagnosed

Wei attributes emotional support as a part of cancer care, but it appears that cancer care also means to self-sufficiently manage stress through spirituality. Angie also spoke of self-reassuring actions related to cancer care:

Cancer care is positive thinking, a lot of prayers... And talk to people.

- Angie, cancer-diagnosed

Her characterisation of cancer care as optimism, spiritual, and social connection demonstrates her viewpoint of cancer care as a multidimensional and motivational approach. Meiwen acknowledged physical and emotional care as mechanisms of support provided by different people:

Well, number one will be the daily care, which my mother is the main caregiver. Then there are friends who provide emotional support, although the time may be brief, but they occur in critical points... and also there are cancer survivors who [are] also friends who share their experiences as well as knowledge that comfort me as well as useful background information.

- Meiwen, cancer-diagnosed

She distinguished the physical care regularly received from her mother as the most critical, followed by emotional support from friends. The friends whom she described as ‘cancer survivors’ were viewed as unique sources of valuable knowledge, due to their own individual cancer experiences. Likewise, Lian indicated the significance of gaining emotional and knowledge support from cancer survivors as well:

[Family] have helped me tremendously at home, and also outside of caring at home, they have a lot of emotional support.

But I felt most helpful is through the support group, because my family, they don't have this kind of experience through cancer. But the survivors [of cancer], they have had this past experience, and I gain... how to cope with this kind of emotional fluctuation through the support group.

- Lian, cancer-diagnosed

Whilst family carers were recognised for their vital role in cancer care, Meiwen and Lian viewed support from cancer survivors as another crucial part of nurturing their emotional coping and learning due to the shared patient experiences. Lian and Meiwen had differences in their viewpoints regarding sources of emotional support. Lian acknowledged that emotional support also came from family carers, whereas Meiwen identified emotional support specifically from friends and cancer survivors. The differences of opinion may be related to the individuals identified as the family carers. Lian's carers were her spouse and adult son. Miewen's carers were her ageing parents.

Most of the study participants expressed the view that family support was a part of cancer care, however, Marie expressed another perspective explaining:

Cancer care is not related to family, but if you are in the cancer care program, it's like... you have another family in that program.

For me, cancer care... it's voicing out yourself, be there with all the groups who have cancer also.

- Marie, cancer-diagnosed

Marie identified her mother as the family carer who "...gave [her] some emotional support, housing and cooked... during [her] treatment", but she defined cancer care as an emotional support intervention or programme that is separate from family. The disconnect of cancer carer from family may be due to her belief that the burden of cancer care should not be placed on family members, which she later described:

... I don't want to give them stress, number one.

...I don't bug them and then I don't open all the time. I carry it myself.

- Marie, cancer-diagnosed

Her concern about the impact of the disease on family shapes her meaning of cancer care. Although many of the study participants later expressed concerns about the cancer care burdens being placed on family members, they described family as an integral part of cancer care.

Amongst the family carers, the notion of cancer care is more broadly perceived as ways to help the patient through treatment, and maintaining quality of life: providing daily physical care, dietary nourishment, emotional support, and treatment information. Many of the family carers recognised emotional support as an essential part of cancer care, but their understanding of this concept has some differences from the point of view of the cancer-diagnosed study participants. For example, Bao identified a spectrum of key ways to care for the individual diagnosed with cancer:

From physical lifestyle caring to emotional support and mentally support.

...A cancer patient, they have emotional ups and downs, and also they have a lot of fear about their condition and diagnosis. So as a family member, we can give them a complete support in terms of care and emotional support.

- Bao, husband and carer of Lian

He viewed cancer care as ways for the family member to holistically care for the cancer patient. Bao specified that a family member can provide “complete support”, a likely indication of his belief that family is accountable for providing a full range of supportive care. He distinguished ‘emotional support’ separately from ‘mental support’, which possibly suggests his perception of cancer having an impact on different levels of the cancer patient’s psychological well-being related to fear and

fluctuating feelings. Meng also described the daily physical, dietary and emotional aspects of caring:

To assist daily life.

Emotional support so the patient doesn't feel fearful to [battle] cancer.

And the third one that's very important during cancer care is diet.

The very important is emotional support so patient can cope and know how to fight the cancer...to keep encouraging patient...

- Meng, brother-in-law and carer of cancer patient

Like Bao, Meng recognised the necessity of emotional support to help the cancer patient overcome the 'fear' of the disease. Emotional caring appears to represent his perception on what is most important for caregiving. In Manali's description of what cancer care meant to her, she pointed out the psychological factor as particularly prominent in caring for someone with cancer:

There is a physiological element...On the cancer care front, I think it's much more psychological because that word [cancer], is such a loaded word. It conjures up the scariest imagery possible... I would make sure my own emotions would not come in the way... there are times you feel very frightened and suddenly you feel like your brain stops working because dealing with the enormity of what might happen...

- Manali, wife and carer of Rajat

She described the 'physiological element' as caring for the somatic well-being which included the physical care and comfort as well as nutritional nourishment. However, the concept of cancer care appeared to carry a greater weight of psychological impact

and responsibility for Manali. Her fears had an enormous influence on herself as the family carer.

These extracts show what how cancer care is understood by the sample population, which includes meanings relating to healing, nurturing, and ‘feeling whole’. The meanings of cancer care were also reflections of how they remember the experience of either giving or receiving care. One component of the cancer care meaning was behavioural. This included the daily physical and nutritional care, peer support from cancer patients/survivors, spiritual practice, instilling motivation, gaining knowledge, and emotional comfort. The other part of the concept represented the emotional and mental health effects as well as desire for cancer care to achieve a sense of emotional balance. This suggests that the sample population experienced many psychological effects resulting from the cancer. The next section of study examines the social and emotional aspects of meanings in cancer care

6.3 Psychosocial burdens

Self-efficacy of coping

The psychosocial significance of the cancer care burden was apparent across the sample population. Three main dimensions of psychological burden emerged from the interviews: self-efficacy of coping with cancer and care; concealing the cancer condition; and the emotions connected to the unknown or uncertainty of the cancer condition. First, self-efficacy with emotional coping are discussed. Self-efficacy is recognised by Knoll, Rieckmann and Schwarzer (2005: p.808) as a “...personal resource factor that may facilitate coping” to overcome difficulties. Several participants with cancer in the sample population discussed their attempt to cope with

their emotions by themselves as well as expressed their desire to avoid placing the emotional burden on their family members.

As patients facing the challenges of medical care needs and cancer treatment, Meiwen and Rajat, felt solely accountable for their family members' welfare. Their descriptions of coping with emotional burdens are reflective of their desire to have some independence with managing their emotional challenges alongside fulfilling family responsibilities. Meiwen relied on her parents for daily care support, but refrained from asking for other additional forms of support for her cancer care:

... I have different treatment choices...

...I feel like, "Okay, that's not something that I want to burden my parents with."

I feel like my job as their daughter, I need to take care of their concerns.

...I try not to again burden them with my emotional ups and downs...

Divorce. By myself...sometimes, that's a different level of emotion that can play a role, but I try my best to cope with.

- Meiwen, cancer-diagnosed

Meiwen seems to have a strong regard for protecting her parents' welfare. In spite of how her illness emotionally affected her and the difficulty of selecting a treatment option, she limited the range of the family carer function. In the previous section, friends and cancer survivors were described as sources of emotional support, but she alludes to feeling occasionally lonely as a divorcée. As an unmarried woman living alone and without other immediate relatives besides her parents, the emotional support from friends may be limited during specific periods or circumstances of

dealing with cancer. The concern of placing accountability on a spouse was evident in Rajat's explanation of some of his emotional challenges:

There's this feeling that all of a sudden not only am I not carrying my weight, I've just become this. And when you're not sure how long it will last. How long she may have to be doing this. It's difficult, yeah.

You don't want to always share your most negative emotions because it influences how the whole family then thinks.

- Rajat, cancer-diagnosed

There are a variety of factors that appear to have a relationship with Rajat's psychosocial burdens: the sense of self-disappointment towards his inability to contribute sufficiently as a husband and father; his uncertainty about the length of time for his recovery and dependency on his wife as the sole family carer; and the belief that his negative feelings may demoralise his family's attitude towards his condition.

These study participants placed priority on the importance of their role and obligations towards the family, which are found to influence feelings of guilt, and avoidance of seeking certain types of cancer care support. Furthermore, other contributing factors such as divorced status, lack of family network or position in the family, may generate the desire for self-efficacy in coping. Participants may perceive these factors as circumstances that cannot improve or change, and therefore being self-sufficient with managing their emotions becomes a mechanism to avoid placing burden that they do not want their family carers and family members to experience. Married couple, Lian (cancer-diagnosed) and Bao (carer), discussed their individual reasons for being silent about their emotional hardships:

They didn't really say it...but because cultural, they kind of hold it in themselves. But from what I observed, they felt, "Oh, how could you get this kind of disease?" They were scared and feeling – didn't know what to do. I just hold onto my feelings and just hope it will pass soon anyway. ...During chemotherapy, it's really harsh on me. And it's very hard to express how bad I felt at that time. Because first, I don't want them to feel as bad as I do, and also I didn't want them to feel like – I most fear at home, not feeling peaceful.

- Lian, cancer-diagnosed

It appears that Lian had major concern for exhibiting the difficulties of her cancer treatment, because she did not want to inflict emotional harm to her husband and son. This affected her perspective of how she should cope with her emotions, in order to alleviate her family from additional emotional burdens. Bao was reluctant about expressing his feelings to Lian and his son:

I felt the most challenging part was when she feeling gloom and feeling pessimistic. And that time I felt I need more strength in counselling her in accepting her condition.

I kept it to myself. I tried to face it myself.

I don't have much relatives around in the United States.

Because my son has to work, and I don't want to burden – give him more burden psychologically.

- Bao, husband and carer of Lian

Bao's choice to self cope with the challenges of his role as a family carer, husband and father seems to be partially attributed from two circumstances: the belief of not

wanting his problems to have an affect on his son's emotional wellness because the son is the only provider for the family's basic welfare needs; and the limited access to family support due to few relatives residing in the U.S.

Concealment

Another aspect of psychosocial burden found in the data is the concealment of the cancer condition from people which included family members, friends, and colleagues. Some of the individuals diagnosed with cancer and family carers experienced an emotional burden from avoiding disclosure of the cancer condition, which occurred for different reasons: shameful and fearful feelings, beliefs about cancer related to harmful or negative choices, desire for privacy, and/or avoiding negative comments and scrutiny. Isabel, Lin's carer, described feelings of shame and fear which stemmed from her mother's assumptions about why people became ill with cancer:

Both me and my mom...we don't like to look bad in front of other people, so we try to like suppress it until we get home, and when we get home we just break down...

I think my mom, in particular, she didn't want people to know that she was sick. So she lied to her friends... I think that [made] it more stressful.

I think my mom, before she even had cancer, she always thought it was people who didn't care for themselves, just irresponsible people that get it. Then there's people around you that judge you. "Oh, you're sick, what did you do wrong?" I don't think she wanted people to do that. She was ashamed.

- Isabel, eldest daughter and carer of Lin

Through Isabel's observation, it appears that the choice not to disclose the cancer diagnosis and struggles with the illness were a result of her mother's beliefs about the disease being a penalty for poor behaviours. For Isabel and Lin, their strong feelings of how they were perceived by others had a substantial impact on their emotional well-being. A concern shared by Meiwen and Angie, was their desire as cancer patients, to maintain privacy in order to keep away from the criticism, unhelpful remarks and/or widespread sharing of personal information:

...Another type of challenge, that is, "Do I disclose my illness with people around me?" My decision has something to do with the culture background.

... I think the Chinese culture tend to – most people [don't] have...knowledge, so they will easily just share...I didn't want to share that information, my information with too many people.

- Meiwen, cancer-diagnosed

Meiwen specifies that her decision of not disclosing the cancer diagnosis was a result of her Chinese cultural background. Based on her explanation about the Chinese cultural influence of sharing information, it appears that she was largely concerned about her cancer condition becoming a part of widespread conversations amongst individuals in her social network and the people connected to them. Angie had similar sentiments with Lin and Meiwen:

Because before, I thought cancer – I don't know. I had an idea that, what is this, is this punishment or something? I'm an old lady, so I have old way of thinking. I want to be private. I don't want people talking about me.

- Angie, cancer-diagnosed

Perhaps Angie's statement, "old way of thinking", was a reference to an age-old Filipino cultural belief about cancer. Her belief of cancer as a penalty gives the impression that she presumed this was how other individuals also viewed cancer and it would influence how people connected to her social network may gossip about her diagnosis. It appears that the study participants diagnosed with cancer expressed greater concern for privacy of their cancer status, because they had particular beliefs about how they would be viewed as an ill person.

These statements reveal how cultural-related attitudes and beliefs can be a source of emotional burden, because they can influence the choices that people make to either comply with cultural norms or avoid assumed consequences of cultural norms. For example, Meiwen explained earlier that Chinese cultural practice typically involves sharing about one's health condition to benefit from the knowledge support from others. However she had a different perception of what it meant to share her cancer diagnosis:

...The challenge [is] two-fold. One is, I didn't feel like I need to tell everyone and explain my situation, because knowing that some, although with good heart, but their comments may not be helpful at all and they are not aware of it.

I do feel like, "Oh, am I hiding something from my friends or people around me?" So that itself is emotional challenge...

So, I constantly [struggled] when people [contacted] me, whether I need to disclose or not, so that [was an] ongoing challenge.

- Meiwen, cancer diagnosed

The awareness of how people culturally respond towards illness led some of the study participants to make a personal choice of carrying the emotional burden that came with concealing their cancer diagnosis. This was a way to protect themselves from further emotional conflict that was connected with their social networks.

The unknown and uncertain

Lastly, psychosocial burden was found to be associated with the uncertainty and lack of knowledge about the cancer patient's clinical condition and outcomes. In this section, 'uncertainty' is defined as the state of being unsure and the unpredictability of life. The concept of 'unknown' pertains to the limited knowledge about a situation or concern. Three types of psychological impact were observed amongst cancer-diagnosed and family carer study participants: stress, sadness, and fear. The psychological effects were described as 'stress' by Wei and as 'depression' by his wife, Shan:

I feel...stress from getting through screening, and all the reports, and it's a lot of steps in between... And to me, I had accumulated a tremendous amount of stress when I [want] to know, that I need to talk to doctor regarding the result.

I think the moment of waiting to know the result is more stressful...

I think in comparison, China doctors can tell the result faster than in the United States. Because in China, they can tell your result right away...in the United States, doctor will have to do the screening in longer stretch of time.

- Wei, cancer-diagnosed

Wei's stress seems to be affected by the following main factors: his anxiety about waiting periods and the unknown status of his medical results; and his expectations

regarding the length of time for physicians to report the medical results to the patient which are influenced by his previous healthcare encounters in China. His family carer, Shan, also experienced difficulty with the periods of waiting for the medical results which she acknowledged as ‘depression’:

Mainly it's mentally, it's depression. Mental pressure. The most depressed comes from the wait for the result. Waiting, ah, terrible. I don't fear the result because I know what kind of result...but it's waiting is terrible.

Another main challenge is...the recurrence, yeah, if it comes back again.

- Shan, wife and carer of Wei

The couple attributed their emotional problems to the experience of waiting, but it also appears that lacking information about Wei’s cancer was a major contributor to their psychosocial burden. Rajat (cancer-diagnosed), Ying (carer), and Linda (carer) emphasised feelings of fear due to uncertainty, the unknown or a combination of both:

I just assumed, okay, I'd be back at work in a couple of months...then once you get into it, you realise this thing's uncertain...it keeps changing on you.

The doctors aren't sure. The uncertainty of the diagnosis, the uncertainty of the outcomes...

...There's a fear of having children and kind of leaving them, you know, if something went wrong, just that realisation that my wife is left to handle them.

- Rajat, cancer-diagnosed

Some of the study participants described being emotionally overwhelmed when they first heard their cancer diagnosis, but the way Rajat described his self-assurance in getting back to his ‘routine’ seemed to exhibit the confidence he had upon receiving his cancer diagnosis. Perhaps this was due to the comprehensive coverage of his

healthcare insurance that his wife, Manali, described as “gold plated insurance”. A comprehensive healthcare insurance may provide wide access to highly rated healthcare institutions and extensive coverage of medical care costs. Despite Rajat’s initial confidence, he later had feelings of ‘uncertainty’ and ‘fear’ which appear to be largely attributed to the unforeseen changing nature of his disease accompanied by his physicians’ doubts. In Ying’s case, some of her emotional obstacles appear to be associated with not being fully informed about her daughter’s cancer condition:

Feeling sad. Emotionally of course was not very well.

Because I just feel like I only know limited facts about her diagnosis and her progress... So I think the most thing that I fear of the difficulty probably is the fear of recurrence...

- Ying, mother and carer of Meiwen

Meiwen opted to restrict certain knowledge from her parents because she did not want to place emotional burden on them. The limited knowledge about her daughter’s condition and outcome of the treatment may have contributed to Ying’s fear of an ‘unknown’ possibility for a relapse of cancer. On the other hand, Linda was fully informed about various aspects of her sister’s clinical cancer care, yet she remained fearful that Luwisa would continue to have the disease:

I think it's the fear of [cancer] not being treated or recurring...The fear is always there. Some are very successful after their treatment... but once you had [cancer], I think it's always there...

- Linda, sister and carer of Luwisa

Linda acknowledged that patients can achieve remission from cancer treatment, yet she has doubts about the clinical validity of cancer remission. Her opinion of “...

cancer not being treated or recurring...” and that “...it’s always there”, appears to indicate that she believes it is a disease that cannot be eliminated or treated to prevent relapse. Her beliefs and doubts seem to be the source of her fears that her sister will become ill again from cancer .

The ‘unknowing’ and ‘uncertainty’ from clinical cancer care appear to have a substantial impact on the study participants’ emotional well-being and fears. The family carers in particular felt fear about the possibility of a cancer recurrence and cancer remission was experienced as a time of uncertainty. The cancer-diagnosed study participants had initial expectations of their clinical cancer care being timely and predictable. However, some aspects of their cancer clinical care fell short of their expectations and prompted the emotional challenge of coping under circumstances that lacked certainty or specific answers for their cancer condition.

6.4 Concluding summary

The findings reveal three major areas associated with the psychosocial burdens: 1) that feelings, opinions, and behaviours are affected by the perceived impact of cancer on other people; 2) that the beliefs about the disease and expectations towards cancer care have been met with undesirable, unknown or uncertain outcomes; and 3) that certain social and economic factors (e.g. marital status, family commitment, financial status) appear to be perceived as permanent life circumstances. This chapter has demonstrated the emotional nuances that accompany the experiences of dealing with cancer care as a family carer or a patient. The study results also reveal the ways in which a sample population, despite their socioeconomic heterogeneity, they have similar psychosocial concerns and the need

for emotional support as part of dealing with cancer. Within the next two chapters, the psychosocial elements are continually explored across the findings related to other major themes in cancer care burdens.

Chapter 7 | Findings: Burdens related to healthcare

7.1 Introduction

Clinical care in cancer can be characterised as complex and multidimensional, in part due to the varied entry points into the healthcare system and variable clinical models for delivering patient care. These two areas of healthcare can intersect with social determinants that shape the cancer care experiences of patients and carers (DelVecchio et al. 2005; Fiscella 2004; Penner et al. 2013; Ramondetta et al 2015). This chapter discusses burdens encountered by cancer-diagnosed and family carer study participants which emerged from the data analysis. In particular, the focus is on three main themes of clinical care components: access to the healthcare system and provider, healthcare communication, and decision making about treatment. Several study participants experienced burdens in more than one component of clinical care. Certain forms of ‘capital’, a conceptual term described earlier in Chapter 3, had an effect on the burdens related to access to healthcare. The study findings observed in this chapter explore the following: how burdens exist across different aspects of healthcare, the factors associated with these burdens, and the compounding nature of challenges related to clinical cancer care.

7.2 Healthcare access

Healthcare access in the U.S. can be viewed as a means of gaining entry into a healthcare system or establishment which includes healthcare insurance, receiving services, and maintaining relationships with health providers. This is critical during all phases of the patient’s cancer care. The inability to have suitable and timely access to health services may create difficulties for a patient’s trajectory with cancer care and

cancer survivorship. Burdens associated with access to the healthcare system and providers are evident through the perspectives and experiences of An, Leila, Lin, and Manali. This section examines the different entry points and experiences related to accessing healthcare.

An encountered several systematic barriers to healthcare access that appear to be affected by her employment, health insurance, and healthcare provider regulations. Despite having employer-sponsored healthcare coverage, she was ineligible for services to be paid by her health insurance due to ‘probation period’ guidelines applied to new employees:

...I found a lump...and I called to my insurance to get an appointment. But during that time because I was a new employee, the agent told me to wait for three months...

(Tears filling eyes) Yeah. I felt sad and unfortunately because the insurance postponed the care that I should have received. At that time the lump has grown in size to like an egg...

- An, cancer-diagnosed

Since An’s household income was moderately low, she found it difficult to pay out-of-pocket fees for an immediate clinic visit and medical tests. Furthermore, her husband’s recent unemployment led to the loss of employee benefits that could have provided An with spousal health insurance. The inability to receive timely healthcare access contributed to her emotional burden, worsened her health symptoms, and delayed her breast cancer diagnosis. The health insurance agent's instruction to wait for clinical care appears to indicate his lack of knowledge of how to help to address health concerns requiring urgent attention. Although another agent eventually

coordinated An's access to clinical care, the arrangement for An's hospital emergency department visit still added another layer for manoeuvring through the healthcare system. An's probationary status did not allow her to receive a direct clinical appointment for medical diagnostic care.

Healthcare organisations may act as gatekeepers for access to clinical care, and can therefore be detrimental towards patient health outcomes and healthcare experiences. For An, she lacked the economic and social capital to obtain immediate medical services to diagnosed her health problem. Furthermore, she could no longer receive care in the public hospital where she had a history of receiving medical care. Medi-Cal typically requires their insurance recipients to seek health services in their residential county. For Leila, transitioning care became a burden because it interfered with her family's long-term knowledge of and trust with "...the only other emergency hospital that [they] knew of...".

It appears that retaining social and cultural capital (e.g. relationship, knowledge, trust) within the healthcare system is a key reason why family carers and patients desire continuity of care with familiar healthcare providers. Lin also dealt with worries about maintaining consistency in her care:

...Most stressful for me, was switching from the company insurance to another self-pay or even [public] insurance, because at that time I was wondering, "Oh, well, in case I have to switch insurance, would I get the same oncologist and would I get the same treatment team? If not, where should I find those competent medical team in treating my diagnosis?"

- Lin, cancer-diagnosed

Her worries about maintaining the same clinical care providers and quality of care she received from them is indicative of her awareness about the system's fragmentation with healthcare provider options. Certain types of health insurance plans will limit patients to a specified network of health providers. In such cases patients must pay out-of-pocket fees to see providers from outside the network. Due to Lin's limited income, she was unable to self-pay for her healthcare coverage obtained from employment nor purchase an equivalent insurance plan. It seems that without sufficient economic capital (e.g. personal income, accepted health insurance), it can become difficult for cancer patients to maintain their continuity of care in healthcare places where patients and their family carers have existing social and cultural capital.

On the other hand, Rajat's health insurance allowed him a wider range of options with choosing health providers. Yet the ability to select the desired healthcare provider for his cancer diagnosis and treatment did not provide him timely access to cancer clinical care. His wife, Manali, described the problems of obtaining a medical appointment despite her husband's "...gold-plated insurance":

(Expressed in a distressed tone)...We can't get an appointment to see an oncologist for...six weeks...Really? In India, because it's a different medical system where you pay out of your pocket if you want an appointment...

(Exhibited frustrated facial expression)...[Six] weeks of not knowing what's going on will kill you. And I was very disappointed about that. So that was one big disappointment I had on accessing specialists [in the US].

- Manali, wife and carer of Rajat

Manali's explanation of the lengthy wait for an appointment with an oncology specialist reflects a level of broken trust towards the U.S. healthcare system. The

reference to “gold-plated insurance” implies that her initial expectations for Rajat’s health insurance were that timely healthcare access and medical diagnosis were guaranteed. However, after experiencing barriers with access, Rajat and Manali resorted to the option of leveraging on their cultural capital of social networks and their knowledge of the medical system in India. These types of cultural and economic capital facilitated prompt access to an oncology specialist in India. Manali described the experience with the physician in India:

...[The doctor has]...an assembly line of people coming to see him...In that five minutes he diagnosed [Rajat] accurately, gave us a complete sense of what we would expect in the U.S. ...We asked him, “How do you diagnose [Rajat] in five minutes when nobody [in the U.S.] could diagnose him...?”

- Manali, wife and carer of Rajat

After experiencing obstacles with U.S. health providers, her account of their healthcare experience in India suggests that: 1) she perceived the “gold-plated insurance” for U.S. healthcare did not carry the same weight as having the financial means to facilitate immediate access to a physician in India; and 2) she developed doubts towards physicians in the U.S. regarding their expertise to quickly and precisely diagnose Rajat’s medical condition. These findings correlate with Wei’s response in Chapter 6, in which he believed physicians in China were more prompt than physicians in the U.S. with medical results. This may be an outcome of Manali and Wei having more knowledge about the healthcare system of the country they recently emigrated from. The expectations shaped by this kind of knowledge was potentially an underlying factor for Manali’s disappointment towards the delay in clinical cancer care in the U.S. Although Manali and Rajat were able to afford an

alternative choice, Manali's frustration indicates that going to India for a physician consultation was still a troublesome course of action to address Rajat's cancer diagnostic needs.

The perspectives of An, Lin, Leila, and Manali exemplify the harsh realities of access to healthcare despite having health insurance coverage. The burdens related to healthcare access appear to be driven by factors associated with institutional and economic barriers as well as patient and family carer expectations towards the healthcare system. An, Lin, and Rajat experienced some form of institutional barrier in which healthcare access was delayed or restricted. For An, she lacked the financial capacity to self-pay healthcare expenses to decrease the wait time for a clinical visit and diagnostic testing. Leila's and Manali's views of clinical cancer care were culturally or socially influenced, in which the norm of healthcare access was expected to be responsive towards the needs and priorities of the patient. Whilst certain types of health determinants influenced different levels of burden with healthcare access, the study findings illustrate how barriers to healthcare contributed hardships in cancer care amongst cancer-diagnosed individuals and family carers.

7.3 Healthcare communication

As patients and carers access healthcare, the communication with health providers is also a vital part of the clinical cancer care experience and outcome. Communication is a vehicle for many cancer care essentials, which include acquiring knowledge, accessing resources, making decisions, and navigating the cancer care trajectory. Study findings in this section exhibit how An and Manali experienced the burden of poor communication in the health provider setting. Their accounts reveal

how burdens in healthcare resulted from inadequate and inappropriate communication approaches relating to the patient's clinical care and condition.

As a limited English-speaking patient who was initially unaware of her Hepatitis carrier status, An relied on medical interpreters to facilitate communication with her health providers. An described how the absence of effective interpreter services were factors contributing a serious adverse effect of the cancer treatment:

...The attending doctor that day, who was not my regular oncologist, should have checked my liver function...The chemo damaged my liver.

During my encounter with this doctor, there was no interpreter.

- An, cancer-diagnosed

An's mention of not having an interpreter during a clinical visit depicts her awareness of the health provider's failure to facilitate language access and the necessary communication to understand what her treatment entailed. It appears that she had to shoulder the burden of the physician's interpretation of what qualified as appropriate patient communication. Although An's limited education may have played a role in her willingness to proceed with the prescribed treatment plan without questioning the physician, medical interpretation was necessary during all of her clinical visits. In addition to problems with language access, the way in which health care professionals communicated to An's family regarding her coma condition was perceived as inappropriate:

The medical team will come in to [tell] my husband...maybe half a chance [I] may get back...a spiritual team will come in and ask him what kind of ritual would you plan or where would you like to bury her. So that really upset him

because he would think [I am] still alive and it's very culturally inappropriate to ask him about all those arrangements.

- An, cancer-diagnosed

An's reference to the "spiritual team" being "culturally inappropriate" suggests that she and her husband have cultural beliefs regarding when it is suitable to discuss end-of-life and funeral arrangements. It appears that the practice of cultural understanding or awareness was not a part of the healthcare communication protocol, and therefore likely to be a factor in her husband's emotional burden as he encountered conflicting communication with the medical and spiritual personnel. The absence of culturally responsive and trustworthy communication during a vulnerable time of An's clinical care brought both healthcare and emotional burdens to the family.

Manali's burden with healthcare communication appears to be mainly associated with the difficulty of understanding the complex information about the medical issues:

...It's just very hard finding somebody who can step back and try to put the whole thing in context. Very frustrating.

(Long pause) It's so hard even talking to them.... I did not expect it to be so hard that they would all be in their little silos. We just felt like everybody was in their silo and you felt like a Ping-Pong ball.

- Manali, wife and carer of Rajat

Regardless of Manali being well educated and English-speaking, it seems that the need for multiple medical expertise involved in Rajat's care made it problematic to fully comprehend his condition and treatment. Her use of the words 'silo' and 'ping-

pong' depicts the fragmented communication between disease specialists that pushed her back and forth. This appears to especially have a significant impact on Manali's burden with healthcare communication, because she required integrated communication for her husband's clinical care. Perhaps the clinicians overlooked assessing and responding to communication needs due to the assumption that their social-economic status (e.g. English-speaking proficiency, post graduate education) enabled them to have sufficient health literacy skills. On the other hand, Manali's discomfort with speaking to the disease specialists may be associated with the social hierarchy in the healthcare environment. The concept of healthcare social hierarchy includes the establishment of a dominant status and power amongst physicians, which can make patients and family carers too uneasy to ask questions, address concerns or problems, and make certain choices. This concept will be re-examined in the next section as a factor affecting the burden of making cancer treatment decisions.

Comprehending the disease and clinical care was expressed as a heavy burden for most of the cancer-diagnosed persons and the family carers. They relied on the healthcare organisation as a primary source for healthcare information and support. Therefore alongside understanding the medical issues, it was also necessary for the communication approach to be a mutual exchange that is linguistically appropriate, honest, considerate, and cohesive. An's experience is an example of how social status (e.g. limited education, English proficiency and health literacy) can influence the healthcare professional to engage in one-sided communication with the patient. The one-sided manner of discussing the next steps for clinical care led to detrimental outcomes for An's health status. The study participants, both non-proficient and proficient English speakers, expressed disappointment and frustration in the poor

communication quality they experienced in healthcare. Yet it appears that the healthcare professionals were also unaware and uninformed about the inadequate communication. This suggests that in parallel with the healthcare professionals' lack of attention to communication needs, the patients and family carers were uncomfortable or reluctant with acknowledging the communication problems. These communication barriers together with other related obstacles have a continual effect on another crucial aspect of the cancer care trajectory - making choices about clinical care.

7.4 Healthcare decision-making

The findings regarding the burden of healthcare communication are also relevant for understanding the experiences with healthcare decisions. As previously discussed, cancer patients and family carers of varying social-economic backgrounds encountered difficulties with gaining helpful knowledge and understanding from their communication with healthcare professionals. In this section, the responses from Meiwen and Leila will reveal how the burden of making healthcare choices intersects with the challenges of healthcare communication and family obligations. Similar to the prior section of findings, these challenges are associated with social, cultural, and institutional factors that affect how the cancer-diagnosed individuals and family carers feel about and deal with the decisions for treatment.

Meiwen made medical decisions on her own because she did not want to her parents to shoulder the responsibility. Although she was proficient in English, it was a challenge to communicate with her physician about concerns and questions as well as to make treatment decisions. She explained, "I feel like my job as their daughter, I

need to take care of their concerns. So, this is not something that I want to burden them with...”. This statement characterises her belief that family accountability is structured around the daughter caring for her parents and relieving them of hardship. Whilst her parents cared for her during medical procedures and treatment, she struggled alone with selecting her cancer treatment:

Chinese, TCM – traditional Chinese medicine had played a big role in my current value system... "Do I go mainstream completely or do I use TCM as my solution?"

...My oncologist – the medical team actually does not deal with the TCM solutions...

- Meiwen, cancer-diagnosed

Meiwen values Traditional Chinese Medicine (TCM), but her healthcare team did not provide support to understand or consider how TCM could be part of her cancer care. TCM is Meiwen’s cultural capital in the form of health knowledge, beliefs and practices originating from her culture and identity. However, TCM appears to be marginalised by her healthcare team because of the lack of expertise and status of TCM within the western medical standards of care. Meiwen's challenge with treatment decision making also coincided with the challenges of communicating with her physician:

...The doctor's the authority and then whatever they say, we accept and...we do not challenge them...Although I...know what things to do, action to take, that part actually still play a big role... There were doubt or things that I feel I need more clarification, but I did not press or challenge the doctor. I can see that in me and sometime will be afterward, I say, "Oh, I really have this

questions. Why didn't I ask my doctors about treatment or can I have a different choice?"

- Meiwen, cancer-diagnosed

She describes the physician as the “authority” figure and her reluctance to confront her concerns. This indicates a social hierarchy in which Meiwen as the patient views herself as inferior to the physician, and therefore she accepts certain limitations in communicating with the physician. The healthcare social hierarchy, the isolation of TCM from cancer care, and the decision-making process are all part of the constructs and realities shaping Meiwen’s burden of making choices for her cancer treatment.

Family carers who were involved in communicating with the medical team also identified understanding or making healthcare choices as a burden. Leila, the eldest daughter, had to undertake the role as the primary decision maker for her mother’s clinical care during An’s comatose state:

My mom has always taken care of [dad] and...everything in the house.

Since I'm the oldest...I usually handled mostly everything...

That's when I felt the burden most when my dad didn't understand it and he put it on me and my sister to decide.... He put that decision on me...

I think mostly for him because he probably didn't understand it that much. The biggest thing is probably language barrier...[knowledge of] medicine too is a big barrier...

...My dad literally shutdown, like he could not handle it whatsoever.

...I just had to step-up and that was basically it. That was really hard.

- Leila, daughter and family carer of An

How Leila described the need to be accountable for An's healthcare decisions suggests that expectations from her father and for herself directed her to function in the 'maternal' role. She attributed her father's inability to communicate in English and understand medical information as a main reason for taking on the decision-making role. Therefore being educated and speaking English were pivotal elements for the family's decision making process. It is evident in her account that she felt shouldering the load was overwhelming but necessary. Her rationale and feelings about the burden of making decisions for her mother's healthcare represents her belief in family commitments.

There are social and institutional factors contributing to Leila's burden with treatment decisions. The primary underlying issues are related to: 1) her father's non-English speaking and limited education status; 2) the social barrier of not being able to communicate in English and comprehend the healthcare issues; and 3) the institutional barrier of the healthcare system which did not appear to support facilitators (i.e. appropriate language and health literacy access) to assist Leila's father to pursue a more active role in An's clinical care. Secondary aspects of Leila's burden with healthcare decision-making include the socially constructed family expectations and Leila's young adulthood. Leila was regarded by the family and herself, as the family custodian because her father assigned the decision making role to her and she felt it was her duty as her parent's firstborn. Although she is the eldest, dealing with the responsibility of medical decision-making for her mother as a young adult added difficulty to the burden of cancer care. In the next chapter, Leila discusses the burden of being a family carer as a young adult because it 'competes' with her priorities.

The perspectives and experiences shared by Meiwen and Leila depict the stress of making the ‘right choices’ and the consequence of communication barriers. The barriers include the difficulty of understanding medical information and the lack of optimal discussion regarding cancer treatment and alternative options. Whilst there are social and cultural determinants affecting the burden of dealing with healthcare decisions, there are institutional healthcare factors (i.e. communication and social hierarchy) that contribute to this burden. These findings suggest the importance of fostering supportive communication approaches that are adaptable in ways designed to benefit the needs of patients and family carers with healthcare decision-making.

7.5 Concluding summary

This chapter has explored the implications of how social, cultural, financial and institutional determinants as well as social, economic and cultural capital affected the obstacles with healthcare access, communication and decision-making. The feelings, opinions and circumstances of the cancer patients and family carers reveal a domino effect of how health determinants impact the burden of cancer care. The study participants with limited English proficiency, low-income, and lower level of education appeared to be especially vulnerable to the healthcare system’s barriers and gaps. Their lack of ‘social and economic capital’ led to inequitable and fewer options in clinical care. Amongst the study participants with the capacity to communicate in English and understand medical information better, there was still a health literacy and communication gap between healthcare professionals and those seeking cancer care or information.

The unique culturally-related knowledge, beliefs and social networks discussed by immigrant study participants are their 'cultural capital', but their experiences portray the lack of acceptance, acknowledgement or ability for these to be used within the U.S. healthcare system. A compelling finding amongst the theme of healthcare burdens is that immigrant cancer patients and family carers are vulnerable consumers of U.S. healthcare. As consumers of healthcare services, they must confront the social hierarchy in healthcare (which includes the institutional policies, constructs, norms, and professionals) that can exacerbate their circumstances in dealing with cancer care. The next chapter will describe the compounding burdens that cancer patients and family carers dealt with. These burdens were exacerbated by competing priorities related to the circumstances with cancer care and their personal individual obstacles.

Chapter 8 | Findings: Competing priorities

8.1 Introduction

As patients and family carers deal with cancer care, there may be other important concerns that impact daily lives, expectations, and the ability to maintain what is perceived as their 'norm'. These concerns can become the 'competing priorities' confronted as part of their burden of cancer care. Competing priorities were not widely identified as a burden in cancer care amongst the sample population, yet the findings about the competing priorities experienced by some of the study participants are critical for understanding how priorities co-exist and conflict with cancer care. This chapter explores different types of competing priorities identified by three cancer-diagnosed individuals and a family carer: mental health, housing, financial security, healthcare option, family role, and life stage transition.

Findings are presented in a case format to examine how individual lives encompass: 1) priorities that compete with cancer care; and 2) social and economic factors related to competing priorities and cancer care burden. Selection of cases were based on commonality with findings from other types of health research unrelated to cancer, which often refer to the problem as 'competing demands'. The case format approach was selected to bring in-depth, multi-faceted examinations of interweaving and complex issues. The cases provide an understanding of the various ways in which competing priorities of cancer care are connected to social-economic determinants, and the impact of this connection on the burden of cancer care.

8.2 Marie: Mental health and housing

Marie confronted two ongoing challenges with cancer care - her mental health condition followed by housing instability. These were issues she struggled with prior to her cancer diagnosis, possibly as correlated obstacles. Although she received treatment for postpartum depression, it appears her condition was difficult to manage alongside the problems of her temporary housing status. When asked about challenges with cancer care, she describes layers of difficulties she has to cope with on a regular basis:

Difficulty on my part because...I don't have my own place. I'm a transient boarder...

I slept in the streets once for two nights. Because the prescription makes me sleepy...

...I cannot stay in one place because I have another problem aside from cancer....

Postpartum psychosis or depression...it's a big thing that's going on between the cancer and this postpartum. This is a big problem, is my postpartum - is it coming back...maybe because of this cancer...? It's not in my own control that I'm going through that postpartum...You can heal the cancer. I'm scared on that other problem...

So I don't know which one I'm gonna take care of first, but I think I am gonna take care of the other one first because the cancer - in the cancer care program, they help you a lot...

Marie's concern for her mental well being as a higher priority than her cancer care seems to be associated with the fears towards dealing with her mental health.

Although she received mental health care through clinical visits and medication, it appears the clinical interventions are inadequate for helping her manage depression and the medication's side effect (i.e. sleepiness). She asserts the struggle with her mental health problem by also explaining "...it's kind of hard to deal with the other problem, but the cancer care is not really hard to deal...". When she identified the cancer care program being immensely supportive, it is implied that she has not accessed services that helped her to effectively cope with depression.

Marie's opinion that depression is a more difficult condition in comparison to cancer suggests the complexity of managing mental illness and the lack of support beyond the clinical care. Her use of the terms "postpartum" and "other problem" in reference to depression potentially indicates her discomfort of saying a word with negative connotations. A negative connotation, such as the stigma of psychological illness, possibly provokes feelings of uneasiness and social marginalisation associated with individuals having depression. With her depression lingering and not receiving the necessary support, the mental health problems compound the other problems she deals with as a cancer patient.

The other problems that appear to be associated with her depression are her feelings of isolation and transient housing status. Marie says, "Sometimes I cannot be alone. Sometimes I cannot sleep [if I'm] alone. I need somebody to be with, just be there beside me there." Her ongoing need to have the presence of a person or people may be an influence on her homelessness. She recognises herself as "...homeless in the sense really I don't have my own place...", because she alternates living in the homes of a few family members and a friend. Her earlier statement of "...I cannot stay in one place because I have another problem aside from cancer..." is a strong

indicator that she may have chosen or accepted the ‘transient boarder’ lifestyle. The uneasiness towards being alone may be a justification for her choices with housing. It is unclear if Marie’s lack of employment and income prevents her from having permanent housing. Although her transient housing circumstance may be connected to her depression and anxiety with loneliness, her low-income status may also limit housing options or dissuade her from considering permanent housing. Marie confirms that not having her own place adds to the difficulty of her mental health care and cancer care. The priorities of managing depression and her transient housing lifestyle reveal strains in her day-to-day functioning and wellness whilst she must also deal with cancer care.

There are aspects of Marie’s social and economic status that appear to have a significant relationship with the competing priorities of her cancer care. She supported herself financially since her divorce and currently relies solely on government public assistance. During her cancer treatment stage, she experienced the loss of employment, income, healthcare insurance coverage, and permanent housing. Marie acknowledged that she was briefly uninsured and unable to access healthcare until she was provided with Medi-Cal public healthcare coverage. This period of social-economic instability potentially had a severe impact on her mental well being and housing status. Whilst it can be speculated that the loss of income and the reoccurrence of depression contributed to her transient housing circumstance, she could have also experienced gaps in health services that created barriers for managing her mental health issues. Potentially the disruption of healthcare insurance coverage had a crucial impact on the care for her mental health, in which she may have been: 1) pressured to prioritise addressing the cancer treatment needs over her mental health

care needs; and/or 2) disconnected her relationship with mental health care professionals who provided services under her employer-sponsored insurance. As a cancer patient with a history of mental illness under poor social-economic conditions, Marie's cancer care burden is connected with coping with her fragile state of mind and capacity to keep up with her difficult housing lifestyle.

