IMPLEMENTATION OF PERSON-CENTERED CARE (PCC): A DESCRIPTIVE CASE STUDY

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To meet the growing demand for community-based adult services (CBAS) adult day
health care (ADHC) programs, it is important these programs make the necessary modifications
in their systems of care to embrace a person-centered care (PCC) model. This study was
designed to create an assessment to determine a community-based CBAS/ADHC program's
readiness to meet the new federal standards as determined by the program's current operational
evidence and by center participants', their families' as well as staff's perspectives. This was
measured by self-report of access to the community, choice of setting, individual rights,
autonomy and independence, choice of services and supports, center accessibility as well as their
needs and preferences in the practice. Results will assist similar CBAS/ADHCs in identifying the
necessary modifications within their own program to continue as a certified licensed entity and
remain a viable agency.

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Life is a journey not a destination. I will continue to develop my dreams and work hard to achieve the goals with my passion to make a difference in my life and in the lives of my family, my friends, and the people around me in my community.

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CHAPTER 1

INTRODUCTION

Long-term services and support, formally referred to as Long-Term Care (LTC), includes a large variety of the services and programs provided to people with limitations of cognition, physical ability, and mental status. The long-term services and supports system includes numerous settings ranging from home to community-based care and services. These include home care, home health care, adult day care, adult day health care, and adult day specialized dementia care centers. There are also various levels of facility-based services, such as continuing care retirement communities and assisted-living facilities, including board care and skilled nursing facilities. Most of the long-term service and support recipients need help with one or more of their ADL and IADL. The older people get, the more likely they will become disabled in two or more ADLs or show a loss of cognition and or face challenges in their mental health status (Gibson et al., 2003). About 50% of all older adults will enter a nursing home at some point in their lives short term or long term, and about 71.3% of those 65 and over are likely to receive Home and Community Based Services (Alecxih, 1997). The average person who needs LTC will receive at least 3 years of care from one or more settings of long-term services and support (Kemper, Komisar, & Alecxih, 2005).

1.1   The Growing Demand for CBAS/ADHC Programs

Despite the continuation of community-based adult services/adult day health care

(CBAS/ADHC) programs (California Department of Aging [CDA], 2019), if these trends for

services continue among the aging population of baby boomers, there will be a critical gap in the

system of care. This gap in the system will be between the increasing demand for access to more

affordable services and supports among older Americans with moderate resources and profound

or moderate levels of disability.

1.1.1   The Aging Population of the United States

Populations worldwide are aging at a rapid pace. The number of individuals 65 and older

is expected to increase continuously over the next several decades. In 2011, the U.S. Census

Bureau projected that by 2040 more than 20% of the population would be 65 years or older,

nearly doubling the proportion of that same group in 2010 (Population Reference Bureau, 2011).

In 1900, 3.1 million people were 65 years and older, comprising about 4.1% of the U.S. population. That group has increased steadily over the years to 12.4% in 2000 (He, Sengupta, Velkoff, & DeBarros, 2005). In the early 21st century there was a dramatic shift in the elderly population; as the *baby boomers* turn 65 this trend is projected to rapidly increase to 74 million people comprising 21% of the total U.S. population by 2030 (Federal Interagency Forum on Aging-Related Statistics, 2016). The gradual increase life expectancy due to medical advances and emerging resources brought about in the health care system (Federal Interagency Forum on Aging-Related Statistics, 2008).

1.1.2   The Aging Population in California

As visualized in Figure 1.1, the elderly population in California is expected to grow more than twice the current size of the elderly population with different growth rates within each of the 58 counties and regions. More than 50% of the counties project a 100% increase in their elderly population; two Central counties show more than a 200% increase; nine counties, mostly in central and southern California, will have a 150% increase.

The oldest age group (85 and older), shows the fastest overall rate of increase (143%) in California, from 1990 to 2020. Two Central California counties, Alpine and Mono, will have more than a 400% increase; and eight counties in Central and Northern California will have more than a 300% increase and will emerge strongly between 2030-2040 (U.S. Census Bureau, 2018).

1.1.3   Racial/Ethnic Diversity among the California Aging Population

California's aging population is not only growing rapidly but has become more culturally diverse. With the increase in the growth rate of the elderly, the realities of globalization - an increase in emigration and immigration - have resulted in a tremendous amount of heterogeneity and diversity among older adults. In 2014, non-Hispanic, single-race, Whites accounted for 78%

of the total population growth. However, the U.S. Census Bureau (2018) projects this trend will

decrease significantly by 2060.
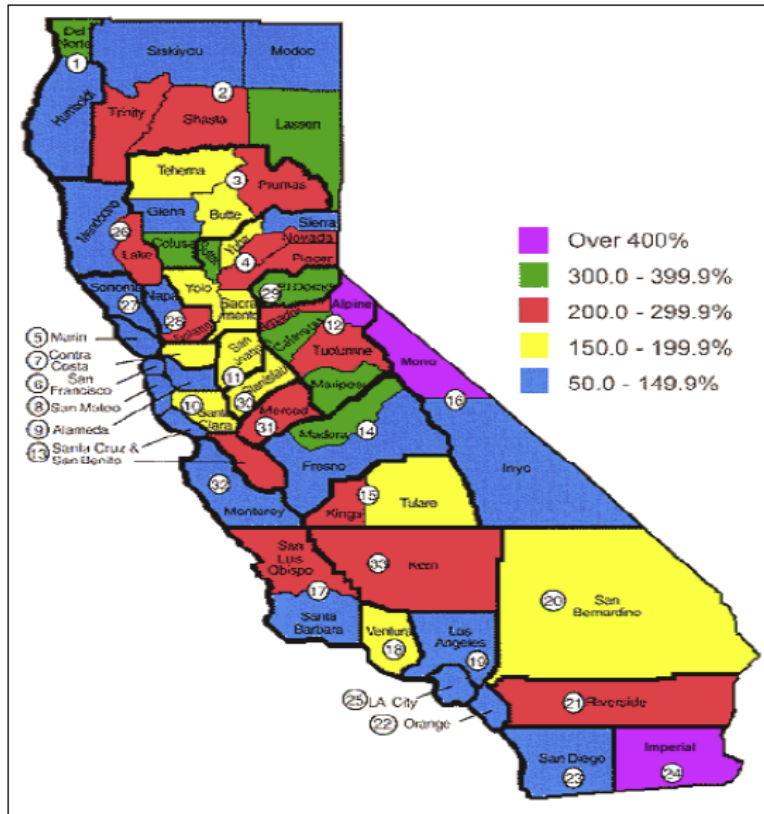
Figure 1.1: Percentage increase of the elderly population aged 85 years and over, 1990 to 2020.

Meanwhile other minority populations (i.e., Non- Hispanic Black, Non-Hispanic Asian,

Hispanic or Latino, and other Non-Hispanic races alone or in combination) are expected to

increase from 194.6 million to 196.8 million over a 10-year period (U.S. Census Bureau, 2012).

However, other minority population's proportion of the total population actually declined from

69% to 64% (U.S. Census Bureau, 2012). Racial and ethnic minority older adult populations

increased from 17.5% (6.3 million) in 2003 to 21.2% (9.5 million) by 2013 (Administration for

Community Living, 2018). As of 2016, the U.S. Census Bureau projected an increase of 11.1

million in adults 65 and older (23%) to 21.2 million (28%) by 2030 (West, Cole, Goodkind, &

He, 2014). In fact, over half of the total population in the United States will be comprised of

diverse racial and ethnic groups by 2060.

1.1.4   The Study Target Population: Aging Asians in the U.S.

Asian Americans are the most rapidly growing group among the aging population in the United States. In 2014, the elderly Asian population totaled 1.9 million. U.S. Census data reports there are 46.2 million Asian Americans 65 and older and another 6.2 million 85 years of age and above; both age groups are projected to double by 2060. By that time, Asians 65 and older will comprise 9% of the nation (Administration for Community Living, 2018). Between 2016 and 2030, the population of older Asian Americans is projected to increase 81% compared with a rise of only 39% in the White, non-Hispanic population (Administration for Community Living, 2018).

First-generation Chinese Americans express a strong belief in *filial piety* - a respect for parents and elders in the Confucian teachings (Miyawaki, 2017). It directs the offspring to recognize the care received from their parents and pay respect and care for them in return (Sung, 2001). Tang (2011) showed that Chinese Americans are followers of Confucian ethics and view caregiving as a normal stage of life and an obligation. Many of the caregivers in Tang's (2011) study reported positive feelings when their care recipients were satisfied and felt well cared for. Many other studies reiterated that a strong belief in filial responsibility was one of their major coping strategies as caregivers (Miyawaki, 2015). Other coping techniques for Chinese American caregivers included family loyalty and responsibility, respect for elders, a cultural commitment to caring for aging parents (Jones, Zhang, Jaceldo-Siegl, & Meleis, 2002; Lai, 2010), as well as religious faith, meditation, prayers, and spiritual beliefs (Vickrey et al., 2007).