8.3 Luwisa: Finance and healthcare options

Before Luwisa's cancer diagnosis, she was working as a self-employed business agent to supplement her retirement income. During her cancer diagnosis and treatment, Luwisa had coverage through an '80/20 healthcare co-insurance plan' acquired as part of her retirement benefits through a former employer. In addition to the typical expenses of insurance premiums (monthly fees) and deductibles (annual fees before insurance can be activated for coverage), she must pay for twenty-percent of the total healthcare costs until she reaches an 'out-of-pocket' limit set by the insurance plan. These are all 'out-of-pocket costs' that must be paid to comply with the healthcare insurance coverage. She explains the competing dilemma of payment towards her home and medical expenses:

My house, my mortgage...I would say financially, you know, problems because of my house. I don't want to lose my house. You know how this experience of losing your house and how can I – I was stressed out, you know stressed out financially.

...I was kind of like stopping mortgage already because I can't, I'm not getting income. Because of my health I cannot go to clients and things.

So my income really went down.

Plummeted. Then I have no way. My husband is retired...the economy is not doing well, that kind of added to my stress.

My medical [insurance] is paying...expenses in the hospital, but of course I have a supplemental...they call it 80/20, so I paid the 20 [percent], but still, I'm still off paying my [medical] bills.

Despite having retirement income and benefits, it seems Luwisa relied heavily on her supplemental income from self-employed work to help afford certain costs of living such as the housing mortgage. The loss of this income created financial hardships and reveals that her fixed retirement income was insufficient to keep up with the simultaneous demands of housing and healthcare expenses. Her choice to stop the mortgage payments over payment of medical bills demonstrates the difficult decisions she had to make in order to maintain her preferred clinical cancer care. It appears that the '80/20 healthcare co-insurance' coverage was important to Luwisa despite the plan's costly out-of-pocket medical fees. Perhaps transitioning to a more affordable alternate healthcare insurance plan would not allow her to maintain access to her medical team or meet her expectations for healthcare delivery. Although Luwisa does not specify expectations for healthcare options, she mentions the value of obtaining a second opinion from another physician and changing healthcare provider organisation through the insurance plan's Preferred Provider Organization (PPO) feature. As a cancer patient with escalating healthcare bills and lack of supplemental income to maintain financial stability, she was pressured to choose between housing and healthcare as competing priorities. Both were pivotal for maintaining her expectations of basic needs and normalcy.

Healthcare costs appear to be a significant factor in Luwisa's cancer care burden because they placed her housing and healthcare status in jeopardy. As a retiree who is dependent on supplemental income through work, Luwisa's moderate income shared with her husband was not adequate to meet the financial demands of housing and oncology healthcare. The '80/20 healthcare co-insurance plan' provides its insured consumers with more flexibility to select medical practitioners from different healthcare provider institutions. However, the insured consumer must have the capacity to pay for the premium, deductible, and twenty-percent of the medical costs associated with clinical care. The escalating medical costs of multiple clinical visits, procedures, and treatment drugs can become overwhelmingly expensive for a cancer patient. For Luwisa, the substantial medical costs she was required to pay had an effect on her competing priorities. She was in a dilemma with paying for home ownership needs (i.e. mortgage) and paying for her medical care costs. Her circumstances depict the harsh reality of how the costly healthcare expenses can potentially worsen the socioeconomic status of cancer patients and their families, which in the prior literature review of Chapter 2 has been labeled as 'financial toxicity'. For immigrants like Luwisa, home ownership may embody socioeconomic well being. It can be a critical source of maintaining social, cultural and economic capital, because home ownership represents financial stability, may further garner social networking, and can establish a cultural norm defined by achieving 'American dream' standards.

8.4 Lin: Parental role and expectations

As Lin faced increasing financial demands to treat her cancer, she experienced emotional conflict as a single parent in order to sustain her family's welfare and financial stability. This was particularly expressed through feelings of shielding her two young adult daughters from the burdens of her illness and care. She first explains that the divorce, loss of employment, and limited income added financial hardships to her cancer burden:

[The divorce] has made somewhat an impact, mostly on the financial standpoint, because [as] a couple...one can still be a breadwinner. But because as a divorcée, I stopped providing for the family. Then the responsibility will fall onto my daughters...

...So I [had] to apply for [self-pay] insurance...because of the policy – which I was making \$1,000 and [the Medi-Cal eligibility] cut-off income was \$900.

(Tears filling eyes) It was really harsh because what my income was from the disability income...most of it pay off for the insurance, plus for every time a doctor visit, the copay has been a struggling issue for our financial standpoint...

Initially Lin's employment income financially supported the family and healthcare costs, but then her poor health condition led to the discontinuance of employment and loss of employer-sponsored healthcare coverage. It appears that the financial strain intensified the competing demands between her role as a parental provider versus expending her limited income on medical care expenses. Lin revealed feeling deeply troubled by the competing priorities of her cancer care which she perceived as a burden on her daughters:

It was quite conflicting for me because I feel I have been a burden, that I have bothered them in many ways. So I have to overcome this difficulty within myself.

[Crying and pause] So that particularly hit harsh on me when I have to see my daughters worrying about my health. Also they have to worry about the financial because they would have to worry about how to pay the medical bills.

But it was really hard that as a responsibility as a parent, I would not want my child to worry about me and also worry about how to get the money to pay for my medical expense, although it was really straightforward in receiving the treatment. But it's just a burden to see my child been worrying and even consider stopping – stop their education for taking care of me.

Despite her daughters being of adult age, Lin values being a contributor for her daughters' welfare. Lin's pause and tears as she discussed the hardships of how her disease affected her daughters, was a strong indication of the heavy psychosocial burden she carried throughout her cancer experience. It appears that the difficulty of juggling her role as an accountable parent and the challenges that came with her cancer (e.g. financial, declining health), was an additional contributor to her emotional struggles that she tried to cope with independently as a divorced mother. She is reluctant to have them become responsible for the family's finances and her cancer care, possibly due to personal and cultural beliefs as an immigrant parent who does not want her daughters to shoulder her burdens. Lin's expectation of being dependable and self-sufficient is a factor in her emotional challenge to cope as a parent with cancer. Her feelings and opinions may indicate a source of emotional

problems encountered by parents with a cancer diagnosis, in which they are distressed by their attempts to maintain a level of normalcy and accountability for the family.

There are two major influences on Lin's burden of competing priorities: her diminished social-economic status and the emotional stress of being a parent with cancer. There are multiple aspects in the decline of her social-economic circumstances. As a divorced single parent who became unemployed due to poor health outcomes, she had no other source of income and healthcare benefit. As a result of her disability income benefit, she was not eligible to receive public healthcare coverage assistance. Yet the self-purchased healthcare insurance premiums and out-of-pocket expenses were unaffordable on her extremely limited income. Without sufficient financial and healthcare resources to leverage on, it became emotionally troubling for Lin to make certain decisions and safeguard her daughters from her cancer care burdens. Coping with the difficulties of her cancer care conflicted with her feelings of obligation to protect her daughters' welfare, because as a parent she recognised that she had to take care of herself and the family.

8.5 Leila: Independence and financial security

Leila faced the dilemma of transitioning into an independent adult whilst meeting the needs of her mother's cancer care and the general welfare of her parents. Establishing self-reliance and financial security were critical milestones she wanted to achieve. She also valued supporting her parents with cancer care, finance, household necessities, and decision-making. Emotionally, it was difficult for her to consider the change in priorities and addressing her parent's disadvantaged circumstances. As a

young adult cancer carer, she described the competing priorities as a stressful load to carry:

You know my mom has always been there for me so..., "It's not about me now...just stop and do what I need to do for [my mom] and my parents."

This was my chance to...do my own thing and it just abruptly ended.... At that time too I was paying for my own rent, I was taking care of myself...In this case, "Okay, I guess I'm putting my dreams on hold to make sure that they're okay." So it was definitely a huge burden.

I was doing it for my parents but you know sometimes it's like you're trying to start your own life and you kind of can't, you have to go back to what you started off and that kind of sucked.

Generational social values appear heavily influential on her conflicting obligations as a family carer. She has the desire to secure independence in ways that meet her individual and societal expectations: moving out of the childhood home, creating accountability for personal finances, and pursuing individual goals. Yet as the eldest child, the family values and expectations had a critical role in shaping the kind of adult she would like to be - a person that is lovingly responsible for the family. The compassionate feelings for her family's welfare and the recognition of her parents' hard work have an effect on her value system as well:

...It was really hard because, like I mentioned, I had to put a lot of my own personal things away and just think about my family...

...[My mom] had to drive herself to her chemo appointments. She was still working. She was working as a janitor at night and it was just knowing that she couldn't rely on us to help her out, because we all were trying to help out

at the house. So that's probably the hardest thing I think knowing my parents worked so hard to be where they are now and for her to...suffer so much... [crying].

[My sister and I have] been working for a really long time to help out. You know if we have extra money then we'll give my mom money...It's still hard for us to like really try to make the money, to be where we want to be.

Her perspective about sufficient family income indicates that she recognises the need to alleviate her parents' financial challenges, but feels that it is also a struggle to build-up her own financial security. Leila's experience as her mother's carer during a major life phase transition conveys the emotional vulnerability that family carers may face when personal milestones compete with their commitment to family.

Although Leila's expectations for achieving personal goals and family responsibilities placed a heavy emotional burden on her role as a cancer carer, the financial problems and her parents' social status appear to have a substantial impact on Leila's competing priorities. Her mother, An, worked during her cancer treatment because of limited household income exacerbated by her husband's job loss. An eventually became unemployed due to the decline in her health condition. Therefore the financial support from Leila and her sister become a source for maintaining their parent's basic living standards. Leila regards attaining financial security as a hardship difficult for her family to overcome, presumably because employment income is insufficient to meet the costly living standards. Her emotional woes seem to be especially connected to the sympathy towards her parents' financial struggles perhaps as limited English speaking immigrants, whom she describes as hard workers. Leila's perspectives as a family carer dealing with competing priorities exhibit how financial

challenges can be embedded as a long-term burden for an immigrant family prior to and during a patient's cancer care.

8.6 Concluding summary

The various cases presented in this chapter illustrate how additional priorities co-exist and compete with cancer care in the lives of cancer patients and a family carer. The study participants' experiences and feelings reveal the difficulties of making decisions between priorities, because allocating additional resources and support were not within easy reach. Most felt their limited financial resources were inadequate to meet their needs and expectations of healthcare, basic living standards, and/or family welfare. Marie's case provides perspectives on how mental illness can be difficult to manage, making cancer care a secondary concern at times. Although personal expectations shaped their approach and views of priorities, the social-economic status (e.g. income, housing, employment) of the study participants made them especially vulnerable to the hardships of overcoming the burden of competing priorities. Competing priorities can be viewed as a 'choosing your battles' scenario, despite the importance of every battle. As a result, cancer patients and family carers may face heavy emotional conflict from recognising that not all battles can be fought and won. The next chapter will discuss how the study findings have unique and critical importance to understanding cancer care burden experiences of Asian American immigrant families.

Chapter 9 | Discussion of findings

9.1 Introduction

This chapter discusses the findings from Chapters 6, 7 and 8 regarding the key themes of psychosocial burdens, healthcare burdens, and competing priorities. The study results provide broad insights on how cancer-diagnosed individuals and family carers defined meanings of cancer care, confronted the factors that shaped their experiences with cancer care burdens, and perceived their burdens in cancer care. The discussion of study findings focuses on how the factors associated with the burdens in cancer care: 1) are parallel with study results found in other populations, but also have some distinct relevance to Chinese, Indian and Filipino American immigrant populations; 2) demonstrate the multifaceted realities of psychosocial and healthcare challenges; and 3) bring new perspectives and knowledge of how both social determinants and the different forms of ‘capital’ affect the burdens placed upon cancer patients and family carers. This chapter also explores how the study findings compare with existing research literature and current knowledge, as well as outlining the strengths and limitations of the study.

9.2 Significance of findings in the sample population

As discussed in Chapter 2, psychosocial and healthcare burdens have been featured in some research literature as major challenges in cancer care experienced by the general American and Asian populations. However, whilst results from the study confirm prior research knowledge, this research has revealed that there are subtle cultural and immigrant factors associated with the cancer care burden experiences of Chinese, Indian and Filipino American immigrant families. The study applied a fluid

interpretation of culture and immigration to better comprehend how these concepts, beyond the racial-ethnic identity and nativity status, interweave with psychosocial dimensions (e.g. expectations, norms) and social-structural conditions (Bourdieu, 1986) impact cancer care burdens.

Psychosocial Burdens

The burdens of self-coping, concealment of the cancer, and feelings towards uncertain cancer outcomes were the main types of emotional challenges identified by the cancer patients and family carers in this study. Fears, worries and frustrations related to the uncertainty of the cancer patient's health status were emotional stressors experienced by several of the cancer patients and family carers. These findings correlate with the general findings from psycho-oncology literature cited in the literature review. Some of the study participants reported experiencing a high level of psychosocial burden during the 'waiting periods' in which the absence of knowledge regarding the cancer patient's prognosis and outcomes produced stressful situations. From the limited research on the psychological and emotional implications of cancer patients and carers waiting, the findings reveal that general populations have a stressful experience waiting for the news about health status and prognosis (Bailey et al. 2007; Mulcahy et al. 2010) which were sometimes described as "traumatising" by patients (Sweeny & Cavanaugh, 2012).

Findings about waiting periods from my study can be specifically attributed to Asian American immigrants, a population that did not appear as part of the sample population in the current research literature related to this topic. For example, Wei (cancer-diagnosed) and Manali (family carer) felt that the U.S. healthcare system had

unnecessarily long waits for access to clinical visits and communication about the medical evaluation. This was a main source of their emotional frustrations during the waiting periods. As immigrants of less than ten years, Wei and Manali had recent knowledge of the healthcare system in their country of origin. After experiencing delays with American healthcare, they viewed healthcare in their native country as being more efficient with timely services and communication that was beneficial for patient care. This perception influenced their disappointment about certain aspects of healthcare delivery in the U.S. and perhaps intensified their emotional difficulties during the waiting period. The study views immigrant healthcare experiences, and knowledge originating from their native country, as a form of cultural capital that can influence expectations and choices for cancer care in the U.S. More research is needed to understand how healthcare professionals can engage the patients and their family members in communication about their own expectations and past experiences with medical care, whilst familiarising them with the mechanism of the US healthcare system. This could establish a more positive rapport conducive for helping patients, carers and family members deal with the waiting periods as well as foster more effective communication that addresses their concerns and questions.

The findings related to the psychosocial burdens of cancer care show perspectives of how self-coping can lead to emotionally isolating situations. Self-coping in the form of internalising emotional problems, was stressful for some of the study participants. Meiwen, Lin, Rajat and Lian (cancer patients) as well as Bao (family carer of Lian) chose to be more self-reliant in managing their emotions as a way to shield others from experiencing their emotional burdens. This was discussed as self-perceived burden in Chapter 6. Despite the presence of family member

support, self-perceived burden influenced some of the study participants to deal with emotions in an insolated way. In other studies assessing forms of self-coping, the findings revealed that self-efficacy was primarily a positive coping mechanism for cancer patients (Ellis et al. 2017; Lev et al. 2001, Zachariae et al. 2003). Another study found that individuals with higher self-coping levels were likely to report better psychosocial health when responding to stress (Hardie et al. 2006). The findings by Solberg Nes et al. (2015) found contrasting results with hematologic cancer patients with higher levels of self-regulatory fatigue. Self-regulatory fatigue, which is characterised in the study as self-controlled reasoning, behaviours and emotional responses to medical treatment, were associated with poorer quality of life outcomes for these cancer patients (Solberg Nes et al., 2015). It appears from my study findings that self-coping and self-reliance had more negative effects on the study participants' emotional wellbeing.

Findings suggest that some of the cancer patients and family carers rationalised their self-reliance as a way to conceal additional cancer burden and limit the effect on other family members. The previously cited literature suggests that whilst self-coping can be a positive approach to dealing with illness and cancer care because it builds upon self-empowerment, the findings from the study suggest that it can have a negative impact on individuals who have difficulty with managing emotional problems or become further isolated from their social network. Self-coping, self-efficacy and self-regulation are mechanisms of self reliance, a concept to be further investigated in the understanding of how immigrants chose to cope with illness and treatment. More research on self-reliance and self-perceived burden

amongst Asian immigrant cancer patients and family carers could inform interventions aiming to foster healthy levels of self-coping.

Similar to the findings of self-coping, concealing the cancer diagnosis developed a pathway for psychosocial isolation as well. Lin, Meiwen, Angie (cancer patients), and Isabel (family carer of Lin) felt that social stigma and attitudes about cancer could generate negative responses and gossip amongst their social networks. There were different types of factors influencing the concealment of the patient's cancer diagnosis, including: cultural and generational values of privacy, assumptions about cancer, and experiences with their social network's negative attitudes towards people with cancer. The stigmas of illness are often socially and culturally constructed within social networks. Knowledge about why and how people stigmatise can be a form of cultural capital gained through the exposure of attitudes and behaviours of a group. Consequently, privacy or concealment can become a social determinant for a group's or individual's approach to coping with illness.

Rather than the social network being considered a 'social capital gain' for supportive resources, some study participants viewed it as counter-conducive towards dealing with cancer. Yet for some of the Asian immigrant cancer patients and family carers, concealing the cancer diagnosis also brought on feelings of loneliness or isolation. The literature review referred to a few studies in which Chinese and South Asian cancer patients and carers felt people had negative opinions about cancer. As revealed by the findings in the current study, the assumptions about how cancer may be perceived, and elicit insensitive responses from others, can impose emotional burdens on patients. In a recent qualitative study conducted in the U.K., Ewing et al. (2016: p.382) found "dealing with reactions of those told [about the illness] was

difficult...” amongst all the advanced lung cancer patients interviewed for the study. Since there were no group comparisons in my study, it is not clear whether or not the emotional burden of revealing a cancer diagnosis is greater or more problematic for immigrant cancer patients. This could be an important question to address in future research.

The wish for privacy during illness, across different sample populations in research, illustrates the underpinning psychosocial issues patients and carers face when being ‘open’ about cancer. The findings from my research draws out concern for immigrant patients who are socially marginalised or whose lives are shaped by social determinants factors that promote compounding burdens in cancer care. For example, there were several factors in Lin’s circumstances that made cancer care challenging as she attempted to disguise her cancer diagnosis: limited English-speaking, single marital status, low-income status, and limited cancer knowledge. Future research should investigate the different types of social support that are impactful on immigrant patient psychosocial well being across the cancer care trajectory. In doing so, novel findings in this area could assist health professionals with tailoring support needs for the cancer patients.

Burdens related to healthcare

Some of the underlying issues related to the healthcare burdens in this study confirm similar healthcare problems for cancer patient populations that have been examined in previously cited literature: delayed access to healthcare services, the harmful financial impact of patient healthcare expenditures, and the challenges of health communication and health literacy. My research findings demonstrate the lack

of cultural and economic capital as barriers for Chinese, Filipino and Indian American immigrant populations. The study illustrates knowledge of how certain types of determinants that shape the lives of Asian immigrant cancer patients and family carers, also influence how they experienced burdens in healthcare. Culture, socio-economic conditions and status, social networks, and psychosocial influences are factors which are now examined across the major themes of burden in healthcare access, communication and decision-making.

The analysis of findings on healthcare burdens promotes understanding of the relationships of social, human and economic capital with healthcare access experiences for Asian immigrant cancer patients and their family carers. Current knowledge on U.S. healthcare barriers to cancer treatment (Freedman et al. 2011; Gorey et al. 2011; Tarazi et al. 2016; Unger et al. 2016) supports the study's findings that limited economic capital can worsen patient access to healthcare due to their inability to pay for healthcare costs. Low-income and poverty status were a primary focus of financial burden risk factors for Asian immigrants in past cancer research papers (Clough, Lee & Chae 2013; Lee et al. 2010), but the findings of my research reveal that the affordability of healthcare was not a specific problem for only low-income cancer patients. Cancer-diagnosed individuals who had moderate income levels were also dealing with the financial toxicity of healthcare expenditures.

Financial toxicity, a concept used to describe the endangerment to personal financial assets (Yousuf Zafar, 2016), redefines how personal income and health insurance should be evaluated as economic capital for cancer patients and families. For some moderate income individuals diagnosed with cancer, their personal income and health insurance were not sufficient to provide them with financial security. The

compounding medical care costs and loss of employment income made it challenging for cancer patients and their family members to maintain financial stability to meet basic needs. Recent evidence from health research shows that financial toxicity of cancer care is a widespread problem for many healthcare insured patients of varying socio-economic levels, because out-of-pocket expenses are exceedingly expensive (Goldstein 2017; O'Connor & Kircher 2016; Peppercorn 2017; Yousuf Zafar 2016). Immigrant cancer patients may be particularly susceptible to the severities of financial toxicity when there is limited economic capital to draw upon from as a 'newcomer to America'. Leila's (family carer of An) description of her immigrant parents' hardships to build financial security for over two decades implies the long-term challenges that immigrant families may face to establish economic capital from resources.

Communication and decision-making challenges were healthcare burdens that encompassed needs for the cancer patients and family carers to have language-appropriate information exchange, mutual understanding, as well as recognition of options, values and preferences for care. In line with the research literature (Karliner et al. 2010; Khosla et al. 2017; Rew et al. 2014; Schinkel et al. 2016), findings from this study suggest that healthcare communication and decision-making were affected by cultural values, linguistic needs, and personal preferences for communication style. The results of this study indicated that the cultural influences were sometimes explicit as well as ambiguous. For example, Meiwen (cancer-diagnosed) wanted to include Traditional Chinese Medicine (TCM) as part of her cancer care because it was part of her Chinese health knowledge, belief and practice. She was well versed about the standard care for treating her disease (human capital) due to relationships with oncology healthcare professionals who provided her with knowledge (social capital).

Meiwen proposed TCM as a part of her treatment plan, but since her medical team did not recognise it as standard care for cancer treatment she entirely opted out of TCM. Meiwen's experience depicts how a Chinese immigrant cancer patient's cultural capital becomes excluded from cancer care. Manali's (carer) and Meiwen's (patient) experiences illustrates an example of the cultural context of treatment decisions and healthcare communication burdens of well-educated, English-speaking immigrants.

Through An's account, it appears that the poor communication may have been influenced by the circumstances of the family in which An's husband was non-English speaking and relied on their young adult daughters to make medical decisions. The culturally inappropriate communication from the medical professionals may stem from their bias perception about the patient's and the family's capacity in making healthcare decision. Health communication expectations seem to be similar across the immigrant cancer patients and family carers, despite the differences in socio-economic backgrounds. Many of the study participants indicated their reliance on the medical care team to communicate all the essential information, appropriately guide their decision-making process, and recommend what was in their best interests. The considerable trust that the cancer patients and family carers placed in their healthcare providers possibly contributed to their vulnerability within the healthcare system.

Part of that vulnerability may include becoming marginalised, to some degree, from the information to help them fully understand the health issues, make well-informed decisions, and to assert their questions, concerns or opinions. Nápoles-Springer et al. (2005) examine findings from their study of how cultural factors influenced the quality of medical care experiences. Some Latinos interviewed in this

study reported ‘patient submissiveness’ that allowed their physician to exercise greater control of their healthcare visits. This suggests that ‘patient submissiveness’ may have prevented these Latino patients from being engaged in a mutually beneficial relationship with their physician. My research findings do not imply ‘submissiveness’ as a dominant characteristic of Chinese, Filipino and Indian immigrant patients. Instead another factor to consider is the feeling of intimidation within the healthcare hierarchy, in which certain types of social determinants (e.g. gender, health literacy, and social status) and immigrant specific experiences make immigrant patients more susceptible to intimidation in the healthcare setting. In the next section, the cancer care burden experiences of An and her family are used to illustrate an example of how they were marginalised throughout the various aspects of An’s encounters with healthcare.

Compounding effects from limited social, economic, and cultural capital

From the study findings, it appears that the limited social, economic and cultural capital of immigrant families may have a relationship with experiencing the severity of compounding effects from burdens in cancer care. This was especially illustrated by An (cancer-diagnosed) and Leila’s (daughter and carer of An) accounts of dealing with the multiple challenges which were related to the family’s moderately low income, the heads of household (An and her husband) having limited English speaking capacity and education levels, and the family being familiar with very few medical institutions (e.g. public hospital). The analysis in Chapters 6, 7 and 8 show that An and her family experienced multiple circumstances of being marginalised in the healthcare setting. The experience of being marginalised was evident throughout

An's access attempt into the healthcare system, medical care, healthcare planning, and hospitalisation.

An's and Leila's experiences are examples of the similar compounding effects of cancer burdens lived by other immigrant cancer patient and their family carers. With the limited economic, social and cultural capital, it appears that immigrant cancer patients and their families were restricted in their healthcare access and options for healthcare, faced difficult circumstances in communicating with the medical staff, and encountered challenging obstacles with making healthcare decisions. The string of factors connected to the compounding burdens in cancer care that were experienced by An's family exhibits the layering affects of how socio-economic status diminishes the ability to gain social, human and economic capital. An's case example is a reflection of how she was constantly marginalised from opportunities to experience more equitable healthcare for her cancer. Although neither Leila nor An identified specific reasons for the poor communication with the medical team, this is an area of concern that could be further explored in future research that examines communication with MediCal patients and families in public county hospitals.

Exploratory findings from a study by Pollak et al. (2010) suggest that socioeconomic status rather than racial identity may have a greater influence on how oncologists and advanced cancer patients perceive patient-centred communication. The authors reported that oncologists were "...less likely to provide a patient-centered response when patient concerns were personal rather than medical" (Pollak et al., 2010: p.2) Comparisons between the cancer patients with self-reported "lower economic security" and "higher economic security" revealed that more patients with

lower socioeconomic status felt that their oncologists were less responsive to their patient-centred communication needs.

Researchers who evaluated the impact of immigration on social capital observed a decline of networking relationships and trust after immigrants move from their home country to another (Kesler & Bloemraad, 2010) and that immigrant monolingual populations often face linguistic isolation (Lueck & Wilson 2010; Nawyn et al. 2012). Linguistic isolation appears to be a major issue for the cancer patients who spoke only Chinese, because they had less knowledge about cancer and medical care, they required a medical interpreter, and sometimes medical interpretation was of poor quality. In regard to networking relationships in the healthcare system, immigrant cancer patients seemed to consider few options for where to receive healthcare or had restrictions on where they could access healthcare. This may have contributed to the obstacles of communicating and making decisions in a healthcare setting where patients and carers lacked patient-centred or networking relationships. Immigrants and their families can experience marginalisation in the healthcare system where they have less social and economic capital as leverage. The discussion of study findings about the psychosocial and healthcare burdens demonstrates that these capital assets appear to be of fundamental importance in how immigrant cancer patients and family carers encounter and deal with their cancer care burdens.

9.3 Relevance of capital theory in immigrant populations

This section will bring together the earlier sections of this chapter with Pierre Bourdieu's theoretical commentary (1986) about the different forms of capital -

social, cultural and financial. These three types of capital can be viewed as factors influencing social and economic status, group norms and expectations, access to knowledge and services, and ability to socially integrate. In turn, these concepts have become the subject of research literature evaluating the ways in which social determinants impact health outcomes. The application of the social, cultural and economic capital theory in the current study raises some important discussion points about how being an immigrant or part of the immigrant family may affect how individuals acquire, use, and accumulate certain types of capital. This section addresses some of the ways in which the presence or lack of social, cultural and economic capital appear to have a relationship with the cancer care burdens experienced by Asian American immigrant cancer patients and their family carers.

The social capital effects on psychosocial burdens

Although social capital can cultivate the needs of support during difficult situations, there are circumstances in which social capital may affect a patient's psychosocial burden when dealing with cancer care. For some people, the family network is a tremendously valuable social capital and therefore the well being of the family may be a greater priority over individual needs. Social capital in the form of peer networks, such as friends bonded by shared culture and language, can make some people feel that disclosure of personal hardships may promote negative opinions and invasion of privacy amongst the social circle.

Chapter 6 reported study findings on psychosocial burdens that were associated with the immigrant cancer patients' own expectation to restrict the cancer care burden on their family. The cancer patients, Meiwen, Lin, Rajat, and Lian, felt

that it was emotionally difficult to alleviate the cancer care burden from having an impact on their family members who witness the daily encounters of treatment, recovery and coping. This concept has been particularly explored in chronic illnesses, palliative care and end-of-life research as ‘self-perceived burden’ in which patients view themselves as a burden to the carer and family members (Lee et al. 2015; Libert et al. 2017; Lofaso & Weigand 2014; McPherson2007; McPherson, Wilson & Murray 2007).

Published research on self-perceived burden show that various types of people have felt they were a burden to others. The current study suggest for future research to consider how self-perceived burden is associated with immigrant expectations to protect their social capital of family as a result of the immigrant experience. The research literature has illustrated that Asian American immigrants experience problems with acculturative stress (i.e. stress associated with adaptation to American life and standards), separation from other close family members and friends, and self-imposed standards for life in the U.S. (Bhattacharya & Schoppelrey 2004; Hao & Johnson 2000; Lee 2007; Lueck & Wilson 2010). The immigrant experience may add layers to how immigrant cancer patients feel and perceive themselves as a burden to their family when supportive care is needed.

Another way that social capital impacted psychosocial burden was how the connection to social networks and cultural norms made it emotionally challenging for the cancer patients, Lin, Meiwen, and Angie. Whilst peer networks appear to be an important social capital for them, there were pressures for them to maintain a persona that did not reveal their cancer diagnosis. Lin and Angie were concerned about being the subject of people’s conversations and judgement related to illness. Meiwen felt

that her social network's cultural practice of sharing personal circumstances as a way to help with problems could lead to comments that cause unintended hurt towards her feelings. Some cultural norms that are embedded in social networks can be a deterrent for cancer patients to seek support from their peers who are a part of this social capital.

The prior literature review highlights this similar notion in which group norms derived from social capital can make it difficult for people to confront their individual preferences or choices (Baum 2016; Kawachi, Subramanian & Kim 2008). Li's et al. (2015) assessment of Mandarin-English speaking immigrants found that those connected to a larger-sized family and large community organisations (e.g. religious, cultural, senior citizen) had increased immigration stress. The negative effect of social capital is concerning because limited interactions with existing social bonds may increase social isolation for immigrant cancer patients who have particular needs (e.g. language) and preferences (e.g. cultural identity and values) for support. Social capital in the form of family and peer networks can be important for general psychosocial well being, but may also generate individual pressures and self-perceived burdens in response to norms, expectations and experiences. These social relationships did not always help them gain more social, cultural or economic capital. It should not be assumed that the presence of social networks provides sufficient psychosocial support for cancer patients and therefore caution should be applied when designing interventions to support immigrant patients.

The absence of cultural and economic capital in immigrant families

In the way that social capital is connected to psychosocial burdens, the lack of cultural and economic capital can contribute to the burdens of healthcare and competing priorities. Chapters 6 and 7 found immigrant cancer patients and their family carers faced barriers with access to healthcare, communicating with the medical team, making treatment decisions, affording healthcare expenses, and fulfilling expectations for self and the family. When immigrants patients such as An and Lin lack certain cultural and economic capital, options become restricted or unavailable for many of the health and wellbeing essentials - communication with healthcare staff, obtaining knowledge, navigating the system, and accessing resources which include healthcare insurance and services. An and Lin lived in the U.S. for more than twenty years, which suggests that immigrants residing in the U.S. for long periods are still at a disadvantage with obtaining or accumulating the necessary cultural (English proficiency, knowledge of healthcare) and economic capital (sufficient personal income) that can help reduce some of the healthcare burdens. Their circumstances exhibits some of the challenges that immigrants face when encountering health problems, in which the lack of language, financial and knowledge assets can lead to later cancer diagnosis, medical errors, adverse health effects, and financial struggles (Cho et al. 2011, Clough et al. 2014; Divi et al. 20017; Gomez et al. 2010; Karliner et al. 2010; Lee et al. 2010).

Despite having healthcare insurance and the ability to communicate well in English, Manali and Luwisa continued to face difficult barriers with the healthcare system. Manali, a family carer, felt it was a difficult choice and burden to have her husband, Rajat, seek a medical consult from a physician in India as the last resort over

waiting for eight weeks to have an oncology consult in the U.S. Manali and Rajat are both immigrants who did not have the cultural capital of knowledge to seek other options for an oncology consult in the American healthcare system. Luwisa, a cancer patient, was conflicted with managing her finances to pay for out-of-pocket fees associated with her medical care alongside with her home mortgage payments. It appears that Luwisa did not know about resources to help her negotiate healthcare insurance payments, manage debt, and other financial assistance needs. In a U.S. study with a sample population (N = 26) in which the majority identified as White race (Europe, the Middle East or North Africa origins), many of the study participants sought knowledge and resources to deal with their medical care financial challenges (Head et al. 2018). Although Manali, Rajat and Luwisa had some cultural and economic capital to gain initial entry into the healthcare system, their experiences illustrate how immigrants with limited cultural capital knowledge can face barriers with timely and affordable healthcare.

Accumulation of capital

The cancer patients and family carers who participated in the study exhibited a high degree of self-reliance towards coping with their negative emotions, acquiring healthcare knowledge, and dealing with financial concerns. For some study participants, the presence of family and peer social capital led to pressures to either lessen the burden on their family members or avoid disclosure of the cancer diagnosis within the social network. Others seem to have limited cultural capital knowledge of the American healthcare system and resources (cultural and financial) that could address their healthcare challenges. Bourdieu's (1986) work on capital theory alludes

to the idea that social capital drives the allocation of cultural and economic capital. Healthcare and public health entities have attempted to distribute cultural capital to populations recognised as vulnerable groups in the form of cultural competency practices (Shim, 2010). Lo and Stacey (2008) highlight criticisms of how cultural competency in health settings is executed, which includes methods that are tailored to respond to known racial or ethnic needs and values. The authors caution this racial-ethnic 'profiling' approach and explain Bourdieu's conceptualisation of 'habitus', in which cultural capital can be pliable and adaptable towards situations (Lo & Stacey, 2008). Bourdieu views culture as being tangible "...dispositions and schemas..." (Lo & Stacey, 2008: p. 745) that are acquired from social conditioning from a particularly position in society. Whilst cultural capital encompasses recognition of cultural identities and is cradled by a system of cultural meanings, Lo and Stacey (2008) emphasise that cultural trajectories and outcomes are not always predictable. In future research, it may be useful to further explore how immigrants and their subsequent family generations access and accumulate social, cultural and economic capital in comparison to other populations.

9.4 Study limits, issues of concern, and strengths

A number of important limitations needs to be considered. First, this study was intended to be an in-depth qualitative exploration, identifying and understanding which factors were associated with the burdens of cancer care amongst Chinese, Indian and Filipino immigrant cancer patients and their family carers. The sample population was small and not represented proportionally by ethnic groups, due to challenges in recruitment in the Indian and Filipino communities. Since this is not a

study focused on health disparities, comparisons were not made between ethnic groups. Whilst the single ethnic population sampling approach could have been used to obtain more knowledge about a particular group, recruitment in three major Asian ethnic groups helped achieve more heterogeneity for social, economic, generational and individual backgrounds (e.g. income, language, education, healthcare coverage, personal beliefs).

A limitation with the data collection methods was that the study did not collect data that allowed for further examination of the study population's perspectives on how they felt their culture, ethnicity, and immigration experience had a relationship with their cancer care burden experiences. In consideration of the study participant's time and general well-being, I was cautious of their time commitment for the interview and responding to potential follow-up questions from me. The approach of the interview was to mainly probe on the topic areas that naturally emerged from participants' responses about meanings, opinions, feelings, and challenges or difficulties with cancer care. Most of the study participants did not explicitly reference culture, ethnic identity, and/or immigrant specific factors as part of their cancer care burden. Shim (2010: p.10) indicates that cultural capital related to health "...may have different exchange values in different situations." When asked questions that alluded to the underlying factors for their cancer care burden, the majority of study participants focused on personal opinions and feelings as well as social determinants that affected their emotional coping, healthcare access, communication, knowledge, and resources during cancer care.

There are two minor concerns related to the circumstances that occurred during data collection. The method for recruitment and collecting data for this study

was conducted through cancer patient-family carer dyads. Although interviews were conducted separately as a way to provide individual privacy, the data from each study participant within the family pair were expected to complement each other and expand the depth of information gained from the interviews. One cancer patient study participant declined to have her family carer interviewed after arrangements were initially made. An unrelated family carer was recruited to participate in order to achieve the sampling aims. This informed me how potential challenges may arise when conducting a dyad approach for the sample population and data collection.

An interview experience I consider unique because I lack experience in research with populations with mental health issues, was with a study participant who had an existing mental health condition disclosed during the interview. Prior to the data analysis, this disclosure generated my concern about the study participant's credibility. I had to reframe myself as a researcher who recruited, accepted and interviewed a study participant who was very willing to share information, opinions and feelings. It was challenging to put aside certain emotions, assumptions and biases, yet it was a critical step for overcoming some of the preconceived ideas that occurs in research and understanding what it means to have an underrepresented voice as part of my work. My concerns were discussed with my thesis supervisors. Advice was sought to reassure the integrity of the data collection and research ethics. This experience demonstrated the importance for researchers, at all calibers, to have trusted support from a cadre of experienced professionals in the research setting. When sampling vulnerable and underrepresented populations, it will be especially critical to have support from those who have experiences with those groups and can be responsive towards their needs.

Although personal influences cannot be fully avoided, the application of reflexivity heightened my critical consciousness of how my positionality can affect the fundamental research components, the research relationships, and the dynamics around constructing knowledge with the study participants. For example, I was cognisant of my sympathy towards the cancer patients who dealt with healthcare obstacles. Being reflexive also helped me recognise that neither the physicians or healthcare representatives had a voice in my research to tell their “side of the story”. Reflexivity may benefit research using a social theoretical framework because it cultivates the researcher’s mindfulness about positionality, and in turn, enrich thinking about the intricate social dynamics, power structures and constructs.

Despite the limitations and concerning issues of my research, this study was able to expand knowledge on the experiences with burdens in cancer care from the immigrant cancer patient and family carer point of view. The findings of this study produce preliminary knowledge about psychosocial and healthcare cancer care burdens in populations who are not well represented in cancer research. Although some of the findings corroborate other study results examined in other populations, the current study contributes to knowledge directly relevant to immigrant cancer patients and family carers from Chinese, Indian and Filipino American groups. Findings from this research provided greater understanding of multiple factors that shaped the experiences and views of cancer care burdens amongst cancer patients and family carers. By applying the social determinant framework and capital theory to develop the research questions and analyse findings, this current study was able to exhibit that there are other factors to explore beyond race and ethnicity to understand cancer experiences and outcomes relevant to minority health. In some ways, this

current study goes against the grain of mainstream minority health research in the U.S. which typically defines disease burden and disparities according to race and ethnicity.

9.5 Concluding summary

My study confirms previous findings from published health and social research, but also brought attention to findings and implications specifically relevant to Chinese, Indian and Filipino American immigrant cancer patients and their family carers. The application of the social determinants of health framework alongside with the social, cultural and economic capital theory developed new ways of understanding the cancer care problems and factors that affect the lives of immigrant family populations. Although they did not imply that their cancer care burdens were associated with immigrant specific experiences, expectations and connection to resources, future research can further explore how this area of how being an immigrant or part of an immigrant group reflects some of the ways in which choices are made with leveraging on and obtaining social, cultural and economic capital. The qualitative findings provide depth for developing new questions related to self-perceived burden, healthcare hierarchy, social and cultural capital, compounding challenges, and competing priorities within the context of immigrant health research.

Chapter 10 | Conclusion

10.1 Re-examining the purpose and findings

The purpose of the study was to understand the factors that influence the cancer care burdens experienced by Chinese, Indian and Filipino American immigrant cancer patients and their family carers. To address the study's purpose, it was essential to explore the following: the social demographics characterising the study participants; what cancer care meant to the cancer patients and their carers; how expectations, choices, and barriers affected their experiences with cancer care; and any problems they encountered with cancer care and the reasons why. The findings from the qualitative data contributed to knowledge about how social, financial and cultural factors shaped the lives of the study participants and the connection between cancer burden and people's lives as a whole.

The study's findings were presented under three main themes of burdens in cancer care: psychosocial, healthcare, and competing priorities. These themes encompassed concurrent challenges faced by several of the study participants, such as confronting emotional issues, communicating with the physician or medical team, making decisions for cancer treatment, and conflicts with individual competing demands. Collectively, the study's sample population faced similar challenges to those identified in previous research literature assessing the challenges of cancer patients, carers, and family members. The emotional and psychosocial difficulties of dealing with cancer as well as challenges with the U.S. healthcare system are well established findings in both prior research and my study.

Whilst the themes of psychosocial and healthcare burdens have been explored in prior research work, the current study provided the opportunity to reframe current knowledge and understanding about cancer care burdens as they relate to Asian American immigrant patients, their family carers, and the social structural elements (i.e. determinants and capital) affecting health. My findings exhibited the complex relationship between the emotional burdens of cancer patients and family carers, their difficulties with healthcare, and the determinants associated with these healthcare challenges. Furthermore, the study findings brought greater attention to the dilemma of competing priorities that the cancer patients and carers dealt with. Prior research appears to assess cancer related burdens in silos rather than as connected or overlapping problems.

10.2 Focusing on competing priorities

The research findings provided a more explicit view of competing priorities through case reviews of individual study participants. Also referred to as ‘competing demands’ in previously published research literature, this area of concern requires more attention with understanding the extent of this problem within subpopulation groups and how it can be addressed effectively in practice. It is important to recognise that helping an individual or family deal with one priority does not necessarily improve the outcome of another competing problem. The complexity of confronting competing priorities may require multi-level resources and interventions, which likely is not feasible from a single organisation, program or service area. Thus, the expertise, services and partnerships derived from multiple disciplines are essential for identifying and delivering solutions for competing priorities.

10.3 Bridging qualitative methods with social determinants research

The qualitative methods implemented in this study delivered some in-depth knowledge of how the burdens of cancer care can be interconnected or compounding challenges associated with social determinants. The data analysis presented in the thesis generated recognition of what the different pathways to cancer care burdens may be for immigrant cancer patients and family carers. These varied cancer care experiences and life circumstances shared by the study participants suggests that the ‘one-size-fits-all’ approach can have more limitations than strengths for effectively understanding and addressing burdens in cancer care. For example, looking at the problem only from the racial-ethnic identity and cultural lens may divert attention away from other important issues such as financial status, connection to social capital, and ability to communicate with the medical team. In that regard, this study provided some important initial insight about how cancer care burdens are rooted in various social determinant factors that have shaped the lives of Chinese, Filipino, and Indian immigrant cancer patients and their family carers.

10.4 Role for intersectionality theory in future research

Earlier in Chapter 3, I described my viewpoint of social factors affecting cancer burden as being “...diverse, fluid and intersecting...”, which suggests that an interpretivist approach to research can have a critical role in evaluating the complex characteristics of cancer experiences and outcomes. This idea also relates to intersectionality concepts in health research. Rooted from Crenshaw’s (1989) intersectionality analysis of African American women’s social and legal status, intersectionality theory examines a health problem within diverse social

stratifications, variables and relationships which exist as interwoven factors in people's lives (Bauer 2014; Green et al. 2017; Hankivsky & Christoffersen 2008; Viruell-Fuentes et al. 2012). It refrains from focusing on one particular social category or a set of social categories that function as silos (Bauer 2014; Hankivsky & Christoffersen 2008; Viruell-Fuentes et al. 2012). Intersectionality theory appears to be more readily integrated in qualitative health research (Mullings & Schulz 2006; Giritli Nygren & Olofsson 2014) because of its interpretivist position for analysing and interpreting social factors (Choo & Ferree, 2010). However use of this theory with quantitative methods are emerging from population health research (Evans et al. 2018; Bauer 2014) and life course analysis (Richardson & Brown, 2016). In light of the cancer burden knowledge reported in prior research publications and in my thesis, applying intersectionality theory in future research can be a way to redefine new meanings and knowledge about the layered and cross-cutting affects of social factors on cancer experiences and outcomes.

10.5 Implications of the research findings

The knowledge and perspectives gained from this thesis have implications for how future research can further investigate cancer burdens and how health practitioners can address the challenges of cancer care. The findings regarding competing priorities and the compounding effects of factors leading to cancer burdens are critical issues that warrant further investigation. Whilst modern cancer treatments have improved health outcomes for general populations, there may be specific groups of people who face several obstacles that make it difficult to achieve desirable cancer care outcomes, satisfactory quality of life, and cancer survivorship.

The participants in this study dealt with similar cancer care burdens, but their individual circumstances led to different needs and outcomes. It is therefore important that healthcare institutions and health practitioners develop and implement interventions that support cancer patients and carers across the various aspects of their cancer care. One of the challenges will be to avoid the one-size-fits-all approach to comprehensive care. Although it is unlikely to be feasible to tailor services and offer personally tailored support for each patient and family, it is critical for healthcare institutions to foster improved communication and resources in ways that do not leave patients and carers feeling lost, unsure, misinformed, or misguided.

There are other complex problems that require structural and policy change in healthcare. For example, healthcare expenditures remain expensive for the general American population, particularly for cancer patients requiring ongoing medical care and high cost treatments. Mechanisms for reducing the financial toxicity of medical care is important for improving the overall quality of life that cancer patients and their families deal with during and after cancer treatment. Another important structural change is ensuring appropriate access to good quality language services for patients requiring interpretation and translation. Despite the HIPAA policy that requires healthcare entities to comply with interpretation and translation needs, the study findings demonstrated that timely and quality language access remains a problem for healthcare delivery.

Lastly, applying the social determinants of health model as well as the social, economic and cultural capital theory framework to this study's research approach, provided a mechanism for examining cancer burdens as micro and macro level issues. Integrating these theoretical frameworks in the methodology of a qualitative study

encourages new ways of thinking about hybrid health research and moving past a traditional positivist understanding of cancer burden as it relates to social determinants. The research paradigm shift of infusing social epidemiology theories as part of this qualitative research study was intended to promote new ways of identifying and understanding problems within the broader public health context, yet leveraging on the individual voices as a source for new knowledge about burdens in cancer care.

10.5 Final reflection

The findings and analysis from the study addressed some of the gaps in knowledge related to the cancer care experiences of Chinese, Indian and Filipino American immigrant cancer patients and their family carers. The thesis, through its thematic analysis of the different forms of cancer care burdens, provides a deeper understanding of how various factors shape the experiences and outcomes in cancer care. The cancer journey, although critical, is one only aspect of the cancer patients' and family carers' lives. Thus it is necessary to have a multifaceted understanding of how the burden of cancer care transcends the various levels of well-being and people's lives as a whole.

Whilst different sectors of the public health field may have a collective aim to reduce the health inequities and disparities in cancer outcomes, it appears that differences in research approaches divide the understanding of cancer burdens. The thesis' use of interpretivist inquiry and a theoretical framework largely used in social epidemiology, puts forward the notion that researchers can consider innovative

reframing - theoretically and methodologically, the way research knowledge contributes to understanding the social dynamics of health.

When I retrace my past work in health disparities and cancer research to the learned outcomes of this study, I find it extremely valuable to reflect on the ways in which the qualitative data have enriched my understanding of cancer burdens. Burdens in cancer cannot be solely defined by big population data and medical interventions, which previously dominated my work in cancer research and public health practice. Continuing the work of subpopulation research, particularly in immigrant and refugee populations, will be especially instrumental in changing the current landscape of what is understood in minority health research. For example, explanations for immigrant and refugee health outcomes have often relied on cultural and acculturation concepts. It will also be important to engage key stakeholders and community constituents that are relevant to the subpopulations being studied, because this may drive the most pertinent questions that need to be asked but are not recognised by the academic community. Fostering a multidisciplinary framework in cancer research may advance promising ways to further study health inequality and disease burdens.

References

- Abel, T. (2008) Cultural capital and social inequality in health. *Journal of Epidemiology & Community Health*, 62(7), pp.1-5.
- Advani, P.S., Ying, J., Theriault, R., Melhem-Bertrand, A., Moulder, S., Bedrosian, I., Tereffe, W., Black, S., Pini, T.M. & Brewster, A.M. (2014) Ethnic disparities in adherence to breast cancer survivorship surveillance care. *Cancer*, 120(6), pp.894-900.
- Ahmed, S., Shahid, R. K., & Gesy, K. (2015) Cancer care burden: aiming at the Achilles heel. *Current Oncology*, 22(3), pp.e134-e138.
- Ahnquist, J., Wamala, S. P., & Lindstrom, M. (2012) Social determinants of health—a question of social or economic capital? Interaction effects of socioeconomic factors on health outcomes. *Social Science & Medicine*, 74(6), pp.930-939.
- Aizer, A.A., Chen, M.H., McCarthy, E.P., Mendu, M.L., Koo, S., Wilhite, T.J., Graham, P.L., Choueiri, T.K., Hoffman, K.E., Martin, N.E. & Hu, J.C. (2013) Marital status and survival in patients with cancer. *Journal of Clinical Oncology*, 31(31), pp.3869-3876.
- Allen, J. P., & Turner, E. (1996) Spatial patterns of immigrant assimilation. *The Professional Geographer*, 48(2), pp.140-155.
- Alvesson, M., & Sköldbberg, K. (2018) *Reflexive methodology: New vistas for qualitative research*. London, UK: Sage.
- Aronson, J. (1995) A pragmatic view of thematic analysis. *The Qualitative Report*, 2(1), pp.1-3.
- Arozullah, A.M., Calhoun, E.A., Wolf, M., Finley, D.K., Fitzner, K.A., Heckinger, E.A., Gorby, N.S., Schumock, G.T. & Bennett, C.L. (2004) The financial burden of cancer: estimates from a study of insured women with breast cancer. *Journal of Supportive Oncology*, 2(3), pp.271-278.
- Ashing-Giwa, K.T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A., Clayton, S., Williams, I. & Hills, D. (2004) Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, 13(6), pp.408-428.
- Ashing, K.T., Padilla, G., Tejero, J., & Kagawa-Singer, M. (2003) Understanding the breast cancer experience of Asian American women. *Psycho-Oncology*, 12(1), pp.38-58.

- Asian American Center for Advancing Justice (2013) *A Community of Contrasts: Asian Americans, Native Hawaiians and Pacific Islanders in California*. Available at <http://www.apalc.org> [Accessed 2 May 2014].
- Attia, M., & Edge, J. (2017) Being a reflexive researcher: a developmental approach to research methodology. *Open Review of Educational Research*, 4(1), pp.33-45.
- Baider, L. E., Cooper, C. L., & Kaplan De-Nour, A. E. (1996) *Cancer and the family*. West Sussex, UK: John Wiley & Sons.
- Bailey, D. E., Wallace, M., & Mishel, M. H. (2007) Watching, waiting and uncertainty in prostate cancer. *Journal of Clinical Nursing*, 16(4), pp.734-741.
- Baldwin, P. K., Pope, N. D., & Marks, A. D. (2017) Cultural implications of filial obligation and the Asian Indian American family caregiver. *Qualitative Research in Medicine & Healthcare*, 1(2), pp.39-43.
- Balneaves, L. G., Bottorff, J. L., Grewal, S. K., Naidu, P., Johnson, J. L., & Howard, A. F. (2007) Family support of immigrant Punjabi women with breast cancer. *Family & Community Health*, 30(1), pp.16-28.
- Bastawrous, M. (2013) Caregiver burden - A critical discussion. *International Journal of Nursing Studies*, 50(3), pp.431-441.
- Bauer, G.R. (2014) Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity. *Social Science & Medicine*, 110, pp.10-17.
- Baum, F. (2016) *The New Public Health*. South Melbourne, Australia: Oxford University Press.
- Benoit, C., Jansson, M., Millar, A., & Phillips, R. (2005) Community-academic research on hard-to-reach populations: Benefits and challenges. *Qualitative Health Research*, 15(2), pp.263-282.
- Benoot, C., Deschepper, R., Saelaert, M., Grypdonck, M., & Bilsen, J. (2015) Informal support needs of cancer patients who are living alone: a qualitative insight. *Psycho-Oncology*, 24(9), pp.1066-1072.
- Berger, R. (2015) Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, 15(2), pp.219-234.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000) From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, 51(6), pp.843-857.

- Berkman, L. F., Kawachi, I., & Glymour, M. M. (eds.) (2014) *Social epidemiology*. New York: Oxford University Press.
- Berry, J. W. (1997) Immigration, acculturation, and adaptation. *Applied Psychology*, 46(1), pp.5-34.
- Bevans, M., & Sternberg, E. M. (2012) Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *Journal of the American Medical Association*, 307(4), pp.398-403.
- Bhattacharya, G. and Schoppelrey, S.L. (2004) Preimmigration beliefs of life success, postimmigration experiences, and acculturative stress: South Asian immigrants in the United States. *Journal of Immigrant Health*, 6(2), pp.83-92.
- Bourdieu, P. (1986) The Forms of Capital. In: Richardson, J. G. (ed.) *Handbook of Theory and Research for the Sociology of Education*. Westport, CT: Greenwood Publishing Group, pp.241–258.
- Bowling, A. (2009) *Research methods in health: investigating health and health services*. England: McGraw-Hill Education.
- Braun, V. & Clarke, V. (2012) Thematic Analysis, In: Cooper, H., Camic, Paul M., Long, D., Panter, A., Rindskof, D. and Sher, K. (eds.) *APA handbook of research methods in psychology*. Washington, DC: American Psychological Association, pp.57-71.
- Braun, V. & Clarke, V. (2013) *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Braveman, P. & Gottlieb, L. (2014) The social determinants of health: It's time to consider the causes of the causes. *Public Health Reports*, 129(1 supp 12), pp.19-31.
- Brédart, A., Kop, J.L., Efficace, F., Beaudeau, A., Brito, T., Dolbeault, S. and Aaronson, N. (2014) Quality of care in the oncology outpatient setting from patients' perspective: a systematic review of questionnaires' content and psychometric performance. *Psycho-Oncology*, 24(4), pp.382-394.
- Bryman, A. (2008) *Social Research Methods*. New York: Oxford University Press.
- Burke, N. J., Villero, O., & Guerra, C. (2012) Passing Through Meanings of Survivorship and Support Among Filipinas With Breast Cancer. *Qualitative Health Research*, 22(2), pp.189-198.

- Cagney K.A. & Wen M. (2008) Social Capital and Aging-Related Outcomes. In: Kawachi I., Subramanian S. & Kim D. (eds.) *Social Capital and Health*, New York, NY: Springer, pp. 239-258.
- Castles, S. & Miller, M.J. (2009) Migration in the Asia-Pacific Region. *Migration Information Source*. Available from <https://www.migrationpolicy.org/article/migration-asia-pacific-region> [Accessed 3 March 2014].
- Chen, M.S. (2005) Cancer health disparities among Asian Americans. *Cancer*, 104(S12), pp. 2895-2902.
- Cho, Y. I., Johnson, T. P., Barrett, R. E., Campbell, R. T., Dolecek, T. A., & Warnecke, R.B. (2011) Neighborhood changes in concentrated immigration and late stage breast cancer diagnosis. *Journal of Immigrant and Minority Health*, 13(1), pp. 9-14.
- Choo, H. Y., & Ferree, M. M. (2010) Practicing intersectionality in sociological research: A critical analysis of inclusions, interactions, and institutions in the study of inequalities. *Sociological Theory*, 28(2), pp.129-149.
- Chou, F.Y., Dodd, M., Abrams, D. and Padilla, G. (2007) Symptoms, self-care, and quality of life of Chinese American patients with cancer. *Oncology Nursing Forum* 34 (6), pp.1162-1167.
- Chou, R. J. A. (2010) Filial piety by contract?. The emergence, implementation, and implications of the “family support agreement” in China. *The Gerontologist*, 51(1), pp.3-16.
- Clark, R. L., Glick, J. E., & Bures, R. M. (2009) Immigrant families over the life course research directions and needs. *Journal of Family Issues*, 30(6), pp. 852-872.
- Clough, J., Lee, S., & Chae, D. H. (2013) Barriers to health care among Asian immigrants in the United States: a traditional review. *Journal of Health Care for the Poor and Underserved*, 24(1), pp. 384-403.
- Coleman, J. (1988) Social capital in the creation of human capital. *American Journal of Sociology, Supplement - Organizations and Institutions: Sociological and economic approaches to the analysis of social structure*, 94, pp.S95-S120.
- Cook, S. A., Salmon, P., Hayes, G., Byrne, A., & Fisher, P. L. (2018) Predictors of emotional distress a year or more after diagnosis of cancer: A systematic review of the literature. *Psycho-Oncology*, 27(3), pp.791-801.
- Corbin, J.M. & Strauss, A. (1990) Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, 13(1), pp. 3-21.

- Coughlin, S. S., Yoo, W., Whitehead, M. S., & Smith, S. A. (2015) Advancing breast cancer survivorship among African-American women. *Breast Cancer Research and Treatment*, 153(2), pp.253-261.
- Crenshaw, K. (1989) Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. In: *Sustainable energy choices for the 90s: Conference Proceedings*. University of Chicago Legal Forum, pp.139-167.
- Creswell, J.W. (2014) *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- D’Cruz, H., Gillingham, P., & Melendez, S. (2007) Reflexivity, its meanings and relevance for social work: A critical review of the literature. *The British Journal of Social Work*, 37(1), pp.73-90.
- Damiani, G., Basso, D., Acampora, A., Bianchi, C. B., Silvestrini, G., Frisicale, E. M., & Ricciardi, W. (2015) The impact of level of education on adherence to breast and cervical cancer screening: Evidence from a systematic review and meta-analysis. *Preventive Medicine*, 81, pp.281-289.
- Dahlgren, G., & Whitehead, M. (1991) Policies and Strategies to Promote Social Equity in Health. Stockholm, Sweden: Institute for Future Studies. Available from <https://core.ac.uk/download/pdf/6472456.pdf> [Accessed 1 June 2014].
- Davies, S., & Rizk, J. (2017) The Three Generations of Cultural Capital Research: A Narrative Review. *Review of Educational Research*, pp.1–35.
- Davis, K., Drey, N., & Gould, D. (2009) What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies*, 46(10), pp.1386-1400.
- Deckx, L., Akker, M., Driel, M., Bulens, P., Abbema, D., Tjan-Heijnen, V., Kenis, C., Jonge, E.T., Houben, B. & Buntinx, F. (2015) Loneliness in patients with cancer: the first year after cancer diagnosis. *Psycho-Oncology*, 24(11), pp.1521-1528.
- DelVecchio, M.J., James, C., Good, B.J. and Becker, A.E. (2005) The culture of medicine and racial, ethnic, and class disparities in healthcare. In: Romero, M. Margolis, E. (eds.) *The Blackwell companion to social inequalities*, pp.396-423.
- DeNavas-Walt, C. & Proctor, B. D. (2014) U.S. Census Bureau, Current Population Reports, Income and Poverty in the United States: 2013. Washington, DC: U.S. Government Printing Office.

- Divi, C., Koss, R. G., Schmaltz, S. P., & Loeb, J. M. (2007) Language proficiency and adverse events in US hospitals: a pilot study. *International Journal for Quality in Health Care*, 19(2), pp.60-67.
- Diwan, S., Lee, S. E., & Sen, S. (2011) Expectations of filial obligation and their impact on preferences for future living arrangements of middle-aged and older Asian Indian Immigrants. *Journal of Cross-cultural Gerontology*, 26(1), pp.55-69.
- Dong, X., & Chang, E. S. (2017) Social networks among the older Chinese population in the USA: findings from the PINE study. *Gerontology*, 63(3), pp.238-252.
- Dong, X., Zhang, M., & Simon, M. A. (2014) The expectation and perceived receipt of filial piety among Chinese older adults in the Greater Chicago area. *Journal of Aging and Health*, 26(7), pp.1225-1247.
- Ellis, K.R., Janevic, M.R., Kershaw, T., Caldwell, C.H., Janz, N.K. and Northouse, L. (2017) The influence of dyadic symptom distress on threat appraisals and self-efficacy in advanced cancer and caregiving. *Supportive Care in Cancer*, 25(1), pp. 185-194.
- Enard, K. R., Mullen, P. D., Kamath, G. R., Dixon, N. M., & Volk, R. J. (2016) Are cancer-related decision aids appropriate for socially disadvantaged patients? A systematic review of US randomized controlled trials. *BMC Medical Informatics and Decision Making*, 16(1), pp.1-15.
- Evans, C. R., Williams, D. R., Onnela, J. P., & Subramanian, S. V. (2018) A multilevel approach to modeling health inequalities at the intersection of multiple social identities. *Social Science & Medicine*, 203, pp. 64-73.
- Ewing, G., Ngwenya, N., Farquhar, M., Gilligan, D., Bailey, S., Benson, J. and Seymour, J. (2016) Sharing bad news: development of an intervention to support patients with lung cancer share news of their cancer diagnosis with family members and friends. *BMJ Supportive & Palliative Care*, 4(1), pp.114-114.
- Falicov, C. J. (2007) Working with transnational immigrants: Expanding meanings of family, community, and culture. *Family Process*, 46(2), pp.157-171.
- Fann, J. R., Hong, F., Halpenny, B., Blonquist, T. M., & Berry, D. L. (2017) Psychosocial outcomes of an electronic self-report assessment and self-care intervention for patients with cancer: a randomized controlled trial. *Psycho-oncology*, 26(11), pp. 1866-1871.
- Fawcett, J. T., & Arnold, F. (1987) Explaining Diversity: Asian and Pacific Immigration Systems. *Center for Migration Studies Special Issues*, 5(3), pp. 453-473.

- Ferrari, R. (2015) Writing narrative style literature reviews. *Medical Writing*, 24(4), pp.230-235.
- Finlay, L. (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), pp.209-230.
- Fiscella, K. (2004) Socioeconomic status disparities in healthcare outcomes: selection bias or biased treatment?. *Medical Care*, 42(10) pp.939-942.
- Frambes, D., Given, B., Lehto, R., Sikorskii, A., & Wyatt, G. (2017) Informal caregivers of cancer patients: review of interventions, care activities, and outcomes. *Western Journal of Nursing Research*, pp.1-29.
- Frayne, S. M., Burns, R. B., Hardt, E. J., Rosen, A. K., & Moskowitz, M. A. (1996) The exclusion of non-English-speaking persons from research. *Journal of General Internal Medicine*, 11(1), pp. 39-43.
- Freedman, R. A., Virgo, K. S., He, Y., Pavluck, A. L., Winer, E. P., Ward, E. M., & Keating, N. L. (2011) The association of race/ethnicity, insurance status, and socioeconomic factors with breast cancer care. *Cancer*, 117(1), pp.180-189.
- Fu, M. R., Xu, B., Liu, Y., & Haber, J. (2008) 'Making the best of it': Chinese women's experiences of adjusting to breast cancer diagnosis and treatment. *Journal of Advanced Nursing*, 63(2), pp.155-165.
- Funk, L. M., Chappell, N. L., & Liu, G. (2013) Associations Between Filial Responsibility and Caregiver Well-Being Are There Differences by Cultural Group?. *Research on Aging*, 35(1), pp.78-95.
- Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L., & Gott, M. (2014) Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. *Palliative Medicine*, 28(5), pp.375-390.
- Gaugler, J. E., Given, W. C., Linder, J., Kataria, R., Tucker, G., & Regine, W. F. (2008) Work, gender, and stress in family cancer caregiving. *Supportive Care in Cancer*, 16(4), pp.347-357.
- Ge, L., & Mordiffi, S. Z. (2017) Factors Associated With Higher Caregiver Burden Among Family Caregivers of Elderly Cancer Patients: A Systematic Review. *Cancer Nursing*, 40(6), pp.471-478.
- Giritli Nygren, K., & Olofsson, A. (2014) Intersectional approaches in health-risk research: A critical review. *Sociology Compass*, 8(9), pp. 1112-1126.

- Given, B. A., Given, C. W., & Kozachik, S. (2001) Family support in advanced cancer. *CA: A cancer journal for clinicians*, 51(4), pp. 213-231.
- Glajchen, M. (2004) The emerging role and needs of family caregivers in cancer care. *The Journal of Supportive Oncology*, 2(2), pp.145-155.
- Goldstein, D. A. (2017) Financial toxicity in cancer care - Edging toward solutions. *Cancer*, 123(8), pp.1301-1302.
- Gomez, S. L., Clarke, C. A., Shema, S. J., Chang, E. T., Keegan, T. H., & Glaser, S. L. (2010) Disparities in breast cancer survival among Asian women by ethnicity and immigrant status: a population-based study. *American Journal of Public Health*, 100(5), pp.861-869.
- Gordon, K., Wilson, J., Tonner, A., & Shaw, E. (2017) How can social enterprises impact health and well-being?. *International Journal of Entrepreneurial Behavior & Research*, 40(4), pp.257-258.
- Gordon, L.G., Merollini, K.M., Lowe, A. and Chan, R.J. (2017) A systematic review of financial toxicity among cancer survivors: we can't pay the co-pay. *The Patient-Patient-Centered Outcomes Research*, 10(3), pp.295-309.
- Gorey, K.M., Luginaah, I.N., Bartfay, E., Fung, K.Y., Holowaty, E.J., Wright, F.C., Hamm, C. and Kanjeekal, S.M. (2011) Effects of socioeconomic status on colon cancer treatment accessibility and survival in Toronto, Ontario, and San Francisco, California, 1996–2006. *American Journal of Public Health*, 101(1), pp.112-119.
- Gotay, C. C. (1996) Cultural variation in family adjustment to cancer. In: Baider, L. E., Cooper, C. L., & Kaplan De-Nour, A. E. (eds.). *Cancer and the Family*. West Sussex, UK: John Wiley & Sons, pp.31-52.
- Graham, H. (2004) Social determinants and their unequal distribution: clarifying policy understandings. *The Milbank Quarterly*, 82(1), pp.101-124.
- Grant, M., Sun, V., Fujinami, R., Sidhu, R., Otis-Green, S., Juarez, G., Klein, L. and Ferrell, B. (2013) Family caregiver burden, skills preparedness, and quality of life in non-small-cell lung cancer. *Oncology Nursing Forum*, 40(4), pp.337-346
- Green, B. N., Johnson, C. D., & Adams, A. (2006) Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. *Journal of Chiropractic Medicine*, 5(3), pp.101-117.
- Green, G., Bradby, H., Chan, A. and Lee, M. (2006) “We are not completely Westernised”: dual medical systems and pathways to health care among Chinese migrant women in England. *Social Science & Medicine*, 62(6), pp.1498-1509.

- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C.C., Willan, A., Viola, R., Coristine, M., Janz, T. & Glossop, R. (2004) Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170(12), pp.1795-1801.
- Gupta, R., & Pillai, V. K. (2000) Caregiver burden in South Asian families: A systems theory perspective. *Journal of Ethnic and Cultural Diversity in Social Work*, 9(1-2), pp.41-53.
- Gupta, R., & Pillai, V. K. (2005) Analysis of caregiver burden in South Asian families in the Dallas-Fort Worth metropolitan area: insights for social practice. *Journal of Applied Social Science*, (2), pp.35-54.
- Gurm, B. K., Stephen, J., MacKenzie, G., Doll, R., Barroetavena, M. C., & Cadell, S. (2008) Understanding Canadian Punjabi-speaking South Asian women's experience of breast cancer: A qualitative study. *International Journal of Nursing Studies*, 45(2), pp.266-276.
- Han, H. R., Choi, Y. J., Kim, M. T., Lee, J. E., & Kim, K. B. (2008) Experiences and challenges of informal caregiving for Korean immigrants. *Journal of Advanced Nursing*, 63(5), pp.517-526.
- Hankivsky, O., & Christoffersen, A. (2008) Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health*, 18(3), pp. 271-283.
- Hao, L. and Johnson, R.W. (2000) Economic, cultural, and social origins of emotional well-being: comparisons of immigrants and natives at midlife. *Research on Aging*, 22(6), pp.599-629.
- Hardie, E. A., Critchley, C., & Morris, Z. (2006) Self-coping complexity: Role of self-construal in relational, individual and collective coping styles and health outcomes. *Asian Journal of Social Psychology*, 9(3), 224-235.
- Harle, M. T., Dela, R. F., Veloso, G., Rock, J., Faulkner, J., & Cohen, M. Z. (2007) The experiences of Filipino American patients with cancer. *Oncology Nursing Forum*, 34(6),pp.1170-1175.
- Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., & Solomon, M. J. (2009) What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer*, 17(8), pp. 1117-1128.
- Hasanpour-Dehkordi, A. (2016) Self-care Concept Analysis in Cancer Patients: An Evolutionary Concept Analysis. *Indian Journal of Palliative Care*, 22(4), pp.388-394.

- Haynes, M. A., & Smedley, B. D. (eds.) (1999) *The Unequal Burden of Cancer:: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. National Academies Press. Available: <http://www.ncbi.nlm.nih.gov/books/NBK1788/> [Accessed 2 June 2014].
- Head, B., Harris, L., Kayser, K., Martin, A., & Smith, L. (2018) As if the disease was not enough: coping with the financial consequences of cancer. *Supportive Care in Cancer*, 26(3), pp. 975-987.
- Hertzman, C. (2000) The case for an early childhood development strategy. University of British Columbia-Centre for Health Services and Policy Research. Available at http://isuma.net/v01n02/hertzman/hertzman_e.shtml [Accessed 21 April 2018].
- Hertzman, C., & Power, C. (2003) Health and human development: understandings from life-course research. *Developmental Neuropsychology*, 24(2-3), pp.719-744.
- Hertzman, C., & Power, C. (2006) A life course approach to health and human development. In: Heymann, J. (ed.) *Healthier societies: From analysis to action*, New York, Oxford University Press, pp.83-106.
- Hiatt, R. A., & Rimer, B. K. (1999) A new strategy for cancer control research. *Cancer Epidemiology and Prevention Biomarkers*, 8(11), pp.957-964.
- Holt-Lunstad, J., Robles, T. F., & Sbarra, D. A. (2017) Advancing social connection as a public health priority in the United States. *American Psychologist*, 72(6), pp.517-530.
- Honjo, K. (2004) Social epidemiology: definition, history, and research examples. *Environmental Health and Preventive Medicine*, 9(5), pp.193-199.
- Howard, A. F., Bottorff, J. L., Balneaves, L. G., & Grewal, S. K. (2007) Punjabi immigrant women's breast cancer stories. *Journal of Immigrant and Minority Health*, 9(4), pp.269-279.
- Hughes, N. D., Closs, S. J., Flemming, K., & Bennett, M. I. (2016) Supporting self-management of pain by patients with advanced cancer: views of palliative care professionals. *Supportive Care in Cancer*, 24(12), pp.5049-5057.
- Hunt, C. K. (2003) Concepts in caregiver research. *Journal of Nursing Scholarship*, 35(1), pp.27-32.
- Ibaraki, A. Y., Hall, G. C. N., & Sabin, J. A. (2014) Asian American cancer disparities: The potential effects of model minority health stereotypes. *Asian American Journal of Psychology*, 5(1), pp.75-81.

- Iton, A. (2006) Chapter 7: Tackling the root causes of health disparities through community capacity building. In: Richard Hofrichter (ed.) *Tackling Health Inequities Through Public Health Practice: A Handbook for Action*, Washington, D.C.: National Association of County and City Health Officials., pp.115-136.
- Jacobson, J. O., & Mulvey, T. M. (2012) Time to focus on inpatient safety: revision of the American Society Of Clinical Oncology/Oncology Nursing Society chemotherapy administration safety standards. *Journal of Clinical Oncology*, 30(10): pp.1021-1029.
- Jasso, G., Massey, D. S., Rosenzweig, M. R., & Smith, J. P. (2004) Immigrant health: selectivity and acculturation. *Critical perspectives on racial and ethnic differences in health in late life*, pp.227-266.
- Kagawa-Singer, M., & Wellisch, D. K. (2003) Breast cancer patients' perceptions of their husbands' support in a cross-cultural context. *Psycho-Oncology*, 12(1), pp.24-37.
- Karliner, L. S., Kim, S. E., Meltzer, D. O., & Auerbach, A. D. (2010) Influence of language barriers on outcomes of hospital care for general medicine inpatients. *Journal of Hospital Medicine*, 5(5), pp.276-282.
- Kawachi I., Subramanian S., Kim D. (2008) Social Capital and Health. In: Kawachi I., Subramanian S., & Kim D. (eds.) *Social Capital and Health*. New York, NY: Springer pp.1-26.
- Keeley, B. (2007) Human Capital: How what you know shapes your life. The Organisation for Economic Co-operation and Development (OECD) Available at: <https://www.oecd.org/insights/humancapitalhowwhatyouknowshapessyourlife.htm> [Accessed 3 December 2016].
- Kesler, C., & Bloemraad, I. (2010) Does immigration erode social capital? The conditional effects of immigration-generated diversity on trust, membership, and participation across 19 countries, 1981–2000. *Canadian Journal of Political Science/Revue Canadienne de Science Politique*, 43(2), pp.319-347.
- Khosla, N., Washington, K. T., Shaunfield, S., & Aslakson, R. (2017) Communication Challenges and Strategies of US Health Professionals Caring for Seriously Ill South Asian Patients and Their Families. *Journal of Palliative Medicine*, 20(6), pp.611-617.
- Kiang, L., Huynh, V. W., Cheah, C. S., Wang, Y., & Yoshikawa, H. (2017) Moving beyond the model minority. *Asian American Journal of Psychology*, 8(1), pp.1-6.

- Kitrungrote, L., & Cohen, M. Z. (2006) Quality of life of family caregivers of patients with cancer: a literature review. *Oncology Nursing Forum*, 33(3), pp.625-632.
- Knoll, N., Rieckmann, N., & Schwarzer, R. (2005) Coping as a mediator between personality and stress outcomes: a longitudinal study with cataract surgery patients. *European Journal of Personality*, 19(3), pp.229-247.
- Kramer, B. J. (1997) Gain in the caregiving experience: Where are we? What next?. *The Gerontologist*, 37(2), pp.218-232.
- Krieger, N. (2001) Theories for social epidemiology in the 21st century: an ecosocial perspective. *International Journal of Epidemiology*, 30(4), pp.668-677.
- Kristjanson, L. J., & Ashcroft, T. (1994) The family's cancer journey: A literature review. *Cancer Nursing*, 17(1), pp.1-17.
- Lackey, N. R., & Gates, M. F. (2001) Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *Journal of Advanced Nursing*, 34(3), pp. 320-328.
- Lahaie, C., Earle, A. and Heymann, J. (2013) An uneven burden: Social disparities in adult caregiving responsibilities, working conditions, and caregiver outcomes. *Research on Aging*, 35(3), pp.243-274.
- Lahelma, E. (2001) Health and social stratification. In: Cockerham, W.C. (ed.), *The Blackwell Companion to Medical Sociology*. Malden, MA: Blackwell Publishing, pp. 64-93.
- Lan, P. C. (2002) Subcontracting filial piety elder care in ethnic Chinese immigrant families in California. *Journal of Family Issues*, 23(7), pp.812-835.
- Landrine, H., Corral, I., Lee, J. G., Eford, J. T., Hall, M. B., & Bess, J. J. (2017) Residential Segregation and Racial Cancer Disparities: A Systematic Review. *Journal of Racial and Ethnic Health Disparities*, 4(6), pp.1195-1205.
- Lapid, M. I., Atherton, P. J., Kung, S., Sloan, J. A., Shahi, V., Clark, M. M., & Rummans, T. A. (2016) Cancer caregiver quality of life: need for targeted intervention. *Psycho-Oncology*, 25(12), pp. 1400-1407.
- Lee, C. J. G. (2012) Reconsidering constructivism in qualitative research. *Educational Philosophy and Theory*, 44(4), pp.403-412.
- Lee, J., & Bell, K. (2011) The impact of cancer on family relationships among Chinese patients. *Journal of Transcultural Nursing*, 22(3), pp.225-234.

- Lee, J.E., Shin, D.W., Cho, J., Yang, H.K., Kim, S.Y., Yoo, H.S., Jho, H.J., Shin, J.Y., Cho, B., Park, K. and Park, J.H. (2015) Caregiver burden, patients' self-perceived burden, and preference for palliative care among cancer patients and caregivers. *Psycho-Oncology*, 24(11), pp.1545-1551.
- Lee, S., Chen, L., Ma, G. X., Fang, C. Y., Oh, Y., & Scully, L. (2013) Challenges and needs of Chinese and Korean American breast cancer survivors: in-depth interviews. *North American Journal of Medicine & Science*, 6(1) pp.1-8.
- Lee, S., Martinez, G., Ma, G. X., Hsu, C. E., Robinson, E. S., Bawa, J., & Juon, H. S. (2010) Barriers to health care access in 13 Asian American communities. *American Journal of Health Behavior*, 34(1), pp.21-30.
- Lee, Y.M. (2007) The immigration experience among elderly Korean immigrants. *Journal of Psychiatric and Mental Health Nursing*, 14(4), pp.403-410.
- Lev, E.L., Daley, K.M., Conner, N.E., Reith, M., Fernandez, C. and Owen, S.V. (2001) An intervention to increase quality of life and self-care self-efficacy and decrease symptoms in breast cancer patients. *Scholarly Inquiry for Nursing Practice*, 15(3), pp.277-294.
- Lewis, F.M. (1986) The impact of cancer on the family: a critical analysis of the research literature. *Patient Education and Counseling*, 8(3), pp.269-289.
- Lewis, F. M. (2006) The Effects of Cancer Survivorship on Families and Caregivers: More research is needed on long-term survivors. *The American Journal of Nursing*, 106, pp.20-25.
- Li, Q. P., Mak, Y. W., & Loke, A. Y. (2013) Spouses' experience of caregiving for cancer patients: a literature review. *International Nursing Review*, 60(2), pp.178-187.
- Li, Y., Hofstetter, C.R., Wahlgren, D., Irvin, V., Chhay, D. and Hovell, M.F. (2015) Social networks and immigration stress among first-generation mandarin-speaking Chinese immigrants in Los Angeles. *International Journal of Social Welfare*, 24(2), pp.170-181.
- Libert, Y., Borghraef, C., Beguin, Y., Delvaux, N., Devos, M., Doyen, C., Dubruille, S., Etienne, A.M., Liénard, A., Merckaert, I. and Reynaert, C. (2017) Factors associated with self-perceived burden to the primary caregiver in older patients with hematologic malignancies: an exploratory study. *Psycho-Oncology*, 26(1), pp.118-124.
- Liu, J. E., Mok, E., & Wong, T. (2005) Perceptions of supportive communication in Chinese patients with cancer: experiences and expectations. *Journal of Advanced Nursing*, 52(3), pp.262-270.

- Lo, M.C.M. & Stacey, C.L. (2008) Beyond cultural competency: Bourdieu, patients and clinical encounters. *Sociology of Health & Illness*, 30(5), pp.741-755.
- Lofaso, C. R., & Weigand, D. A. (2014) Individual characteristics and self-perceived burden in cancer patients. *Current Psychology*, 33(2), pp.174-184.
- Longman, A. J., Atwood, J. R., Sherman, J. B., Benedict, J., & Shang, T. C. (1992) Care needs of home-based cancer patients and their caregivers: Quantitative findings. *Cancer Nursing*, 15(3), pp. 182-190.
- Lortet-Tieulent, J., Kulhánová, I., Jacobs, E. J., Coebergh, J. W., Soerjomataram, I., & Jemal, A. (2017) Cigarette smoking-attributable burden of cancer by race and ethnicity in the United States. *Cancer Causes & Control*, 28(9), pp.981-984.
- Lortet-Tieulent, J., Soerjomataram, I., Lin, C. C., Coebergh, J. W. W., & Jemal, A. (2016) US burden of cancer by race and ethnicity according to Disability-Adjusted Life Years. *American Journal of Preventive Medicine*, 51(5), pp. 673-681.
- Luborsky, M. R., & Rubinstein, R. L. (1995) Sampling in qualitative research: Rationale, issues, and methods. *Research on Aging*, 17(1), pp.89-113.
- Lueck, K. and Wilson, M. (2010) Acculturative stress in Asian immigrants: The impact of social and linguistic factors. *International Journal of Intercultural Relations*, 34(1), pp.47-57.
- Lui, C. W., Ip, D., & Chui, W. H. (2009) Ethnic experience of cancer: a qualitative study of Chinese–Australians in Brisbane, Queensland. *Social Work in Health Care*, 48(1), pp.14-37.
- Lynch, J., & Smith, G. D. (2005) A life course approach to chronic disease epidemiology. *Annual Review Public Health*, 26, pp,1-35.
- Manning, J., & Kunkel, A. (2013) *Researching interpersonal relationships: Qualitative methods, studies, and analysis*. Thousand Oaks, CAL Sage Publications.
- Manser, C. N., & Bauerfeind, P. (2014) Impact of socioeconomic status on incidence, mortality, and survival of colorectal cancer patients: a systematic review. *Gastrointestinal Endoscopy*, 80(1), pp.42-60.
- Marmot, M. (2005) Social determinants of health inequalities. *The Lancet*, 365(9464), pp.1099-1104.

- Marmot, M., & Bell, R. (2016) Social inequalities in health: a proper concern of epidemiology. *Annals of Epidemiology*, 26(4), pp.238-240.
- Marmot, M., & Wilkinson, R. (eds.) (2005) *Social Determinants of Health*. Denmark: Oxford University Press.
- Marshall, C. A., Larkey, L. K., Curran, M. A., Weihs, K. L., Badger, T. A., Armin, J., & García, F. (2011) Considerations of culture and social class for families facing cancer: the need for a new model for health promotion and psychosocial intervention. *Families, Systems, & Health*, 29(2), pp.81-94.
- Maskarinec, G., Sen, C., Koga, K., & Conroy, S. M. (2011) Ethnic differences in breast cancer survival: status and determinants. *Women's Health*, 7(6), pp.677-687.
- McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007) Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative Medicine*, 21(2), pp. 115-128.
- McPherson, C. J., Wilson, K. G., Lobchuk, M. M., & Brajtman, S. (2007) Self-perceived burden to others: patient and family caregiver correlates. *Journal of Palliative Care*, 23(3), pp. 135-142.
- McQueen, D. V., Kickbusch, I., Potvin, L., Pelikan, J. M., Balbo, L., & Abel, T. (2007) *Health and modernity: the role of theory in health promotion*. New York, NY: Springer Science & Business Media.
- Mead, E. L., Doorenbos, A. Z., Javid, S. H., Haozous, E. A., Alvord, L. A., Flum, D. R., & Morris, A. M. (2013) Shared decision-making for cancer care among racial and ethnic minorities: a systematic review. *American Journal of Public Health*, 103(12), pp.e15-e29.
- Mellon, S., Northouse, L. L., & Weiss, L. K. (2006) A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nursing*, 29(2), pp.120-131.
- Miyawaki, C. E. (2015) A Review of Ethnicity, Culture, and Acculturation Among Asian Caregivers of Older Adults (2000-2012). *SAGE Open*, 5(1),pp.1-18.
- Mor, V., Masterson-Allen, S., Houts, P., & Siegel, K. (1992) The changing needs of patients with cancer at home. A longitudinal view. *Cancer*, 69(3), pp. 829-838.
- Mukwato, K. P., Mweemba, P., Makukula, M. K., & Makoleka, M. M. (2010) Stress and coping mechanisms among breast cancer patients and family caregivers: A Review of literature. *Medical Journal of Zambia*, 37(1), pp.40-45.