While the offspring still fulfill their filial obligations, the Chinese elders' attitudes toward direct caregiving by family members have changed. From the investigation conducted by Pang,

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Jordan-Marsh, Silverstein, and Cody (2003), family dynamics have altered from sharing households to living independently and helping when needed. The elders' expectations have shifted from relying on family members to provide care to taking care of themselves. The Chinese elders express their concerns of not being willing to bother the family when minor problems occur or be a burden to the grown children (Pang et al., 2003).

Due to the cultural beliefs and linguistic barriers, most of the first-generation Chinese American tended to count on family members more than seeking out formal support (Miyawaki, 2015). They wished to have more emotional support, as well as financial and material support from their families and ethnic communities (Lai, 2010). Those who were more educated and wealthier would accept the idea of utilizing formal help and hire bilingual Chinese paid-caregivers to fulfill their filial responsibilities (Hsueh, Hu, & Clarke-Ekong, 2008).

Chinese American caregivers expressed the linguistic barrier as their biggest challenge that prevented them from using formal services and support. Other barriers also mentioned were

- Lack of appropriate formal support (Jones et al., 2002)
- Culturally sensitive services (Tang, 2011)
- Services for refugees (Miyawaki, 2015)
- Lack of funds to hire outside formal help (Miyawaki, 2015)

Health care providers, caregivers, staff, and family members all need to collaborate in creating relationships that care for the person first, before responding to their limitations. Programs must allow elderly people to stay engaged socially and foster autonomy thereby enhancing wellness and quality of life (Eilers, Lucey, & Stein, 2007). Models that resemble person-centered care (PCC) in home and community-based services place a focus on the individual, while addressing and catering to their diverse needs related to chronic illnesses and functional limitations (Kogan, Wilber, & Mosqueda, 2016).

The Golden State's 250 Community-Based Adult Service (CBAS) centers are a portrait of the diversity that will spread throughout the nation. This shows the importance of a study focused on programs like this that serve the elderly in California. Among the CBAS centers, English only is spoken in eight of the sites; Spanish is spoken in 167; Tagalog in nine; Russian in 67; and Chinese Mandarin in 59, which is indicative of the complexities of the racial and ethnic composition of the state with the nation's largest elderly population.

With the demographic shift and rapid aging of the U.S. population and the number of chronic conditions associated with age, the need for long-term care services and support for older Americans and their family members will become increasingly more known and used over time (Khatutsky, Wiener, Greene, & Thach, 2017). Older individuals are more likely to have complex care needs that affect daily living and it is important that services and adult programs are structured to promote successful aging. Iwamasa and Iwasaki (2011) examined successful aging through the six dimensions of health among Japanese American older adults. They found program participants reported maintaining high cognitive and physical function; coping with stress through spiritual practices; and having financial security were important factors to Japanese American older adults in avoiding disease later in life. One major difference among this group, however, was the value placed on autonomy and independence. The researchers emphasized the collective Japanese cultural value of "adjusting one's needs to maintain group harmony" (Iwamasa & Iwasaki, 2011, p. 274), which is different from individualistic cultures that concentrate on expressing one's need through independence and autonomy.

1.2   U.S. Legislation and Provision of Supportive Services for the Elderly

Over the past 50 years, Congress has passed a series of policies that create an infrastructure to support an affordable system of care for older adults who might otherwise be

left destitute as the costs of living increases while the value of their post-retirement income and savings decline. Some of the most influential policies include Medicaid, Medicare, and the Older Americans Act created in 1965 along with the Americans with Disabilities Act of 1990 and the Olmstead Supreme Court decision of 1999 (Elderweb, 2014). In addition, there have been significant effects of the Affordable Care Act of 2010 in reshaping the financial incentives for providing quality care in the most cost-effective manner.

When a senior reaches a juncture when his or her health declines to the point where they are no longer able to perform basic daily living activities, but they lack access to extensive family support, they turn to nursing homes. Once their savings are spent down and they become destitute, they turn to Medicaid, the payer of last resort (Centers for Medicare & Medicaid Services [CMS], 2019). Intended as a safety-net, Medicaid was designed as a medical insurance system for very poor children, pregnant women, and the elderly. The Affordable Care Act expanded its reach to assist low income adults who cannot otherwise afford health insurance. Now, the program is the largest payer of long-term care (Gleckman, 2018).

1.2.1   U.S. Legislation Protecting Older Adults

A series of high-profile stories of elder abuse and neglect in the 1970s and 1980s led Congress to commission a study by the Institute of Medicine in 1986 (Koren, 2010). The results led to the 1987 Nursing Home Reform Act, which specifically demands that all citizens "be provided with services sufficient to attain and maintain his or her highest practicable physical, mental, and psychosocial well-being" (Koren, 2010, p. 312). Additionally, the Nursing Home Reform Act requires nursing homes to provide a comprehensive care plan for each resident that includes social services, nursing services, periodic assessments, pharmaceutical services, dietary services, and rehabilitation services. Nursing facilities with more than 120 beds must have a full-

time social worker on staff (Koren, 2010). This also led to a national standard for a Resident's

Bill of Rights (Special Committee on Aging, 2013). The legislation establishes that nursing

home residents have the right to

- Freedom from abuse, mistreatment, and neglect
- Freedom from physical restraints
- Privacy
- Accommodation of medical, physical, psychological, and/or social needs
- Participate in resident and family groups, to be treated with dignity, to exercise self-determination, to communicate freely, to participate in the review of one's care plan, and to be informed fully in advance about any changes in care, treatment, or change of status in the facility, and to voice grievances without discrimination or reprisal

1.2.2 Reimbursement for Long-Term Care Services for the Older Adults

At one time, long-term care providers could depend on significant profit margins from

the generous Medicare payments paid for short-term rehabilitation, and Medicaid payments for

lower-income patients that were actually enough to cover the cost of the care. However, over the

course of the last decade, both programs' reimbursement rates have been drastically reduced in

managed care contracts.

In the skilled-nursing industry, profit margins are about 1%, while assisted-living is more

commonly 3 to 12%, with higher margins serving higher-end clients. Industry publications have

compared the struggles of long-term care to supermarkets. The grocery store analogy may be

apropos given they face tight regulations and no chain has profit margins above 5% because they

are greatly limited by competition and the customers sensitivity to price (O'Connor, 2012). A

wide-selection of services and a high volume of residents may be the only way to make a profit

in what is becoming a thin profit-margin business.

The long-term care industry faces several challenges in addition to the challenge of

offering a profitable and competitive service. The nature of the service is one where it is easy to

fall into the psychology of being a routine service provider. However, in order to gain the respect of your customers, it is important to focus on image the way retail stores do, considering every aspect of a customer's experience, and focusing on that experience in marketing and in improving the experience from year-to-year. Competition is growing from those offering the same residential service of in-home care or high-tech alternatives that delay the need to move into a community that can provide institutional-level care (Alwan, 2012; Bercovitz, Sengupta, & Jamison, 2010).

Genworth Financial's (2007) report, "The Future of Long-Term Care in America," focused on the role of unpaid caregivers. Family members play a critical role in the decision to pay for long-term care services. If a relative or close friend can provide basic care, then they will most often be the front-line in the care struggle and their assistance will be used until they reach the point of exhaustion.

However, the field has evolved dramatically over the years from long-term care into long-term services and supports or managed long-term services and supports. The old idea suggested one moves into a facility and remains there for the rest of one's life. This new description infers that services are to be provided at home and in community-settings and need not be permanent. The new perspective focuses on receiving support on an as-needed basis, so they can live in the least restrictive environment possible and enabling them to live in their homes and providing their heavily burdened family or informal caregivers some respite. However, the efficacy for achieving positive health outcomes and cost-benefit for delays in premature institutionalization has yet to be conducted.

1.3   Background of this Research

Over the last decade, there have been many studies examining the efficacy of ADHC for

seniors and persons with disabilities. These center-based programs have emerged as one of the essential seminal topics in social work and gerontology (Browne, Braun, Mokuau, & McLaughlin, 2002). Long-term care professionals, researchers, and policymakers have all acknowledged the importance of certified and licensed CBAS and ADHC programs for improving the health and quality of life among older adults (Senate Select Committee on Aging and Long-Term Care, 2014). Many of these programs are being used as system intermediaries; aiding elderly people to age in place while reducing health care costs and the growing demand on long-term care institutions. However, limited work has been conducted on the utility of these community-based medical and social models in assisting seniors and seniors and persons with disabilities in maintaining or restoring their optimal capacity for functioning thereby avoiding institutionalization.