- Mulcahy, C. M., Parry, D. C., & Glover, T. D. (2010) The “patient patient”: The trauma of waiting and the power of resistance for people living with cancer. *Qualitative Health Research*, 20(8), pp. 1062-1075.
- Mullings, L., & Schulz, A. J. (2006) Intersectionality and Health: An Introduction. In A. J. Schulz & L. Mullings (eds.), *Gender, race, class, & health: Intersectional approaches*. San Francisco, CA: Jossey-Bass, pp. 3-17.
- Nápoles-Springer, A. M. & Stewart, A. L. (2006) Overview of qualitative methods in research with diverse populations: Making research reflect the population. *Medical Care*, 44(11), pp.S5-S9.
- National Cancer Institute (2015) *National Cancer Act of 1937*. Available at <http://legislative.cancer.gov/history/1937> [Accessed 20 December 2014].
- Nawyn, S. J., Gjakaj, L., Agbényiga, D. L., & Grace, B. (2012) Linguistic isolation, social capital, and immigrant belonging. *Journal of Contemporary Ethnography*, 41(3), pp.255-282.
- Ncho, C. D., & Wright, S. C. (2013) Health maintenance and low socio-economic status: A family perspective. *Curationis*, 36(1), pp.1-7.
- Neta, G., Sanchez, M.A., Chambers, D.A., Phillips, S.M., Leyva, B., Cynkin, L., Farrell, M.M., Heurtin-Roberts, S. & Vinson, C. (2015) Implementation science in cancer prevention and control: a decade of grant funding by the National Cancer Institute and future directions. *Implementation Science*, 10(1), pp.1-10.
- Nichols, R. (2013) The Origins and Effects of Filial Piety: How Culture Solves an Evolutionary Problem for Parents. *Journal of Cognition and Culture*, 13(3-4), pp.201-230.
- Northfield, S. (2010) The caregiving journey for family members of relatives with cancer: how do they cope?. *Clinical Journal of Oncology Nursing*, 14(5), pp, 567-577.
- O'Connor, J. M. & Kircher, S. M. (2016) Financial toxicity in cancer care. *The Journal of Community and Supportive Oncology*, 14(3), pp.101-106.
- O'Keefe, E. B., Meltzer, J. P., & Bethea, T. N. (2015) Health disparities and cancer: racial disparities in cancer mortality in the United States, 2000–2010. *Frontiers in Public Health*, 3(51),pp.1-15..
- O'Regan, P., & Hegarty, J. (2017) The importance of self-care for fatigue amongst patients undergoing chemotherapy for primary cancer. *European Journal of OncologyNursing*, 28, pp.47-55.

- Oliffe, J. (2009) Health behaviors, prostate cancer, and masculinities: a life course perspective. *Men and Masculinities*, 11(3), pp.346-366.
- Ornelas, I. J., Amell, J., Tran, A. N., Royster, M., Armstrong-Brown, J., & Eng, E. (2009) Understanding African American men's perceptions of racism, male gender socialization, and social capital through photovoice. *Qualitative Health Research*, 19(4), pp. 552-565.
- Ose, D., Winkler, E. C., Berger, S., Baudendistel, I., Kamradt, M., Eckrich, F., & Szecsenyi, J. (2017) Complexity of care and strategies of self-management in patients with colorectal cancer. *Patient Preference and Adherence*, 11, pp.731-742.
- Östlin, P., Eckermann, E., Mishra, U. S., Nkowane, M., & Wallstam, E. (2006) Gender and health promotion: A multisectoral policy approach. *Health Promotion International*, 21(suppl_1), pp.25-35.
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007) Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology*, 12(1), pp. 89-102.
- Pamuk, A. (2004) Geography of immigrant clusters in global cities: a case study of San Francisco. *International Journal of Urban and Regional Research*, 28(2), pp. 287-307.
- Parveen, S. & Morrison, V. (2009) Predictors of Familism in the Caregiver Role A Pilot Study. *Journal of Health Psychology*, 14(8), pp.1135-1143.
- Patel, G., Harcourt, D., Naqvi, H., & Rumsey, N. (2014) Black and South Asian women's experiences of breast cancer: a qualitative study. *Diversity and Equality in Health and Care*, 11(2), pp.135-149.
- Payne, S., Jarrett, N., & Jeffs, D. (2000) The impact of travel on cancer patients' experiences of treatment: a literature review. *European Journal of Cancer Care*, 9(4), pp.197-203.
- Penner, L. A., Hagiwara, N., Eggly, S., Gaertner, S. L., Albrecht, T. L., & Dovidio, J. F. (2013) Racial healthcare disparities: A social psychological analysis. *European Review of Social Psychology*, 24(1), pp.70-122.
- Peppercorn, J. (2017) Financial toxicity and societal costs of cancer care: Distinct problems require distinct solutions. *The Oncologist*, 22(2), pp.123-125.
- Peto, J. (2001) Cancer epidemiology in the last century and the next decade. *Nature*, 411(6835), pp. 390-395.

- Pew Research Center (2012) *The Rise of Asian Americans*, Available at: <http://www.pewsocialtrends.org/2012/06/19/the-rise-of-asian-americans/> [Accessed 15 June 2015].
- Piercy, K. W., & Chapman, J. G. (2001) Adopting the caregiver role: A family legacy. *Family Relations*, 50(4), pp.386-393.
- Pinquart, M., & Sörensen, S. (2005) Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45(1), pp.90-106.
- Pitceathly, C., & Maguire, P. (2003) The psychological impact of cancer on patients' partners and other key relatives: a review. *European Journal of Cancer*, 39(11), pp.1517-1524.
- PolicyLink and University of Southern California Program for Environmental and Regional Equity (2017) *An Equity Profile of the Nine-County San Francisco Bay Area Region*. Available at <http://nationalequityatlas.org/> [Accessed on 15 November 2017].
- Polite, B.N., Adams-Campbell, L.L., Brawley, O.W., Bickell, N., Carethers, J.M., Flowers, C.R., Foti, M., Gomez, S.L., Griggs, J.J., Lathan, C.S. & Li, C.I. (2017) Charting the future of cancer health disparities research: A position statement from the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute. *CA: A cancer journal for clinicians*, 67(5), pp. 353-361.
- Pollak, K. I., Alexander, S. C., Grambow, S. C., & Tulsky, J. A. (2010) Oncologist patient-centered communication with patients with advanced cancer: Exploring whether race or socioeconomic status matter. *Palliative Medicine*, 24(1), pp.96-98.
- Porter, L. S., & Dionne-Odom, J. N. (2017) Supporting cancer family caregivers: How can frontline oncology clinicians help?. *Cancer*, 123(17), p.p 3212-3215.
- Putnam, Robert D. (1993) The prosperous community. *The American Prospect*, 4(13), pp.35-42.
- Raffaetà, R., Krause, K., Zanini, G. and Alex, G. (2017) Medical pluralism reloaded. *L'Uomo Società Tradizione Sviluppo*, 42(1), pp.95-124.

- Ramondetta, L.M., Meyer, L.A., Schmeler, K.M., Daher, M.E., Gallegos, J., Scheurer, M., Montealegre, J.R., Milbourne, A., Anderson, M.L. and Sun, C.C. (2015) Avoidable tragedies: disparities in healthcare access among medically underserved women diagnosed with cervical cancer. *Gynecologic Oncology*, 139(3), pp.500-505.
- Raphael, D. (2006) Social determinants of health: present status, unanswered questions, and future directions. *International Journal of Health Services*, 36(4), pp.651-677.
- Rew, K. T., Clarke, S. L., Gossa, W., & Savin, D. (2014) Immigrant and refugee health: cross-cultural communication. *FP Essentials*, 423, pp.30-39.
- Richardson, L. J., & Brown, T. H. (2016) (En) gendering racial disparities in health trajectories: A life course and intersectional analysis. *SSM-Population Health*, 2, pp. 425-435.
- Riger S. & Sigurvinsdottir R. (2015) Thematic Analysis. In: Jason, L. & Glenwick, D. (eds.) *Handbook of methodological approaches to community-based research: Qualitative, Quantitative, and Mixed methods*. New York, NY: Oxford University Press., pp.33-41.
- Ritchie, J., Lewis, J. (2003) *Qualitative research practice: A guide for social science students and researchers*. London: Sage.
- Rocco, L., & Suhrcke, M. (2012) Is Social Capital Good for Health?: A European Perspective. Copenhagen, Denmark: WHO Regional Office for Europe. Available at: <http://www.euro.who.int/en/publications/abstracts/is-social-capital-good-for-health-a-european-perspective> [Accessed 15 December 2016].
- Rolland, J.S. (2005) Cancer and the family: an integrative model. *Cancer*, 104(S11), pp.2584-2595.
- Rose, J. H. (1990) Social support and cancer: Adult patients' desire for support from family, friends, and health professionals. *American Journal of Community Psychology*, 18(3), pp.439-464.
- Rubin, H. and Rubin, I. (2005) *Qualitative Interviewing: The Art of Hearing Data*, 2nd edition. London: Sage.
- Rumbaut, R. G. (2004) Ages, life stages, and generational cohorts: decomposing the immigrant first and second generations in the United States. *International Migration Review*, 38(3), pp.1160-1205.

- Sadler, G. R., Lee, H. C., Lim, R. S. H., & Fullerton, J. (2010) Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nursing & Health Sciences*, 12(3), pp. 369-374.
- Salamonsen, A., Kiil, M. A., Kristoffersen, A. E., Stub, T., & Berntsen, G. R. (2016) "My cancer is not my deepest concern": life course disruption influencing patient pathways and health care needs among persons living with colorectal cancer. *Patient Preference and Adherence*, 10, pp.1591-1600.
- Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000) The unmet supportive care needs of patients with cancer. *Cancer*, 88(1), pp. 226-237.
- Santoro, M. S., Van Liew, C., Holloway, B., McKinnon, S., Little, T., & Cronan, T. A. (2016) Honor thy parents: an ethnic multigroup analysis of filial responsibility, health perceptions, and caregiving decisions. *Research on Aging*, 38(6), pp.665-688.
- Sauvaget, C., Ramadas, K., Fayette, J. M., Thomas, G., Thara, S., & Sankaranarayanan, R. (2011) Socio-economic factors & longevity in a cohort of Kerala State, India. *The Indian Journal of Medical Research*, 133(5), pp.479-486.
- Scheffler, R.M., Borgonovi, F., Brown, T. Sassi, F. Dourgnon, P. Sirven, N. (2010) Social capital, Human capital and Health: What is the evidence? Organisation for Economic Co-operation and Development (OECD) Available at: <http://www.oecd.org/edu/research/45760738.pdf> [Accessed 15 December 2016].
- Schinkel, S., Schouten, B. C., Street Jr, R. L., van den Putte, B., & van Weert, J. C. (2016) Enhancing Health Communication Outcomes Among Ethnic Minority Patients: The Effects of the Match Between Participation Preferences and Perceptions and Doctor–Patient Concordance. *Journal of Health Communication*, 21(12), pp.1251-1259.
- Schmidt, H., Boese, S., Bauer, A., Landenberger, M., Lau, A., Stoll, O., Schmoll, H.J., Mauz-Koerholz, C., Kuss, O. & Jahn, P. (2017) Interdisciplinary care programme to improve self-management for cancer patients undergoing stem cell transplantation: a prospective non-randomised intervention study. *European Journal of Cancer Care*, 26(4),pp.1-13.
- Schubart, J. R., Kinzie, M. B., & Farace, E. (2008) Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro-Oncology*, 10(1), pp.61-72.
- Schulz, A. J., Parker, E. A., Israel, B. A., Allen, A., Decarlo, M., & Lockett, M. (2002) Addressing social determinants of health through community-based participatory research: the East Side Village Health Worker Partnership. *Health Education & Behavior*, 29(3), pp. 326-341.

- Schwartz, S.J., Weisskirch, R.S., Hurley, E.A., Zamboanga, B.L., Park, I.J., Kim, S.Y., Umana-Taylor, A., Castillo, L.G., Brown, E. & Greene, A.D. (2010) Communalism, familism, and filial piety: Are they birds of a collectivist feather?. *Cultural Diversity and Ethnic Minority Psychology*, 16(4), pp. 548-560.
- Shavers, V.L. (2007) Measurement of socioeconomic status in health disparities research. *Journal of the National Medical Association*, 99(9), pp.1013-1023.
- Sherman, A. C., Pennington, J., Simonton, S., Latif, U., Arent, L., & Farley, H. (2008) Determinants of participation in cancer support groups: The role of health beliefs. *International Journal of Behavioral Medicine*, 15(2), pp.92-100.
- Shieh, S. C., Tung, H. S., & Liang, S. Y. (2012) Social support as influencing primary family caregiver burden in Taiwanese patients with colorectal cancer. *Journal of Nursing Scholarship*, 44(3), pp.223-231.
- Shim, J.K. (2010) Cultural health capital: a theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *Journal of Health and Social Behavior*, 51(1), pp.1-15.
- Siegel K, Raveis VH, Houts P, Mor V. (1991) Caregiver burden and unmet patient needs. *Cancer*, 68(5), pp.1131–1140.
- Siegel, R. L., Miller, K. D., & Jemal, A. (2016) Cancer statistics, 2016. *CA: A cancer journal for clinicians*, 66(1), pp.7-30.
- Silverman, D. (2011) *Interpreting qualitative data*. Los Angeles, CA: SAGE Publications.
- Singh–Carlson, S., Nguyen, S. K. A., & Wong, F. (2013) Perceptions of survivorship care among South Asian female breast cancer survivors. *Current Oncology*, 20(2), pp.e80-e89.
- Singh, G. K., Williams, S. D., Siahpush, M., & Mulhollen, A. (2011) Socioeconomic, rural-urban, and racial inequalities in US cancer mortality. *Journal of Cancer Epidemiology*, pp.1-27.
- Smith-McLallen, A., Fishbein, M., & Hornik, R. C. (2011) Psychosocial determinants of cancer-related information seeking among cancer patients. *Journal of Health Communication*, 16(2), pp.212-225.
- Solberg Nes, L., Ehlers, S. L., Patten, C. A., & Gastineau, D. A. (2014) Self-regulatory fatigue, quality of life, health behaviors, and coping in patients with hematologic malignancies. *Annals of Behavioral Medicine*, 48(3), pp.411-423.

- Spring, M., Westermeyer, J., Halcon, L., Savik, K., Robertson, C., Johnson, D.R., Butcher, J.N. and Jaranson, J. (2003) Sampling in difficult to access refugee and immigrant communities. *The Journal of Nervous and Mental Disease*, 191(12), pp. 813-819.
- Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010) Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19(10), pp.1013-1025.
- Sun, K. C. (2012) Fashioning the reciprocal norms of elder care: a case of immigrants in the United States and their parents in Taiwan. *Journal of Family Issues*, 33(9) pp.1240-1271.
- Surveillance, Epidemiology, and End Results (SEER) Program (2014) *SEER*Stat Database: Age-Adjusted SEER Incidence Rates By Age At Diagnosis/Death All Sites, All Races, Both Sexes 2000-2011 (SEER 18)*, National Cancer Institute. Available at: <http://seer.cancer.gov> [Accessed 2 May 2014].
- Sweeny, K., & Cavanaugh, A. G. (2012) Waiting is the hardest part: A model of uncertainty navigation in the context of health news. *Health Psychology Review*, 6(2), pp. 147-164.
- Szreter, S., & Woolcock, M. (2004) Health by association? Social capital, social theory, and the political economy of public health. *International Journal of Epidemiology*, 33(4), pp.650-667.
- Tarazi, W.W., Bradley, C.J., Harless, D.W., Bear, H.D. and Sabik, L.M. (2016) Medicaid expansion and access to care among cancer survivors: a baseline overview. *Journal of Cancer Survivorship*, 10(3), pp.583-592.
- Taylor, C. (2015) Stratified follow up: supporting patients to self-manage. *Cancer Nursing Practice*, 14(6), pp.14-19.
- Thomas, C., & Morris, S. M. (2002) Informal carers in cancer contexts. *European Journal of Cancer Care*, 11(3), pp.178-182.
- Thomas, C., Morris, S. M., & Harman, J. C. (2002) Companions through cancer: the care given by informal carers in cancer contexts. *Social Science & Medicine*, 54(4), pp.529-544.
- Tsai, T. I., Morisky, D. E., Kagawa-Singer, M., & Ashing-Giwa, K. T. (2011) Acculturation in the adaptation of Chinese-American women to breast cancer: a mixed-method approach. *Journal of Clinical Nursing*, 20, pp.3383-3393.

- U.S. Census Bureau (2013) *Language Use in the United States: 2011*, Available at: <https://www.census.gov/prod/2013pubs/acs-22.pdf> [Accessed 1 May 2015].
- U.S. Census Bureau (2014) *English-Speaking Ability of the Foreign-Born*, Available at: <https://www.census.gov/prod/2014pubs/acs-26.pdf> [Accessed 1 May 2015].
- U.S. Department of Health & Human Services (2018) *Health Insurance Portability and Accountability Act of 1996*. Available at: <https://aspe.hhs.gov/report/health-insurance-portability-and-accountability-act-1996> [Accessed 1 May 2018].
- Unger, J.M., Cook, E., Tai, E. and Bleyer, A. (2016) The role of clinical trial participation in cancer research: barriers, evidence, and strategies. *American Society of Clinical Oncology Educational Book*, 36, pp.185-198.
- Ussher, J. M., Sandoval, M., Perz, J., Wong, W. T., & Butow, P. (2013) The gendered construction and experience of difficulties and rewards in cancer care. *Qualitative Health Research*, 23(7), pp.900-915.
- van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M., & Rowland, J. (2011) Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue?. *Psycho-Oncology*, 20(1), pp.44-52.
- Veach, T. A., & Nicholas, D. R. (1998) Understanding families of adults with cancer: Combining the clinical course of cancer and stages of family development. *Journal of Counseling & Development*, 76(2), pp. 144-156.
- Villa-Torres, L., Gonzalez-Vazquez, T., Fleming, P.J., González-González, E.L., Infante-Xibille, C., Chavez, R. and Barrington, C. (2017) Transnationalism and health: a systematic literature review on the use of transnationalism in the study of the health practices and behaviors of migrants. *Social Science & Medicine*, 183, pp.70-79.
- Viruell-Fuentes, E. A., Miranda, P. Y., & Abdulrahim, S. (2012) More than culture: structural racism, intersectionality theory, and immigrant health. *Social Science & Medicine*, 75(12), pp.2099-2106.
- Von Wagner, C., Good, A., Whitaker, K. L., & Wardle, J. (2011) Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. *Epidemiologic Reviews*, 33(1), pp.135-147.
- Walker, G.V., Grant, S.R., Guadagnolo, B.A., Hoffman, K.E., Smith, B.D., Koshy, M., Allen, P.K. & Mahmood, U.(2014) Disparities in stage at diagnosis, treatment, and survival in nonelderly adult patients with cancer according to insurance status. *Journal of Clinical Oncology*, 32(28), pp.3118-3125.

- Walker, R., & Schafran, A. (2015) The strange case of the Bay Area. *Environment and Planning A: Economy and Space*, 47(1), pp.10-29.
- Ward-Schofield, J. W. (1993) Increasing the generalizability of qualitative research. In: Hammersley, M. (ed.) *Social research: philosophy, politics and practice*. London: Sage, pp. 200-225.
- Wen, K. Y., Fang, C. Y., & Ma, G. X. (2014) Breast cancer experience and survivorship among Asian Americans: a systematic review. *Journal of Cancer Survivorship*, 8(1), pp.94-107.
- Wheeler, S. B., Reeder-Hayes, K. E., & Carey, L. A. (2013) Disparities in breast cancer treatment and outcomes: biological, social, and health system determinants and opportunities for research. *The Oncologist*, 18(9), pp.986-993.
- White, M. J., Biddlecom, A. E., & Guo, S. (1993) Immigration, naturalization, and residential assimilation among Asian Americans in 1980. *Social Forces*, 72(1), pp. 93-117.
- Wilkinson, R. G., & Marmot, M. (2003) *Social determinants of health: the solid facts*. Copenhagen, Denmark: World Health Organization.
- Williamson, T.S., (2008) The shift of oncology inpatient care to outpatient care: The challenge of retaining expert oncology nurses. *Clinical Journal of Oncology Nursing*, 12(2), pp.186.
- Wilson, K. B., Thorpe Jr, R. J., & LaVeist, T. A. (2017) Dollar for dollar: racial and ethnic inequalities in health and health-related outcomes among persons with very high income. *Preventive Medicine*, 96, pp.149-153.
- Wingens, M., Windzio, M., De Valk, H., & Aybek, C. (2011) *A life-course perspective on migration and integration*. London, Springer Science & Business Media.
- Wolff, S. N. (2007) The burden of cancer survivorship. In Feuerstein, M., *Handbook of cancer survivorship*. New York: Springer, pp.7-18.
- Wong-Kim, E., Sun, A., Merighi, J. R., & Chow, E. A. (2005) Understanding quality-of-life issues in Chinese women with breast cancer: a qualitative investigation. *Cancer Control*, 12(2), pp.6-12.
- Wong, S. T., Yoo, G. J., & Stewart, A. L. (2006) The changing meaning of family support among older Chinese and Korean immigrants. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(1), pp.S4-S9.

- World Health Organization (2008) Closing the gap in a generation: health equity through action on the social determinants of health: Commission on Social Determinants of Health final report. Available at: https://www.who.int/social_determinants/thecommission [Accessed 1 Dec 2017].
- World Health Organization (2018) Social determinants of health, Available at: http://www.who.int/social_determinants/en/ [Accessed 1 Dec 2017].
- Wuest, J., Merritt-Gray, M., Berman, H., & Ford-Gilboe, M. (2002) Illuminating social determinants of women's health using grounded theory. *Health care for Women International*, 23(8), pp.794-808.
- Yabroff, K. R., Lawrence, W. F., Clauser, S., Davis, W. W., & Brown, M. L. (2004). Burden of illness in cancer survivors: findings from a population-based national sample. *Journal of the National Cancer Institute*, 96(17), pp.1322-1330.
- Yates, P. (1999) Family coping: issues and challenges for cancer nursing. *Cancer Nursing*, 22(1), pp.63-71.
- You, J., & Lu, Q. (2014) Sources of social support and adjustment among Chinese cancer survivors: gender and age differences. *Supportive Care in Cancer*, 22(3), pp.697-704.
- Youn, G., Knight, B. G., Jeong, H. S., & Benton, D. (1999) Differences in familism values and caregiving outcomes among Korean, Korean American, and White American dementia caregivers. *Psychology and Aging*, 14(3), pp.355-364.
- Young, A.L., Rowe, I.A., Absolom, K., Jones, R.L., Downing, A., Meader, N., Glaser, A. & Toogood, G.J. (2016) The effect of Liver Transplantation on the quality of life of the recipient's main caregiver—a systematic review. *Liver International*, 37(6), pp.794-801.
- Yousuf Zafar, S. (2015) Financial toxicity of cancer care: It's time to intervene. *Journal of the National Cancer Institute*, 108(5), Available at: <https://doi.org/10.1093/jnci/djv370> [Accessed 30 December 2015].
- Yu, Z., & Myers, D. (2007) Convergence or divergence in Los Angeles: Three distinctive ethnic patterns of immigrant residential assimilation. *Social Science Research*, 36(1), pp. 254-285.
- Yun, Y. H., Rhee, Y. S., Kang, I. O., Lee, J. S., Bang, S. M., Lee, W. S., & Hong, Y. S. (2004) Economic burdens and quality of life of family caregivers of cancer patients. *Oncology*, 68(2-3), pp.107-114.

- Zachariae, R., Pedersen, C.G., Jensen, A.B., Ehrnrooth, E., Rossen, P.B. and von der Maase, H. (2003) Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *British Journal of Cancer*, 88(5), p.658-665.
- Zahnd, W. E., & McLafferty, S. L. (2017) Contextual effects and cancer outcomes in the United States: a systematic review of characteristics in multilevel analyses. *Annals of Epidemiology*, 27(11), pp.739-748.
- Zhang, Y., Kwekkeboom, K., & Petrini, M. (2015) Uncertainty, self-efficacy, and self-care behavior in patients with breast cancer undergoing chemotherapy in China. *Cancer Nursing*, 38(3), pp.E19-E26.

Appendix A | Pen portraits of the study participants

Individuals diagnosed with cancer

An: An is a 50 to 59-years-old, married Chinese female in remission with her disease. She has resided in the U.S. for over 20 years and is very limited English speaking. She completed an education up to the 8th grade. She has a moderately low income for a 5-person household (\$39,736 to \$64,553) with her husband and young adult children. She had been the main decision-maker and homemaker for the household. An has some family relatives who live close to her and received some financial support for food when she became unemployed during the course of her cancer treatment. Her husband became unemployed shortly before her cancer diagnosis and during her cancer treatment. An was denied a medical appointment because she was under a new employee probation period. She lost healthcare insurance coverage as a result of not being able to work during treatment. She then obtained Medi-Cal coverage for cancer treatment at a county public hospital. An was unaware of being a Hepatitis carrier nor received screening for this condition. Her hepatitis condition led to a major adverse effect with her cancer treatment. Her daughter, Leila, lives with her and is family carer for the study.

Angie: Angie is a 70 to 79-years-old widowed Filipina in remission with her disease. She has resided in the U.S. for over 40 years, is bilingual English speaking, Master's degree educated, and retired from her career of over 30 years. She has a moderately high income for a 1-person household (\$39,736 -\$64,553). Her treatment was covered by a retirement employer-sponsored private insurance. She is a parent of adult children with some relatives who live near her. Her relatives from abroad have been

present for her medical care support. She initially did not disclose her cancer diagnosis to her children until after her first initial treatment. She avoided disclosure of her cancer diagnosis amongst those outside the family, including friends and colleagues. She has been living alone, but her daughter, Sofia, was her live-in family carer during cancer treatment. Sofia is her family carer for the study.

Lian: Lian is a 60 to 69-years-old married Chinese female, who is currently in remission for her disease. As retirees from China, she and her husband are dependent on their son's moderately low income for a 4-person household (\$39,736 - \$64,553). The couple does not drive, but take public transportation. Most of their family and close friends live in China. She is non-English speaking and has lived in the U.S. for no more than 5 years. Shortly after arriving to the U.S., she was diagnosed with cancer as a result of experiencing symptoms. Lian was uninsured prior to and during her cancer diagnostic testing. Her husband and son assisted with her cancer care, with her husband as the main carer. During cancer treatment, she was insured under Medi-Cal and received care at a county public hospital. Her husband, Bao, is her family carer for the study.

Lin: Lin is a 50 to 59 years-old divorced Chinese female whose cancer condition is monitored by a physician, but currently not receiving active treatment. She resided in the U.S. for over 20 years, is limited English speaking, and completed a high school degree. She expressed having limited knowledge about her cancer disease. She shares a moderately low-income household (\$39,736 - \$64,553) with her two young adult children. She became unemployed as a result of her illness and lost her employer-sponsored private health insurance during the course of her cancer treatment. She

purchased a private insurance to continue her treatment and was later insured by Medi-Cal for her treatment in a county public hospital. Her financial hardships as a cancer patient was especially impacted when she wasn't eligible for Medi-Cal, because her household income was about \$100 dollars above the poverty income criteria. Her daughter, Isabel, lives with her and the family carer for the study.

Luwisa: Luwisa is a 60 to 69-years-old married Filipina in remission with her disease. She has a moderate household income (\$39,736 -\$64,553) with her husband. Although she retired from her previous employer, she is currently self-employed to supplement her retiree income. She resided in the U.S. for over 30 years, is bilingual English speaking, and completed a Bachelor's degree. Her retiree employer-sponsored insurance covered 80 percent of the medical bill. Therefore the out-of-pocket fees for her medical care created financial worries. During cancer treatment, she was not qualified for Medi-Care insurance due to age criteria. She is a parent of adult children with some family relatives who live near her. Her husband assisted with some of her care needs. Her husband relies on Luwisa for many of the household responsibilities and decision-making. She expressed that she has limited knowledge about her cancer disease. Linda, her sister, is her family carer for the study.

Marie: Marie is a 50 to 59 years old, divorced Filipina in remission with her disease. She is bilingual English speaking and resided in the U.S. for over 20 years. She completed a Bachelor's degree, but did not professionally pursue her field of study while living in the U.S. She has low income for a 1-person household (\$20,592.00 or less) with transient housing circumstances. She worked for 13 years in the U.S and became unemployed during the course of cancer treatment. As a result, she lost her

employer-sponsored private health insurance and her remaining cancer treatment was transitioned to a public county hospital as a Medi-Cal patient. Marie described her transient housing status as homelessness. Prior to her cancer diagnosis, she struggled with postpartum depression after giving birth. She is a parent of adult children with few relatives living near places of her temporary housing. Marie identified her mother as her family carer (not a participant in this study). Her mother is over 80-years-old working as a live-in carer in a nursing home, where Marie has housing accommodation for a few number of days each week.

Meiwen: Miewen is a 50 to 59 years old, divorced Chinese female in remission with her disease. She is bilingual English speaking, has resided in the U.S. for over 20 years, and completed a Master's degree. She has high income for a 1-person household (\$64,554.00 to \$104,086.00) and is currently employed. Her treatment was covered by employer-sponsored private insurance under the healthcare provider of her choice. She practices traditional Chinese medicine. Meiwen is the main carer of her ageing parents who are recent immigrants and speak very limited English. Her mother, Ying, cared for her during the course of cancer treatment. She has no relatives living near her except her parents. Maintaining the privacy of her cancer diagnosis, including amongst relatives, was important to Meiwen. Her mother, Ying, is her family carer for the study.

Rajat: Rajat is a 50 to 59-years-old, married Indian male in remission with his disease. He has resided in the U.S. for over 15 years, is bilingual English speaking, and Master's degree educated. He has very high income for a 4-person household (\$191,150 or more) and is currently employed. His employer-sponsored health

insurance allowed him to seek treatment for his cancer with any oncology provider, but there was still several weeks of delay for an appointment with an oncologist. His cancer condition and treatment resulted in other health problems requiring multiple specialist to treat his health problems. His family includes adolescent/teen children, but other family members live in India. Manali is his wife and family carer for the study.

Wei: Wei is a 60 to 69-years-old, married Chinese male who is currently being treated for his disease at a county hospital as a Medi-Cal/Medicare recipient. He lived in the U.S. for less than 10 years, is non English speaking, and has some family relatives residing near his residential area. He completed an Associate degree related to his field of employment. He is the sole contributor for his low income 2-person household (\$20,593 - \$39,735), which is dependent on his current employment status. He is unable to drive a car and therefore spends 2 hours each way on public transportation, between his home and work. He relies on his wife and family carer Shen, to provide language interpretation and transportation. She is his family carer for the study.

Family carers

Bao: Bao is a 70 to 79-years-old Chinese male, who is the husband and carer of Lian. He resided in the U.S. for no more than 5 years, is non-English speaking, and has an Associate degree (typically 1-2 year undergraduate education). He is a retiree from his employment in China. Bao provided physical and emotional care to his wife. He planted a garden at their home to provide Lian with fresh vegetable, fruit and herbal produce.

Isabel: Isabel is a 25 to 29-years-old, single Chinese female who is the eldest daughter and family carer of her Lin. She is U.S. born, bilingual English speaking, completed her Bachelor's degree, and is currently employed. She lives with her mother and contributes to the moderately low household income. When her mother was first diagnosed and treated for cancer, Isabel was attending a university away from home.

Leila: Leila is a 25 to 29-years-old, single Chinese female, eldest daughter and family carer of her mother, An. She is U.S. born, bilingual English speaking, and completed her Bachelor's degree. Leila shares the moderately low household income with her parents and sibling through her employment. Due to the limited English proficiency and education of both parents, Leila often interpreted and provided additional explanation for them. Leila has been working since her early teens and considers herself accountable for the family since her mother's diagnosis with cancer. During her mother's cancer treatment, Leila was attending a university.

Linda: Linda is a 60 to 69-years-old married Filipina who is the sister and carer of Luwisa. As an immigrant, she has resided in the U.S. for nearly 30 years, is bilingual English speaking, and completed a Bachelor's degree. She has a high income for a 3-person household (\$104,087 or \$191,149) and is currently retired. She has some prior experiences with providing ill friends friends with supportive care. Linda's role as a main family carer was important because she was able to fulfil multiple aspects of caring for Luwisa, which included hygiene care, cooking meals, and emotional support.

Manali: Manali is a 40 to 49-years-old, Indian female who is the wife and family carer of Rajat. She resided in the U.S. for over 15 years, is bilingual English speaking, and completed her Master's degree. Alongside Rajat, she helps raise their two children and contributes to the household income with her employment. Her entire family resides in India. Manali had prior experience as a family carer for her mother when she was a teenager.

Meng: Meng is a 70 to 79-years-old, married Chinese male who served as a full time, live-in carer for his brother-in-law with cancer (not a participant of this study). He is non-English speaking and resided in the U.S. for more than 20 years. He completed up to 2 years of a high school education. He has a moderately low 2-person household income (\$20,593 to \$39,735) and is retired with occasional part time work to fill his time with activities. He served as the primary family carer in order for his sister, the wife of the cancer patient, to maintain employment. He noted that hiring a professional carer was too expensive. As leisurely fisherman, he caught fresh fish daily for his brother-in-law's meals.

Shan: Shan is a 60 to 69-years-old, married Chinese female who is the wife and family carer of Wei. She is a retiree from her employment in China and resided in the U.S. for less than 10 years. She is bilingual English-speaking with a Bachelor's degree education. Wei often relies on her for car transportation, decision-making, interpretation and knowledge about cancer. Their only adult son lives in China, but she has some family members living near her.

Sofia: Sofia is a 30 to 39-years-old married Filipina who is the daughter and carer of Angie. She is U.S. born, only English-speaking, and completed a Bachelor's degree. She has a low income for a 3-person household (\$20,592 or less) as a result of being unemployed for the last 3 years. This has impacted household financial conditions, but she has been able to maintain permanent housing. Prior to her unemployment, she worked for nearly 20 years and. Although she lives separately from her mother, she was her live-in carer during cancer treatment. Initially, she was not told of Angie's diagnosis which she eventually learned about from a relative. Sofia was also pregnant during the time of providing cancer care for her mother.

Ying: Ying is a 80 to 89-years-old, married Chinese female who is the mother and family carer of Meiwen. She is limited English-speaking and resided in the U.S. for less than 10 years. She is retired from her employment as a nurse in China with a Bachelor's degree, and experienced caring for other cancer patients in the family. She has a low 2-person household income (\$20,592.00 or less). Ying had very limited involvement with the medical context of Meiwen's cancer care, due to language barriers and Meiwen's preference to not place medical responsibility on her parents. Ying relies on daughter or spouse for transportation on a regular basis.

Appendix B | Literature search terms, databases, online journals, search criteria, categorical names

Initial search terms:

cancer, care, caregiving, caregiver, patient*, burden, challenge*, family*, Chinese, Indian, South Asian*, Filipino*, Asian*, immigrant*, emigrant*.

Additional search terms:

oncology, caregiver*, carer*, support, illness, palliative, obstacle*, hardship*, barrier*, experience*, problem*, quality of life (QoL), health related quality of life (HRQoL), financial, financial toxicity*, emotional, psychological, stress, communication, culture, filial obligation, filial piety, filial responsibility, foreign born, minority*, American*, Punjabi, Hindi, Cantonese, Mandarin, Tagalog, Ilocano, predictor*, determinant*, factor*, disparities, differences, social, hierarchy, social capital, financial capital, cultural capital, systematic review, literature review

NIH MeSH terms:

- caregivers: caregiver, carer, spouse caregiver, family caregiver
- communication barriers: language barriers
- cost of illness: illness cost, disease cost, economic burden of disease, burden of illness
- culture: culture, custom, belief, background
- decision making: shared decision making
- family: filiation, kinship, networks, relatives, adult children, intergenerational, spouse, parent, marital status
- healthcare disparities: health inequalities
- health care quality, access, and evaluation: attitude of health professional, health resources, practice patterns, professional-patient relations
- health services accessibility: availability of health services, accessibility, access to health care, health equity
- psychosocial support systems: sociological factors, sociological environment, social support, psychosocial
- sociological factors: norms, social class, community networks, loneliness, culture, acculturation, hierarchy, social marginalisation

Databases:

Academic Search Complete, ERIC, Web of Science, PubMed, CINAHL, PsycInfo, Biosis, IBSS, Ovid. Wiley Library Oxford library, SocINDEX, PsychArticles, MEDLINE Complete, EMBASE

Online Journals:

Asian Pacific Family Medicine; Journal of Immigrant Health; Journal of Immigrant and Minority Health; Social Theory & Health; Journal of Health & Social Behavior; Journal of Social, Behavioural and Health Sciences; British Journal of Social Medicine; Sociology of Health & Illness

Journal of Family Relationships; Family Relations, Couple & Family Psychology; Family Process; Journal of Family Practice; Journal of Family Psychology; Journal of Family Issues; Journal of Family Nursing; Journal of Family and Community Medicine; Journal of Family Social Work, Family Health Research; Family Systems & Health

Psycho-oncology; Cancer, Journal of Cancer; Journal of Cancer Survivorship; American Journal of Cancer Research; Supportive Care in Cancer; British Journal of Cancer; International Journal of Cancer

Categorical names assigned to publications from search

Ageing	Family filial piety
Burden caregiver	Family illness general
Burden patient	Gender
Cancer experience patient	Healthcare cancer
Cancer experience Asian	Healthcare general
Cancer experience general	Immigration
Cancer financial	Marital status
Cancer psychosocial	Race-ethnicity
Cancer psychosocial asian	Self-care
Caregiving Asian	Social determinants cancer
Caregiving cancer Asian cancer	Social determinants health
Caregiving cancer general	Social epidemiology
Cultural and health	Social epidemiology cancer
Family cancer Asian	Social theory
Family cancer general	

Appendix C | Table 2.3 Literature review publications featuring relevant findings

Area of Focus: General cancer patient experience and burden			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Kagawa-Singer, M. et al. (2003) <i>Psycho-Oncology</i> .	Mix methods	U.S. - Euro-American (EA), Chinese, Japanese	Chinese and Japanese believed expectation of “self-sacrificing” and “nurturing” for husband and family. EA women believed they could be dependent. Chinese and Japanese valued non-verbal communication. EA valued more verbal communication.
Rose, J. H. (1990) <i>American Journal of Community Psychology</i> .	Quantitative	U.S. - majority White	Preferred types and sources of support identified by patients: emotional and daily living support were desired from family; learning from friends who were cancer survivors; open communication from health professionals. Patients also wanted support for self-esteem, decision-making, and problem-solving responsibilities from family, friends and health professionals.
Wolff, S. N. (2007) <i>Handbook of cancer survivorship</i> .	Quantitative	U.S. - majority White	Cancer patient views of cancer burden: 49% reported unmet “non-medical” needs; 53% of those who had “non-medical” needs viewed their practical and emotional difficulties with cancer as being harder than medical issues; 72% reported dealing with cancer related depression.
Yabroff, K. R. et al. (2004) <i>Journal of the National Cancer Institute</i> .	Quantitative	U.S.	Measures of health burdens were compared between cancer survivor sample and matched-demographics control sample who never had cancer diagnosis. Cancer survivors had greater reporting of poor health with all measures of health utility, work productivity, and general health.
Cook, S. A. et al. (2018) <i>Psycho-Oncology</i> .	Literature review - Quantitative	Europe, U.K. U.S., Canada, Australia, Japan, Hong Kong, Korea	Consistent significant predictors for long-term distress in patients were the distress and neuroticism levels measured at baseline. Moderate evidence existed for poor physical health. Very few studies reported demographic variables (younger age, lower education, low income) as significant predictors. No evidence of social support variables as significant predictors.
Deckx, L. et al. (2015) <i>Psycho-Oncology</i> .	Literature review - Quantitative	Turkey, Netherlands, Belgium, Israel, Japan, U.S.	Lack of social support was correlated to increasing level of loneliness. Unmarried, widowed or divorced status were key factors for loneliness. Low income was associated with loneliness, though not statistically significant.
Harrison, J. D. et al. (2009) <i>Supportive Care in Cancer</i> .	Literature review - Qualitative, Quantitative	Thailand, Australia, Turkey, U.K., U.S., Canada	Patients’ most frequently reported unmet needs: daily life support, followed by psychological, information, psychosocial, and physical support. Greater number of patients reported unmet needs occurred during post-treatment.
McPherson, C. J. et al. (2007) <i>Palliative Medicine</i> .	Literature review - Qualitative, Quantitative	Australia, Japan, Kenya, Korea, U.K., U.S., Canada	Significant percentage of terminally ill patients perceived themselves as a burden. Self-perceived burden was found to be related to the patients’ decisions related to: medical care, treatment, and advance directive; place of care during end of life; and making haste with death.

Area of Focus: Asian cancer patient experience and burden			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Ashing, K.T. et al. (2003) <i>Psycho-Oncology</i> .	Qualitative	U.S. - Asian, Korean, Chinese	Breast cancer patients had limited breast cancer knowledge, financial support for medical expenses, and patient time with physician. There were communication barriers due to lack of language access. Family challenges of the patients were: role and obligations, "self-sacrifice", concerns about children's welfare, and being a burden to the family. Patients' cultural beliefs discouraged use of psychosocial or emotional support.
Ashing-Giwa, K.T. et al. (2004) <i>Psycho-Oncology</i> .	Qualitative	U.S. - various race and ethnicities	Breast cancer patient were concerned about: self image, cancer reoccurrence or metastasis; family role and obligations; worries related to children's welfare and being a burden to the family. Their medical challenges were: the limited cancer and resource knowledge; difficulties with health insurance coverage/expenses; limited time with physician; lack of language access and cultural sensitivity from physician. Cultural beliefs discouraged patients to access psychosocial or emotional support.
Burke, N. J. et al. (2012) <i>Qualitative Health Research</i> .	Qualitative	U.S. - Filipino	Meanings of cancer survivorship and support of breast cancer survivors: 1) Belief in cancer can as one of many challenges in life, it relates to family welfare. 2) Caregiving means: different types of support; incorporates family support including relatives in the Philippines; involves religious and spiritual support. 4) A "caregiver" provides constant support for various needs.
Fu, M. R. et al. (2008) <i>Journal of Advanced Nursing</i> .	Qualitative	China	Female breast cancer patients' intentions for dealing with their diagnosis and treatment included minimising how cancer affected their family and friends. Their approaches for dealing with cancer are similar to findings in western breast cancer diagnosed populations, but have social, cultural, and historical Chinese influences.
Gurm, B. K. et al. (2008) <i>International Journal of Nursing Studies</i> .	Qualitative	Canada - South Asian, Punjabi	Perspectives varied amongst breast cancer patients regarding preferences of how to receive news of diagnosis and to have family involved with decision making. Some viewed family involvement as stressful. Not everyone was open to sharing diagnosis and discussing their cancer experiences. Patient reported desire to connect with Punjabi-speaking hospital staff.
Harle, M. T. et al. (2007) <i>Oncology Nursing Forum</i> .	Qualitative	U.S. - Filipino	Due to prior hardships in the Philippines, patients expected emotional and physical coping to be self-tolerated and accepted. Indirect communication was preferred, which involved being asked about their feelings. There was preference for family to be part of planning and treatment and the desire to maintain family role/responsibilities.
Howard, A. F. et al. (2007) <i>Journal of Immigrant and Minority Health</i> .	Qualitative	Canada - South Asian, Punjabi	Breast cancer patients viewed their diagnosis as a contributor to "family crisis". Cancer was another health problem for breast cancer patients. Having cancer led to ongoing fear and emotional hardships. Their experiences were also affected by encounters with healthcare professionals, their community, and their culture.

Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Lee, S. et al. (2013) <i>North American Journal of Medicine & Science.</i>	Qualitative	U.S. - Chinese, Korean	Breast cancer patients had limited resources for coping and access to linguistic and culture related programs/services. They relied on daily life family support and were reluctant to consider other sources of support. They did not want to be a burden on family. Psychological issues were commonly experienced, but rarely brought up as a problem to family or friends. Being an immigrant in the U.S. was viewed as a factor for not having sufficient or trusted social support.
Liu, J. E. et al. (2005). <i>Journal of Advanced Nursing.</i>	Qualitative	China	Informational support and emotional support were the two main desired forms of supportive communication. Chinese patients preferred discussing emotional support needs to only specific family members. Beliefs about revealing emotional needs and placing burden on others likely influenced their avoidance to seek support or help from others.
Lui, C. W. et al. (2009) <i>Social Work in Health Care.</i>	Qualitative	Australia - Chinese	Perception of cancer has negative connotations and stigma for the patient and the family, thus the illness is kept private and the family role in caregiving becomes more essential. Patients who spoke English as a second language still faced difficulties with healthcare communication.
Patel, G. et al. (2014) <i>Diversity and Equality in Health and Care.</i>	Qualitative	U.K. - Black, South Asian	Most women were supported primarily by family and few had a very limited network of support. South Asian women experienced inappropriate response from the community about their cancer diagnosis. South Asian women were uncomfortable with having male healthcare professionals as part of their medical care.
Singh-Carlson, S. et al. (2013) <i>Current Oncology.</i>	Quantitative	Canada - South Asian	Breast cancer survivors who were <44 years and 45-54 years old, had great concern of how cancer impacted their family. Women who were age 55 or older, were primarily concerned about family duties.
Tsai, T. I., et al. (2011). <i>Journal of Clinical Nursing.</i>	Mix methods	U.S. - Chinese, Taiwanese	Types of health beliefs were significantly associated with the level of acculturation. Cultural values and beliefs influenced how cancer survivors responded to and dealt with cancer. Life stressors from immigration experience contributed to negative experiences with breast cancer.
Wong-Kim, E. et al. (2005) <i>Cancer Control.</i>	Qualitative	U.S. - Chinese	Family relationships and support were viewed as essential. Foreign-born and American-born cancer patients reported cultural stigma, "karma", and fatalism associated with their illness. Foreign-born patients viewed their lower income and stressors from immigration experiences as having negative impact. Breast cancer was considered part of life's compounding challenges.
You, J., & Lu, Q. (2014) <i>Supportive Care in Cancer.</i>	Quantitative	China	Support from family was the greatest source of support. Males and females differed on negative correlation of support. For males, family support had reduce negative affect on their quality of life. For females, support from "special others" reduce negative affect on their quality of life.
Wen, K. Y., Fang, C. Y., & Ma, G. X. (2014) <i>Journal of Cancer Survivorship.</i>	Literature review - Qualitative, Quantitative	U.S. - Asian	Literature review on Asian American breast cancer experiences revealed the dimensions of cancer experiences affecting quality of life. Individual dimensions: physical health, emotional health, cancer related medical factors, and health efficacy. System level dimensions: demographic and socio-ecological factors, cultural, and healthcare system.

Area of Focus: General cancer patient self-care			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Chou, F.Y. et al. (2007) <i>Oncology Nursing Forum.</i>	Quantitative	U.S. - Chinese	Sample was immigrant Chinese patients with low levels of acculturation, most could not read English, and the majority had very low income. Patients reported approximately 14 symptoms each week whilst undergoing treatment. Self-care activities were applied to alleviate symptoms, but were low to moderately effective. Their quality of life scores were low to moderate.
Fann, J. R. et al. (2017) <i>Psycho-Oncology.</i>	Quantitative	U.S.	Patients received either control intervention or investigational approach on symptom management and quality of life. Patients who were currently employed at the beginning of the study, scored better with social, emotional, and role functioning as well as were less depressed.
Hughes, N. D. et al. (2016) <i>Supportive Care in Cancer.</i>	Qualitative	U.K.	Patients preferred some or total independence with managing pain. Professionals were concerned about potentially harmful impact of self management. They believed demographic background influenced patient's ability with learning and understanding pain management.
O'Regan, P. et al. (2017) <i>European Journal of Oncology Nursing.</i>	Mix methods	Republic of Ireland	Most patients reported moderate fatigue (48.8%), followed by severe fatigue (26%). Females were more likely to have higher fatigue levels. Patients who were divorced/separated had significant higher frequency of fatigue than those who were single status. Patients used self-care approaches.
Ose, D. et al. (2017) <i>Patient Preference and Adherence.</i>	Qualitative	Germany	Colorectal cancer patients self managed/coped with: treatment side effects and management; uncertainty and worry of illness; change in family relationships; socio-economic welfare; tracking medical care history. Patients wanted to proactively manage their medical care and needs.
Zhang, Y. et al. (2015). <i>Cancer Nursing.</i>	Quantitative	China	Breast cancer patients undergoing chemotherapy had an average score of low level self-efficacy, moderate level self-care behaviour, and high level of uncertainty. Authors suggested that patients likely did not engage in self-care because they received chemotherapy whilst hospitalised.
Hasanpour-Dehkordi, A. (2016) <i>Indian Journal of Palliative Care.</i>	Literature review - Qualitative	Europe, U.K., U.S., Australia, Iran	Major concepts of cancer patient self-care addressed in the literature review: patient's self-esteem and self-efficacy; the resources, cultural issues, and social networks within the patient's environment or healthcare system; healthcare professional's support of patient's self-care.
Taylor, C. (2015) <i>Cancer Nursing Practice.</i>	Commentary	U.K.	Cancer patients need for self-care management: tailor to patient needs based on their individual circumstances, disease, and capabilities; provide enough time for diagnosis and treatment recovery; give access to supportive services, education and communication; facilitate self-management consultation with patient.

Area of Focus: General cancer carer experience and burden			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Bevans, M. et al. (2012) <i>Journal of the American Medical Association.</i>	Qualitative	U.S.	The dimensions and complexities of a female caregiver's various responsibilities are described, highlighting the hardships and challenges of outpatient caregiving as a sole caregiver with limited financial means and support system. The caregiver faced great difficulty with emotional coping and mental wellness.
Gaugler, J. E. et al. (2008) <i>Supportive Care in Cancer.</i>	Quantitative	U.S.	Regardless of employment status, women were more likely to take on daily cancer care tasks. In comparison to men who worked, women who worked were more likely to report "fatigue and exhaustion" from caregiving.
Grant, M. et al. (2013) <i>Oncology Nursing Forum.</i>	Quantitative	U.S.	Caregivers rated their subjective stress as "high" throughout the study. They initially viewed themselves as well prepared for caregiving, but self-perception of skill readiness level diminished over time. Psychological well being scored more poorly when compared to social, spiritual, and physical well being. Initially, quality of life was rated as moderate and then worsen over time.
Grunfeld, E. et al. (2004) <i>Canadian Medical Association Journal.</i>	Quantitative	Canada	During the start of palliative care, more family caregivers were found to have anxiety than breast cancer patients. Caregivers anxiety and depression levels increased from start of palliative care to start of terminal care for the patient. The cost of prescription drugs was the primary reason for financial burden. The financial burden was higher for those without additional health insurance coverage compared to those with additional health insurance coverage.
Schubart, J. R., Kinzie, M. B., & Farace, E. (2008) <i>Neuro-Oncology.</i>	Qualitative	U.S.	Family caregivers felt unprepared to provide care for the brain cancer patient. They reported lack of coordination with healthcare team and navigation of healthcare system. Financial hardships were related to employment issues, insufficient or loss of income, and additional medical expenses. Some caregivers had limited understanding about health insurance coverage, financial assistance benefits, and the neurocognitive changes experienced by the patient.
Siegel K, Raveis VH, Houts P, Mor V. (1991) <i>Cancer.</i>	Quantitative	U.S.	Patients were more likely to report unmet need(s) if: their caregiver was not a spouse or relative, their caregiver experienced high caregiving burden, or they received care under government health insurance due to low income.
Thomas, C. et al. (2002). <i>Social Science & Medicine.</i>	Mix methods	U.K.	Female carers had greater need for caregiving help such as nutrition advice. Carers ages 50 years or younger were likely to report need for childcare assistance. Carers with their own chronic health problems had a greater demand for assistance with financial issues, fatigue, distress, and transport. A considerable portion of carers considered help with fatigue or distress as "important or very important", and also reported transportation challenges and needs.

Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Ussher, J. M. et al. (2013) <i>Qualitative Health Research</i> .	Qualitative	Australia	Cancer patients perceived that friends and family had insufficient knowledge or misunderstanding about cancer nor didn't understand how to empathised with them. They felt the need to "protect" friends and family from dealing with their cancer issues by not discussing of feelings or concerns.
van Ryn, M. et al. (2011) <i>Psycho-Oncology</i> .	Quantitative	U.S.	The majority of caregivers dealt with multiple demands or stressors as part of caring for the patient: caring for another person, employment, and dealing with "poor to fair" health issues. 28% of caregivers who were employed, rated cancer care and work responsibilities as "extremely difficult" to balance. Caregivers had less confidence for supporting the patient's emotional needs.
Frambes, D. et al. (2017) <i>Western Journal of Nursing Research</i> .	Literature Review - Quantitative	Europe, U.S., Australia	Main types of informal caregiving responsibilities: communicating with the patient, family, and healthcare professionals; making decisions and solving problems; managing cancer and co-existing health conditions; accessing resources in the community. Most studies on informal caregiving measure psychological and emotional outcomes in relation to caregivers' well being.
Ge, L., & Mordiffi, S. Z. (2017) <i>Cancer Nursing</i> .	Literature Review - Quantitative	Europe, U.K., U.S., Canada	The social demographics that is more frequently correlated with higher caregiving burden: being employed, lower education, single marital status, younger age, non-White, male gender. Well-being characteristics that is more frequently correlated with higher caregiving burden: low scores with quality of life and self-efficacy, having anxiety or migraine.
Hunt, C. K. (2003) <i>Journal of Nursing Scholarship</i> .	Literature Review - Qualitative, Quantitative	U.S.	Author distinguishes the definitions of objective burden versus subjective burden that are discussed in caregiving research literature. Objective burdens can be characterised and defined through observation. Subjective burdens are the perceptions, assessment, and feelings associated with caregiving experiences. Research findings suggest that caregivers who provide an account of more subjective burdens have high risk for psychological issues.
Kitrungrote e.g. (2006) <i>Oncology Nursing Forum</i> .	Literature Review - Quantitative	U.S., Canada	The literature review identified various key types of dimensions that researcher assessed regarding the quality of life of family caregivers: general quality of life; spiritual, psychological, and physical aspects; social relationships; cancer patient's health and treatment factors; social and individual characteristics of caregivers.
Kramer, B. J. (1997) <i>The Gerontologist</i> .	Literature Review - Qualitative, Quantitative	U.S.	The term and concept of caregiver and caregiving burden in research was explicitly examined across 29 studies. The author highlights the importance of evaluating the characteristics of the caregiving recipient and the caregiver within the circumstances of care provision.
Northfield, S. (2010) <i>Clinical Journal of Oncology Nursing</i> .	Literature Review - Qualitative, Quantitative	Australia, U.K., U.S., Canada	A review on research literature reveal various influences on supportive care systems: gender of the caregiver, culture, dynamics within the family, access to external professional support, and social support network.

Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Pitceathly et al. (2003) <i>European Journal of Cancer</i> .	Literature Review - Qualitative, Quantitative	U.K., U.S.	A review of the literature identified characteristics of carers that are likely to face greater psychological burden with caregiving: female gender, younger age, use of avoidance as coping style, having existing psychological issues, and having limited or lack of social support.
Stenberg et al. (2010) <i>Psycho-Oncology</i> .	Literature Review - Qualitative, Quantitative	Europe, U.K., U.S. Canada, Australia, Asia, Africa	Over 200 kinds of burdens and problems relating to caregivers and patients were identified. Specific problems and burdens were recognised by key categories: social problems; information and communication needs; emotional problems and reactions; impact on daily life and related responsibilities; physical health problems.
Bastawrous, M. (2013) <i>International Journal of Nursing Studies</i> .	Commentary	Canada, U.S., Europe	Various interpretations of caregiver burden in research has made it challenging to apply towards evaluation and interventions. Studies assessing caregiver burden lack a theoretical framework. Quantitative measurements insufficiently characterise varying dimensions of caregiver burden.
Glejchen, M. (2004) <i>The Journal of Supportive Oncology</i> .	Commentary	U.S.	Major types of unmet needs identified in the research literature: psychosocial support, financial assistance, transportation, medical information, adjusting to the patient's illness, care support in the home. Some studies have shown that Hispanics and African Americans were less inclined to use supportive resources/services and more likely to reduce work hours to care for the patient.
Thomas et al. (2002). <i>European Journal of Cancer Care</i> .	Commentary	U.K.	Authors describe "emotional labour" as a distinctive area in psycho-oncology research that assesses the carers' emotional work and efforts of providing care for the patient. Psycho-oncology research studies have demonstrated that carers have high levels of depression and anxiety associated with caregiving.

Area of Focus: Asian cancer carer experience and burden			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Balneaves, L. G. et al. (2007) <i>Family & Community Health</i> .	Qualitative	Canada - Punjabi	Family members who were new immigrants, were especially unfamiliar with the healthcare system and information communicated by health professionals. They lacked awareness of resources and support. The patient's cancer diagnosis was kept private due to fear of stigma, misjudgement, and isolation. The families approached supportive care with a positive attitude.
Lee, J. et al. (2011) <i>Journal of Transcultural Nursing</i> .	Qualitative	Canada - Chinese	Family members provided the patient with ongoing physical, emotional, and daily caregiving support. They felt high levels of distress and helplessness towards caring for the patient, due to multiple demands and insufficient knowledge around caregiving. Family members were concerned about social stigma associated with cancer.
Lui, C. W. et al. (2009) <i>Social Work in Health Care</i> .	Qualitative	Australia - Chinese	Women were usually the primary carers and family carers described caring for the patient as "natural". Carers who were not English proficient had more difficulties with the caregiving role. Seeking help from resources/services was a last resort.
Shieh, S. C. et al. (2012) <i>Journal of Nursing Scholarship</i> .	Quantitative	Taiwan	Caregivers with higher levels of caregiving burden, were those with a chronic health condition, had lower education, did not take breaks from caregiving, or was the only caregiver for the patient. Social support was a distinct predictor of caregiving burden, in which lower burden in caregiving was associated with availability of social support.
Li, Q. P., Mak, Y. W., & Loke, A. Y. (2013) <i>International Nursing Review</i> .	Literature Review - Qualitative, Quantitative	Europe, U.K. U.S., China, Taiwan, Israel	Female spouses viewed their caregiving experiences as more negative, which was impacted by having reduced psychological and physical well being, poorer health in relation to quality of life, less satisfaction with life, and diminished satisfaction with their marital relationship.

Area of Focus: General family cancer and psychosocial issues			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Yates, P. (1999) <i>Cancer Nursing</i> .	Qualitative	Australia	Family members reported disruptive and emotional strain levels related to patient caregiving. Tiredness and lack of sleep were the most commonly experienced disruptions and the most challenging to deal with. Other strains included the constant need to be available for care, physical hardships, uncertainty of daily routine, and urgency required in dealing with change.
Mellon, S. et al. (2006) <i>Cancer Nursing</i> .	Quantitative	U.S. - White, African American	Cancer survivors reported higher quality of life, higher social support, having less fear of cancer recurrence than their family caregivers. The amount of stressors were the same for both groups. Caregivers who were employed or a homemaker had lower quality of life than the retired caregivers. Survivor and caregiver quality of life were positively correlated.
Baider, L. E. et al. (1996) <i>Cancer and the family</i> .	Expert-based Qualitative, Quantitative	Europe, U.K., U.S.	The book examines the varying dimensions of how a cancer diagnosis impacts family life and relationships. These dimensions primarily relate to psychological and social aspects of dealing with cancer in the family throughout different stages of the illness .
Krisjansson, L. J., & Ashcroft, T. (1994) <i>Cancer Nursing</i> .	Literature review - Qualitative, Quantitative	General	The major themes found in existing research regarding family experiences with cancer: how the family life cycle is affected, communication and transitions in the family, the family behaviours in response to cancer, and the behaviours of healthcare professionals.
Lewis, F.M. (1986) <i>Patient education and counseling</i> .	Literature review - Qualitative, Quantitative	U.S.	The author identified and reviewed 11 main issues of study findings on how cancer affects the family. The majority of research on family caregivers were primarily focused on the spousal experiences and challenges of caregiving.
Mukwato, K. P. et al. (2010) <i>Medical Journal of Zambia</i> .	Literature review - Qualitative	U.K, U.S., Europe, Middle East	The focus on resolving problems and emotions were the coping approaches found in studies evaluating stress in breast cancer patients and their family caregivers. Caregivers reported lack of information and emotional support to help them cope.
Given, B. A. et al. (2001) <i>CA: A cancer journal for clinicians</i> .	Commentary	U.S.	Characteristics of the patient and caregiver as well as cancer status are recognised as factors affecting the caregiving situation. The main types of demands in caregiving are: direct and indirect care, comfort and symptom management, and information needs.
Lewis, F. M. (2006) <i>The American Journal of Nursing</i> .	Commentary	U.S.	Challenges of dealing with cancer survivorship in the family; the psychological impact of cancer on family members; intersecting understanding and responsiveness within the family; dealing with issues that lead to or call attention to family tensions; challenges with sustaining fundamental roles/responsibilities when caring for a long-term cancer patient.
Rolland, J.S. (2005) <i>Cancer</i> .	Commentary	U.S.	As an approach to address quality of life issues in families dealing with cancer, the Family System illness model is discussed as a framework for recognising and understanding the various psychosocial issues underlining the challenges that families face.

Area of Focus: General caregiving			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Lahaie, C. et al (2013) <i>Research on Aging</i> .	Quantitative	U.S.	Females, Hispanics, and immigrant caregivers were more likely to lack the support from their employment, which includes less access to paid leave and flexibility with schedule. Caregiving responsibilities were more likely to impede with the quality of life of females, first generation Americans, and lower educated caregivers.
Piercy, K. W. et al. (2001) <i>Family Relations</i> .	Qualitative	U.S.	Various factors affect the formation of the caregiving role in the family: family norms, rules, and expectations; religious beliefs and practices; family dynamics of the caregiving role transition and fulfillment. A case study of one family revealed that intergenerational challenges have an impact on the way family members transition and adopt the caregiving role.
Pinquart, M. et al. (2005) <i>The Gerontologist</i> .	Literature Review - Qualitative, Quantitative	U.S.	The Asian, Hispanic and African American caregivers were younger, had lower socio-economic status, and more likely to be an informal non-spousal caregiver. They had stronger beliefs about family obligation towards caring for a family member. Hispanic and Asian caregivers reported more depression than White caregivers. Asian and African-American caregivers had a greater number of care tasks than White caregivers.
Young, A.L. et al. (2016) <i>Liver International</i> .	Literature Review - Quantitative	U.S., Spain, Israel, Taiwan, Thailand	Caregivers of patients experienced more caregiving strains after the liver transplant procedure. The diminished quality of life in relation to caregivers' health may contribute to the exacerbated patient outcomes from the liver transplant. Caregivers who continually dealt with caregiving burdens after the liver transplant had lower health related quality of life.
Area of Focus: Asian general caregiving			
Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Han, H. R. et al. (2008) <i>Journal of Advanced Nursing</i> .	Qualitative	U.S. - Korean	Family caregivers faced competing priorities with their obligations to care for parents versus their personal and other family responsibilities. Daughters were more likely to believe in commitment to filial piety. Caregivers felt they lacked the ability to control circumstances as well as had insufficient knowledge and resources.
Wong, S. T. et al. (2006) <i>The Journals of Gerontology Series B: Psychological Sciences and Social Sciences</i> .	Qualitative	U.S. - Chinese, Korean	Elder immigrant parents viewed themselves as a burden on their adult children and struggled with establishing their own independence. They believed their position in the family is less prominent and the approach to elder care is different due to changes in cultural norms and environment.

Author(s), Year, Publication	Research Method/ Writing	Region/Population	Relevant Findings
Youn, G., Knight, B. G., Jeong, H. S., & Benton, D. (1999) <i>Psychology and Aging</i> .	Quantitative	Korea U.S. - Korean American, White	Korean caregivers had the highest level of familism, which was followed by Korean Americans and then Whites. The same pattern occurred with anxiety levels. Koreans and Korean Americans had the same levels of caregiving burden, and were significantly higher than Whites. Koreans scored higher for depression and lack of well being. Korean women had highest depression levels when compared with female sub-groups.
Miyawaki, C. E. (2015) <i>SAGE Open</i> .	Literature Review - Qualitative, Quantitative	Canada and U.S. - Chinese, Filipino, Japanese, Korean, Vietnamese	Chinese Canadian, Chinese American and Korean American caregivers had strong beliefs in filial piety/obligation. Filipino American and Japanese American caregivers reported high levels of stress associated with caregiving. Except for Japanese Canadian and Japanese American caregivers, all groups faced immigrant challenges with cultural assimilation in Canada and the U.S.

Area of Focus: Filial piety related to culture, race-ethnicity, and/or Asian group			
Author(s), Year, Publication	Methodology/ Publication Type	Region/ Population	Relevant Findings
Baldwin, P. K. et al. (2017) <i>Qualitative Research in Medicine & Healthcare</i> .	Qualitative	U.S. - Indian	As part of his values towards filial obligations, a son fulfills the role as a primary caregiver for his father. Thus he left employment to fulfil a caregiving role, whilst the parents rely on him and his wife to provide financial support. His mother's caregiving role is limited due to limited English proficiency and health knowledge, but she makes final decisions.
Diwan, S. et al. (2011) <i>Journal of Cross-cultural Gerontology</i> .	Quantitative	U.S. - Indian	Filial obligation scores increased with less preference to live in a retirement community and with greater preference to live closer to adult children. The most preferred living arrangement was to live closer to adult children and the least preferred was cohabiting with their children. Expectation of filial obligation was not correlated with any number of years living in the U.S.
Dong, X. et al. (2014) <i>Journal of Aging and Health</i> .	Quantitative	U.S. - Chinese	Expectations for filial piety was highest for those living in the U.S. for 21-30 years and lowest for those living in the U.S. for more than 31 years. 58.0% of the sample preferred the filial obligation of care.
Funk, L. M. et al. (2013) <i>Research on Aging</i> .	Quantitative	Canada - Caucasian, Chinese Hong Kong - Chinese	Greater filial expectancy was correlated with poor self-rated health. Hong Kong Chinese participants were likely to self-rate health as poor in comparison to Chinese Canadians.

Author(s), Year, Publication	Methodology/ Publication Type	Region/ Population	Relevant Findings
Gupta, R. et al. (2000) <i>Journal of Ethnic and Cultural Diversity in Social Work</i> .	Quantitative	U.S. - Indian, Pakistani	Family caregivers with strong commitment to filial piety values were less likely to report high levels of elder caregiving burden. The number of years living in the U.S. did not have a correlation with the degree of caregiving burden.
Gupta, R. et al. (2005) <i>Journal of Applied Social Science</i> .	Quantitative	U.S. - Indian, Pakistani	Family members with greater conflict and overload with their elder caregiving role (i.e. role demands), had more caregiving burden. Caregivers with a large network of support and strong belief in filial piety had fewer role demands and less caregiving burden.
Lan, P. C. (2002) <i>Journal of Family Issues</i> .	Qualitative	U.S. - Chinese, Taiwanese	Immigrant elder parents deal with role status change because they have less ability to communicate, insufficient income, and limited access to social resources. Children honour filial piety regardless of circumstances, but parents are displeased with how children fulfil obligations.
Parveen, S. et al. (2009) <i>Journal of Health Psychology</i> .	Quantitative	U.K. - South Asian, Caucasian	Age was the most significant predictor of familism, followed by gender, ethnicity, and the diagnosed illness (cancer or dementia) of care recipient. South Asians had higher levels of familism than Caucasian.
Santoro, M. S. et al. (2016) <i>Research on Aging</i> .	Quantitative	U.S. - White, Hispanic, Black, Asian/Pacific Islander	White and Hispanic participants' perception of hiring a Health Care Advocate (HCA) was influenced by their views of an elderly parent's medical condition and need for external assistance. Asian/Pacific Islander participants preferred HCA regardless of medical condition severity or views about external assistance. Blacks did not view HCA as a resource.
Schwartz, S.J. et al. (2010) <i>Cultural Diversity and Ethnic Minority Psychology</i> .	Quantitative	U.S.	An individual's cultural or ethnic background may be related to a higher degree of collectivism and regards towards family obligations. Values of familism and filial piety seem to be upheld more firmly by minority groups than by Whites.
Sun, K. C. (2012) <i>Journal of Family Issues</i> .	Qualitative	U.S., Taiwan - Chinese	Parents opt for a transnational relationship with their American family because living in Taiwan is less lonely, they don't want to be a burden, and feel lack of an identity in the U.S. American family members perceived that it is challenging to accommodate parents who do not speak English, have limited social network in the U.S., and are unfamiliar with American ways of life.
Chou, R. J. A. (2010) <i>The Gerontologist</i> .	Commentary	China	In China, informal support for elders is provided by the adult children, in which filial piety is a core value in the Chinese family. Formal support is from the government's inequitable public welfare program and the diminishing public pension system. The Chinese government implemented a 'voluntary' contract intervention to promote obligatory fulfillment of informal support through the family.
Nichols, R. (2013) <i>Journal of Cognition and Culture</i> .	Commentary	General	Chinese filial piety is suggested to be a cultural value that originates from Confucian philosophy. It conditions family members to practice moral obedience towards parents particularly fathers. It is designed to provide parents with the ability to further allocate resources from their children.

Area of Focus: Family cancer with culture and/or race-ethnicity issues			
Author(s), Year, Publication	Methodology/ Publication Type	Region/ Population	Relevant Findings
Gotay, C. C. (1996) In Baider, et al. (eds.). <i>Cancer and the Family</i> .	Expert-based Qualitative, Quantitative	General	Cultural meanings, beliefs, dynamics, and differences influence the family experiences and outcomes with cancer. Cultural norms have an effect on the family attitudes, medical communication preferences, understanding of disease, conveyance of needs/pain, and ways of coping with cancer.
Marshall, C. A. et al. (2011) <i>Families, Systems, & Health</i> .	Commentary	U.S.	Cultural is recognised as a key element in shaping how people express the need for and attain support. Population disparities in cancer appear to have an impact on caregiving experiences and types of support available.
Area of Focus: Financial burden			
Author(s), Year, Publication	Methodology/ Publication Type	Region/ Population	Relevant Findings
Arozullah, A.M. et al. (2004) <i>Journal of Supportive Oncology</i> .	Quantitative	U.S.	Breast cancer patients dealt with a financial burden of \$1,455 each month for out-of-pocket expenditures and income losses. Most common out-of-pocket expenditure was for medications (80%), then followed by transit (78%), and clinic visit fee (66%). Indirect costs accounted for nearly half of the monthly financial burden. 45% percent of patients lost employment-related income.
Yun, Y. H. et al. (2004) <i>Oncology</i> .	Quantitative	Korea	Losses in family savings income and unemployment were major contributors to financial burdens. The patient's delayed diagnosis, lower cancer performance status, and high medical expenditures were key contributors towards the loss of family savings. The loss of family savings was associated with poorer quality of life for family caregivers.
Gardiner, C. et al.(2014) <i>Palliative Medicine</i> .	Literature review - Qualitative, Quantitative	U.K., Australia, Sweden, Canada, U.S., Hong Kong	Three major sources of financial burdens correlated with caregiving: employment income losses, out-of-pocket expenditures paid by the caregivers, and cost of carer's time. Financial burden became a factor towards emotional challenges, coping problems, strains with caregiving, and family conflict. Caring for patients with advanced stage cancer and high level of caregiving needs increased the financial burden/strain.
Gordon, L.G. (2017) <i>The Patient-Patient-Centered Outcomes Research</i> .	Literature review - Qualitative, Quantitative	Global	Female gender, younger age, and low-income status are the most frequently reported social determinants related to financial burden (i.e. financial toxicity). Patients dealing with financial toxicity had poorer quality of life. Financial toxicity was found to be a factor in non-adherence to cancer treatment criteria, experiencing more delays in healthcare; opting to give up care; and losing healthcare insurance.

Appendix D | Semi-structured interview scripts

Characterisation of the interview respondent (Family Carer)

Sociodemographics

1. Can you please tell me your age?
2. What zip code do you live in?
3. I'm going to show you a chart of the different household income groups. This represents the different groups of household income per year. Can you tell me which household income group you belong to?
 - How many people contribute to this household income?
 - How many people live in your home?
4. I'm going to show you another chart of different education levels. What is highest level of education you completed?
5. Are you currently employed, unemployed or retired?
 - If employed: How many years have you worked?
 - If unemployed: How many years have you been unemployed? Did you ever work? (If yes) How many years?
 - If retired: How many years did you work before you retired?
6. What is your ethnicity or race? You can provide more than one if you need to.
7. Which languages do you mostly speak?
 - Are you able to read well in any of those languages? Which ones?

Relation with Cancer Patient

1. Can you explain to me how you are related to your family member who is the cancer patient involved in this study?

Factors related to cancer care burdens (Family Carer)

Caregiving Background

1. How many people do you think help your family member with her/his cancer care?
2. Are there any family members who help? Who are those people in the family that help?
3. Do you have any friends or neighbours that help too?

Study Objective 1: Define what cancer care is regarded as from the viewpoint of cancer patients and their carers.

1. Can you share with me your opinions about what you think cancer care is?

Probe:

- Where do you think these opinions come from?
- Do you think your opinions are different from your family's or (cancer family member's) opinion about cancer care?

Study Objective 2: Illustrate the cancer care burdens experienced within the family, based on the expectations, choices and barriers recognised by the study participants.

1. What were your expectations about your (cancer family member's) cancer care?

- Probe: What were the reasons why you expected these things?

2. What kind of choices did you and/or your family make for (cancer family member's) cancer care?

- Probe: What were the reasons why you made these choices?

3. Were there any issues that prevented you and/or your family from making certain choices for (cancer family member's) cancer care?

- Probe: What were these issues and the reasons for why it was happening?

4. What would say were the challenges or difficulties you and your family experienced in dealing with (cancer family member's) cancer care?

- Probe: Can you explain to me why these were challenges or difficulties?

Characterisation of the interview respondent (Cancer diagnosed)

Sociodemographics

1. Can you please tell me your age?

2. What zip code do you live in?

3. I'm going to show you a chart of the different household income groups. This represents the different groups of household income per year. Can you tell me which household income group you belong to?

- How many people contribute to this household income?
- How many people live in your home?

4. I'm going to show you another chart of different education levels. What is highest level of education you completed?

5. Are you currently employed, unemployed or retired?

- If employed: How many years have you worked?
- If unemployed: How many years have you been unemployed? Did you ever work? (If yes) How many years?
- If retired: How many years did you work before you retired?

6. What is your ethnicity or race? You can provide more than one if you need to.
7. Which languages do you mostly speak?
 - Are you able to read well in any of those languages? Which ones?
8. What year did you immigrate to the United States?
 - What was the main reason why you immigrated to the United States?

Health Information (Cancer diagnosed)

Next, I'm going to ask about health information related to your cancer diagnosis and cancer care.

1. Were you diagnosed with cancer only one time?
 2. Did your cancer diagnosis occur 3 years ago or less?
 3. Did your cancer diagnosis occur at the age of 50 years old or older?
 4. What is your current status with the cancer diagnosis: are you currently ill with cancer or are you in remission?
5. I'm going to show you a list of healthcare insurances. Can you please tell me which type of health insurance did you have for your cancer treatment?
- Did you have health insurance before you had cancer?
 - Did you have health insurance at the time you were diagnosed with cancer?
 - What was the reason why you did not have health insurance coverage?

Factors related to cancer burden (Cancer diagnosed)

Caregiving Background

1. How many people help you with your cancer care?
2. Are there any family members who help? Who are those people in the family?
3. Do you have any friends or neighbours that help too?

Study Objective 1: Define what cancer care is regarded as from the viewpoint of cancer patients and their carers.

1. Can you share with me your opinions about what you think cancer care is?
Probe
 - Where do you think these opinions come from?
 - Do you think your opinions are different from your family's opinion about cancer care?

Study Objective 2: Illustrate the cancer care burdens experienced within the family, based on the expectations, choices and barriers recognised by the study participants.

1. What were your expectations about your cancer care?
 - Probe: What were the reasons why you expected these things?
2. What kind of choices did you and/or your family make for your cancer care?
 - Probe: What were the reasons why you made these choices?

3. Were there any issues that prevented you and/or your family from making certain choices for your cancer care?

- Probe: What were these issues and the reasons for why it was happening?

4. What would say were the challenges or difficulties you and your family experienced in dealing with your cancer care?

- Probe: Can you explain to me why these were challenges or difficulties?

Appendix E | Forms for the informed consent process

The informed consent form used for all study participants.

STANFORD UNIVERSITY Research Consent Form
Protocol Director: Kim Rhoads, MD
Protocol Title: Cancer Care Experiences in Chinese, Indian and Filipino American Immigrant Families

IRB Use Only
Approval Date: February 19, 2015
Expiration Date: January 31, 2016

Researcher Name: Rachel Mesia
Telephone: 650.723.7119
Email: rmesia@stanford.edu
Mailing Address: 1070 Arastradero Rd., MC #, Suite 300, Palo Alto, CA 94304

Information about the study: You are invited to participate in this research study about cancer care, because you are either a patient who was diagnosed with cancer or a family caregiver of the patient. The researcher would like to learn about the challenges with cancer care among Chinese, Indian and Filipino immigrant families living in the United States.

What will happen in this study: With your permission, the researcher would like to collect information about your background, opinions and family experiences related to cancer care. The researcher will ask you questions about:

- What cancer care means to you.
- Caregiving in your family.
- The challenges of cancer care experienced by you and your family.
- The factors related to these family challenges in cancer care.
- Information about your health and background:
 - ➔ If you were diagnosed with cancer, the researcher will ask about your sociodemographic background, year of immigration to the U.S., health information related to your cancer diagnosis and cancer care.
 - ➔ If you are a family caregiver, the researcher will ask about your sociodemographic background and relation to the cancer patient.

The researcher would like to collect this information about you during an interview. The interview will be conducted separately and privately from your family member. This study does not involve any treatment.

If you would like to be interviewed in another language (Mandarin, Cantonese, Hindi, Punjabi, Tagalog or Ilocano), an interpreter will help the researcher with the interview. The interpreter will follow the rules of protecting your confidentiality and privacy.

The interview will be audiotaped with your permission. Your name will not be recorded in the audio recording. The audio recording will be transcribed by a professional service. This professional service will have temporary access to the audio recording. The transcription will help the researcher review and learn from the discussion.

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The information collected and audio recording will be stored securely. The audio recording will only be accessed by the researcher and the transcription service. The audio file will be erased after the researcher receives her academic degree.

Only the researcher in this study will have access to information related to your personal identity. Your identity will not be disclosed. The results of this research study will be published and presented for the researcher's academic thesis. Findings may be presented at scientific, educational and professional meetings. The researcher may also published the findings in scientific journals and writings about health topics. Your name will not be used in any writings or presentations.

The risks and benefits of the study: The risks associated with this study are that it may cause emotional stress. The researcher will provide you a list of places that can help you with emotional stress. You will not receive any direct benefit from participation. We cannot and do not guarantee or promise that you will receive any benefits from this study.

The time involvement for the study: Your participation in the study will take approximately 1 hour.

Payment for participating in the study: After you complete the interview, you will receive a gift valued at approximately \$10.00.

Your rights as a participant of the study: If you have read this form and have decided to participate in this project, please understand your participation is voluntary. You have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

The results of this research study will be published and presented for the researcher's academic thesis. Findings may be presented at scientific and professional meetings. Findings may also published in scientific journals and health articles. Your identity will not be disclosed. You have the right to refuse to answer particular questions.

There are some limits to confidentiality in the study: If you say something that makes the researcher think that you or someone else are at risk of being harmed, she will have to break confidentiality and speak to a professional counselor. If this happens, the researcher will tell you about it.

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Contact information for the study:

Questions, Concerns, or Complaints

If you have any questions, concerns or complaints about this research study, its procedures, risks and benefits, you can address them at anytime to the Protocol Director, Dr. Kim Rhoads. You may contact her at 650.721.3094 or kim.rhoads@stanford.edu

You should contact Dr. Rhoads at any time you feel that you have been hurt from being a part of this study.

Independent Contact

- If you are not satisfied with how this study is being conducted or
- If you have any concerns, complaints, or general questions about the research or your rights as a participant;

Please contact the Stanford Institutional Review Board (IRB) to speak to someone independent of the research team at 650.723.5244 or toll free at 1.866.680.2906.

You can also write to the Stanford IRB, Stanford University, 3000 El Camino Real, Five Palo Alto Square, 4th Floor, Palo Alto, CA 94306.

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Please initial the statements you agree to:

	I have read the study information and fully understand what is expected of me.
	I had the opportunity to ask any questions and to have my questions answered.
	I understand that my interview will be audio recorded and made into an anonymous written transcript.
	I understand that the researcher will keep the audio recording until she is awarded her academic degree.
	I understand that my participation in this study is voluntary. I understand my right to leave this study at any time without giving any reason and without losing any benefits which I may be entitled to.
	I understand that when my data becomes anonymous and analyzed, it may not be possible to remove it from the researcher's writing. Every attempt will be made to remove my data, up to the point of the publication.
	I understand that the information from my interview will be made anonymous, grouped with other study participants' responses, and will be published.
	I consent to use the information and quotes from my interview for written materials, presentations, teaching, and scientific or professional meetings.
	I understand that any information I give will be strictly confidential and anonymous, unless the researcher believes there is a risk of harm to myself or others. In this case, the researcher may need to share this information with a professional counselor.
	I consent for the researcher to keep written transcriptions of my interview for 10 years, after she is awarded her academic degree.
	I consent to having an interpreter present in this interview.

Please sign below if you consent to take part in the above study. An extra copy of this signed and dated consent form will be given to you.

Signature of Participant

Date

Print First Name

Print Last Initial

The HIPAA Authorization Form accompanied the informed consent form when consenting a cancer-diagnosed patient. This is a Stanford University IRB requirement when conducting interviews with a patient sample population and/or the data collected is health or medical information (<http://researchcompliance.stanford.edu/hs/index.html>).

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Authorization To Use Your Health Information For Research Purposes

Because information about you and your health is personal and private, it generally cannot be used in this research study without your written authorization. If you sign this form, it will provide that authorization. The form is intended to inform you about how your health information will be used or disclosed in the study. Your information will only be used in accordance with this authorization form and the informed consent form and as required or allowed by law. Please read it carefully before signing it.

What is the purpose of this research study and how will my health information be utilized in the study?

The purpose of the study is to learn about the challenges with cancer care among Chinese, Indian and Filipino immigrant families living in the United States. The researcher will ask about your background, opinions and family experiences related to your cancer care. Your health information will be used to explain the types of cancer patients that were interviewed for this study. Your personal identity will not be linked with this health information.

This information will be reported in the researcher's academic thesis publication and presentation. Findings may be presented at scientific, educational and professional meetings. The researcher may also publish the findings in scientific journals and writings about health topics.

Do I have to sign this authorization form?

You do not have to sign this authorization form. But if you do not, you will not be able to participate in this research study.

If I sign, can I revoke it or withdraw from the research later?

If you decide to participate, you are free to withdraw your authorization regarding the use and disclosure of your health information (and to discontinue any other participation in the study) at any time.

After any revocation, your health information will no longer be used or disclosed in the study, except to the extent that the law allows us to continue using your information (e.g., necessary to maintain integrity of research).

STANFORD UNIVERSITY Research Consent Form
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Protocol Title: Cancer Care Experiences in Chinese, Indian and Filipino American Immigrant Families

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Approval Date: February 19, 2015
Expiration Date: January 31, 2016

If you wish to revoke your authorization for the research use or disclosure of your health information in this study, you must write to: Rachel Mesia
Mailing Address: 1070 Arastradero Rd., MC #, Suite 300, Palo Alto, CA 94304
Email: rmesia@stanford.edu

What Personal Information Will Be Obtained, Used or Disclosed?

Your health information related to this study, may be used or disclosed in connection with this research study. The researcher will ask:

- If you were diagnosed with cancer only one time.
- If you were diagnosed during the age of 50 years old or older.
- If you were diagnosed within the last 3 years or less.
- Your current status with cancer.
- The type of health insurance you had for your cancer care.
- The status of your health insurance coverage.
- Your first name and initial of your last name.
- Your phone number, email, zip code, and age.
- The year you immigrated to the U.S.

Who May Use or Disclose the Information?

The following parties are authorized to use and/or disclose your health information in connection with this research study:

- The Protocol Director: Dr. Kim Rhoads, MD
- The Researcher: Rachel Mesia
- The Stanford University Administrative Panel on Human Subjects in Medical Research and any other unit of Stanford University as necessary

Who May Receive or Use the Information?