My goal was to conduct a mixed-methods study addressing the gap in the gerontology research literature on the efficacy of person-centered ADHC programs. I also aimed to create a model for assessing an ADHC/CBAS level of readiness for meeting the new state and federal regulations for PCC model programs. Findings may inform best practices by translational research for use by ADHC/CBAS programs throughout California as well as the rest of the nation.

According to Rohrbach, Grana, Sussman, and Valente (2006) translational research requires a long-term collaborative commitment between researches, practitioners, and policymakers because it is rarely conventional but must contend with various obstacles including insufficient resources; a shortage of qualified researchers; and, an academic culture that hinders collaboration (Minna & Gazdar, 1996). Additionally, it has also been argued that successful translation requires effective practices, products, and services to be institutionalized as part of the

program (Rohrbach, Grana, Sussman, & Valente, 2006).

Recent, PCC has gained attention in research and practice, shifting the focus away from a translational medical model to a more person-focused care model (Santana et al., 2018). The goal of this model is to heal by treating the whole individual; the participant is the focal point of self-care and self-healing. It is more flexible and not a one-directional construct of medical care to recipients and their family members. While the demand for CBAS/ADHC facilities is increasing, there are no best practices for implementing a PCC model despite being the standard for the highest quality of care. With this study, I sought to address this gap by developing and testing protocols for assessing and implementing these standards that can be used to replicate programs throughout the nation.

1.4   Purpose of the Study

The purpose of this study was to determine the readiness of a CBAS/ADHC program's practices and operations to implement a PCC model to meet the new standards for certification and licensing requirements by the California Department of Aging (CDA) and California Department of Public Health (CDPH). Using this study, I sought to identify evidence-based best practices that should be integrated into the CBAS/ADHC systems of care to meet the standards set forward by the federal CMS, the CDA, and the DHCS to be certified and licensed as a CBAS or an ADHC.

1.5   Quantitative Research Questions and Related Hypotheses

RQ1:   How do the study participants' health statuses compare to the rest of ADHC
        program participants throughout California ADHC programs.

RQ2:   What is the relationship between 6 PC elements, social support, system of care
        (administration) and co-variates (age, gender, education, marital status, location.
        income, country of origin, and years in the U.S.) and implementing a successful
        person-centered care ADHC program?

H$_1$: There is a relationship among 6 PC elements, social support, system of care (administration) and co-variates (age, gender, education, marital status, location. income, country of origin, and years in the U.S.) and implementing a successful person-centered care ADHC program.

H$_0$: There is no relationship among 6 PC elements, social support, system of care (administration) and co-variates (age, gender, education, marital status, location, income, country of origin, and years in the U.S.) and implementing a successful person-centered care ADHC program.

1.6   Qualitative Research Questions

The following questions were used to guide the study:

RQ1: What are the experiences of the facility's staff, participants, and family members with person-centered care?

RQ2: What are the specific practices and strategies currently employed in the center to support person-centered care development?

RQ3: What are the operational challenges, if any, for implementation of person-centered care practice in the facility?

RQ4: What recommendations do administrators and program directors from other agencies have for implementing person-centered care in their ADHC programs?

RQ5: What differentiates this facility from other California CBAS/ADHC centers when it comes to person-centered care?

1.7   Rationale for Study

As an integral part of the new standards of care, the lack of research surrounding PCC in ADHC/CBAS programs is the primary motivation for this dissertation study. In this study, I provide a timely account of best practices for translational application of PCC in the field. It includes tools for self-study to assess a program's current model of care formally, identify areas for improvement, and offer strategies for modifying organizational systems to meet the new federal and state requirements for certification and licensing.

Stakeholders in geriatric research, social science, clinical research, and practitioners whose work is concerned with PCC models could learn from these results. The findings will provide

guidance for transforming the framework of a program including the work routines, care delivery process, and physical setting necessary for an ADHC center to implement a PCC model. The results reflect the cooperative culture required of the entire organization to increase the quality of life experience for program participants, and the employees and family members who care for them.

1.8   Background of the Field of Adult Day Services
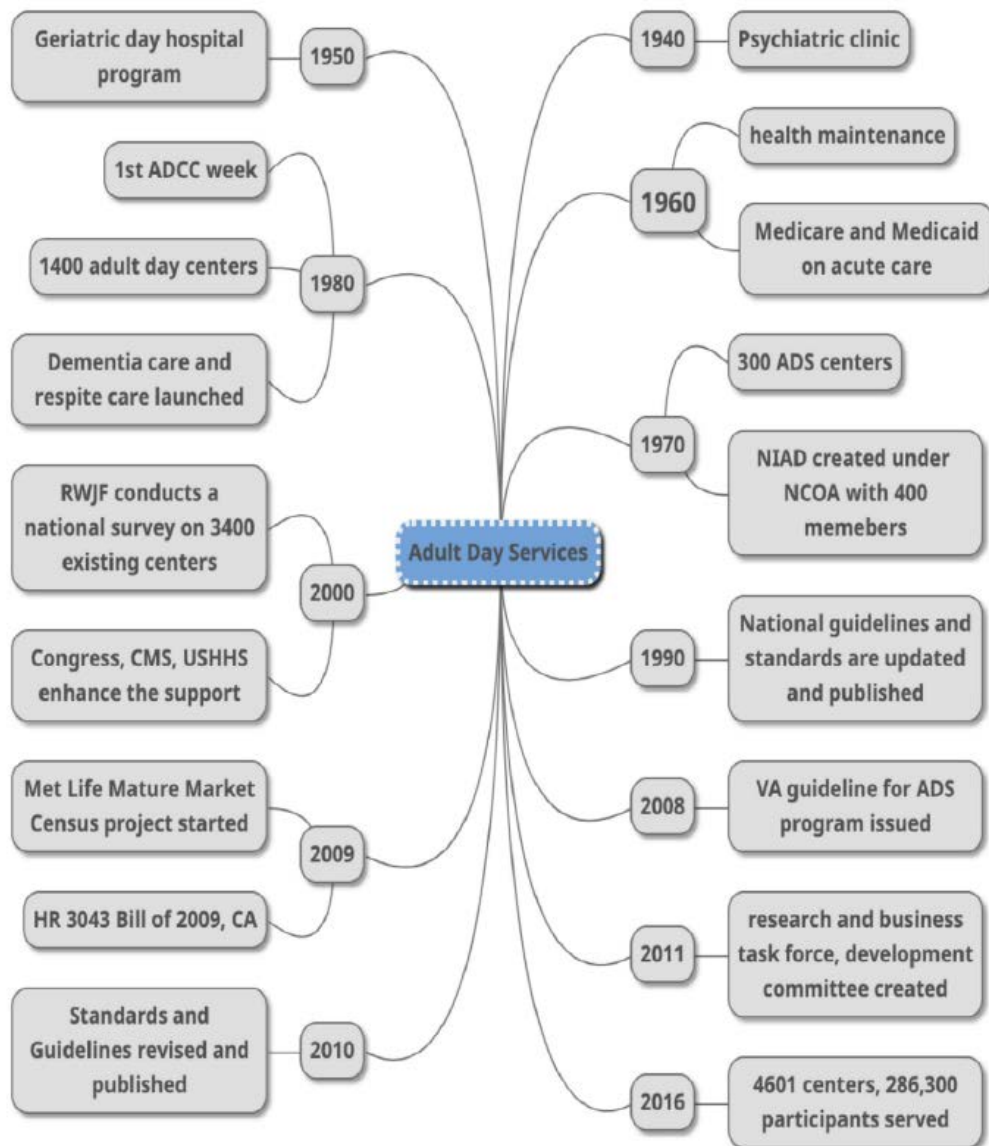
Figure 1.2: History of California's adult day services, 1940-2016.

Adult Day Services (ADS) began in the United States in the 1940s to serve individuals with mental health issues (National Adult Day Services Association, 2019). In the 1960s, this concept expanded from a purely psychiatric focus to include other health maintenance and acute care. Since the 1970s, ADS have been the platform and essential source for chronic disease management including individuals with Alzheimer's diseases and dementia, their family, and caregivers - providing comprehensive health care services and support in the community. In response to the needs of the increasing population of seniors, ADS are evolving into a source of long-term care. Figure 1.2 details the historical aspects of Adult Day Services.

1.8.1   Adult Day Program (ADP)/Adult Day Health Care (ADHC) in the State of California

Since the 1970s, California has led the nation in ADHC services. As shown in Figure 1.3, California used a medical and social model program serving individuals 18 and over with mental and physical disabilities.

In September 1976, the California Commission on Aging and the U.S. Senate Special Committee on Aging held hearings and published a report titled, "Adult Day Facilities for Treatment, Health Care, and Related Services," which outlined a comprehensive approach to care for individuals over age 55. This marked an opportunity for creating a venue for senior services beyond the stigma of *daycare* by replicating the approach modeled by San Francisco's On Lok Senior Health Services - a "Program of All-Inclusive Care for the Elderly" (PACE; Medicare.gov., 2018, para. 1). Today, PACE is mandated by the federal government; there are over 250 ADHC/CBAS PACE programs offered in 23 counties of California. Of these, 11 provide both medical and social services.
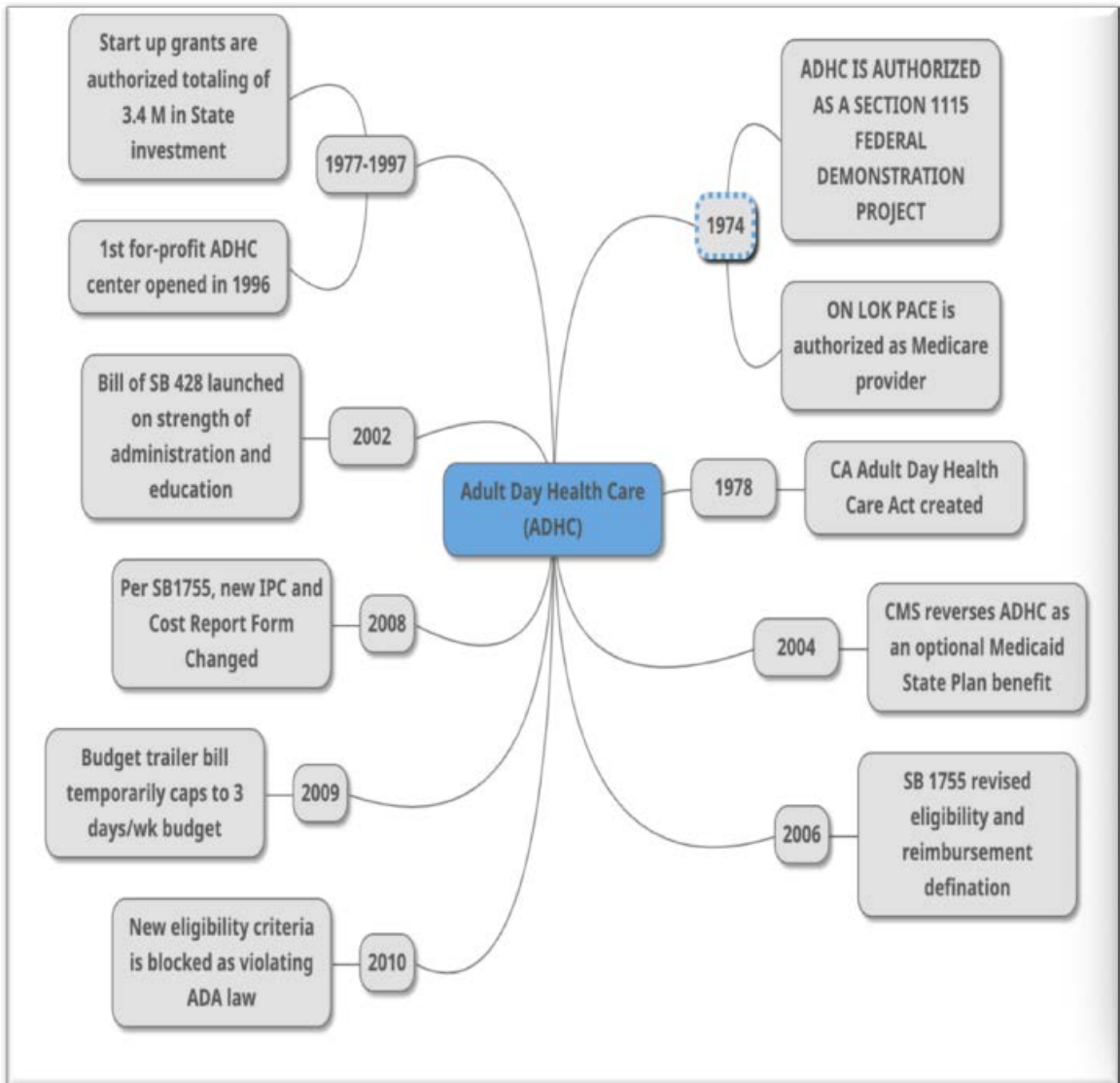
Figure 1.3: Adult day health care, 1974-2010.

1.8.2   The Transition of Community-Based Adult Services (CBAS) in California

In 2015, the CDA and the DHCS came together to develop a consensus for a system of care for CBAS. The committee's work plan included two goals.

The first goal was to assure CBAS providers compliance with the program requirements through improved state oversight, monitoring, and transparency activities. There are a total of 10 objectives under this goal such as revising Individual Plan of Care (IPC) and Participants Characteristic Report reporting, formalizing communication and collaboration between providers

and managed care plans, standardizing the forms and validating compliance with requirements for training of center staff as well as publishing data on CDA's website about provider's information and compliance. The second goal focused on improving the service delivery by promoting CBAS best practices, specifically focused on PCC as evidence-based care with seven objectives:

1 Creating training standards

2 Establishing PCC core practice

3 Developing participants/caregiver's satisfaction survey

4 Identifying assessment/screening tools for participants specific conditions

5 Informing and assisting advanced care planning

6 Tacking monthly therapy hours

7 Setting up the multidisciplinary team (MDT) best practice process.

As of 2016, there were 4,601 adult day services centers (an increase of 35% since 2002) across the nation serving 286,300 participants and their family members (an increase of 65% since 2002) (Lendon & Rome, 2018). Despite the increase in adult day services, few studies focus on the efficacy of a PCC model along with wrap-around services (described previously) in this setting. Little has been explored concerning the cooperative environment required among medical practitioners (i.e, M.D., PT, OT, RN), mental health providers (i.e., psychologists and LFSW), and social service providers (i.e., case managers and health/peer navigators/advocates) along with entry-level employees to implement a multi-tiered, medical-social model system of care to a very low income, multi-ethnic population.

1.9   Significance of the Study

This study offered me an opportunity to develop a self-study process for evaluating an Adult Day Health Care Center's readiness for integrating the current model of care into a PCC

model. In this study, I identified the necessary changes in organizational systems to implement a

PCC model successfully. The self-study focused on the innovative features, organizational

qualities and processes, along with worker insights that will be operational in implementing the

PCC model. The findings of the self-study will be instrumental to administrators working to

engage in organization-wide modifications to improve participant quality of care while

improving workforce satisfaction (Coulourides Kogan, Wilber, & Mosqueda, 2016). This

research will provide tools and skills that could benefit CBAS/ADHC facilities throughout

California.

1.10   Study Limitations

This research was limited by the following assets:

- This research focused solely on one ADHC (MIKKON). Therefore, the interpretation

of the results cannot be interpreted as representing the views of all participants of ADHCs;

- The sample population comprises the entire population of one ADHC (MIKKON).

However, this was not a diverse population, all study participants self-reported race as Chinese

including line staff, administrators, program participants, and their families. Given the racially

and culturally diversity of California, inferences cannot be made concerning other racial and

ethnic groups making comparative insights impracticable.

1.11   Summary and Conclusion

Since the early 1970s thousands of community-based agencies have provided important

day care services to the elderly. To meet the growing demand for these services, it is important

these programs make the necessary modifications in their systems of care to embrace a PCC

model. This study was designed to create an assessment to determine a community-based ADHC

program's readiness to meet the new federal standards as determined by the program's current

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operational evidence and by center participants', their families' as well as staff's perspectives. This was measured by self-report of access to the community, choice of setting, individual rights, autonomy and independence, choice of services and supports, center accessibility as well as their needs and preferences in the practice. Results will assist similar ADHCs in identifying the necessary modifications within their own program to continue as a certified licensed entity and remain a viable agency.

1.12   Definition of Terms

The following terms are presented for clarification of usage in the following discussion.

- *Caregiving*: Providing nurturance and performing routine tasks necessary to maintain the person's emotional well-being, physical health, and appearance.

- *Chinese/Chinese American*: A person of Chinese/Chinese American descent and identified as such in the U.S.

- *Client*: A person who receives services from home health and home services agencies or other services providers on the community-based settings.

- *Participants of CBAS/ADHC Center*: A person who is eligible to be the participant, enrolled and receives services from CBAS/ADHC center.

- *Patient*: A person who is admitted to the hospital, or receives services from a medical care facility, agency, or clinic.

- *Person-centered care*: PCC provides choice, purpose, and meaning in daily life of the individual across all settings of long-term care services and support.

- *Research participant*: A person or human subject who participated in this research by answering the survey questions, being interviewed, or involved in focus group discussion.

- *Resident*: A person who is admitted to the residential settings of the facility and receives 24 hours of services in that place.