The parties listed in the preceding paragraph may disclose your health information to the following persons and organizations for their use in connection with this research study:

- The Office for Human Research Protections in the U.S. Department of Health and Human Services

When will my authorization expire?

Your authorization for the use and/or disclosure of your health information will end on December 31, 2030 or when the research project ends, whichever is earlier.

Signature of Participant

Date

Appendix F | List of conceptual codes used for the data analysis of transcripts

Accountability to employer	Emotional challenge - family unable to cope
Belief - cultural/cultural practices	Emotion - cried
Belief about cancer	Emotion - pause
Belief - generational, phase	Emotion - distress voice
Care - complexity	Emotion - irritated voice
Cancer care meaning - medical care and tx	Emotion - frustration face
Cancer care meaning - accessible support	Employment needed
Cancer care meaning - physical care	Expectations for family
Cancer care meaning - emotional care	Expectations for healthcare
Cancer care meaning - spiritual	Expectations for medical team
Cancer care meaning - knowledge	Housing status - unstable
Cancer status	Fear - general
Cancer disclosure - negative impact	Fear - cancer status
Change in family role	Fear - cancer outcome
Change in health outcomes	Fear - reoccurrence
Concerns/worries about children	Filial piety
Communication in family	Financial stress
Communication in healthcare	Financial hardship
Competing priorities/problems	Frustration
Complexity of care	Hardship - build American life
Concurrent health conditions	Health communication - lack of patient centred
Disclosure of cancer - to friends	Health communication - complex
Disclosure of cancer - to family	Health communication - medical team to family
Disclose of treatment details - to family	Healthcare finance challenge
Distance home to hospital	Healthcare insurance - uninsured
Distance from home to work	Healthcare insurance - underinsured
Distance from family	Healthcare insurance - Medi-Cal
Decision-making burden	Healthcare insurance - Medi-Cal problem
Decision-making difficult tx choices	Health insurance - wide range options
Decision-making only Western tx option	Healthcare oversight of patient outcome
Delay in healthcare	Healthcare - public hospital
Delay in diagnosis	Healthcare - private hospital
Denial of cancer by carer	Housing concern
Dependent on cancer patient	Knowledge of other healthcare system - outside US
Dependent on child	Income - adequate during employment
Disagreement of medical advice	Income - inadequate during unemployment
Difficulty understanding cancer	
Difficulty understanding medical care	
Difficulty navigating medical care	
Emotional burden	

Income - low	Privacy
Income - low-moderate	Psychological issues
Income - moderate	Question medical approach
Income - high	Question medical integrity
Language barrier	Rebuilding normalcy
Lifestyle change for patient	Reliance on family support for daily clinical visits
Lifestyle change for carer	Responsibility of family
Limited income	Searching for information
Limited knowledge	Silos - healthcare
Limited transportation	Trust in medical team/physician
Limitations of carer - language	Tx adverse effects
Limitations of carer - knowledge	Tx choices
Lost of health insurance	Tx waiting time
Lone decision maker	Types of support
Main breadwinner	Uncertainty of cancer status
Main caregiver	Uncertainty of cancer outcomes
Maintaining normalcy	Unemployment
Making decisions - carer	Unspoken truths
Marking decisions - patient	Value - cultural
Marital status - single, divorced	Value - generational
Placing burden on carer	Waiting for medical news
Placing burden on other family	Waiting for appointment
Patriarchal medical approach	Working during tx
Preparation for cancer outcome	
Priorities on hold	

Appendix G | Table summaries of social and economic characteristics of the sample population

Table 5.1 Social and economic status of the cancer-diagnosed sample population by ethnicity (N = 9)

Gender	Chinese (N = 5)	Filipino (N = 3)	Indian (N = 1)	Highest education level completed	Chinese (N = 5)	Filipino (N = 3)	Indian (N = 1)
Male	1	-	1	Intermediate (up to 8th yr.)	1	-	-
Female	4	3	-	High school diploma	2	-	-
Age range				Associate degree	1	-	-
50 - 59	3	1	1	Bachelor's degree	-	2	-
60 - 69	2	1	-	Master's degree	1	1	1
70 - 79	-	1	-	Annual household income			
Health insurance for cancer treatment				\$20,592 or less		1	-
Current/former employer or	1	1	1	\$20,593 to \$39,735	2		-
Medi-Cal	3	1	-	\$39,736 to \$64,553	2	2	-
Employer or Union with Medicare	-	1	-	\$64,554 to \$104,086	1	-	-
Medi-Cal with Medicare	1	-	-	\$104,087 to \$191,149	-	-	-
Age range of diagnosis				\$191,150 or more	-	-	1
50 - 64	4	2	1	Language proficiency			
65 and older	1	1	-	Non/limited English	4	-	-
				Bilingual, proficient English	1	3	1

Table 5.2 Social and economic status of family carer sample population by ethnicity (N = 9)

Gender	Chinese (N = 6)	Filipino (N = 2)	Indian (N = 1)	Highest education level completed	Chinese (N = 6)	Filipino (N = 2)	Indian (N = 1)
Male	2	-	-	High school (up to 10th yr.)	1	-	-
Female	4	2	1	Associate degree	1	-	-
Age range				Bachelor's degree	4	2	-
25 - 29	2	-	-	Master's degree	-	-	1
30 - 39	-	1	-	Annual household income			
40 - 49	-	-	1	\$20,592 or less	1	1	-
50 - 59	-	-	-	\$20,593 to \$39,735	3	-	-
60 - 69	1	1	-	\$39,736 to \$64,553	2	-	-
70 - 79	2	-	-	\$64,554 to \$104,086	-	-	-
80 - 89	1	-	-	\$104,087 to \$191,149	-	1	-
Relation with cancer-diagnosed individual				\$191,150 or more	-	-	1
Spouse	2	-	1	Language proficiency			
Child	2	1	-	Non/limited English	3	-	-
Parent	1	-	-	Bilingual, proficient English	3	1	1
Sister/ Brother (sibling or in-law)	1	1	-	English speaking only	-	1	-

Table 5.3 Other social and economic characteristics of sample population by ethnicity (N = 18)

	Person with Cancer Diagnosis			Family Carer		
	Chinese (N = 5)	Filipino (N = 3)	Indian (N = 1)	Chinese (N = 6)	Filipino (N = 2)	Indian (N = 1)
Nativity Status						
U.S. Immigrant	5	3	1	4	1	-
U.S. Born	-	-	-	2	1	1
Years in the U.S.						
5 years or less	1	-	-	1	-	-
6 - 9 years	1	-	-	2	-	-
10 - 19 years	-	-	1	-	-	1
20 - 29 years	3	-	-	1	-	-
20 - 29 years	-	1	-	-	-	-
30 - 39 years	-	1	-	-	1	-
40 - 49 years	-	1	-	-	-	-
Marital / Domestic Partner Status						
Not married	-	-	-	2	-	-
Married	3	1	1	4	2	1
Divorced	2	1	-	-	-	-
Widowed	-	1	-	-	-	-
Current Employment Status						
Employed	2	-	1	2	-	1
Unemployed	2	1	-	-	1	-
Retired	1	2	-	4	1	-
Main Mode of Transportation						
Public transit (unable to drive or no car)	2	1	-	2	-	-
Public transit (able to drive own car)	1	-	-	1	-	-
Car	2	2	1	3	2	1

Appendix H | Research ethics application

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research involving
direct contact with human participants

Instructions **[for additional advice on completing this form, hover PC mouse over 'guidance']**

1. Apply to the committee by submitting:
 - a. The University's **Stage 1 Self Assessment (part A only)** and the **Project Questionnaire**. These are available on the Research Support Office website: [LU Ethics](#)
 - b. The completed application **FHMREC form**
 - c. Your full research proposal (background, literature review, methodology/methods, ethical considerations)
 - d. All accompanying research materials such as, but not limited to,
 - 1) Advertising materials (posters, e-mails)
 - 2) Letters/emails of invitation to participate
 - 3) Participant information sheets
 - 4) Consent forms
 - 5) Questionnaires, surveys, demographic sheets
 - 6) Interview schedules, interview question guides, focus group scripts
 - 7) Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing handbooks or measures, which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. **Submit all the materials electronically** as a **SINGLE email attachment in PDF format by the deadline date**. **Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.**
3. **Submit one collated and signed paper copy of the full application materials in time for the FHMREC meeting**. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Applications must be submitted by the deadline date, to:
Dr Diane Hopkins
B14, Furness College
Lancaster University,
LA1 4YG
d.hopkins@lancaster.ac.uk
5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application.
6. Attend the committee meeting on the day that the application is considered, if required to do so.

1. **Title of Project:** Cancer Care Experiences in Chinese, Indian and Filipino American Immigrant Families

2. **Name of applicant/researcher:** Rachel J. Mesia

3. **Type of study**

- Includes *direct* involvement by human subjects.
- Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: [LU Ethics](#). Submit this, along with all project documentation, to Diane Hopkins.

October 2014

4. If this is a student project, please indicate what type of project by marking the relevant box: (please note that UG and taught PG projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#))

PG Diploma Masters dissertation DClinPsy SRP PhD Thesis

PhD Pall. Care

PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD

DClinPsy Thesis

Applicant Information

5. **Appointment/position held by applicant and Division within FHM** Postgrad student, Division of Health Research

6. **Contact information for applicant:**
E-mail: r.mesia@lancaster.ac.uk
Telephone: 1-510-468-8788 (please give a number on which you can be contacted at short notice)
Address: 35369 Terra Cotta Circle, Fremont, CA 94536, USA

7. **Project supervisor(s), if different from applicant:** Carol Thomas

8. **Appointment held by supervisor(s) and institution(s) where based (if applicable):**
 Professor of Sociology and Director of PhD in Health Research Programme
 Faculty of Health and Medicine, Division of Health Research (DHR), Lancaster University

9. **Names and appointments of all members of the research team (including degree where applicable)**

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. **Summary of research protocol in lay terms (indicative maximum length 150 words):**

11. **Anticipated project dates (month and year only)**
 Start date: _____ End date: _____

12. **Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):**

13. **How will participants be recruited and from where? Be as specific as possible.**

Signatures: Applicant: *Rachel Mesia*

Date: 4 March, 2015

*Project Supervisor (if applicable):

Date:

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

STANFORD UNIVERSITY

Stanford, CA 94305 [Mail Code 5579]

David D Oakes, M.D.
CHAIR, PANEL ON MEDICAL HUMAN SUBJECTS

(650) 723-5215
(650) 725-8013

Certification of Human Subjects Approvals

Date: February 19, 2015
To: Kim Rhoads, MD, Surgery - General Surgery
Rachel J Mesia MPH/PhD(c)
From: David D Oakes, M.D., Administrative Panel on Human Subjects in Medical Research

Protocol Cancer Experiences in Chinese, Indian and Filipino American Immigrant Families
Protocol ID: 33186 **IRB Number:** 6208 (Panel: 8)

The IRB approved human subjects involvement in your research project on 02/19/2015. **'Prior to subject recruitment and enrollment, if this is: a Cancer-related study, you must obtain Cancer Center Scientific Review Committee (SRC) approval; a CTRU study, you must obtain CTRU approval; a VA study, you must obtain VA R and D Committee approval; and if a contract is involved, it must be signed.'**

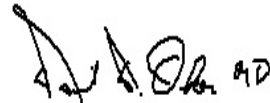
The expiration date of this approval is 01/31/2016 at Midnight. If this project is to continue beyond that date, you must submit an updated protocol in advance for the IRB's re-approval. If this protocol is used in conjunction with any other human use it must be re-approved. Proposed changes to approved research must be reviewed and approved prospectively by the IRB. No changes may be initiated without prior approval by the IRB, except where necessary to eliminate apparent immediate hazards to subjects. (Any such exceptions must be reported to the IRB within 10 working days.) Unanticipated problems involving risks to participants or others and other events or information, as defined and listed in the Report Form, must be submitted promptly to the IRB. (See Events and Information that Require Prompt Reporting to the IRB at <http://humansubjects.stanford.edu>.)

All continuing projects and activities must be reviewed and re-approved on or before Midnight of the expiration date. The approval period will be less than one year if so determined by the IRB. It is your responsibility to resubmit the project to the IRB for continuing review and to report the completion of the protocol to the IRB within 30 days.

Please remember that all data, including all signed consent form documents, must be retained for a minimum of three years past the completion of this research. Additional requirements may be imposed by your funding agency, your department, or other entities. (See Policy 1.9 on Retention of and Access to Research Data at <http://doresearch.stanford.edu/policies/research-policy-handbook>)

This institution is in compliance with requirements for protection of human subjects, including 45 CFR 46, 21 CFR 50 and 56, and 38 CFR 16.

Waiver of Individual Authorization for recruitment under 45 CFR 164.512(i)(2)(ii)(A),(B),(C), pursuant to information provided in the HIPAA section of the protocol application.



David D Oakes, M.D., Chair

Approval Period: 02/19/2015 THROUGH 01/31/2016
Review Type: EXPEDITED - NEW
Funding: None
Expedited Under Category: 6, 7
Assurance Number: FWA00000935 (SU)

Title: Cancer Experiences in Chinese, Indian and Filipino American Immigrant Families
Approval Period: 02/19/2015 - 01/31/2016

Protocol Director				
Name Kim Rhoads		Degree (program/year if student) MD		Title Asst Prof-Med Ctr Line
Dept Surgery - General Surgery	Mail Code 5641	Phone (650) 721-3094	Fax (650) 725-0791	E-mail kim.rhoads@stanford.edu
CITI Training current				Y

Admin Contact				
Name Kim Rhoads		Degree (program/year if student) MD		Title Asst Prof-Med Ctr Line
Dept Surgery - General Surgery	Mail Code 5641	Phone (650) 721-3094	Fax (650) 725-0791	E-mail kim.rhoads@stanford.edu
CITI Training current				Y

Co-Protocol Director				
Name Rachel J Mesia		Degree (program/year if student) MPH/PhD(c)		Title Program Manager & Research Associate
Dept Cancer Clinical Trials Office	Mail Code 5757	Phone (650) 723-7119	Fax (650) 724-4042	E-mail rmesia@stanford.edu
CITI Training current				Y

Other Contact				
Name		Degree (program/year if student)		Title
Dept	Mail Code	Phone	Fax	E-mail
CITI Training current				

Faculty Sponsor				
Name		Degree (program/year if student)		Title
Dept	Mail Code	Phone	Fax	E-mail
CITI Training current				

Other Personnel

Participant Population(s) Checklist

Yes/No

Protocol # 33186 (New)
 PD: Kim Rhoads
 Review Type: Expedited
 Medical

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- Children (under 18) N
- Pregnant Women and Fetuses N
- Neonates (0 - 28 days) N
- Abortuses N
- Impaired Decision Making Capacity N
- Cancer Subjects Y
- Laboratory Personnel N
- Healthy Volunteers Y
- Students N
- Employees N
- Prisoners N
- Other (i.e., any population that is not specified above) N

Study Location(s) Checklist

Yes/No

- Stanford University Y
- Clinical & Translational Research Unit (CTRU)
- Stanford Hospital and Clinics
- Lucile Packard Children's Hospital (LPCH)
- VAPAHCS (Specify PI at VA)
- Other (Click ADD to specify details) Y

Location / Country	Location	Contact Name	Contact Phone	Contact Email	Permission ?	IRB?
Fremont Public Library (Fremont, CA)	US				N	N
Newark Public Library (Newark, CA)	US				N	N
Milpitas Public Library (Milpitas, CA)	US				N	N
Castro Valley Public Library (Castro Valley, CA)	US				N	N
Belmont Public Library (Belmont, CA)	US				N	N

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San Mateo Main Library (San Mateo, CA)	US				N	N
John Daly Library (Daly City, CA)	US				N	N
Palo Alto City Library (Palo Alto, CA)	US				N	N
San Jose Public Libraries (San Jose, CA)	US				N	N
Capital One Community Room (San Francisco, CA)	US				N	N
Umpqua Bank Meeting Room (San Francisco, CA)	US				N	N
Critosphere Meeting Space (Fremont, CA)	US				N	N

General Checklist

Multi-site

Yes/No

- Is this a multi-site study? A multi-site study is generally a study that involves one or more medical or research institutions in which one site takes a lead role.(e.g., multi-site clinical trial)

N

Collaborating Institution(s)

Yes/No

- Are there any collaborating institution(s)? A collaborating institution is generally an institution that collaborates equally on a research endeavor with one or more institutions.

N

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Cancer Institute **Yes/No**

- Cancer-Related Studies (studies with cancer endpoints), Cancer Subjects (e.g., clinical trials, behavior/prevention) or Cancer Specimens (e.g., blood, tissue, cells, body fluids with a scientific hypothesis stated in the protocol). Y

Drug /Device **Yes/No**

- Investigational drugs, biologics, reagents, or chemicals? N
- Commercially available drugs, reagents, or other chemicals administered to subjects (even if they are not being studied)? N
- Investigational Device / Commercial Device used off-label? N
- IDE Exempt Device (Commercial Device used according to label, Investigational In Vitro Device or Assay, or Consumer Preference/Modifications/Combinations of Approved Devices) N
- Protocol involves studying potentially addicting drugs? N

Clinical Trials **Yes/No**

- Click "yes" to confirm that you have accessed the website and read the clinicaltrials.gov reporting requirements provided.
- This study will be registered on clinicaltrials.gov?

Tissues and Specimens **Yes/No**

- Human blood, cells, tissues, or body fluids (tissues)? N
- Tissues to be stored for future research projects? N
- Tissues to be sent out of this institution as part of a research agreement? For guidelines, please see <http://stanford.edu/group/ICO/researcher/reMTA.html> N

Biosafety (APB) **Yes/No**

- Are you submitting a Human Gene Transfer investigation using biological agent or recombinant DNA vector? If yes, please complete and attach the Gene Transfer Protocol Application Supplemental Questions to section 16 of the eProtocol application. N
- Are you submitting a Human study using biohazardous/infectious agents? If yes, refer to N

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the <http://www.stanford.edu/dept/EHS/prod/researchlab/bio/index.html> Administrative Panel on BioSafety website prior to performing studies.

- Are you submitting a Human study using samples from subjects that contain biohazardous/infectious agents? If yes, refer to the <https://ehsapprd1.stanford.edu/eprobio/> Administrative Panel on BioSafety website prior to performing studies. N

Human Embryos or Stem Cells

Yes/No

- Human Embryos or gametes? N
- Human Stem Cells (including hESC, iPSC, cancer stem cells, progenitor cells). N

Veterans Affairs (VA)

Yes/No

- The research recruits participants at the Veterans Affairs Palo Alto Health Care System(VAPAHCS). N
- The research involves the use of VAPAHCS non-public information to identify or contact human research participants or prospective subjects or to use such data for research purposes. N
- The research is sponsored (i.e., funded) by VAPAHCS. N
- The research is conducted by or under the direction of any employee or agent of VAPAHCS (full- time, part-time, intermittent, consultant, without compensation (WOC), on-station fee-basis, on- station contract, or on-station sharing agreement basis) in connection with her/his VAPAHCS responsibilities. N
- The research is conducted using any property or facility of VAPAHCS. N

Equipment

Yes/No

- Use of Patient related equipment? If Yes, equipment must meet the standards established by Hospital Instrumentation and Electrical Safety Committee (650-725-5000) N
- Medical equipment used for human patients/subjects also used on animals? N
- Radioisotopes/radiation-producing machines, even if standard of care? http://www.stanford.edu/dept/EHS/prod/researchlab/radlaser/Human_use_guide.pdf More Info N

Payment

Yes/No

- Subjects will be paid for participation? See payment considerations. Y

Funding

Yes/No

Protocol # 33186 (New)
PD: Kim Rhoads
Review Type: Expedited
Medical

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- Training Grant? N
- Program Project Grant? N
- Federally Sponsored Project? N
- Industry Sponsored Clinical Trial? N

Funding

NONE

Funding - Grants/Contracts
Funding - Fellowships
Gift Funding
Dept. Funding
Other Funding

Expedited Form

A protocol must be no more than minimal risk (i.e., "not greater than those ordinarily encountered in daily life") AND must only involve human subjects in one or more of the following paragraphs.

Select one or more of the following paragraphs:

1. N **Clinical studies of drugs and medical devices only when condition (a) or (b) is met.**
 - a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.)
 - b) Research on medical devices for which
 - i) an investigational device exemption application (21 CFR Part 812) is not required; or
 - ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.
2. N **Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:**
 - a) from healthy, nonpregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or
 - b) from other adults and children, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml

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or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

3. N **Prospective collection of biological specimens for research purposes by non invasive means.**
4. N **Collection of data through non invasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.)**
Examples:
- a) physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy;
 - b) weighing or testing sensory acuity;
 - c) magnetic resonance imaging;
 - d) electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography;
 - e) moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.
5. N **Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). (NOTE: Some research in this paragraph may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)**
6. Y **Collection of data from voice, video, digital, or image recordings made for research purposes.**
7. Y **Research on individual or group characteristics or behavior(including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)**

Resources:

a) **Qualified staff.**

Please state and justify the number and qualifications of your study staff.

Protocol Director: Kim Rhoads, MD, MS, MPH is an Assistant Professor of Surgery in colon and rectal surgery at Stanford. She is also the Director of the Stanford Cancer Institute Community Partnership Program. She brings select expertise to this project in understanding cancer disparities in treatment and outcomes, social research methods, and community health. Dr. Rhoads has served as a mentor and faculty sponsor for medical residents and PhD students interested in cancer health disparities research. She oversees the Community Partnership Program work of Ms. Mesia.

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Co-Protocol Director: Rachel Mesia, MPH and PhD(c) is a Program Manager with the Stanford Cancer Institute. Ms. Mesia has extensive experience in addressing health disparities in the field of cancer control, through community-engaged projects, coalitions and programs. She is a PhD candidate at the University of Lancaster's Faculty of Health and Medicine Department. She is supervised by 2 senior faculty members of the University of Lancaster, who are providing academic guidance on her research project, thesis writing and dissertation defense. Ms. Mesia will lead all aspects of the project: recruiting and screening eligibility of potential participants; providing oversight of interpreters' and transcriptionists' compliance with Human Subjects Protection and HIPAA policies; conducting the informed consent and research interviews; securing, managing and analyzing research data; writing the dissertation, scientific manuscripts and other written works; presenting findings for her dissertation defense as well as at scientific, educational and professional meetings.

Eligibility Screening Interpreters: Language Translation Inc. will provide interpreter services for the eligibility screening of potential participants who do not speak English or are limited English speaking. Their interpreters abide by the Interpreter Code of Ethics, comply with HIPAA guidelines, and are required to sign the agency's confidentiality agreement.

Interview Interpreters: The interpreters will be experienced in health settings as well as proficient in English and the language spoken by the research participant. The Researcher will provide oversight of ensuring that the interview interpreters are trained in Human Subjects Protection and are CITI certified. The interpreters will be required to sign a confidentiality agreement form.

Professional Transcription Service: Verbal Ink will provide the transcription service of the audio recorded interviews, which will be completed by trained transcriptionists. Verbal Ink is fully compliant with HIPAA requirements and the Association for Healthcare Documentation Integrity's code of ethics for medical transcriptionists. They also have confidentiality procedures to ensure that the research data will remain private, which will include confidentiality agreements, background checks, and other technical safeguards.

b) Training.

Describe the training you will provide to ensure that all persons assisting with the research are informed about the protocol and their research-related duties and functions.

Rachel Mesia, the Researcher, has completed the Collaborative Institutional Training Initiative (CITI) Human Subjects Research Protections Curriculum and HIPAA Certification for Clinical Researchers through Stanford University. Dr. Rhoads is also CITI and HIPAA certified through Stanford University

Ms. Mesia will provide oversight of the Interview Interpreters' Human Subjects Protection training and completion of the CITI certification. Both the Interpreters and Professional Transcription Service will be required to sign and abide by a confidentiality agreement which outlines HIPAA and Human Subjects Protection policies as well as procedures for handling the audio recording files of interviews (specific to transcription service).

c) Facilities.

Please describe and justify.

The interviews will take place in private meeting rooms in local public libraries and meeting space facilities in the San Francisco Bay Area. All interview locations are selected to maintain the highest level of confidentiality, but also to protect the physical safety of the Researcher. These places are not associated

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with community organization and support/social group settings where recruitment will take place. Furthermore, the private meeting rooms are located in buildings where there are employees present, so that the Researcher does not conduct the interview as a 'lone worker'. Various locations were selected in order to provide the participant convenience with commuting to and from the place of interview.

d) Sufficient time.

Explain whether you will have sufficient time to conduct and complete the research. Include how much time is required.

This study has a projected timeline of 3 years, beginning March 2015 and ending December 2017. A standing monthly meeting will serve as infrastructure for driving the work forward. Months 1-8: The first 8 months will be used to recruit and screen potential participants, conduct key informant interviews, transcribe interviews, and conduct initial data analysis. Months 9-22: The Researcher will analyze the research data and write dissertation. Months 23-26: These 4 months will be spent on finalizing the dissertation for the Viva (i.e. oral defense of dissertation). Months 27-28: These 2 months will be spent on preparing for and completing Viva as well as making final corrections for the submission of the thesis publication. Months 29-36: The last 7 months will focus on writing and production of manuscripts for peer reviewed journals and health literature.

e) Access to target population.

Explain and justify whether you will have access to a population that will allow recruitment of the required number of participants.

The Researcher has current partnerships with community-based organizations (CBO) in the San Francisco Bay Area who reach and serve the community members that are representative of the study's sample population. The CBOs will invite the Researcher to their community meetings/ events, educational programs and support/social groups, so that she can provide a general overview of the study and disseminate recruitment materials. Flyers will be posted in CBO community spaces.

f) Access to resources if needed as a consequence of the research.

State whether you have medical or psychological resources available that participants might require as a consequence of the research when applicable. Please describe these resources.

The main risks for participants are loss of privacy and emotional distress from the recollection of cancer care experiences. The Researcher compiled a list of local resources that can provide support groups and/or psychological support, if the participants experience emotional distress. The types of questions in the interview will be described to the participants during the consent process, which will allow for the participant to consider in advance the topic area/question she/he does not want to answer or decline participation in the interview.

g) Lead Investigator or Coordinating Institution in Multi-site Study.

Please explain (i) your role in coordinating the studies, (ii) procedures for routine communication with other sites, (iii) documentation of routine communications with other sites, (iv) planned management of communication of adverse outcomes, unexpected problems involving risk to participants or others, protocol modifications or interim findings.

1. Purpose

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a) **In layperson's language state the purpose of the study in 3-5 sentences.**

The purpose of the study is collect data on factors related to the burden (i.e. challenges, obstacles) in cancer care, experienced by Chinese, Indian and Filipino American immigrant families. The study findings are expected to enhance the limited knowledge about the circumstances and conditions of Asian American families when caring for illness. With new knowledge, public health practitioners and health professionals can better understand ways to address cancer support needs and health disparities.

b) **State what the Investigator(s) hope to learn from the study. Include an assessment of the importance of this new knowledge.**

This study will address the gaps in knowledge about Asian American health and immigrant populations. The study aims to learn about: 1) what cancer care is regarded as from the viewpoints of cancer patients and their carers; 2) the cancer care burdens experienced within the family, based on the expectations, choices and barriers recognized by the study participants; and 3) the main determinants of health that affect the burdens in cancer care. American cancer experiences have been broadly examined in different context, but there is limited research about cancer experiences in Asian American families. Generating evidence in this topic area may improve understanding of how to address the cancer burden and health disparities in Asian American communities.

c) **Explain why human subjects must be used for this project. (i.e. purpose of study is to test efficacy of investigational device in individuals with specific condition; purpose of study is to examine specific behavioral traits in humans in classroom or other environment)**

This is a qualitative study aiming to examine the background, perspectives, and experiences of individuals diagnosed with cancer and their family carers. Therefore, human subjects are necessary for providing feedback related to the Researcher's research aims.

2. Study Procedures

a) **Please SUMMARIZE the research procedures, screening through closeout, which the human subject will undergo. Refer to sections in the protocol attached in section 16, BUT do not copy the clinical protocol. Be clear on what is to be done for research and what is part of standard of care.**

RECRUITMENT: The Researcher will conduct recruitment at community meetings/events, educational programs and support/social group meetings. At the recruitment settings, the Researcher will provide a brief overview of the study and distribute the study flyer and information sheet. The potential participants will be invited to directly contact the Researcher over the phone or email to obtain more study information or inform the Researcher of her/his interest in joining the study. At the recruitment settings, the Researcher will not collect responses about enrolling in the study. Also partnering community organizations will post/display the study recruitment flyer in their community space. If a potential participant inquires about the study, she/he will be invited to contact the Researcher directly for more information and express interest in joining the study. The CBOs will be instructed: 1) to only acknowledge study information that is available on the flyer; 2) to not collect information from the potential participants; and 3) to not ask if the potential participant plans to join the study.

Opt Out Opportunity #1: During recruitment, potential participant can choose not to respond to the Researcher's invitation to be screened and join the study.

STUDY ELIGIBILITY SCREENING: The Researcher will screen the potential participant eligibility over the telephone. If a potential participant does not speak English, the Researcher will seek her/his permission

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to involve an interpreter to assist with communication during the screening. After the screening, the Researcher will seek permission from non-English speaking potential participant to have an interpreter present during the informed consent process and interview.

If the potential participant decides not to proceed with the study, the Researcher will inform that any information collected about her/him associated with the recruitment and screening will be destroyed. Among the potential participant who meet the eligibility criteria and agree to an interview, the Researcher will proceed with scheduling an interview appointment over the phone. The potential cancer patient participants will be asked to identify the 'family carer' she/he would like to involve in the study. The Researcher will ask the potential participant to invite the 'family carer' to contact the Researcher. If the family carer informs the Researcher of her/his interest in joining the study, the Researcher will conduct the eligibility screening as described earlier.

Opt Out Opportunity #2: Before screening begins and during the screening, the Researcher will give the opportunity for the potential participant to opt out of responding to the Researcher's screening questions. After the screening, the Researcher will provide another opportunity for the potential participant to opt out of scheduling a meeting to be interviewed.

STUDY INTERVIEW: At the interview site, the Researcher will escort the participant into the private meeting room. The informed consent process and interviews will be structured around the participant's preferred spoken language. Therefore if necessary, an interpreter will be physically present to assist with the informed consent process and interview.

Opt Out Opportunity #3: During the informed consent process and before signing the form, the Researcher will provide the potential participant to opt out of the study. The participant will also be informed that they can end their participation in the study at any time.

After welcome and introductions in the meeting room, the Researcher will proceed with the informed consent process. Before the participant signs the form, the Researcher will ask if there are concerns/questions as well as confirm if the interview can be continued with the interpreter present. After the participant agrees to participate and signs the consent form, a copy will be provided. If the participant declines to participate, the Researcher will inform that any information collected about her/him associated with the recruitment and screening will be destroyed.

The Researcher will begin the interview letting the participant know that audio recording and interview has begun. The Researcher will conclude the interview by reviewing the key themes of what the Researcher understood from the interview. At the end of the interview, the Researcher will let the participant know that the audio recording has stopped. Then the Researcher will ask if there are any concerns or questions to be addressed. The participants will also be asked of their interest in seeing their own de-identified data with aggregated thematic comments in the preliminary part of the data analysis. Lastly, the Researcher will provide the participant a listing of local support resources and thank the participant with the gift.

b) Explain how the above research procedures are the least risky that can be performed consistent with sound research design.

The following explains how the research procedures minimize risks to the participants:

- 1) The Researcher will screen the participants over the telephone, so that the participant does not feel subjected to being physically identified during the screening and prior to the informed consent/interview meeting.
- 2) The Researcher will ask the cancer patient participant to identify and invite the family carer to participate

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in the study, so that the cancer patient participant has the free choice of selecting who she/he would like to involve in the study.

3) In order to involve minority populations who may be non-English or limited English speaking, a CITI certified interpreter with health experience will help to provide the least bias and most accurate interpretation under strict confidentiality and privacy guidelines of HIPAA and human subject research.

4) Data will be collected from the participant during a one time, audio recorded interview. The audio recording and its transcription will allow the Researcher to analyze the collected data more accurately without additional post interview follow-up.

5) The Researcher will conduct the interview individually in a private meeting room. This will allow for the participant to feel more comfortable or secure about sharing certain types of information with the Researcher and without required presence of the other family member involved in the study.

- c) **State if deception will be used. If so, provide the rationale and describe debriefing procedures. Since you will not be fully informing the participant in your consent process and form, complete an alteration of consent (in section 13). Submit a debriefing script (in section 16).**

N/A

- d) **State if audio or video recording will occur. Describe what will become of the recording after use, e.g., shown at scientific meetings, erased. Describe the final disposition of the recordings.**

Audio recording of the interviews will occur. This will enable the production of transcripts which will support the Researcher's work in conducting high quality data analysis (e.g. identification of important themes from direct participant quotes). The audio recordings will be transcribed by a professional transcription service. The participant's name will not be identifiable on the audio recording. All participants will be identified on the interview recording by their ID code. Audio recordings will be digital and stored at the earliest convenience (no more than 24 hours) to: 1) an encrypted external hard drive kept in the in the Researcher's locked cabinet located in her Stanford office suite with restricted entry; and 2) in the Researcher's 'Stanford Medicine Box' account within the designated restricted HIPAA compliant data folders. The transcription service provider will be required to transcribed from a password protected encrypted computer as well as to delete the audio recording files after transcription service has been completed. Audio recording files will be kept until the Researcher's degree is awarded. After degree has been awarded, the audio recording files will be deleted from the encrypted external hard drive and the Researcher's 'Stanford Medicine Box' account.

- e) **Describe alternative procedures or courses of treatment, if any, that might be advantageous to the participant. Describe potential risks and benefits associated with these. Any standard treatment that is being withheld must be disclosed in the consent process and form. (i.e. standard-of-care drug, different interventional procedure, no procedure or treatment, palliative care, other research studies).**

N/A

- f) **Will it be possible to continue the more (most) appropriate therapy for the participant(s) after the conclusion of the study?**

N/A

- g) **Study Endpoint. What are the guidelines or end points by which you can evaluate the different treatments (i.e. study drug, device, procedure) during the study? If one proves to be clearly more effective than another (or others) during the course of a study, will the study be terminated before the projected total participant population has been enrolled? When will the study end if no important differences are detected?**

N/A

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3. Background

- a) Describe past experimental and/or clinical findings leading to the formulation of the study.
- b) Describe any animal experimentation and findings leading to the formulation of the study.

4. Radioisotopes or Radiation Machines

- a) List all standard of care procedures using ionizing radiation (radiation dose received by a subject that is considered part of their normal medical care). List all research procedures using ionizing radiation (procedures performed due to participation in this study that is not considered part of their normal medical care). List each potential procedure in the sequence that it would normally occur during the entire study. http://www.stanford.edu/dept/EHS/prod/researchlab/radlaser/Human_use_guide.pdf
 More Info

Identify Week/Month of study	Name of Exam	Identify if SOC or Research
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- b) For research radioisotope projects, provide the following radiation-related information:
 Identify the radionuclide (s) and chemical form (s).

 For the typical subject, provide the total number of times the radioisotope and activity will be administered (mCi) and the route of administration.

 If not FDA approved provide dosimetry information and reference the source documents (package insert, MIRD calculation, peer reviewed literature).
- c) For research radiation machine projects, provide the following diagnostic procedures:
 For well-established radiographic procedures describe the exam.

 For the typical subject, identify the total number of times each will be performed on a single research subject.

 For each radiographic procedure, provide the setup and technique sufficient to permit research subject dose modeling. The chief technologist can usually provide this information.

 For radiographic procedures not well-established, provide FDA status of the machine, and information sufficient to permit research subject dose modeling.
- d) For research radiation machine projects, provide the following therapeutic procedures:
 For a well-established therapeutic procedure, identify the area treated, dose per fraction and number of fractions. State whether the therapeutic procedure is being performed as a normal part of clinical management for the research participants's medical condition or whether it is being performed because the research participant is participating in this project.

 For a therapeutic procedure that is not well-established, provide FDA status of the machine, basis for dosimetry, area treated, dose per fraction and number of fractions.

5. Devices

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- a) Please list in the table below all Investigational Devices (including Commercial Devices used off-label) to be used on participants
- b) Please list in the table below all IDE Exempt Devices (Commercial Device used according to label, Investigational In Vitro Device or Assay, or Consumer Preference/Modifications/Combinations of Approved Devices) to be used on participants.

6. Drugs, Reagents, or Chemicals

- a) Please list in the table below all investigational drugs, reagents or chemicals to be administered to participants.
- b) Please list in the table below all commercial drugs, reagents or chemicals to be administered to participants.

7. Medical Equipment for Human Subjects and Laboratory Animals

If medical equipment used for human patients/participants is also used on animals, describe such equipment and disinfection procedures.

N/A

8. Participant Population

- a) State the following: (i) the number of participants expected to be enrolled at Stanford-affiliated site(s); (ii) the total number of participants expected to enroll at all sites; (iii) the type of participants (i.e. students, patients with certain cancer, patients with certain cardiac condition) and the reasons for using such participants.
- None of the participants will be enrolled at Stanford-affiliated sites. A total of 18 participants are expected to enroll in this study. The types of participants are: 1) adults diagnosed with cancer for the first time within the last 3 years; and 2) individuals who are identified as an adult family carer by the cancer patient. The Researcher does not intend to recruit Stanford cancer patients. The purpose for recruiting these types of participants is to collect data from 2 types of perspectives relating to family experiences with cancer care.
- b) State the age range, gender, and ethnic background of the participant population being recruited.
- Both genders will be included. Individuals who were diagnosed with cancer will be aged 50 years old or older and self-identified as Chinese, Filipino or Indian. Individuals who are 'family carers', will be aged 25 years old or older and self-identified any racial/ethnic background.
- c) State the number and rationale for involvement of potentially vulnerable subjects in the study (including children, pregnant women, economically and educationally disadvantaged, decisionally impaired, homeless people, employees and students). Specify the measures being taken to minimize the risks and the chance of harm to the potentially vulnerable subjects and the additional safeguards that

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have been included in the protocol to protect their rights and welfare.

There will be a total of 9 cancer diagnosed individuals and 9 of their family carers enrolled in the study. Minority cancer patients/survivors and their family carers could be considered vulnerable under the current definition, with specific regard to having experienced a cancer illness, being possibly economically and educationally disadvantaged, and possibly marginalized as a result of their ethnicity, immigrant or language background. Without research from these populations, evidence-based knowledge will not be available to help identify and reduce health disparities and cancer burden. Knowledge from this study contributes to some of the ways Stanford Cancer Institute advances its mission in comprehensive patient care, research discovery, advanced professional training, and community outreach. The Researcher will: 1) provide participants several opportunities to opt out of the eligibility screening and study interview; 2) inform participants about the types of questions that will be asked prior to the start of the interview; 3) ask participants their permission to have an interpreter present during the screening and interview; and 4) give participants a list of local resources for accessing psychological/social support.

- d) **If women, minorities, or children are not included, a clear compelling rationale must be provided (e.g., disease does not occur in children, drug or device would interfere with normal growth and development, etc.).**

Minors will not be included, because there is no foreseen benefit of involving minors in a study focused on adult cancer patient/survivors and adult family carers.

- e) **State the number, if any, of participants who are laboratory personnel, employees, and/or students. They should render the same written informed consent. If payment is allowed, they should also receive it. Please see Stanford University policy.**

None of the research participants will be a student, laboratory personnel and/or employee of the Researcher.

- f) **State the number, if any, of participants who are healthy volunteers. Provide rationale for the inclusion of healthy volunteers in this study. Specify any risks to which participants may possibly be exposed. Specify the measures being taken to minimize the risks and the chance of harm to the volunteers and the additional safeguards that have been included in the protocol to protect their rights and welfare.**

9 healthy volunteers who are family carers of the cancer patients will be enrolled. Family carers are necessary for this study, because the purpose of the study is learn from different perspectives related to cancer care challenges in families. As described above, the Researcher will: 1) provide participants several opportunities to opt out of the eligibility screening and study interview; 2) inform participants about the types of questions that will be asked prior to the start of the interview; 3) ask participants their permission to have an interpreter present during the screening and interview; and 4) give participants a list of local resources for accessing psychological/social support.

- g) **Describe how potential participants will be identified for recruitment (e.g., chart review, referral from individual's treating physician, responses to an ad). Describe how participants will be recruited and how they will initially learn about the research (e.g., clinics, advertising). If this is a clinical trial, indicate the recruitment option selected in registering the trial on the Stanford Clinical Trials web site-whether recruitment is limited to "invitation only" (e.g. your own patients), or whether recruitment will be open to the general public. Attach recruitment materials in Section #16 (Attachments). You may not contact potential participants prior to IRB approval. See guidance Advertisements: Appropriate Language for Recruitment Material.**

The sample population will be recruited through purposive and snowball sampling. Recruitment will be conducted in local SF Bay Area communities. The Researcher has partnerships with community-based organizations (CBO) who outreach and serve members representing the sample population. The CBOs will provide the Researcher with opportunities to conduct recruitment at their community meetings/events,

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educational programs and support/social group meetings. At the recruitment settings, the Researcher will provide a brief overview of the study and distribute the study flyer and information sheet. The flyers and information sheet will be available in English, Tagalog, Chinese, Hindi and Punjabi. The potential participants will be invited to directly contact the Researcher over the phone or email to obtain more study information or inform the Researcher of her/his interest in joining the study. At the recruitment settings, the Researcher will not collect responses about enrolling in the study.

Partnering CBOs will post/display the study recruitment flyer in their community space. If a potential participant inquires about the study, she/he will be invited to contact the Researcher directly for more information and express interest in joining the study. The CBOs will be instructed: 1) to only acknowledge study information that is available on the flyer; 2) to not collect information from the potential participants; and 3) to not ask if the potential participant plans to join the study.

If the potential participant corresponds with the Researcher over email, the Researcher will respond via secure email any questions or concerns the potential participant may have as well as provide the study information sheet. If the potential participant requests to be contacted over telephone, the Researcher will call the participant to review the study information and answer questions or concerns.

h) Inclusion and Exclusion Criteria.

Identify inclusion criteria.