1.13   Design of this Dissertation

This chapter contains the purpose of and the rationale for the study. Chapter 2 is a summary of the literature relevant to ADHC/CBAS programs in California; an overview of the federal and state regulations governing ADHC/CBAS programs is highlighted. Though some studies have investigated translational models, there is a need for more literature that suggests that PCC can have a positive impact on the organizational structure of CBAS/ADHC. In Chapter 3, I describe the mixed-methods study conducted to assess the readiness of a CBAS/ADHC serving a predominantly Asian population to implement a PCC model. Chapter 4 encompasses the results of the analyses of the study's quantitative and qualitative data; and, Chapter 5 incorporates a discussion of the findings and the responses to the research questions cited in the following section. It addresses dissemination of the study outcomes along with suggestions for future research needed in this area.

CHAPTER 2

LITERATURE REVIEW

The purpose of this study was to determine the readiness of a CBAS/ADHC program's

practices and operations to implement a PCC model to meet the new standards for certification

and licensing requirements by the California Department of Aging (CDA) and California

Department of Public Health (CDPH). The purpose of this literature review was to identify the

body of knowledge surrounding the efficacy of integrating a PCC model into ADHC/CBAS

programs. I sought to identify evidence-based best practices for translating the PCC model into

the CBAS/ADHC systems of care to meet the standards set forward by the federal CMS, the

CDA, and the DHCS to be certified and licensed.

2.1   Historical Background

For several decades, organizational behavior and the provision of care in long-term

settings have been provider-driven, focused primarily on the achievement of medical goals

(Caspar & O'Rourke, 2008). However, recent literature in aging and healthcare delivery systems

has shown a shift away from the traditional medical model of care to a more inclusive,

transformational approach that strives to prioritize resident care and the management of chronic

conditions through the involvement of family members, nursing staff, and the community.

2.1.1   Translational Models of Care

Six translational models were described by Sussman, Valente, Rohrbach, Skara, and

Pentz (2006): (a) the five-phase model, (b) the eight-phase model, (c) the classification for

application model, (d) the program development model, (e) the diffusion of innovations model,

and (f) the national institute of health type 1 and type 2 model. These models evolved from work

conducted by Glasgow, Lichtenstein, and Marcus (2003). Glasgow et al. (2003) concluded the

five-phases being used by many investigators in translational healthcare research - which included basic research, methods development, efficacy trials, effectiveness trials, and dissemination of research - were too general. They warned this could lead to a disconnect between efficacy and effectiveness in healthcare settings and required a method to adjust for diverse populations in various settings with minimal modifications, training, and adaptation time and cost. The eight-phase model added additional hypothesis development to the first phase, using pilot-applied research, prototype evaluation studies, and contributing implementation effectiveness trials to fulfill the five-phase model. The next three models of the classification included application models, program development models, and diffusion of innovations models focused on the elements of the five-phase model. Finally, the National Institute of Health Type 1 and Type 2 models emphasize the bi-directional influences between basic and applied science and contribute to the five-phase model as an important variant (Sussman et al., 2006).

Although there are many issues of personnel roles, communication between multidisciplinary teams, the concern about the time needed, and barriers for the translation process, there is growing interest from scholars, practitioners, and researchers in translational research and practice in health care professions. However, implementation of interventions in clinical-settings requires behavior change throughout the organization starting with

- The systems associated with the professional involvement
- Determining the staff's level of skills and expertise required for program success
- Identifying existing opportunities and information within the clinical-setting
- Developing evidence-based tools
- Developing an effective strategic plan the decision-making process

These elements all target the providers behavior such that, service provision will be the most cost-effective, best practices and sustainable methods that include motivational factors and

removes any barriers that would influence their decision-making, and the role-playing required

for licensure and accreditation (Griffin, 2012). Concerns for implementation should address

various issues, such as patient safety (i.e., privacy and inclusion of family members), obtaining

and understanding the information needed for outcome measures, the inter-relationship of

multiple providers working collaboratively, and staff's confidence with the utility and efficacy of

the intervention (Coyne, Holmström, & Söderbäck, 2018; Sussman et al., 2006).

2.1.2   Documentation of Literature Search

To examine the evidence of the efficacy of PCC practice in ADHC/CBAS programs

electronic searches were conducted using: Google Scholar, PubMed, Medline, and

EBSCOHOST with the key terms shown in Figure 2.1.
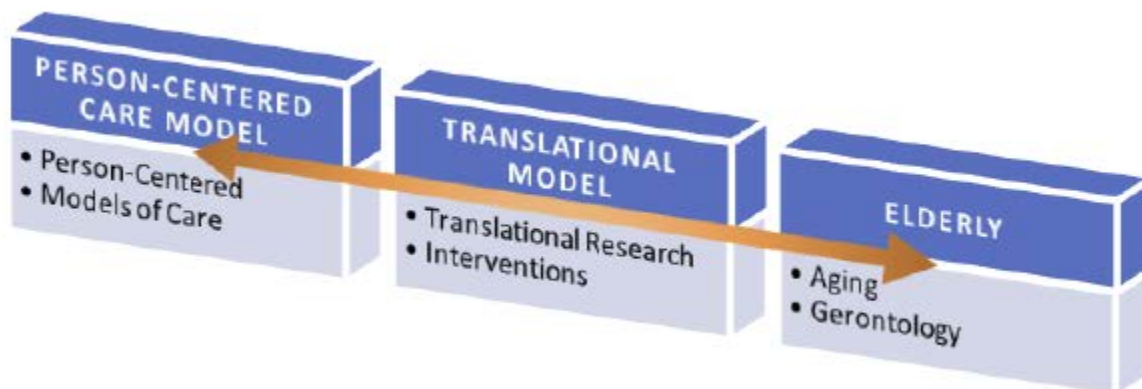
Figure 2.1: Terms and subtitles used for literature search.

Approximately 250 abstracts of empirically-based publications including book chapters,

peer-reviewed journal articles, conference abstracts, and published theses and dissertation

pertaining to implementation of PCC, translational model, patient satisfaction with

medical/social models, residents' perspective, evidence-based medicine, patient-centered

medicine, family-centered care, and benefits of LTC were identified and reviewed. Irrelevant

citations were discarded based on title and abstract. The full texts of the 120 deemed potentially

relevant were retrieved then reviewed using the following criteria:

a. The study had to be conducted using a mixed-methods design in which participants narratives were highlighted;
b. The study population was explicitly older adults; at least 80% of participants were 65 years of age or older; and
c. The study was only concerned with person-centered and translational models in community-based settings that utilized scalable and replicable best practice models of care.

Thirty studies met the inclusion criteria for review. Ten additional studies were

identified through references of included articles. Ninety percent of the articles identified were in

English and 10% in Chinese. Figure 2.2 characterizes the flow of the selection of studies. Table

2.1 shows the studies that met the study criteria.

References identified by databases using chosen keywords $N = 250$

Irrelevant Studies identified By Title and Abstract $n_1 = -130$

Potentially relevant studies $N = 120$

CRITERIA FOR ELIGIBIITY
1. Mixed Methods
2. Study Population 65+ years
3. Person-centered Community-based $n_2 = -90$

Eligible Studies for Literature Review

Additional studies identified from references of eligible studies.

Final Articles for Literature Review $N = 106$

Figure 2.2: Flow of selection of literature for review.

Table 2.1: Studies that Met Criteria

Authors	Setting	Aim	Design and Collection	Study Sample	Main Findings/Barriers
Cohen, Menon, Shorey, Le, & Temple (2017)	RCFE	To understand a) how physical and emotional neglect relate to other forms of maltreatment and b) to determine physical and emotional neglect's unique impact on prospective mental health functioning	Person-centered and longitudinal	(N = 580) high school students	Early neglect-exposure poses a risk for the subsequent development of internalizing symptoms and substance use behaviors among emerging adults.
Curro, Robbins, Naftolin, Grill, Vena, & Terracio (2015)	Clinical	To illustrate a model that utilizes an existing infrastructure supporting the 'person' and merges the principles of clinical research with that of clinical practice to create a continuous data base that facilitates best practice and the regulatory approval process.	Explanatory	N/A	Person-centric clinical trials define the N-of-1 using a GCP practice- based translational network that offers both a philosophy and model to accommodate issues of clinical drug development and healthcare.
De Grood, Leigh, Bagshaw, Dodek, Fowler, Forster, Boyd, Stelfox (2018)	Hospital	To better understand the patient, family, and provider experiences with transfers from ICU to hospital ward	A multi-centre qualitative study: Cohort study that used standardized surveys and case report forms	(N = 35) patients consented to an interview	Transitions of care between the ICU and hospital ward are challenging and high risk. Top three overarching themes perceived as barriers or facilitators to high-quality patient transfers are: resource availability, communication, and institutional culture.
Dong, Neufeld, & Higgins (2008)		To test Klein and Sorra's innovation implementation model	survey	(N = 209) employees in seven organizations	A successful implementation depends on a strong implementation climate and innovation values fit. Organizations need to help potential users internalize the innovation while creating a strong environment to facilitate the adoption process.
Gilmore-Bykovskyi, Roberts, Bowers, & Brown (2015)	SNF	To identify sequential associations between caregiver person- centered actions, task-centered actions, and resident behavioral symptoms and the temporal variation within these associations.	Qualitative approach using video recording	(N = 33, 724min) between 12 nursing home (NH) residents with dementia and eight certified nursing assistants	The person-centeredness of caregivers is sequentially and temporally related to behavioral symptoms in individuals with dementia.
Hill, Penrod, & Milone-Nuzzo (2014)	Clinical	The article describes one approach to developing an infrastructure to support	Explanatory	N/A	Translational research has direct clinical nursing implications since it bridges the gap between

Authors	Setting	Aim	Design and Collection	Study Sample	Main Findings/Barriers
		patient-centered care within translational research, establishing a Community Based Nursing Research Network.			research and practice, and community-based research has the potential to address several critical and common gaps in the care continuum such as transitions between care settings.
Johnson Thornton, Roter, Powe, & Cooper (2004)	Clinical	To better understand the association between patient race/ethnicity and patient-physician communication during medical visits	Compiled data from 2 brief cohort studies using audiotapes and questionnaires	Total of (N = 202) White patients and (N = 256) African American patients with (N = 110) White patients and (N = 142) African American patients in the 1998 cohort and (N = 92) White patients and (N = 114) African American Patients in the 2002 cohort	Physicians were 23% more verbally dominant and engaged in 33% less patient-centered communication with African American patients than with White patients. Both African American patients and their physicians exhibited lower levels of positive affect than White patients and their physicians did.
Klein, Conn, Smith, & Sorra (2001)	Staff	This study examined three possible antecedents of agreement among group members' perceptions of the work environment: (a) demographic homogeneity, (b) social interaction and work interdependence, and (c) the wording of survey items used to measure perceptions of the work environment	Survey	N/A	Group member social interaction and work interdependence were significantly positively related to within-group agreement regarding perceptions of the work environment.
Kogan, Wilber, & Mosqueda (2016)	All settings	The purpose of this study was to explore aging literature on PCC for older adults by eliciting feedback and opinions regarding operationalization of PCC from leaders at exemplar health and social service organizations serving older adults.	Qualitative research method	(N = 9) leaders within community-based healthcare and social service organizations	Dedication to implementing PCC programs requires organizational leadership, commitment and support, and financial investment and training. Unanticipated outcomes (positive and negative) uncovered in the present study include ambiguity regarding the definition of PCC, inconsistent language, and staff-level factors. Models of PCC

Authors	Setting	Aim	Design and Collection	Study Sample	Main Findings/Barriers
					for older adults may lead to better patient and client outcomes and have the potential to affect the providers positively delivering the care and services, thereby contributing to its viability for continued expansion across medical and nonmedical settings.
Paasche-Orlow & Roter (2003)	Clinical	This paper adds insight into FP and IM differences in both physician-patient communication and predictors of patient satisfaction	Data collected by audiotapes and evaluated with Roter Interaction Analysis System	(N = 277) patients encounters with (N = 29) FP physicians and (N = 287) patients encounters with (N = 30) IM physicians	Patient satisfaction was similar for IM and FP, but FP physicians were more patient-centered than IM physicians
Poey, Hermer, Cornelison, Kaup, Drake, Stone, & Doll (2017)	SNF	This study examines whether PCC practices improve satisfaction with QoL and quality of care and services among nursing home residents	Longitudinal, retrospective cohort study using qualitative research method	(N = 6214) nursing home residents in 2013-2014 and (N = 5538) residents in 2014-2015.	It is necessary to implement PCC in nursing homes as it's proven that incorporating the residents' perspective can provide critical feedback for nursing homes to ensure a high level of quality and services that meet the residents' need and desires.
Rosen, Lachs, Teresi, Eimicke, Van Haitsma, & Pillemer (2016)	SNF	To identify common staff responses to Resident-to-resident elder mistreatment (R-REM)	Mixed method research using individual private interviews with a convenience sample	(N = 282) CNA in 5 urban nursing homes	Most common actions by the CNAs were: physically intervening/ separating residents (51), talking calmly to settle residents down (50), no intervention (39), and verbally intervening to defuse the situation (38). Less common were notifying a nurse (13) or documenting in behavior log (4).
Sacristán (2013)	Clinical	This work discusses the objectives and characteristics of patient-centered medicine (PCM), and the implications of this model for medical research and clinical practice.	Systematic literature review	N/A	Evidence-based medicine and patient centered medicine are not contradictory but complementary movements. It is not possible to practice patient-centered medicine this is not based on evidence, nor is it possible to practice evidence-based medicine at a distance from the individual patient. The development of information-based technologies can help to close the gap between clinical research

Authors	Setting	Aim	Design and Collection	Study Sample	Main Findings/Barriers
					and clinical practice, a fundamental step for any advance in this field.
Shields (2015)	Clinical	To explain the term "family-centered care"	Explanatory	N/A	Family centered care needs the commitment of those who will use it, the health professionals, health service staff and children, young people and parents for whom it is designed.
Specht (2013)	Hospital	This article is to discuss the need for use of evidence-based practice (EBP) in LTC, the current use of evidence in LTC facilities and what we know about adoption of the use of EBP in LTC.	Literature review	(N = 48) LTC facilities	There is clear evidence of the need and the benefits to residents of LTC and to the health care system but the adoption of EBP is slow and sporadic. Residents in LTC deserve the best care possible and EBPs represent an important vehicle by which to do this.
Tay, Thompson, Nieh, Nieh, Koh, Tan, & Yap (2018)	Hospital	This article evaluates the effectiveness of PCC protocol adoption in an acute hospital dementia unit (Care for Acute Mentally Infirm Elders [CAMIE])	6-month cohort study with quantitative research method	(N = 170) PWDs in the CAMIE unit and (N = 60) PWDs in usual care wards	PCC for PWDs in acute hospitals improves clinical outcomes for patients and is cost-effective. PCC shall be adopted to deliver better care to PWDs.
Wan, T. T. H., Terry, A., Cobb, E., McKee, B., Tregerman, R., & Barbaro, S. D. S. (2017)	Clinical	To investigate how the 8 guiding principles of choice: rest, environment, activity, trust, interpersonal relationships, outlook, and nutrition reduce HF readmissions.	Systematic review and meta-analysis	(N = 113) related studies for systematic review and (N = 67) studies for meta-analysis	Interventions with human factor principles are more likely to reduce readmission probabilities among HF patients.
Whitstock, M. T. (2003)	RCFE	To better understand the gaps between available medical research evidence and current medical practice	Systematic literature review	N/A	Reciprocal communication between practicing clinicians and clinical researchers should be supported as an essential part of the clinical research process. Reciprocal communication between patients' group and clinical researchers is essential to bridge the gap between "the best available evidence" and current clinical practice.

The following section is an overview of the research on the various models of care implemented at ADHC/CBAS across California and throughout the nation. Included is a purposeful selection highlighting the generational divide in California. In addition, an examination of the intersectionality of ageism, race, class, and gender diversity in California was included to stress the importance of inclusion and the barriers that researchers need to overcome when implementing new strategies in clinical-settings in this state. Additionally current California policies and laws that govern CBAS/ADHC program were examined.

2.2   Models of Care

Throughout the years a number of models of care advanced to serve seniors and disabled adults best in need of long-term care including medical models of care; person-centered models of care - such as the Eden Alternative, the Greenhouse model, and the Wellspring model of care; the managed-care model; the behavioral model of care; the care coordination model; the care transition intervention model; and the PACE model. All are described in the next sections.

2.2.1   The Medical Model of Long-Term Care

The medical model of long-term care emphasizes the provision of clinical services to patients not the needs of the patients of a medical clinic, but for individuals in hospital or subacute settings, residents in a facility-based program, clients of in-home supportive services or home health care, and participants in adult day services or adult day health care programs. The development of a patient's care plan is based on the physician's diagnosis with little to no concern for the patient's wishes and preferences. Assisted living and nursing facilities typically house 120+ beds where residents share the bedrooms and bathrooms. They are divided into 20-40 bed units with a nurses' stations located in the center. The nurses control the activities in the facility. Staffing in the residential medical model is segmented into different departments by task

specialization (i.e., administration, maintenance, housekeeping, and nurses). The organizational leadership, the service recipients, and their families make decisions; other employees are not involved in the decision-making process (Green House Project, 2010).