Participant diagnosed with cancer: 1) Received diagnosis of cancer only one time, within the last 3 years or less, at the age of 50 years old or older; 2) Self-identifies as Chinese, Filipino or Indian; 3) Immigrated to the U.S. at the age of 25 years old or older; 4) Received cancer treatment in the U.S.

Participant who was identified as a 'family carer' by the cancer diagnosed participant: Was or is currently involved with the cancer patient participant's care at the age of 25 years old or older.

Identify exclusion criteria.

- 1) The person has had a reoccurring cancer diagnosis.
- 2) The person cannot speak a language spoken by the investigator or interpreter: English, Mandarin, Cantonese, Tagalog, Ilocano, Hindi or Punjabi.
- 3) The person's place of residence is not in the U.S.
- 4) The person's cancer care was not received in the U.S.
- 5) The person is outside the age range specified in the inclusion criteria.
- 6) The interview cannot take place in any of the proposed locations.

i) Describe your screening procedures, including how qualifying laboratory values will be obtained. If you are collecting personal health information prior to enrollment (e.g., telephone screening), please request a waiver of authorization for recruitment (in section 15).

Screening procedures will be performed over the telephone and with an interpreter if necessary. After the potential participant expresses interest in joining the study, the Researcher will ask permission to screen the potential participant with study eligibility questions. In order to classify the participant type, the Researcher will ask the potential participant to identify if she/he is participating in the study either as an individual diagnosed with cancer or as a family carer of the cancer patient. If the potential participant responds to being a cancer patient, the Researcher will proceed with asking if the participant has only been diagnosed with cancer 1 time, if the diagnosis occurred 3 years ago or less, and if the diagnosis occurred at age 50 years old or older. Collecting health information about the cancer patient prior to enrollment in the study is necessary, because the Researcher has a specific criteria for the type of sample population she is studying.

j) Describe how you will be cognizant of other protocols in which participants might be enrolled. Please explain if participants will be enrolled in more than one study.

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It is possible that the participant may be enrolled in a clinical trial as part of her/his cancer care. However, since this is a non-interventional study for data collection purposes, the Researcher will not ask the participant's enrollment status in a clinical trial. This will also limit the amount of health information that the participant is being asked to disclose for the study.

- k) **Payment. Explain the amount and schedule of payment, if any, that will be paid for participation in the study. Substantiate that proposed payments are reasonable and commensurate with the expected contributions of participants and that they do not constitute undue pressure on participants to volunteer for the research study. Include provisions for prorating payment. See payment considerations**

The participants will receive a payment for their participation in the study, in the form of a \$10 value gift item. The gift item will not be promoted in the study recruitment flyer and summary sheet, but will be disclosed during the informed consent process. This is to avoid a potential situation during recruitment, in which a participant chooses to enroll in the study to receive the gift item.

- l) **Costs. Please explain any costs that will be charged to the participant.**

N/A

- m) **Estimate the probable duration of the entire study. Also estimate the total time per participant for: (i) screening of participant; (ii) active participation in study; (iii) analysis of participant data.**

This study has a projected timeline of 3 years and 10 months, beginning March 1, 2015 and ending December 31, 2018. Each participant is expected to be screened for 15 minutes. The time for active participation in the study is 15 - 25 minutes for informed consent process and 1 hour for the interview. The participant may voluntarily express interest in reviewing their own de-identified data with aggregated thematic comments during the Researcher's preliminary part of the data analysis. However, this is not mandatory. Data collection is anticipated for 7 months. The estimated time for the Researcher's data analysis is 32 months.

9. Risks

- a) For the following categories include a scientific estimate of the frequency, severity, and reversibility of potential risks. Wherever possible, include statistical incidence of complications and the mortality rate of proposed procedures. Where there has been insufficient time to accumulate significant data on risk, a statement to this effect should be included. (In describing these risks in the consent form to the participant it is helpful to use comparisons which are meaningful to persons unfamiliar with medical terminology.)

Investigational devices.

N/A

Investigational drugs. Information about risks can often be found in the Investigator's brochure.

N/A

Commercially available drugs, reagents or chemicals. Information about risks can often be found in the package insert.

N/A

Procedures to be performed. Include all investigational, non-investigational and non-invasive procedures (e.g., surgery, blood draws, treadmill tests).

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Radioisotopes/radiation-producing machines (e.g., X-rays, CT scans, fluoroscopy) and associated risks.

N/A

Physical well-being.

N/A

Psychological well-being.

There is a potential risk of psychological or emotional distress related to recalling experiences associated with their cancer care experiences as well as the conditions and circumstances they live in. The frequency of psychological or emotional distress in study interviews is uncommon and severity is minimal.

Economic well-being.

N/A

Social well-being.

N/A

Overall evaluation of Risk.

Low - innocuous procedures such as phlebotomy, urine or stool collection, no therapeutic agent, or safe therapeutic agent such as the use of an FDA approved drug or device.

b) In case of overseas research, describe qualifications/preparations that enable you to both estimate and minimize risks to participants.

N/A

c) Describe the planned procedures for protecting against and minimizing all potential risks. Include the means for monitoring to detect hazards to the participant (and/or to a potential fetus if applicable). Include steps to minimize risks to the confidentiality of identifiable information.

- 1) The Researcher will screen the participants over the telephone, so that the participant doesn't feel subjected to being physically identified prior to the informed consent process/interview meeting.
- 2) The Researcher will ask permission from the participant to have a CITI certified interpreter physically present for assisting with the informed consent process and interview. The interpreter will be required to sign a confidential agreement form which outlines compliance with HIPAA and Human Subject Protection policies. The Researcher will not proceed with the interview if the participant does not want to disclose information with the presence of an interpreter.
- 3) Prior to beginning the interview, the Researcher will provide information about the types of questions that will be asked. This will occur during recruitment, study inquiry, and informed consent process. The participant will be made aware that she/he may decline to answer a question and stop the interview at any time.
- 4) Before the interview begins, the participant will be instructed to not identify/say their own name or any person's name. If this occurs, the Researcher will edit out the names from the audio recording in order to de-identify any person mentioned.
- 5) The Researcher will stop the interview if the participant displays distress. The Researcher will ask the participant whether or not she/he would like to proceed with the interview. If the Researcher believes that the participant is not emotionally fit to continue, she will stop the interview permanently.
- 6) The informed consent process and interview will be conducted individually in a private room, to provide the participant a place where they can confidentially be fully informed about the study, decline to join or

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consent to join the study, and respond to the Researcher's questions.

7) After the interview, the Researcher will ask the participant if she/he has any question or concerns. The Researcher will provide the participants a list of local support resources that can help arrange for professional or social support intervention.

- d) **Explain the point at which the experiment will terminate. If appropriate, include the standards for the termination of the participation of the individual participant Also discuss plans for ensuring necessary medical or professional intervention in the event of adverse effects to the participants.**

The Researcher will stop the interview if the participant is believed to be not emotionally fit to continue or indicates harm to self/others. If the participant is not emotionally fit to continue the interview, the Researcher will refer psychological support services to the participant. If the participant indicates harm to self or others, the Researcher will contact a mental health professional service trained in dealing with crisis intervention.

The study will close after the Researcher completes the publication of her dissertation, manuscripts and other related health literature.

10. Benefits

- a) **Describe the potential benefit(s) to be gained by the participants or by the acquisition of important knowledge which may benefit future participants, etc.**

It is possible that the information from the study will help other researchers and the general public learn more about the challenges with cancer care in Chinese, Indian and Filipino families living in the U.S. Findings may introduce new knowledge and potential solutions for addressing the burden in cancer care.

11. Privacy and Confidentiality

Privacy Protections

- a) **Describe how the conditions under which interactions will occur are adequate to protect the privacy interests of participants (e.g., privacy of physical setting for interviews or data collection, protections for follow-up interactions such as telephone, email and mail communications).**

Participants will be directed to contact the Researcher about the study via recruitment methods. Therefore, the Researcher will be the only research staff with access to the participants' communication about the study (email, telephone). With the exception of involving an interpreter in the screening and interview, the participant will only disclose their personal identifiers or health information to the Researcher. The telephone calls for study inquiry and screening will be conducted in a private Stanford office room or the private home office room of the Researcher. Any email correspondence with the participant will be conducted over Stanford's secure encrypted email. The Researcher will interview the cancer patient and family carer separately, so that the data collected remains confidential between the participant, Researcher and if necessary, the interpreter. The interview will be conducted in a private room. If needed, a CITI certified interpreter will be physically present to assist with the interview. The interpreters will be required to comply with HIPAA and Human Subject Protection policies and sign a confidential agreement form. The participant will only need to participate in a one time interview, so the Researcher does not anticipate to communicate with the participant after the interview. If the participant reaches out to the Researcher after

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the interview, she will take the same precautions with telephone and email as described above. Also if the the participant ask to see the initial analysis of her/his own de-identified data, the Researcher will either send the participant the document via encrypted email or the Researcher will personally give the document to the participant at her Stanford office.

Confidentiality Protections

- b) **Specify PHI (Protected Health Information). PHI is health information linked to HIPAA identifiers (see above). List BOTH health information AND HIPAA identifiers. If you are using STRIDE, use the Clinical Data Work Sheet to ensure that your request will match your IRB-approved protocol. Be consistent with information entered in section 15a.**

Health Information: the participant has a one time cancer diagnosis, the cancer diagnosis occurred within 3 years or less, the cancer diagnosis occurred at age 50 years old or older, the status of the cancer diagnosis (i.e. currently ill with cancer or in remission), the type(s) of health insurance of the cancer patient participant, the status of health insurance coverage of the cancer patient participant.

Identifiers: first name, last name initial, phone number, email, zip code, age, year of immigration to the U.S.

- c) **You are required to comply with University Policy that states that ALL electronic devices: computers (laptops and desktops; OFFICE or HOME); smart phones; tablets; external hard disks, USB drives, etc. that may hold identifiable participant data will be password protected, backed up, and encrypted. See <http://med.stanford.edu/datasecurity/> for more information on the Data Security Policy and links to encrypt your devices.**

Provide any additional information on ALL data security measures you are taking. You must use secure databases such as RedCap <https://clinicalinformatics.stanford.edu/services/redcap.html>. If you are unsure of the security of the system, check with your Department IT representative. Please see <http://med.stanford.edu/irt/security/> for more information on IRT Information Security Services and http://www.stanford.edu/group/security/securecomputing/mobile_devices.html for more information for securing mobile computing devices. Additionally, any PHI data on paper must be secured in an locked environment.

By checking this box, You affirm the aforementioned. Y

The code sheet, research notes, data analysis files, and interview transcripts will be kept in the Researcher's locked cabinet located in her Stanford office suite with restricted entry and as electronic documents/files stored in the Researcher's password protected, encrypted, backed up laptop. The laptop password will only be known by the Researcher.

The audio recordings will be digital and stored at the earliest convenience (no more than 24 hours) to: 1) a password protected, encrypted, backed up external hard drive kept in the Researcher's Stanford office suite (protected as described above); and 2) to the Researcher's secured, HIPAA compliant 'Stanford Medicine Box' online file account within the Researcher's designated restricted data folders.

- d) **Describe how data or specimens will be labeled (e.g. name, medical record number, study number, linked coding system) or de-identified. If you are de-identifying data or specimens, who will be responsible for the de-identification? If x-rays or other digital images are used, explain how and by whom the images will be de-identified.**

Before the interview begins, the participant will be instructed to not identify/say their name or any person's name. If this occurs, the Researcher will edit out the names from the audio recording in order to de-identify the participant's name or any person mentioned.

The participants will not be personally identifiable on the audio recording, research notes, transcriptions and

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data analysis files, by excluding the participants real names on these files and using an assigned an ID code for each participant. A code sheet to associate the participant's number to their name and contact information will be kept separately from the audio recording, research notes, transcriptions and data analysis files. This code sheet will be in the form of a paper to be kept in the Researcher's locked cabinet located in her Stanford office suite with restricted entry and in an electronic document stored in the Researcher's password protected, encrypted, backed up laptop. The Researcher will responsible for the di-identification of data.

- e) **Indicate who will have access to the data or specimens (e.g., research team, sponsors, consultants) and describe levels of access control (e.g., restricted access for certain persons or groups, access to linked data or specimens).**

Only the Researcher will have access and view of the code sheet, participants' identifiers/health information, research notes, data analysis files, and interview transcripts. Only the Researcher and transcription service provider will have access to the di-identified audio files. The transcription service provider will be granted temporary access until the transcription of the audio recording files are completed.

- f) **If data or specimens will be coded, describe the method in which they will be coded so that study participants' identities cannot be readily ascertained from the code.**

All participants will be assigned an ID code. The participants' identity will be coded by linking a systematic ID (letter and numerical combination such as p101, p102, etc.).

- g) **If data or specimens will be coded, indicate who will maintain the key to the code and describe how it will be protected against unauthorized access.**

A code sheet to associate the participant's ID code to their name and contact information will be kept separately from the audio recording, research notes, transcriptions and data analysis files. This code sheet will be in the form of a paper to be kept in the Researcher's locked cabinet located in her Stanford office suite with restricted entry and in an electronic document stored in the Researcher's password protected, encrypted, backed up laptop. Only the Researcher will have access to the code sheet. The laptop password will only be known by the Researcher. Only the Researcher will have access to the key of her locked file cabinet located at her Stanford office.

- h) **If you will be sharing data with others, describe how data will be transferred (e.g., courier, mail) or transmitted (e.g., file transfer software, file sharing, email). If transmitted via electronic networks, describe how you will secure the data while in transit. See <http://www.stanford.edu/group/security/securecomputing/>. Additionally, if you will be using or sharing PHI see http://hipaa.stanford.edu/policy_security.html**

The Researcher will grant temporary access for the transcription service provider to obtain the participant ID coded audio recording file. The audio recording files will be made temporarily accessible through the Researcher's HIPAA compliant 'Stanford Medicine Box' folder for the duration of the transcription service. After transcription is completed, the Researcher will discontinue the transcription service provider's access to the files on 'Stanford Medicine Box'. In order to download these files, the transcription service provider will be required to have a password protected encrypted computer. The transcription provider will be asked to sign a confidentiality agreement form requiring them to comply with the HIPAA and Human Subject Protection policies as well as to delete the audio recording files after service has been completed.

- i) **How will you educate research staff to ensure they take appropriate measures to protect the privacy of participants and the confidentiality of data or specimens collected (e.g. conscious of oral and written communications, conducting insurance billing, and maintaining paper and electronic data)?**

The Researcher will orient the interview interpreters on how to take appropriate measures to protect the privacy of the participants and the confidentiality of data. This will be part of the Human Subjects

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Training/CITI certification. The Researcher will also confirm with the transcription service provider to ensure that the transcriptionists working on the audio recording files are oriented on protecting the privacy of the participants and confidentiality of the data.

12. Potential Conflict of Interest

New PHS regulations require that financial interests must be disclosed by investigators, and those that are identified as financial conflicts of interest must be eliminated or managed prior to final approval of this protocol.

When the Personnel section of this protocol is completed, the faculty investigators will receive an email notifying them of the OPACS requirement. They may either answer "No" to the Financial Interest question from the email, or go to their OPACS dashboard to answer the question.

Investigators who have not received an email from OPACS can still complete their disclosures by going to their OPACS dashboard directly at opacsprd.stanford.edu. They should contact their school's <http://doresearch.stanford.edu/research-scholarship/conflicts-interest/coi-school-contacts> COI Manager with any issues with OPACS.

The table below displays the names of investigators and whether they have entered their financial interest disclosure, & S/B disclosure, if any, in OPACS and the status of review of conflicts of interest.

You will not be able to submit this protocol until the "Financial Interest" question has been answered in OPACS for all investigators listed in the table below.

Review of this protocol by IRB will occur when all investigators listed below have answered Yes or No to the Financial Interest question in OPACS.

Approval of this protocol will only occur when all investigators who have Financial Interests have submitted their OPACS disclosure and review of the information has been completed by the COI Manager.

Note: If any changes to disclosures are made while this page is open, simply reload the page to see current information.

Investigators	Role	Email	Has Financial Interest?	Date Financial Interest Answered	Date OPACS Disclosure Submitted	Date OPACS Review Completed
Kim Rhoads	PD	kim.rhoads@stanford.edu	N	01/21/2015	N/A	N/A
Rachel J Mesia	COP D	rmesia@stanford.edu	N	01/21/2015	N/A	N/A

13. Consent Background

Title: Cancer Experiences in Chinese, Indian and Filipino American Immigrant Families
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13.1 Consent Informed Consent Form English

Sponsor's Consent Version Number: (if any): version 2 - 02.18.15

- a) Describe the informed consent process. Include the following.
- i) Who is obtaining consent? (The person obtaining consent must be knowledgeable about the study.)
 - ii) When and where will consent be obtained?
 - iii) How much time will be devoted to consent discussion?
 - iv) Will these periods provide sufficient opportunity for the participant to consider whether or not to participate and sign the written consent?
 - v) What steps are you taking to minimize the possibility of coercion and undue influence?
 - vi) If consent relates to children and if you have a reason for only one parent signing, provide that rationale for IRB consideration.

The Researcher is obtaining the consent. Consent will be conducted during the scheduled meeting of the interview in a private meeting room of the interview location. Approximately 15-25 minutes will be devoted towards the consent discussion (depending on the need for an interpreter), which will allow for the participant sufficient time to consider whether or not she/he would like to participate in the study. The participant will have at least 2 times to opt out of the study prior to the informed consent process. The Researcher will do the following to minimize the possibility of coercion and undue influence: 1) The \$10 gift item as the 'payment' for participating in the study will not be advertised in the recruitment flyer and study information sheet. It will be disclosed during the informed consent process; 2) There will be at least 3 opportunities for the participant to opt out of the study (recruitment, screening and informed consent process); and 3) The Researcher will orient and instruct the referring CBOs to not question the participant's intent to join the study.

- b) What is the Procedure to assess understanding of the information contained in the consent? How will the information be provided to participants if they do not understand English or if they have a hearing impairment? See /hrpp/Chapter12.html#ch12_2 HRPP Chapter12.2 for guidance.

When reviewing the consent form, the Researcher will ask the participant after each major section review whether or not she/he has any question or concerns. The last page of the form outlines individual items of consent, which provide another opportunity for the Researcher to review these items individually and provide clarifications if needed. Before the participant signs the form, the Researcher will ask if the participant has questions or concerns. If the participants does not understand English, the informed consent using a full version of a translated form, will be conducted with a CITI certified interpreter who will be present in person. The interpreter will be proficient in the participant's language and English.

- c) What steps are you taking to determine that potential participants are competent to participate in the decision-making process? If your study may enroll adults who are unable to consent, describe (i) how you will assess the capacity to consent, (ii) what provisions will be taken if the participant regains the capacity to consent, (iii) who will be used as a legally authorized representative, and (iv) what provisions will be made for the assent of the participant.

During the informed consent process, the Researcher will ask the participant "What more would you like to know?" and assess if the individual expressed a choice about whether or not to participate. This study will not enroll adults who are unable to consent.

14. Assent Background (less than 18 years of age)

15. HIPAA Background

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15.1 Waiver of Authorization for waiver of authorization for recruitment

Recruitment

- a) **Describe the protected health information (PHI) needed to conduct screening or recruitment. PHI is health information linked to HIPAA identifiers (see section 11). List BOTH health information AND HIPAA identifiers. If you are using STRIDE, use the Clinical Data Work Sheet to ensure that your request will match your IRB-approved protocol. Be consistent with information entered in section 11b.**

The responses for the following health information will be collected as yes or no: the participant had a one time cancer diagnosis, the cancer diagnosis occurred within 3 year or less, the cancer diagnosis occurred at the age of 50 years old or older. Identifiers: first name, last name initial, phone number, email.

- b) Please Answer:

Y **Do you certify that the use or disclosure of protected health information involves no more than a minimal risk to the privacy of individuals?**

Y **Do you certify that the research could not practically be conducted with out the waiver?**

Y **Do you certify that you have adequate written assurances that the protected health information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research project, or for other research for which the use or disclosure of protected health information would be permitted?**

Y **Do you certify that the research could not practically be conducted with out access to and use of the protected health information?**

- c) **Please describe an adequate plan to protect any identifiers from improper use and disclosure.**

The eligibility screening document that will be used to record the responses will be saved as an electronic document, if the potential participant is eligible and elects to participate in the interview. The document will be stored in the PI's password protected, encrypted, backed up laptop. The laptop password will only be known by the PI. Only the PI will have view and access to the eligibility screening document. The potential participant's first name, last initial, phone number and email, will not be identifiable on the eligibility screening document. The PI will use an assigned ID code for each participant that completes the screening and elects to participate in the interview. The screened participant code sheet will associate the participant's ID to their identifiers and interview schedule. This code sheet will be kept separately from the eligibility screening document. The code sheet will be in the form of a paper to be kept in the PI's locked cabinet located in her Stanford office suite with restricted entry as well as an electronic document to be kept in the PI's password protected, encrypted, backed up laptop.

- d) **Please describe an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law.**

The code sheet created for documenting the screened participant's ID code, identifiers and interview schedule will be destroyed in Stanford's protected health information shred bin, after the PI completes all of the interviews.

15.2 Authorization hipaa authorization

16. Attachments

Protocol # 33186 (New)
PD: Kim Rhoads
Review Type: Expedited
Medical

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Attachment Name	Attached Date	Attached By	Submitted Date
Email Script Template	02/02/2015	rmesia	
SRC not required - confirmation	02/02/2015	rmesia	
Study flyer English (revised v2)	02/18/2015	rmesia	
Information Sheet English (revised v2)	02/18/2015	rmesia	
Interview questions (revised)	02/18/2015	rmesia	
Phone Script for Study Inquiry & Screening (v2)	02/18/2015	rmesia	
Scientific and Scholarly Review	02/19/2015	kmurphy	

Obligations

The Protocol Director agrees to:

- Adhere to principles of http://humansubjects.stanford.edu/research/documents/eval_study_designGUI03017.pdf sound scientific research designed to yield valid results
- Conduct the study according to the protocol approved by the IRB
- Be appropriately qualified to conduct the research and be trained in Human Research protection, ethical principles, regulations, policies and procedures
- Ensure all research personnel are adequately trained and supervised
- Ensure that the rights and welfare of participants are protected including privacy and confidentiality of data
- Ensure that, when de-identified materials are obtained for research purposes, no attempt will be made to re-identify them.
- Disclose to the appropriate entities any potential conflict of interest
- Report promptly any new information, modification, or http://humansubjects.stanford.edu/research/documents/Events-Info-Report-to-IRB_GUI03P13.pdf unanticipated problems that raise risks to participants or others
- Apply relevant professional standards.

VA Protocol Directors also certify that:

- All unanticipated internal or local SAEs, whether related or unrelated to the research, will be/have been reported to the IRB
- All subjects entered onto the master list of subjects for the study will sign/have signed an informed consent form prior to undergoing any study interactions or interventions, unless granted a waiver by the IRB.

Protocol # 33186 (New)
PD: Kim Rhoads
Review Type: Expedited
Medical

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Any change in the research protocol must be submitted to the IRB for review prior to the implementation of such change. Any complications in participants or evidence of increase in the original estimate of risk should be reported at once to the IRB before continuing with the project. Inasmuch as the Institutional Review Board (IRB) includes faculty, staff, legal counsel, public members, and students, protocols should be written in language that can be understood by all Panel members. The investigators must inform the participants of any significant new knowledge obtained during the course of the research.

IRB approval of any project is for a maximum period of one year. For continuing projects and activities, it is the responsibility of the investigator(s) to resubmit the project to the IRB for review and re-approval prior to the end of the approval period. A Notice to Renew Protocol is sent to the Protocol Director 7 weeks prior to the expiration date of the protocol.

Department Chair must approve faculty and staff research that is not part of a sponsored project. VA applicants must have Division Chief or Ward Supervisor approval. E-mail the Department Chair approval to IRBCoordinator@lists.stanford.edu.

All data including signed consent form documents must be retained for a minimum of three years past the completion of the research. Additional requirements may be imposed by your funding agency, your department, or other entities. (Policy on Retention of and Access to Research Data, Research Policy Handbook,

<http://doresearch.stanford.edu/policies/research-policy-handbook/conduct-research/retention-and-access-research-data>)

PLEASE NOTE: List all items (verbatim) that you want to be reflected in your approval letter (e.g., Amendment, Investigator's Brochure, consent form(s), advertisement, etc.) in the box below. Include number and date when appropriate.

Y By checking this box, I verify that I, as the Protocol Director (PD) responsible for this research protocol, have read and agree to abide by the above obligations, or that I have been delegated authority by the PD to certify that the PD has read and agrees to abide by the above obligations.

Protocol ID: 33186

Protocol Director: Kim Rhoads, MD

STANFORD has policies and procedures for reviewing the scientific and scholarly validity of all proposed research studies. For research that does not otherwise undergo scientific review, the Division Chief, Department Chair, or their designee must provide review of the scientific and scholarly validity of the proposed research. See guidance Evaluating Sound Study Design.

<i>If the Protocol Director is from:</i>	<i>Review is done by:</i>
School of Medicine	Division Chief, Department Chair, or designee
All other schools	Appropriate School Dean or designee

The IRB will rely on your careful consideration and review of the following four questions:

- a. Are the research procedures the least risky procedures that can be performed consistent with sound research design?XYes No
- b. Is the research likely to achieve its aims?.....XYes No
- c. Is the proposed research of sufficient scientific importance to justify the risks entailed?XYes No
- d. Are there adequate resources (e.g. facilities, qualified staff, access to population that will allow recruitment of the required number of participants) to complete the study?.....XYes No

eProtocol application references

q. 2(b) medical
q. 2(a) nonmedical

q. 1(a), 2(a) on medical & nonmedical

q. 1(b), 9(a) medical
q. 1(b), 5(a) nonmed

Resources section a-g on medical & nonmedical

Save form to your computer, attach completed form to email message and send to IRB Manager.

Name of reviewer: Beverly Mitchell

Title of reviewer: Director, Stanford Cancer Institute

Date: 02/19/2015

Reviewer's comments (optional), if any: This study poses no risk to participants and will further the objectives of obtaining additional information on the perceptions of cancer care in underserved populations.

Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University

Application for Amendment to Previously Approved Research

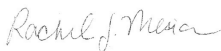
Instructions: Please re-submit your original research ethics approval documents with any amendments highlighted in yellow, attaching this form as a cover sheet. Completed documentation should be submitted as a single PDF by email and in **signed** hard copy to:

Dr Diane Hopkins
 Faculty of Health & Medicine
 B03, Furness College
 Lancaster University
 LA1 4YT
d.hopkins@lancaster.ac.uk

1. Name of applicant: Rachel J. Mesia
2. E-mail address and phone number of applicant: r.mesia@lancaster.ac.uk +1-510-468-8788
3. Title of project: Cancer Care Experiences in Chinese, Indian and Filipino American Immigrant Families
4. Project reference number: RS2014-30
5. Date of original project approval as indicated on the official approval letter (month/year) May 2015

Amendment request
6. Please outline the requested amendment(s): 1. Modified study participant criteria (cancer patient): Time of diagnosis with cancer modified to 10 years or less 2. Additional recruitment methods: Place study information on non-profit/community related websites and communication e-mail lists
7. Please explain your reason(s) for requesting the above amendment(s): 1. The criteria for time of diagnosis with cancer is being modified to 10 years or less, to make recruitment of cancer patients in this study more feasible and help the investigator reach her maximum sample population size for cancer patients. 2. Additional recruitment methods are being added to better aid the recruitment of eligible participants.

Signatures

Applicant:  Date: 02-12-2016
 Project Supervisor: _____ Date: _____
 (if applicable)

February 2014

STANFORD UNIVERSITY

Stanford, CA 94305 [Mail Code 5579]

David D. Oakes, M.D.

(650) 723-5215

CHAIR, PANEL ON MEDICAL HUMAN SUBJECTS

(650) 725-8013

Certification of Human Subjects Approvals

Date: January 31, 2016

To: Robert Haile, DrPH, Medicine - Med/Oncology
Shannon C. Nguyen BS, Rachel J Mesia MPH/PhD(c)

From: David D. Oakes, M.D., Administrative Panel on Human Subjects in Medical Research

Protocol Cancer Experiences in Chinese, Indian and Filipino American Immigrant Families

Protocol ID: 33186

IRB Number: 6208 (Panel: 8)

The IRB approved human subjects involvement in your research project on 01/31/2016. **Prior to subject recruitment and enrollment, if this is: a Cancer-related study, you must obtain Cancer Center Scientific Review Committee (SRC) approval; a CTRU study, you must obtain CTRU approval; a VA study, you must obtain VA R and D Committee approval; and if a contract is involved, it must be signed.**

The expiration date of this approval is 01/31/2017 at Midnight. If this project is to continue beyond that date, you must submit an updated protocol in advance for the IRB's re-approval. If this protocol is used in conjunction with any other human use it must be re-approved. Proposed changes to approved research must be reviewed and approved prospectively by the IRB. No changes may be initiated without prior approval by the IRB, except where necessary to eliminate apparent immediate hazards to subjects. (Any such exceptions must be reported to the IRB within 10 working days.) Unanticipated problems involving risks to participants or others and other events or information, as defined and listed in the Report Form, must be submitted promptly to the IRB. (See Events and Information that Require Prompt Reporting to the IRB at <http://humansubjects.stanford.edu>.)

All continuing projects and activities must be reviewed and re-approved on or before Midnight of the expiration date. The approval period will be less than one year if so determined by the IRB. It is your responsibility to resubmit the project to the IRB for continuing review and to report the completion of the protocol to the IRB within 30 days.

Please remember that all data, including all signed consent form documents, must be retained for a minimum of three years past the completion of this research. Additional requirements may be imposed by your funding agency, your department, or other entities. (See Policy 1.9 on Retention of and Access to Research Data at <http://doresearch.stanford.edu/policies/research-policy-handbook>)

This institution is in compliance with requirements for protection of human subjects, including 45 CFR 46, 21 CFR 50 and 56, and 38 CFR 16.

Waiver of Individual Authorization for recruitment under 45 CFR 164.512(i)(2)(ii)(A),(B),(C), pursuant to information provided in the HIPAA section of the protocol application.



David D. Oakes, M.D., Chair

Approval Period: 01/31/2016 THROUGH 01/31/2017

Review Type: EXPEDITED - CONTINUING REVIEW

Funding: None

Expedited Under Category: 6, 7

Assurance Number: FWA00000935 (SU)

Title: Cancer Experiences in Chinese, Indian and Filipino American Immigrant Families

Approval Period: 01/31/2016 - 01/31/2017

Continuing Review Form

1. Participant Enrollment

- a. **Number of participants entered (or number of specimens examined or charts reviewed) since the beginning of study. If this is a combined VA-Stanford study, in addition indicate how many of the participants (or number of VA specimens examined or VA charts reviewed) enrolled with a VA consent. If this is a multi-site study, in addition to the number of participants enrolled locally, include the number of participants enrolled study-wide.**

A total of 8 participants (5 cancer patients and 3 caregivers) were enrolled.

- b. **Number of males, # of females.**

1 Male Cancer Patient
4 Female Cancer Patients
1 Male Caregiver
2 Female Caregivers

- c. **Minority status of participants entered since beginning of study.**

8 participants with minority status

- d. **Number of children (less than 18 years) entered since beginning of study.**

Not applicable

- e. **Number of other potentially vulnerable subjects (if applicable) entered since the beginning of study, including prisoners, pregnant women, economically and educationally disadvantaged, decisionally impaired and homeless people.**

5 cancer patients

2. Study Problems/Complications

- a. **Number of withdrawals of participants from the research (both participant and investigator initiated) since the beginning of the research study. Provide reasons for the withdrawals.**

None

- b. **Number of participants lost to follow-up since the beginning of the study.**

None

- c. **Provide a narrative summary of the adverse events since the last renewal. Indicate whether adverse events experienced by participants are different from those originally anticipated.**

Not applicable

- d. **Provide a narrative summary (not a list) of the unanticipated problems involving risks to participants or others that have occurred in the research in the past year. Confirm that all events and information that require prompt reporting to the IRB /research/documents/Events-Info-Report-to-IRB_GUI03P13.pdf (guidance GUI-P13) have been reported as required.**

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None

- e. **Provide a narrative summary of all relevant reports received in the past year whether or not the report has been previously submitted to the IRB. Summarize adverse event reports, audit results, and any other reports. Include corrective actions taken as a result of any audits.**

Not applicable

- f. **Complaints about the research in the past year.**

None

- g. **Noncompliance: Has there been any agency, institutional, or other inquiry into noncompliance in the study, or any finding of noncompliance concerning a member of the research team? If yes, please explain.**

None

3. Study Assessment

- a. **Provide a narrative summary of any interim findings from your data in the past year.**

Based on the 8 interviews with individuals who were diagnosed with cancer and their caregivers, there were a variety of challenges faced during the patient's cancer care: the desire to not be a burden to family, emotional coping of diagnosis and treatment, making treatment decisions, other competing priorities, delays in care, and financial support.

- b. **Provide a narrative summary of any recent relevant literature.**

The burden of cancer care in families is frequently described as 'caregiver burden' (Kramer, 1997). There are two types of carer burden described in the literature: objective and subjective. 'Objective burden' results from the physical functions and resources of caring that can change or impede the carer's life (Bastawrous, 2013, Hunt 2003). 'Subjective burden' comes from the psychological, emotional or attitudinal responses towards the 'objective burden' (Bastawrous, 2013). Although most research studies regarding cancer care burden are mainly concerned with how it affects individuals caring for the ill patient, some literature demonstrates the burden from the cancer patient perspectives on both the family carers and themselves. McPherson, Wilson and Murray (2007) identified an expanding area of research that was concerned with how cancer patients who received end-of-life care, perceived themselves as a burden on others. The authors' literature review also demonstrated that the social relationship component of dealing with care during the end of life stage was a major source of self-perceived burden (McPherson, Wilson & Murray, 2007). In a survey study sampling cancer survivor respondents, forty-nine percent reported unmet needs that were 'non-medical' and fifty-three percent "[agreed] that the practical and emotional consequences with cancer were often harder than the medical issues" (Wolff, 2007: p. 8).

- c. **Attach Data Safety Monitoring Reports in section 16 received in the past year which have not previously been submitted to the IRB.**

Not applicable

- d. **Provide a narrative summary of benefits experienced by participants in the past year.**

None

Protocol # 33186 (Continuing Review)
PD: Robert Haile
Review Type: Expedited
Medical

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e. Provide an assessment of whether the relationship of risks to potential benefits has changed.

None

4. Description of remainder of project:

- a. Y Is the study open to enrollment?
- b. N Is the study permanently closed to enrollment of new participants?
- c. N Have all participants completed all research-related interventions?
- d. Y Are you still engaged in research-related intervention(s)? If yes, please describe.
I am still interviewing participants to meet study objectives.
- e. N Do you wish to renew this study only for long term follow-up?
- f. N Are you only doing data analysis?

5. Potential Conflict of Interest

- N Is there a change in the conflicting interest status of this protocol?

6. Protocol Changes

Please note that if these changes involve changes to Radiation Safety or Biosafety, the IRB will hold its approval until Radiation Safety or Biosafety forwards its approval to the IRB.

- Summarize all of the proposed changes to the protocol application including consent form changes.

None

- Indicate Level of Risk

No Change

- Describe any other changes.

None

Protocol Director				
Name		Degree (program/year if student)		Title
Robert Haile		DrPH		Professor
Dept	Mail Code	Phone	Fax	E-mail

Protocol # 33186 (Continuing Review)
 PD: Robert Haile
 Review Type: Expedited
 Medical

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CITI Training current				Y
Admin Contact				
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CITI Training current				Y
Co-Protocol Director				
Name Rachel J Mesia		Degree (program/year if student) MPH/PhD(c)		Title Program Manager
Dept Cancer Clinical Trials Office	Mail Code 5757	Phone (650) 723-7119	Fax (650) 724-4042	E-mail rmesia@stanford.edu
CITI Training current				Y
Other Contact				
Name		Degree (program/year if student)		Title
Dept	Mail Code	Phone	Fax	E-mail
CITI Training current				
Faculty Sponsor				
Name		Degree (program/year if student)		Title
Dept	Mail Code	Phone	Fax	E-mail
CITI Training current				
Other Personnel				

Participant Population(s) Checklist

Yes/No

- Children (under 18) N
- Pregnant Women and Fetuses N

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- Neonates (0 - 28 days) N
- Abortuses N
- Impaired Decision Making Capacity N
- Cancer Subjects Y
- Laboratory Personnel N
- Healthy Volunteers Y
- Students N
- Employees N
- Prisoners N
- Other (i.e., any population that is not specified above) N

Study Location(s) Checklist

Yes/No

- Stanford University Y
- Clinical & Translational Research Unit (CTRU)
- Stanford Hospital and Clinics
- Lucile Packard Children's Hospital (LPCH)
- VAPAHCS (Specify PI at VA)
- Other (Click ADD to specify details) Y

Location / Country	Location	Contact Name	Contact Phone	Contact Email	Permission ?	IRB?
Fremont Public Library (Fremont, CA)	US				N	N
Newark Public Library (Newark, CA)	US				N	N
Milpitas Public Library (Milpitas, CA)	US				N	N
Castro Valley Public Library (Castro Valley, CA)	US				N	N
Belmont Public Library (Belmont, CA)	US				N	N
San Mateo Main Library	US				N	N

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San Mateo, CA)						
John Daly Library (Daly City, CA)	US				N	N
Palo Alto City Library (Palo Alto, CA)	US				N	N
San Jose Public Libraries (San Jose, CA)	US				N	N
Capital One Community Room (San Francisco, CA)	US				N	N
Umpqua Bank Meeting Room (San Francisco, CA)	US				N	N
Critosphere Meeting Space (Fremont, CA)	US				N	N

General Checklist

Multi-site

Yes/No

- Is this a multi-site study? A multi-site study is generally a study that involves one or more medical or research institutions in which one site takes a lead role.(e.g., multi-site clinical trial)

N

Collaborating Institution(s)

Yes/No

- Are there any collaborating institution(s)? A collaborating institution is generally an institution that collaborates equally on a research endeavor with one or more institutions.

N

Cancer Institute

Yes/No

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- Cancer-Related Studies (studies with cancer endpoints), Cancer Subjects (e.g., clinical trials, behavior/prevention) or Cancer Specimens (e.g., blood, tissue, cells, body fluids with a scientific hypothesis stated in the protocol). Y

Drug /Device

Yes/No

- Investigational drugs, biologics, reagents, or chemicals? N
- Commercially available drugs, reagents, or other chemicals administered to subjects (even if they are not being studied)? N
- Investigational Device / Commercial Device used off-label? N
- IDE Exempt Device (Commercial Device used according to label, Investigational In Vitro Device or Assay, or Consumer Preference/Modifications/Combinations of Approved Devices) N
- Protocol involves studying potentially addicting drugs? N

Clinical Trials

Yes/No

- Click "yes" to confirm that you have accessed the website and read the clinicaltrials.gov reporting requirements provided.
- This study will be registered on clinicaltrials.gov?

Tissues and Specimens

Yes/No

- Human blood, cells, tissues, or body fluids (tissues)? N
- Tissues to be stored for future research projects? N
- Tissues to be sent out of this institution as part of a research agreement? For guidelines, please see <http://stanford.edu/group/ICO/researcher/reMTA.html>
<http://stanford.edu/group/ICO/researcher/reMTA.html> N

Biosafety (APB)

Yes/No

- Are you submitting a Human Gene Transfer investigation using biological agent or recombinant DNA vector? If yes, please complete and attach the Gene Transfer Protocol Application Supplemental Questions to section 16 of the eProtocol application. N
- Are you submitting a Human study using biohazardous/infectious agents? If yes, refer to the <http://www.stanford.edu/dept/EHS/prod/researchlab/bio/index.html> Administrative Panel on BioSafety website prior to performing studies. N
- Are you submitting a Human study using samples from subjects that contain biohazardous/infectious agents? If yes, refer to the <https://ehsapprdl.stanford.edu/eprobio/> N

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PD: Robert Haile
Review Type: Expedited
Medical

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Administrative Panel on BioSafety website prior to performing studies.

	Yes/No
Human Embryos or Stem Cells	
<ul style="list-style-type: none">• Human Embryos or gametes?• Human Stem Cells (including hESC, iPSC, cancer stem cells, progenitor cells).	N N
Veterans Affairs (VA)	
<ul style="list-style-type: none">• The research recruits participants at the Veterans Affairs Palo Alto Health Care System(VAPAHCS).• The research involves the use of VAPAHCS non-public information to identify or contact human research participants or prospective subjects or to use such data for research purposes.• The research is sponsored (i.e., funded) by VAPAHCS.• The research is conducted by or under the direction of any employee or agent of VAPAHCS (full- time, part-time, intermittent, consultant, without compensation (WOC), on-station fee-basis, on- station contract, or on-station sharing agreement basis) in connection with her/his VAPAHCS responsibilities.• The research is conducted using any property or facility of VAPAHCS.	N N N N N
Equipment	
<ul style="list-style-type: none">• Use of Patient related equipment? If Yes, equipment must meet the standards established by Hospital Instrumentation and Electrical Safety Committee (650-725-5000)• Medical equipment used for human patients/subjects also used on animals?• Radioisotopes/radiation-producing machines, even if standard of care? http://www.stanford.edu/dept/EHS/prod/researchlab/radlaser/Human_use_guide.pdf More Info	N N N
Payment	
<ul style="list-style-type: none">• Subjects will be paid/reimbursed for participation? See payment considerations.	Y
Funding	
<ul style="list-style-type: none">• Training Grant?• Program Project Grant?• Federally Sponsored Project?	N N N

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- Industry Sponsored Clinical Trial?

N

Funding

NONE

Funding - Grants/Contracts

Funding - Fellowships

Gift Funding

Dept. Funding

Other Funding

Expedited Form

A protocol must be no more than minimal risk (i.e., "not greater than those ordinarily encountered in daily life") AND must only involve human subjects in one or more of the following paragraphs.