2.2.2 Person-Centered Long-Term Care: Concept and Models

The PCC conceptual model has been delineated through several researchers, institutions, and organizations that seek to promote individual choice and purpose along *with a meaningful life.*

2.2.2.1 Researchers

According to Kogan et al. (2016), PCC touches 17 different principles or values and 19 different elements. This was delineated after a study of the commonality among 15 definitions related to PCC or similar terms (American Geriatrics Society Expert Panel on Person-Centered Care, 2016). The inclusion of the client, as well as their family members and the service provider throughout the participants stay, was consistently included in the descriptions. Empowering these three groups to express their needs and desires and make collaborative decisions on the care of the individual was included as well as to form realistic goals towards the best quality of life possible.

2.2.2.2 Institutions

The American Geriatrics Society Expert Panel on Person-Centered Care (2016) defined eight (8) essential elements of PCC practices for realizing and supporting long-term care of older adults with functional limitations, chronic diseases, and conditions. These include:

- Comprehensive medical, functional, social and mental assessments with good understanding of their needs and desires

- Individual on-going plan of care with achievable goals and address the changes of the individual's medical, functional, social and mental conditions

- Supported by an inter-disciplinary professional team

- A primary health provider

- Coordinated among all necessary health and care services providers

- Ongoing communication and support

- Education and training for the providers

- Quality assurance and performance improvement
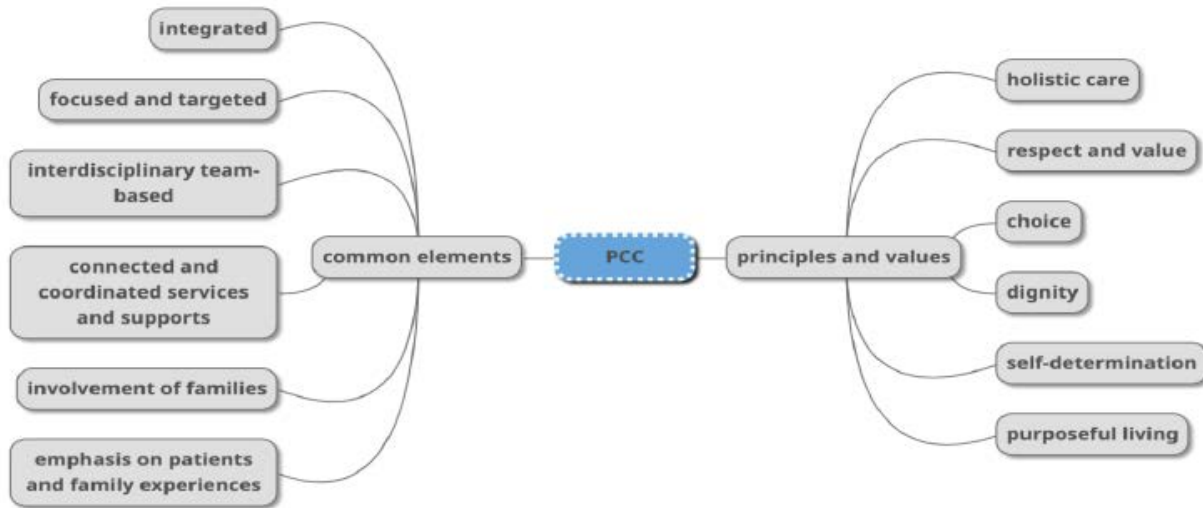
Figure 2.3: The PCC models.

The International Alliance of Patients' Organizations (2006) classified the PCC model as having five principles which include respect, choice and empowerment, patient involvement in health policy, access and support, and organizational information to practice and achieve a person-first quality of care. These principles were then expanded in 2013 to include coordination and integration of care; communication and education; physical, mental, and emotional support; family and community involvement; and overall respect for patient's values, needs, and preferences (Picker Institute, 2013). Further research from Kogan et al. (2016) identified a total of 27 principles and values, 17 central principles and/or values after reviewing nearly 3,000

articles about PCC, and identified the six most-prominent domains of PCC include holistic care, respect and value, choice, dignity, self-determination, and purposeful living as shown in Figure 2.3.

2.2.3   Various Person-Centered Care Models

2.2.3.1   Eden Alternative

William Thomas, a renowned U.S. geriatrician, championed the PCC model based on the principles to promote individual choice, purpose, and meaning in life (Lusk & Fater, 2013). Thomas believed life beyond the youthful stage was trajectory and one in which man must modify a human habitat worth enhancing sustainable growth required by the long-term care habitats (Koren, 2010). His goal was to deinstitutionalize nursing homes by revitalizing and energizing them with children, plants, and animals that make them homes away from home and eliminating the feeling of loneliness that eventually transforms into dementia and hopelessness. Thomas conceptualized the Eden Alternative to create a home-like setting where nurses have expansive roles ranging from meal preparation and medication management to handling special needs of the residents (Stein-Parbury et al., 2012). It is a sustainable model of residential care founded on 10 principles offering a guide to create an environment that soothes the souls of the residents and staff.

The first principle of the Eden alternative model addresses loneliness, helplessness, and boredom - emotions that a large proportion of seniors experience - by using person-directed morals with the capacity to put the person first (Brownie & Nancarrow, 2013). Specifically, the model embraces exclusive needs and preferences of residents and families by considering their choices and actions by encompassing option, self-worth, respect, independence, and purposeful

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living. The culture shifts are targeted on changing both long and short-term living situations in the home and community-based environments.

The second principle requires the provider to establish a human habitat rich with animals, plants, and children (Brownie & Nancarrow, 2013). The association helps the residents to embrace a life worth living and promotes a higher level of satisfaction.

The third philosophy asserts that the sole remedy to loneliness is loving companionship therefore, opportunities for interactions by both humans and animals must be maintained (Brownie & Nancarrow, 2013). In this sense, the elders have an opportunity to learn from other human beings while animals make them have a feeling of home away from home.

The fourth principle posits that an elder-centered community allows residents to give and receive care, offering a remedy for helplessness (Brownie & Nancarrow, 2013). Another philosophy reiterates that an elder-centered community instills daily life with diversity and freedom by generating a situation in which unforeseen and unpredictable connections take place, which is the solution to underlying boredom. The model also notes that pointless activity destroys the human spirit. Therefore, it is necessary to engage in activities that are meaningful to a human's health. Even medical treatment must be provided in a genuine human caring manner, as opposed to a forceful act. This can be achieved through interactive training, offering consultation along with useful materials and products to support ongoing services.

Alternatively, the model calls for honoring residents through the care they receive by discouraging top-down bureaucratic power, but instead, maintaining the decision-making ability in the hands of the residents and/or their families. Further, the care need not isolate human growth from human life, given that the two form the basis of survival of residents in care. Finally, the model states that wise leadership is critical because there is no substitution for such

skills (Brownie & Nancarrow, 2013).

Since the inception of the Eden alternative about thirty years ago, various senior living facilities and programs have implemented modified models at facilities in the U.S. and around the world (Young, & Chesson, 2008). For example, the Wellspring and Green House models are part of the many that have evolved to initiate culture change to include the human approach and person-centered-care at the center of their manifesto (Brownie & Nancarrow, 2013).

2.2.3.2   The Green House Model

According to Wagner (2014), Dr. William Thomas created the green house model housing seven to 10 elders with high care treatment demands in need of long-term care. The model is inventive, recognizing the independence, option, privacy, and dignity of the residents. The home creates a space for forming relationships between the residents and the workers (Wan, 2018). However, food is prepared in an open kitchen and offered to the residents, visitors, and the staff at a well-prepared dining table where they eat as a family (Whitstock, 2003). The living room has a warm open design with the dining room and kitchen and acts as the center of life in the green house home. The word Shahbazim is used in the green house which means *royal falcon* (Wagner, 2014). The green house model philosophy contains the elements of PCC in a small house atmosphere that values the elders and staff, autonomy and choice, dignity, privacy, reciprocal relationship between elders and staff, enjoyment, meaningful activity engagement, maximal functional independence, physical well-being comprehensive care, and security. The outcomes of the green house are improving the quality of life and quality of care, for the elders as well as their families' and staff's satisfaction (Green House Project, 2010).

2.2.3.3   The Wellspring Model

The Wellspring, established in 1994, is a collection of independent nonprofit

organizations based in Wisconsin that provide senior-living facilities that foster "change from the clinical quality of care and the organizational culture in its member facilities" (Brownie & Nancarrow, 2013, p. 10). Wellspring's philosophy is to provide the residents with the best quality of care and quality of life with a decrease in reimbursement, limited human resources, and increased consumer acuity and demand. The Wellspring culture respects and treasures each employee, no matter where they are coming from and what they do, regardless of what departments (Kehoe & Van Heesch, 2008).