Select one or more of the following paragraphs:

1. N **Clinical studies of drugs and medical devices only when condition (a) or (b) is met.**
 - a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.)
 - b) Research on medical devices for which
 - i) an investigational device exemption application (21 CFR Part 812) is not required; or
 - ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.
2. N **Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:**
 - a) from healthy, nonpregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or
 - b) from other adults and children, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.
3. N **Prospective collection of biological specimens for research purposes by non invasive means.**

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4. N **Collection of data through non invasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.)**
Examples:
- physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy;
 - weighing or testing sensory acuity;
 - magnetic resonance imaging;
 - electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography;
 - moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.
5. N **Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). (NOTE: Some research in this paragraph may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)**
6. Y **Collection of data from voice, video, digital, or image recordings made for research purposes.**
7. Y **Research on individual or group characteristics or behavior(including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)**

Resources:

a) **Qualified staff.**

Please state and justify the number and qualifications of your study staff.

Protocol Director: Robert W. Haile, DrPH, is a Professor in the Division of Oncology at Stanford University School of Medicine and the Associate Director for Population Sciences at the Stanford Cancer Institute. His main areas of research interest include genetics, cancer epidemiology and cancer health disparities. Dr. Haile has served as faculty sponsor and research mentor to postdoctoral fellows.

Co-Protocol Director: Rachel Mesia, MPH and PhD(c) is a Program Manager with the Stanford Cancer Institute. Ms. Mesia has extensive experience in addressing health disparities in the field of cancer control, through community-engaged projects, coalitions and programs. She is a PhD candidate at the University of Lancaster's Faculty of Health and Medicine Department. She is supervised by 2 senior faculty members of the University of Lancaster, who are providing academic guidance on her research project, thesis writing

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and dissertation defense. Ms. Mesia will lead all aspects of the project: recruiting and screening eligibility of potential participants; providing oversight of interpreters' and transcriptionists' compliance with Human Subjects Protection and HIPAA policies; conducting the informed consent and research interviews; securing, managing and analyzing research data; writing the dissertation, scientific manuscripts and other written works; presenting findings for her dissertation defense as well as at scientific, educational and professional meetings.

Eligibility Screening Interpreters: Language Translation Inc. will provide interpreter services for the eligibility screening of potential participants who do not speak English or are limited English speaking. Their interpreters abide by the Interpreter Code of Ethics, comply with HIPAA guidelines, and are required to sign the agency's confidentiality agreement.

Interview Interpreters: The interpreters will be experienced in health settings as well as proficient in English and the language spoken by the research participant. The Researcher will provide oversight of ensuring that the interview interpreters are trained in Human Subjects Protection and are CITI certified. The interpreters will be required to sign a confidentiality agreement form.

Professional Transcription Service: Verbal Ink will provide the transcription service of the audio recorded interviews, which will be completed by trained transcriptionists. Verbal Ink is fully compliant with HIPAA requirements and the Association for Healthcare Documentation Integrity's code of ethics for medical transcriptionists. They also have confidentiality procedures to ensure that the research data will remain private, which will include confidentiality agreements, background checks, and other technical safeguards.

b) Training.

Describe the training you will provide to ensure that all persons assisting with the research are informed about the protocol and their research-related duties and functions.

Rachel Mesia, the Researcher, has completed the Collaborative Institutional Training Initiative (CITI) Human Subjects Research Protections Curriculum and HIPAA Certification for Clinical Researchers through Stanford University. Dr. Haile is also CITI and HIPAA certified through Stanford University

Ms. Mesia will provide oversight of the Interview Interpreters' Human Subjects Protection training and completion of the CITI certification. Both the Interpreters and Professional Transcription Service will be required to sign and abide by a confidentiality agreement which outlines HIPAA and Human Subjects Protection policies as well as procedures for handling the audio recording files of interviews (specific to transcription service).

c) Facilities.

Please describe and justify.

The interviews will take place in private meeting rooms in local public libraries and meeting space facilities in the San Francisco Bay Area. All interview locations are selected to maintain the highest level of confidentiality, but also to protect the physical safety of the Researcher. These places are not associated with community organization and support/social group settings where recruitment will take place. Furthermore, the private meeting rooms are located in buildings where there are employees present, so that the Researcher does not conduct the interview as a 'lone worker'. Various locations were selected in order to provide the participant convenience with commuting to and from the place of interview.

d) Sufficient time.

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Explain whether you will have sufficient time to conduct and complete the research. Include how much time is required.

This study has a projected timeline of 3 years, beginning March 2015 and ending December 2017. A standing monthly meeting will serve as infrastructure for driving the work forward. Months 1-8: The first 8 months will be used to recruit and screen potential participants, conduct key informant interviews, transcribe interviews, and conduct initial data analysis. Months 9-22: The Researcher will analyze the research data and write dissertation. Months 23-26: These 4 months will be spent on finalizing the dissertation for the Viva (i.e. oral defense of dissertation). Months 27-28: These 2 months will be spent on preparing for and completing Viva as well as making final corrections for the submission of the thesis publication. Months 29-36: The last 7 months will focus on writing and production of manuscripts for peer reviewed journals and health literature.

e) Access to target population.

Explain and justify whether you will have access to a population that will allow recruitment of the required number of participants.

The Researcher has current partnerships with community-based organizations (CBO) in the San Francisco Bay Area who reach and serve the community members that are representative of the study's sample population. The CBOs will invite the Researcher to their community meetings/ events, educational programs and support/social groups, so that she can provide a general overview of the study and disseminate recruitment materials. Flyers will be posted in CBO community spaces.

f) Access to resources if needed as a consequence of the research.

State whether you have medical or psychological resources available that participants might require as a consequence of the research when applicable. Please describe these resources.

The main risks for participants are loss of privacy and emotional distress from the recollection of cancer care experiences. The Researcher compiled a list of local resources that can provide support groups and/or psychological support, if the participants experience emotional distress. The types of questions in the interview will be described to the participants during the consent process, which will allow for the participant to consider in advance the topic area/question she/he does not want to answer or decline participation in the interview.

g) Lead Investigator or Coordinating Institution in Multi-site Study.

Please explain (i) your role in coordinating the studies, (ii) procedures for routine communication with other sites, (iii) documentation of routine communications with other sites, (iv) planned management of communication of adverse outcomes, unexpected problems involving risk to participants or others, protocol modifications or interim findings.

1. Purpose

a) In layperson's language state the purpose of the study in 3-5 sentences.

The purpose of the study is collect data on factors related to the burden (i.e. challenges, obstacles) in cancer care, experienced by Chinese, Indian and Filipino American immigrant families. The study findings are expected to enhance the limited knowledge about the circumstances and conditions of Asian American families when caring for illness. With new knowledge, public health practitioners and health professionals

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can better understand ways to address cancer support needs and health disparities.

- b) **State what the Investigator(s) hope to learn from the study. Include an assessment of the importance of this new knowledge.**

This study will address the gaps in knowledge about Asian American health and immigrant populations. The study aims to learn about: 1) what cancer care is regarded as from the viewpoints of cancer patients and their carers; 2) the cancer care burdens experienced within the family, based on the expectations, choices and barriers recognized by the study participants; and 3) the main determinants of health that affect the burdens in cancer care. American cancer experiences have been broadly examined in different context, but there is limited research about cancer experiences in Asian American families. Generating evidence in this topic area may improve understanding of how to address the cancer burden and health disparities in Asian American communities.

- c) **Explain why human subjects must be used for this project. (i.e. purpose of study is to test efficacy of investigational device in individuals with specific condition; purpose of study is to examine specific behavioral traits in humans in classroom or other environment)**

This is a qualitative study aiming to examine the background, perspectives, and experiences of individuals diagnosed with cancer and their family carers. Therefore, human subjects are necessary for providing feedback related to the Researcher's research aims.

2. Study Procedures

- a) **Please SUMMARIZE the research procedures, screening through closeout, which the human subject will undergo. Refer to sections in the protocol attached in section 16, BUT do not copy the clinical protocol. Be clear on what is to be done for research and what is part of standard of care.**

RECRUITMENT: The Researcher will conduct recruitment at community meetings/events, educational programs and support/social group meetings. Also study recruitment information will be promoted via relevant non-profit and community websites and communication e-mail lists. At the recruitment settings, the Researcher will provide a brief overview of the study and distribute the study flyer and information sheet. The potential participants will be invited to directly contact the Researcher over the phone or email to obtain more study information or inform the Researcher of her/his interest in joining the study. At the recruitment settings, the Researcher will not collect responses about enrolling in the study. Also partnering community organizations will post/display the study recruitment flyer in their community space. If a potential participant inquires about the study, she/he will be invited to contact the Researcher directly for more information and express interest in joining the study. The CBOs will be instructed: 1) to only acknowledge study information that is available on the flyer; 2) to not collect information from the potential participants; and 3) to not ask if the potential participant plans to join the study.

Opt Out Opportunity #1: During recruitment, potential participant can choose not to respond to the Researcher's invitation to be screened and join the study.

STUDY ELIGIBILITY SCREENING: The Researcher will screen the potential participant eligibility over the telephone. If a potential participant does not speak English, the Researcher will seek her/his permission to involve an interpreter to assist with communication during the screening. After the screening, the Researcher will seek permission from non-English speaking potential participant to have an interpreter present during the informed consent process and interview.

If the potential participant decides not to proceed with the study, the Researcher will inform that any

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information collected about her/him associated with the recruitment and screening will be destroyed. Among the potential participant who meet the eligibility criteria and agree to an interview, the Researcher will proceed with scheduling an interview appointment over the phone. The potential cancer patient participants will be asked to identify the 'family carer' she/he would like to involve in the study. The Researcher will ask the potential participant to invite the 'family carer' to contact the Researcher. If the family carer informs the Researcher of her/his interest in joining the study, the Researcher will conduct the eligibility screening as described earlier.

Opt Out Opportunity #2: Before screening begins and during the screening, the Researcher will give the opportunity for the potential participant to opt out of responding to the Researcher's screening questions. After the screening, the Researcher will provide another opportunity for the potential participant to opt out of scheduling a meeting to be interviewed.

STUDY INTERVIEW: At the interview site, the Researcher will escort the participant into the private meeting room. The informed consent process and interviews will be structured around the participant's preferred spoken language. Therefore if necessary, an interpreter will be physically present to assist with the informed consent process and interview.

Opt Out Opportunity #3: During the informed consent process and before signing the form, the Researcher will provide the potential participant to opt out of the study. The participant will also be informed that they can end their participation in the study at any time.

After welcome and introductions in the meeting room, the Researcher will proceed with the informed consent process. Before the participant signs the form, the Researcher will ask if there are concerns/questions as well as confirm if the interview can be continued with the interpreter present. After the participant agrees to participate and signs the consent form, a copy will be provided. If the participant declines to participate, the Researcher will inform that any information collected about her/him associated with the recruitment and screening will be destroyed.

The Researcher will begin the interview letting the participant know that audio recording and interview has begun. The Researcher will conclude the interview by reviewing the key themes of what the Researcher understood from the interview. At the end of the interview, the Researcher will let the participant know that the audio recording has stopped. Then the Researcher will ask if there are any concerns or questions to be addressed. The participants will also be asked of their interest in seeing their own de-identified data with aggregated thematic comments in the preliminary part of the data analysis. Lastly, the Researcher will provide the participant a listing of local support resources and thank the participant with the gift.

b) Explain how the above research procedures are the least risky that can be performed consistent with sound research design.

The following explains how the research procedures minimize risks to the participants:

- 1) The Researcher will screen the participants over the telephone, so that the participant does not feel subjected to being physically identified during the screening and prior to the informed consent/interview meeting.
- 2) The Researcher will ask the cancer patient participant to identify and invite the family carer to participate in the study, so that the cancer patient participant has the free choice of selecting who she/he would like to involve in the study.
- 3) In order to involve minority populations who may be non-English or limited English speaking, a CITI certified interpreter with health experience will help to provide the least bias and most accurate interpretation under strict confidentiality and privacy guidelines of HIPAA and human subject research.

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4) Data will be collected from the participant during a one time, audio recorded interview. The audio recording and its transcription will allow the Researcher to analyze the collected data more accurately without additional post interview follow-up.
5) The Researcher will conduct the interview individually in a private meeting room. This will allow for the participant to feel more comfortable or secure about sharing certain types of information with the Researcher and without required presence of the other family member involved in the study.

- c) **State if deception will be used. If so, provide the rationale and describe debriefing procedures. Since you will not be fully informing the participant in your consent process and form, complete an alteration of consent (in section 13). Submit a debriefing script (in section 16).**

N/A

- d) **State if audio or video recording will occur. Describe what will become of the recording after use, e.g., shown at scientific meetings, erased. Describe the final disposition of the recordings.**

Audio recording of the interviews will occur. This will enable the production of transcripts which will support the Researcher's work in conducting high quality data analysis (e.g. identification of important themes from direct participant quotes). The audio recordings will be transcribed by a professional transcription service. The participant's name will not be identifiable on the audio recording. All participants will be identified on the interview recording by their ID code. Audio recordings will be digital and stored at the earliest convenience (no more than 24 hours) to: 1) an encrypted external hard drive kept in the in the Researcher's locked cabinet located in her Stanford office suite with restricted entry; and 2) in the Researcher's 'Stanford Medicine Box' account within the designated restricted HIPAA compliant data folders. The transcription service provider will be required to transcribed from a password protected encrypted computer as well as to delete the audio recording files after transcription service has been completed. Audio recording files will be kept until the Researcher's degree is awarded. After degree has been awarded, the audio recording files will be deleted from the encrypted external hard drive and the Researcher's 'Stanford Medicine Box' account.

- e) **Describe alternative procedures or courses of treatment, if any, that might be advantageous to the participant. Describe potential risks and benefits associated with these. Any standard treatment that is being withheld must be disclosed in the consent process and form. (i.e. standard-of-care drug, different interventional procedure, no procedure or treatment, palliative care, other research studies).**

N/A

- f) **Will it be possible to continue the more (most) appropriate therapy for the participant(s) after the conclusion of the study?**

N/A

- g) **Study Endpoint. What are the guidelines or end points by which you can evaluate the different treatments (i.e. study drug, device, procedure) during the study? If one proves to be clearly more effective than another (or others) during the course of a study, will the study be terminated before the projected total participant population has been enrolled? When will the study end if no important differences are detected?**

N/A

3. Background

- a) **Describe past experimental and/or clinical findings leading to the formulation of the study.**

N/A

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- b) Describe any animal experimentation and findings leading to the formulation of the study.

N/A

4. Radioisotopes or Radiation Machines

- a) List all standard of care procedures using ionizing radiation (radiation dose received by a subject that is considered part of their normal medical care). List all research procedures using ionizing radiation (procedures performed due to participation in this study that is not considered part of their normal medical care). List each potential procedure in the sequence that it would normally occur during the entire study. http://www.stanford.edu/dept/EHS/prod/researchlab/radlaser/Human_use_guide.pdf
More Info

Identify Week/Month of study	Name of Exam	Identify if SOC or Research
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- b) For research radioisotope projects, provide the following radiation-related information:

Identify the radionuclide (s) and chemical form (s).

For the typical subject, provide the total number of times the radioisotope and activity will be administered (mCi) and the route of administration.

If not FDA approved provide dosimetry information and reference the source documents (package insert, MIRD calculation, peer reviewed literature).

- c) For research radiation machine projects, provide the following diagnostic procedures:

For well-established radiographic procedures describe the exam.

For the typical subject, identify the total number of times each will be performed on a single research subject.

For each radiographic procedure, provide the setup and technique sufficient to permit research subject dose modeling. The chief technologist can usually provide this information.

For radiographic procedures not well-established, provide FDA status of the machine, and information sufficient to permit research subject dose modeling.

- d) For research radiation machine projects, provide the following therapeutic procedures:

For a well-established therapeutic procedure, identify the area treated, dose per fraction and number of fractions. State whether the therapeutic procedure is being performed as a normal part of clinical management for the research participants' medical condition or whether it is being performed because the research participant is participating in this project.

For a therapeutic procedure that is not well-established, provide FDA status of the machine, basis for dosimetry, area treated, dose per fraction and number of fractions.

5. Devices

- a) Please list in the table below all Investigational Devices (including Commercial Devices used off-label) to be used on participants

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- b) Please list in the table below all IDE Exempt Devices (Commercial Device used according to label, Investigational In Vitro Device or Assay, or Consumer Preference/Modifications/Combinations of Approved Devices) to be used on participants.

6. Drugs, Reagents, or Chemicals

- a) Please list in the table below all investigational drugs, reagents or chemicals to be administered to participants.
- b) Please list in the table below all commercial drugs, reagents or chemicals to be administered to participants.

7. Medical Equipment for Human Subjects and Laboratory Animals

If medical equipment used for human patients/participants is also used on animals, describe such equipment and disinfection procedures.

N/A

8. Participant Population

- a) State the following: (i) the number of participants expected to be enrolled at Stanford-affiliated site(s); (ii) the total number of participants expected to enroll at all sites; (iii) the type of participants (i.e. students, patients with certain cancer, patients with certain cardiac condition) and the reasons for using such participants.

None of the participants will be enrolled at Stanford-affiliated sites. A total of 18 participants are expected to enroll in this study. The types of participants are: 1) adults diagnosed with cancer for the first time within the last 10 years; and 2) individuals who are identified as an adult family caregiver by the cancer patient. The Researcher does not intend to recruit Stanford cancer patients. The purpose for recruiting these types of participants is to collect data from 2 types of perspectives relating to family experiences with cancer care.

- b) State the age range, gender, and ethnic background of the participant population being recruited.

Both genders will be included. Individuals who were diagnosed with cancer will be aged 50 years old or older and self-identified as Chinese, Filipino or Indian. Individuals who are 'family carers', will be aged 25 years old or older and self-identified any racial/ethnic background.

- c) State the number and rationale for involvement of potentially vulnerable subjects in the study (including children, pregnant women, economically and educationally disadvantaged, decisionally impaired, homeless people, employees and students). Specify the measures being taken to minimize the risks and the chance of harm to the potentially vulnerable subjects and the additional safeguards that have been included in the protocol to protect their rights and welfare.

There will be a total of 9 cancer diagnosed individuals and 9 of their family carers enrolled in the study. Minority cancer patients/survivors and their family carers could be considered vulnerable under the current definition, with specific regard to having experienced a cancer illness, being possibly economically and

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educationally disadvantaged, and possibly marginalized as a result of their ethnicity, immigrant or language background. Without research from these populations, evidence-based knowledge will not be available to help identify and reduce health disparities and cancer burden. Knowledge from this study contributes to some of the ways Stanford Cancer Institute advances its mission in comprehensive patient care, research discovery, advanced professional training, and community outreach. The Researcher will: 1) provide participants several opportunities to opt out of the eligibility screening and study interview; 2) inform participants about the types of questions that will be asked prior to the start of the interview; 3) ask participants their permission to have an interpreter present during the screening and interview; and 4) give participants a list of local resources for accessing psychological/social support.

- d) If women, minorities, or children are not included, a clear compelling rationale must be provided (e.g., disease does not occur in children, drug or device would interfere with normal growth and development, etc.).**

Minors will not be included, because there is no foreseen benefit of involving minors in a study focused on adult cancer patient/survivors and adult family carers.

- e) State the number, if any, of participants who are laboratory personnel, employees, and/or students. They should render the same written informed consent. If payment is allowed, they should also receive it. Please see Stanford University policy.**

None of the research participants will be a student, laboratory personnel and/or employee of the Researcher.

- f) State the number, if any, of participants who are healthy volunteers. Provide rationale for the inclusion of healthy volunteers in this study. Specify any risks to which participants may possibly be exposed. Specify the measures being taken to minimize the risks and the chance of harm to the volunteers and the additional safeguards that have been included in the protocol to protect their rights and welfare.**

9 healthy volunteers who are family carers of the cancer patients will be enrolled. Family carers are necessary for this study, because the purpose of the study is learn from different perspectives related to cancer care challenges in families. As described above, the Researcher will: 1) provide participants several opportunities to opt out of the eligibility screening and study interview; 2) inform participants about the types of questions that will be asked prior to the start of the interview; 3) ask participants their permission to have an interpreter present during the screening and interview; and 4) give participants a list of local resources for accessing psychological/social support.

- g) How will you identify participants for recruitment? (E.g., by: chart review; referral from treating physician; response to ad). Attach recruitment materials in Section #16 (Attachments). All Final or revised recruitment materials, flyers, etc. must be submitted to the IRB for review and approval before use. You may not contact potential participants prior to IRB approval. See Advertisements: Appropriate Language for Recruitment Material.**

The sample population will be recruited through purposive and snowball sampling. Recruitment will be conducted in local SF Bay Area communities. The Researcher has partnerships with community-based organizations (CBO) who outreach and serve members representing the sample population. The CBOs will provide the Researcher with opportunities to conduct recruitment at their community meetings/events, educational programs and support/social group meetings. At the recruitment settings, the Researcher will provide a brief overview of the study and distribute the study flyer and information sheet. The flyers and information sheet will be available in English, Tagalog, Chinese, Hindi and Punjabi. The potential participants will be invited to directly contact the Researcher over the phone or email to obtain more study information or inform the Researcher of her/his interest in joining the study. At the recruitment settings, the Researcher will not collect responses about enrolling in the study.

Partnering CBOs will post/display the study recruitment flyer in their community space. If a potential

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participant inquires about the study, she/he will be invited to contact the Researcher directly for more information and express interest in joining the study. The CBOs will be instructed: 1) to only acknowledge study information that is available on the flyer; 2) to not collect information from the potential participants; and 3) to not ask if the potential participant plans to join the study.

If the potential participant corresponds with the Researcher over email, the Researcher will respond via secure email any questions or concerns the potential participant may have as well as provide the study information sheet. If the potential participant requests to be contacted over telephone, the Researcher will call the participant to review the study information and answer questions or concerns.

h) Inclusion and Exclusion Criteria.

Identify inclusion criteria.

Participant diagnosed with cancer: 1) Received diagnosis of cancer only one time, within the last 10 years or less, at the age of 50 years old or older; 2) Self-identifies as Chinese, Filipino or Indian; 3) Immigrated to the U.S. at the age of 25 years old or older; 4) Received cancer treatment in the U.S.

Participant who was identified as a 'family carer' by the cancer diagnosed participant: Was or is currently involved with the cancer patient participant's care at the age of 25 years old or older.

Identify exclusion criteria.

- 1) The person has had a reoccurring cancer diagnosis.
- 2) The person cannot speak a language spoken by the investigator or interpreter: English, Mandarin, Cantonese, Tagalog, Ilocano, Hindi or Punjabi.
- 3) The person's place of residence is not in the U.S.
- 4) The person's cancer care was not received in the U.S.
- 5) The person is outside the age range specified in the inclusion criteria.
- 6) The interview cannot take place in any of the proposed locations.

i) Describe your screening procedures, including how qualifying laboratory values will be obtained. If you are collecting personal health information prior to enrollment (e.g., telephone screening), please request a waiver of authorization for recruitment (in section 15).

Screening procedures will be performed over the telephone and with an interpreter if necessary. After the potential participant expresses interest in joining the study, the Researcher will ask permission to screen the potential participant with study eligibility questions. In order to classify the participant type, the Researcher will ask the potential participant to identify if she/he is participating in the study either as an individual diagnosed with cancer or as a family carer of the cancer patient. If the potential participant responds to being a cancer patient, the Researcher will proceed with asking if the participant has only been diagnosed with cancer 1 time, if the diagnosis occurred 10 years ago or less, and if the diagnosis occurred at age 50 years old or older. Collecting health information about the cancer patient prior to enrollment in the study is necessary, because the Researcher has a specific criteria for the type of sample population she is studying.

j) Describe how you will be cognizant of other protocols in which participants might be enrolled. Please explain if participants will be enrolled in more than one study.

It is possible that the participant may be enrolled in a clinical trial as part of her/his cancer care. However, since this is a non-interventional study for data collection purposes, the Researcher will not ask the participant's enrollment status in a clinical trial. This will also limit the amount of health information that the participant is being asked to disclose for the study.

k) Payment. Explain the amount and schedule of payment, if any, that will be paid for participation in the study. Substantiate that proposed payments are reasonable and commensurate with the expected contributions of participants and that they do not constitute undue pressure on participants to

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volunteer for the research study. Include provisions for prorating payment. See payment considerations

The participants will receive a payment for their participation in the study, in the form of a \$10 value gift item. The gift item will not be promoted in the study recruitment flyer and summary sheet, but will be disclosed during the informed consent process. This is to avoid a potential situation during recruitment, in which a participant chooses to enroll in the study to receive the gift item.

l) Costs. Please explain any costs that will be charged to the participant.

N/A

m) Estimate the probable duration of the entire study. Also estimate the total time per participant for: (i) screening of participant; (ii) active participation in study; (iii) analysis of participant data.

This study has a projected timeline of 3 years and 10 months, beginning March 1, 2015 and ending December 31, 2018. Each participant is expected to be screened for 15 minutes. The time for active participation in the study is 15 - 25 minutes for informed consent process and 1 hour for the interview. The participant may voluntarily express interest in reviewing their own de-identified data with aggregated thematic comments during the Researcher's preliminary part of the data analysis. However, this is not mandatory. Data collection is anticipated for 7 months. The estimated time for the Researcher's data analysis is 32 months.

9. Risks

- a) For the following categories include a scientific estimate of the frequency, severity, and reversibility of potential risks. Wherever possible, include statistical incidence of complications and the mortality rate of proposed procedures. Where there has been insufficient time to accumulate significant data on risk, a statement to this effect should be included. (In describing these risks in the consent form to the participant it is helpful to use comparisons which are meaningful to persons unfamiliar with medical terminology.)

Investigational devices.

N/A

Investigational drugs. Information about risks can often be found in the Investigator's brochure.

N/A

Commercially available drugs, reagents or chemicals. Information about risks can often be found in the package insert.

N/A

Procedures to be performed. Include all investigational, non-investigational and non-invasive procedures (e.g., surgery, blood draws, treadmill tests).

N/A

Radioisotopes/radiation-producing machines (e.g., X-rays, CT scans, fluoroscopy) and associated risks.

N/A

Physical well-being.

N/A

Psychological well-being.

There is a potential risk of psychological or emotional distress related to recalling experiences associated

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with their cancer care experiences as well as the conditions and circumstances they live in. The frequency of psychological or emotional distress in study interviews is uncommon and severity is minimal.

Economic well-being.

N/A

Social well-being.

N/A

Overall evaluation of Risk.

Low - innocuous procedures such as phlebotomy, urine or stool collection, no therapeutic agent, or safe therapeutic agent such as the use of an FDA approved drug or device.

- b) **If you are conducting international research, describe the qualifications/preparations that enable you to both estimate and minimize risks to participants. Also complete the 'http://humansubjects.stanford.edu/research/documents/intl_rsch_APP-11.doc' International Research Form and attach it in the Attachments section. If not applicable, enter N/A.**

N/A

- c) **Describe the planned procedures for protecting against and minimizing all potential risks. Include the means for monitoring to detect hazards to the participant (and/or to a potential fetus if applicable). Include steps to minimize risks to the confidentiality of identifiable information.**

- 1) The Researcher will screen the participants over the telephone, so that the participant doesn't feel subjected to being physically identified prior to the informed consent process/interview meeting.
- 2) The Researcher will ask permission from the participant to have a CITI certified interpreter physically present for assisting with the informed consent process and interview. The interpreter will be required to sign a confidential agreement form which outlines compliance with HIPAA and Human Subject Protection policies. The Researcher will not proceed with the interview if the participant does not want to disclose information with the presence of an interpreter.
- 3) Prior to beginning the interview, the Researcher will provide information about the types of questions that will be asked. This will occur during recruitment, study inquiry, and informed consent process. The participant will be made aware that she/he may decline to answer a question and stop the interview at any time.
- 4) Before the interview begins, the participant will be instructed to not identify/say their own name or any person's name. If this occurs, the Researcher will edit out the names from the audio recording in order to de-identify any person mentioned.
- 5) The Researcher will stop the interview if the participant displays distress. The Researcher will ask the participant whether or not she/he would like to proceed with the interview. If the Researcher believes that the participant is not emotionally fit to continue, she will stop the interview permanently.
- 6) The informed consent process and interview will be conducted individually in a private room, to provide the participant a place where they can confidentially be fully informed about the study, decline to join or consent to join the study, and respond to the Researcher's questions.
- 7) After the interview, the Researcher will ask the participant if she/he has any question or concerns. The Researcher will provide the participants a list of local support resources that can help arrange for professional or social support intervention.

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- d) **Explain the point at which the experiment will terminate. If appropriate, include the standards for the termination of the participation of the individual participant Also discuss plans for ensuring necessary medical or professional intervention in the event of adverse effects to the participants.**

The Researcher will stop the interview if the participant is believed to be not emotionally fit to continue or indicates harm to self/others. If the participant is not emotionally fit to continue the interview, the Researcher will refer psychological support services to the participant. If the participant indicates harm to self or others, the Researcher will contact a mental health professional service trained in dealing with crisis intervention.

The study will close after the Researcher completes the publication of her dissertation, manuscripts and other related health literature.

10. Benefits

- a) **Describe the potential benefit(s) to be gained by the participants or by the acquisition of important knowledge which may benefit future participants, etc.**

It is possible that the information from the study will help other researchers and the general public learn more about the challenges with cancer care in Chinese, Indian and Filipino families living in the U.S. Findings may introduce new knowledge and potential solutions for addressing the burden in cancer care.

11. Privacy and Confidentiality

Privacy Protections

- a) **Describe how the conditions under which interactions will occur are adequate to protect the privacy interests of participants (e.g., privacy of physical setting for interviews or data collection, protections for follow-up interactions such as telephone, email and mail communications).**

Participants will be directed to contact the Researcher about the study via recruitment methods. Therefore, the Researcher will be the only research staff with access to the participants' communication about the study (email, telephone). With the exception of involving an interpreter in the screening and interview, the participant will only disclose their personal identifiers or health information to the Researcher. The telephone calls for study inquiry and screening will be conducted in a private Stanford office room or the private home office room of the Researcher. Any email correspondence with the participant will be conducted over Stanford's secure encrypted email. The Researcher will interview the cancer patient and family carer separately, so that the data collected remains confidential between the participant, Researcher and if necessary, the interpreter. The interview will be conducted in a private room. If needed, a CITI certified interpreter will be physically present to assist with the interview. The interpreters will be required to comply with HIPAA and Human Subject Protection policies and sign a confidential agreement form. The participant will only need to participate in a one time interview, so the Researcher does not anticipate to communicate with the participant after the interview. If the participant reaches out to the Researcher after the interview, she will take the same precautions with telephone and email as described above. Also if the the participant ask to see the initial analysis of her/his own de-identified data, the Researcher will either send the participant the document via encrypted email or the Researcher will personally give the document to the participant at her Stanford office.

Confidentiality Protections

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- b) **Specify PHI (Protected Health Information). PHI is health information linked to HIPAA identifiers (see above). List BOTH health information AND HIPAA identifiers. If you are using STRIDE, use the Clinical Data Work Sheet to ensure that your request will match your IRB-approved protocol. Be consistent with information entered in section 15a.**

Health Information: the participant has a one time cancer diagnosis, the cancer diagnosis occurred within 10 years or less, the cancer diagnosis occurred at age 50 years old or older, the status of the cancer diagnosis (i.e. currently ill with cancer or in remission), the type(s) of health insurance of the cancer patient participant, the status of health insurance coverage of the cancer patient participant.

Identifiers: first name, last name initial, phone number, email, zip code, age, year of immigration to the U.S.

- c) **You are required to comply with University Policy that states that ALL electronic devices: computers (laptops and desktops; OFFICE or HOME); smart phones; tablets; external hard disks, USB drives, etc. that may hold identifiable participant data will be password protected, backed up, and encrypted. See <http://med.stanford.edu/datasecurity/> for more information on the Data Security Policy and links to encrypt your devices.**

Provide any additional information on ALL data security measures you are taking. You must use secure databases such as RedCap <https://clinicalinformatics.stanford.edu/services/redcap.html>. If you are unsure of the security of the system, check with your Department IT representative. Please see <http://med.stanford.edu/irt/security/> for more information on IRT Information Security Services and http://www.stanford.edu/group/security/securecomputing/mobile_devices.html for more information for securing mobile computing devices. Additionally, any PHI data on paper must be secured in an locked environment.

By checking this box, You affirm the aforementioned. Y

The code sheet, research notes, data analysis files, and interview transcripts will be kept in the Researcher's locked cabinet located in her Stanford office suite with restricted entry and as electronic documents/files stored in the Researcher's password protected, encrypted, backed up laptop. The laptop password will only be known by the Researcher.

The audio recordings will be digital and stored at the earliest convenience (no more than 24 hours) to: 1) a password protected, encrypted, backed up external hard drive kept in the Researcher's Stanford office suite (protected as described above); and 2) to the Researcher's secured, HIPAA compliant 'Stanford Medicine Box' online file account within the Researcher's designated restricted data folders.

- d) **Describe how data or specimens will be labeled (e.g. name, medical record number, study number, linked coding system) or de-identified. If you are de-identifying data or specimens, who will be responsible for the de-identification? If x-rays or other digital images are used, explain how and by whom the images will be de-identified.**

Before the interview begins, the participant will be instructed to not identify/say their name or any person's name. If this occurs, the Researcher will edit out the names from the audio recording in order to de-identify the participant's name or any person mentioned.

The participants will not be personally identifiable on the audio recording, research notes, transcriptions and data analysis files, by excluding the participants real names on these files and using an assigned an ID code for each participant. A code sheet to associate the participant's number to their name and contact information will be kept separately from the audio recording, research notes, transcriptions and data analysis files. This code sheet will be in the form of a paper to be kept in the Researcher's locked cabinet located in her Stanford office suite with restricted entry and in an electronic document stored in the Researcher's password protected, encrypted, backed up laptop. The Researcher will responsible for the di-identification

Zimbra

rmesia@stanford.edu

Re: Concern re: SRC oversight for my study

From : SRC-Office <src-office@stanford.edu>
Subject : Re: Concern re: SRC oversight for my study
To : rmesia@stanford.edu
Cc : src-office <src-office@stanford.edu>

Fri, Jan 23, 2015 11:19 AM

Hi Rachel,

The chair said if there are only going to be 9 patients, SRC review is **not** required. However, if you decide to enroll more patients a full statistical section and SRC review will be required.

Thanks!

Jennifer Dylewski
PRMS Coordinator
Stanford Cancer Institute
800 Welch Road, FC301
MC5757
Stanford, CA 94305
Tel: 650-724-4926
Fax: 650-725-9204

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On Jan 23, 2015, at 11:12 AM, Rachel Mesia <rmesia@stanford.edu> wrote:

Hi Jennifer,

I would like to get official confirmation over email if my study, 'Cancer Care Experiences in Chinese, Indian and Filipino American Immigrant Families' (Protocol ID 33186), is exempt from SRC review.

Thanks,
Rachel

On 1/7/15, 8:48 AM, Jennifer Dylewski wrote:

Hi Rachel,

At this point the SRC Chair does not think this requires SRC review. He has asked for input from others, but I predict the answer will stay the same and will let you know otherwise.

Thanks!

Jennifer Dylewski
PRMS Coordinator
Stanford Cancer Institute
800 Welch Road, FC301
MC5757
Stanford, CA 94305
Tel: 650-724-4926
Fax: 650-725-9204

Cancer Care in the Family

Volunteers needed for research interviews



A research study is being conducted to learn about the cancer care experiences of Chinese, Indian and Filipino families living in the United States.

The purpose of the study is to learn about family challenges with cancer care. A researcher would like to interview a cancer patient and a family member.

You will be asked to share information about your background, opinions and experiences related to cancer care during an interview. The interview will take place in a local library or meeting space in the San Francisco Bay Area.

The languages available for the interview:
English, Cantonese, Mandarin, Tagalog, Ilocano, Hindi, Punjabi

This study has been reviewed and approved by the Stanford University Institutional Review Board, Protocol #33186. For general information about participants rights, contact 1-866-680-2906.

What types of volunteers are needed?

2 family members who can be interviewed separately and privately for 1 hour each.

A current or former cancer patient:

- Identifies as Chinese, Indian or Filipino.
- Immigrated to the U.S. at the age of 25 years old or older.
- Has only been diagnosed with cancer one time, 10 years ago or less, at the age of 50 years old or older.
- Received cancer care in the U.S.

A family caregiver of the cancer patient:

- Helped care for the cancer patient at the age of 25 years old or older.
- The cancer patient will identify the family caregiver to be interviewed.

Are interested in joining this study?

Would you like more information? Contact Rachel at rmesia@stanford.edu or 650.924.9599. Email contact is only available in English. If you are interested, you will be screened for your eligibility to join the study.

Email Information to Inquiring Potential Subjects Script Template

Encrypted email correspondence:

Dear _____,

Thank you for your interest in my interview study. The purpose of the study is to learn about the challenges with cancer care among Chinese, Indian and Filipino immigrant families living in the United States.

If potential participant has questions:

To answer your question about....

Please let me know if there is anything else you would like to know more about?

OR

I'm attaching the study information sheet which will provide you with more details. I can address any questions or concerns you may have.

If you would like to participate in this study, please let me know if you would like to proceed with an eligibility screening. I will need to conduct this screening over the telephone. So if you agree, please provide me with the best telephone number and time I can reach you.

You may decline to participate in the eligibility screening process. However, I will not be able to enroll you in the study if you decline.

Please let me know how you would like to proceed. You can contact me at 650.723.7119 or rmesia@stanford.edu.

Sincerely,

Email Information to Inquiring Potential Subjects Script Template

Instructions to respondent for accessing encrypted email:

Dear _____,

To protect your privacy, I will send correspondence about the study via encrypted mail. Please follow the instructions below. I appreciate your understanding about taking the extra step to protect your privacy.

1. You will be sent an email with the phrase "Secure:" in the subject line.
2. You will need to register with the secure email service the first time you open a secure email. When you receive this email, you will need to register with Cisco Registered Envelope Service (CRES) before you can open secure email. Below are the instructions for registration.

Instructions to register for Secure Email: The first time you receive a secure email from us, you will be required to register your email address with the Cisco Registered Envelope Service (CRES) in order to retrieve the message. For subsequent emails, you'll only need to enter your password to retrieve messages.

1. Open the message. It will have "Secure:" in the subject line and will have an attachment below the email.
2. Open the attachment.
3. Depending on your email program, click Open or Register.
4. Fill out the short registration form and then click Register.
5. You will be prompted to provide the following information:
 - Your name
 - A password
 - Answers to three security questions in case you forget your password
6. When the New User Registration page is displayed, close your browser window.
7. Check your email and open the message with the subject "Please activate with CRES".
8. On the Activation page, click the link titled "Click here to activate this account". Note: This page contains your cancellation number if you want to close your CRES account.
9. The Email Address Confirmed page is displayed when your account has been activated. Close your browser window.
10. Return to your email Inbox. Open your secure message and then open the attachment.
11. Enter your CRES password and then click Open to read the message.

**Information about the Study & Screening of Potential Subjects
Telephone Phone Script**

SCRIPT FOR RESPONDING TO STUDY ELIGIBILITY SCREENING

Hello, this is Rachel Mesia from Stanford.

I am returning your message about your interest in my study. Is it okay for us to talk right now? Do you have any questions for me?

During this call, I will check if you are eligible to join this study that is collecting information about the challenges with cancer care among Chinese, Indian and Filipino families living in the U.S. I will need to review information about this screening process and with your permission I will ask you the screening questions. This will take about 15 minutes. May I continue?

I am going to go through a list of questions. You may choose not to answer these questions. You also may choose to stop participating in this screening at any time; if you want to stop, please tell me. Information about you that you give me during this interview will be kept as confidential as possible as required by law. You can choose if you want or do not want to take part in this research screening procedure – it is up to you. If you refuse to answer the questions or stop answering them at any time, there will be no penalty, and you will not lose any benefits to which you otherwise would be entitled.

The risk to taking part in this interview is very small. The screening interview will ask you for some sensitive personal information, so it is possible that you may feel uncomfortable answering these questions.

If you qualify to take part in the study and are interested in taking part, then I will record your name and information; this will be kept confidential. If you are not interested in the study, then I will destroy the personal information you give me. There are no benefits to you to taking part in this screening interview. However, it is possible that the information from the study that we will be doing may help researchers learn more about the challenges with cancer care in Chinese, Indian and Filipino families living in the U.S. and may benefit others in the future.

If you do not want to answer these questions, we can stop this screening process. However, I will not be able to involve you in the study without having information that will help me determine if you are eligible to participate. You will not be paid for answering questions in this interview since it is only to see whether you qualify to take part in the study.

If you have any questions, concerns, or complaints about this interview, contact me. My name is Rachel Mesia and you can call me at 650-723-7119. If you want to talk to someone separate from the research team about a concern or complaint or your rights as a possible research subject, please contact the Stanford Institutional Review Board (IRB) to speak to an informed person who is separate from the research team, at 650-723-5244 or toll-free at 1-866-680-2906. In addition, please call the Stanford IRB at these numbers if you cannot reach me.

**Information about the Study & Screening of Potential Subjects
Telephone Phone Script**

Eligibility questions for family caregiver:

1. When you helped cared for your family member with cancer, were you at least 25 years old or older?	_____ Yes _____ No
2. Do you currently live in the United States?	_____ Yes _____ No
3. (If screening is being done in English) Do you prefer to speak another language other than English for the interview?	Participant requires another language: _____ Tagalog _____ Ilocano
4. <u>IF YES:</u> Which language do you speak? Is it okay to have an interpreter present during our interview?	_____ Mandarin _____ Chinese
5. If screening is done in another language, check the language	_____ Hindi _____ Punjabi

ELIGIBLE SCRIPT: Based on the information you gave me, it looks like you are eligible for this study. At this point, you have two choices. We can set up an appointment for an interview for the study, or you can let me know you are not interested in joining the study. I will not keep the information collected on this phone call and will destroy it.

INELIGIBLE SCRIPT: Based on the information you gave me, it looks like you are not eligible for this study because.... I appreciate your interest in this study.

STEPS TAKEN:

_____ INTERESTED, SET UP INTERVIEW APPOINTMENT ON THIS CALL

Date: _____

Time: _____

Location: _____

Best way to remind apt: Phone _____ Email _____

_____ NOT INTERESTED (***destroy all information collected***)

_____ NOT ELIGIBLE (***destroy all information collected***)

Thank you for your time. Good-bye.