2.2.3.4   The Managed Care Model

With the inception of PCC came model long-term services that support care coordination. In the past, caregivers relied on clients remembering what each of their doctors told them (Siminerio, Piatt, Zgibor, 2005). The accuracy of this information depended on the client's health literacy and competence to comply with medical instructions. This system was disorganized, ineffective, and dangerous. When health care providers are not aware of other clinical care, they may give conflicting advice, or be unaware of possible dangers interactions with treatments prescribed by others. Until now, health care providers were allocated a fixed, per-member, per-month capitated payment. Their profit was the difference between the capitated rate and the actual costs. However, if these costs were more, they were at risk of operating at a loss. Furthermore, if they do not meet specific quality standards and goals, their payment is reduced. Additionally, traditional Medicare will not pay for wrap-around services such as transportation, even when it is relatively low cost and could prevent higher expenses in the future (Siminerio et al., 2005). However, it will pay for repeated hospitalizations of someone (except within 30-days of a hospital discharge).

In a managed care model, a private company is responsible for all patient care and may

be more flexible and willing to invest in prevention realizing the cost-benefit for the future (Siminerio et al., 2005). The company reaps the financial benefits of avoiding the use of higher cost hospitalizations.

2.2.3.5   Behavioral Model of Care

The PCC model goes beyond the medical perspective of analyzing functional and mental limitations and challenges all members to keep the care recipient, or older individual, at the center of the care planning and decision-making process. This behavioral model of care prioritizes active listening, effective communication and attentive observing so that proper care is provided that is tailored to the client's needs, regardless of cognitive abilities (National Nursing Home Quality Improvement Campaign, 2017). Open and honest communication with healthcare professionals facilitates the involvement of older adults to actively participate in the management of their health. Relationships that consider older adults as partners in the discussion of treatment help to increase feelings of control and self-efficacy, which is crucial in achieving optimal health (Small, Bower, Chew-Graham, Whalley, & Protheroe, 2013).

2.2.3.6   The Care Transition Model

This new program is reforming long-term services and supports - the care transition intervention model developed by Dr. Eric Coleman. It is well-documented that re-hospitalization of seniors in long-term care are common and very costly to the health care system. Poorly managed transitions at discharge contribute to hospital readmissions totaling 15 to 17 billion dollars per year from the Medicare funds, and the physical and emotional pain on the patient and their family. (Coleman, Chalmers, & Min, 2006; Centers for Medicare & Medicaid Services, 2014). This model is a series of relatively modest steps aimed at improving the management of care for patients over 65 years of age following hospital discharge. The design includes a patient-

centered medical record, follow-up physician visits, and assistance from advanced-practice nurse transition coaches (Coleman, Roman, Hall, & Min, 2015).

In a randomized, controlled trial, the care transition model reduced hospitalizations and re-hospitalizations, along with the mean hospitalization costs over 180 days from $2,546 to $2,058 (Coleman et al., 2006). Additional research has shown that a managed-care model partnered with a transitional care center - that can provide rehabilitation and geriatric evaluation - showed improvements in health outcomes and lower healthcare costs after hospital discharge (Sternberg, Lee, & Huard, 2004). There are four pillars in the care transition intervention model:

- Managing medication
- Maintaining personal health records and sharing with all providers
- Follow-up of appointments with PCP and specialists
- Understanding and responding to their critical conditions and indications

2.2.3.7   Programs of All-Inclusive Care for the Elderly (PACE) Model

The most comprehensive and holistic care model that has been shown to be a successful service delivery is the PACE model. It combines medical care, adult day services, and in-home health and supports services for people aged 55 and older with extensive care needs. PACE participants are both Medicare and Medicaid recipients certifiable for nursing home level-of-care (Federal Register, 2005) but are still able to live independently at home at the time of enrollment. Preventable hospitalization rates among PACE participants are half that of eligible seniors not in a program and about 40% that of nursing home residents. Thirty-day all-cause readmissions are about 19% for PACE compared to 23% for eligible not in a program while mean hospital stays are shorter (Temkin-Greener, Cai, Zheng, Zhao, & Mukamel, 2012).

PACE programs are typically implemented at a PACE Center by an interdisciplinary team comprising physicians, nurse practitioners, nurses, social workers, therapists, registered dietitian, licensed clinical social worker, van drivers, and program aides. The program is with an on-site physician; medical supervision; skilled nursing care; physical therapy; occupational therapy; recreational therapy; therapeutic activities and exercises; nutrition services; three meals of lunch, breakfast, and snacks; transportation; social services, dental services; audiologist; optometrist; and podiatrist services. PACE also provides outpatient services such as lab test, radiology/X-ray, and outpatient surgery. Medical specialists in podiatry, cardiology, and rheumatology services are offered as well. Inpatient services such as emergency room visits, hospitalization, inpatient specialist, and skilled inpatient rehabilitation services are all a part of the program. At the core of this efficient and effective program is a comprehensive interdisciplinary assessment that is used to develop and implement an individualized *tailored* plan of care that is used to coordinate all services providers and empower the participants and their families to engage in their care (Boult & Wieland, 2010).

PACE is highly rated on satisfaction by participants and their family caregivers, as evidenced by an annual attrition rate of only 7% and enrollees are very satisfied with the care and services they received (Temkin-Greener, Bajorska, & Mukamel, 2006). According to Damons' (2001) research in Tennessee, the PACE participant satisfaction level and family caregiver's satisfaction level were as high as 96.9 %. They are more likely to feel happier, healthier and live longer than other home and community-based waiver programs (Boult & Wieland, 2010). The study also found that PACE reduces the need for costly nursing home care (S. M. Friedman, Steinwachs, Rathouz, Burton, & Mukamel, 2005), and decreases the risk of hospitalization and hospital re-admission rates as well as shortening hospital stays when they do

occur (Rylander, Jackenheimer, Dayan Colon-Sanchez, Keniston, & Nussbaum, 2017). By keeping people out of hospitals and nursing homes, PACE was also found to be associated with improvements in quality of life (White, 2000). However, cost savings are uncertain. Some studies have shown that while PACE can reduce Medicare costs by avoiding hospitalizations, it may increase Medicaid costs. Estimates of the net cost of PACE are highly variable and most research is based on data that are now quite old - often from the late 1990s and early 2000s. Studies that compare PACE participants to nursing home residents find that PACE may reduce Medicaid costs, while those that measure PACE against non-PACE participants receiving home-based care find it may increase costs (Foster et al., 2007).

2.2.3.8   Fee-for-Service vs the Managed Care Model

Despite the potential benefits of care coordination, transitioning from today's fee-for-service model carries risks and challenges for the managed care entities, consumers, and providers alike. Managed Care Organizations (MCOs) will be responsible for full financial risk for patient care. Because managing both health care and long-term support services is relatively untested, these providers must negotiate reimbursement rates with payers as well as payments to their various partners. Some may negotiate very aggressively with Medicare and Medicaid, thus winning business but risking unsustainably low returns. This may be especially true in a fully capitated system.

Of course, lower margins to the MCOs may result in lower-than-expected payments to their network providers. Concerns are beyond financial; mission-based providers and patient advocates are concerned with implementation of an integrated system and quality of care. For instance, will a MCO fully-responsible for a patient's care and the related costs withhold

services? This would be a major concern for extremely high-cost patients who are nearing the end of life.

Another critical challenge will be delivering community care for indigent people who may not have family nor informal supports. In the current fee-for-service system, these people would likely be living in a nursing home. However, most managed care models include strong incentives to deliver care to this population at home, with the assistance of professional case managers. Therefore, it will be important to develop appropriate systems of care, given the likely financial constraints and the difficulties of caring for this population.

In theory, enhanced quality measures are aimed at mitigating against these risks. The demonstrations, for instance, include provisions for withholding payment for managed care entities that fall short of quality standards. MCOs participating in New York's managed care demonstration are subject to gradually increasing financial penalties if they do not meet 69 quality benchmarks. These include falls prevention, reductions in hospital readmissions, and improvement in activities of daily living. However, many metrics measure processes, not outcomes. And, few are truly patient-centered but are focused more on easily quantifiable measures, such as falls, rather than on the harder-to-measure quality of life. These standard benchmarks, combined with an ingrained focus of many MCOs on health care, leaves many providers and policy analysts worried that managed care partnerships will "medicalize" social supports and services.

2.2.4   Integral Components of Person-Centered Care

2.2.4.1   Empowerment

Empowerment, one of the five main principles associated with the PCC models, is a social process that permeates to policymakers, patients, family members, and professionals

providing healthcare-related services. The personal and social-contextual constructs of empowerment theory supports the self-capacity of care recipients and social services of others involved in the care process to improve the well-being of older individuals.

Empowerment is very fluid and dynamic in nature; facilitating self-awareness in the participation of healthcare decisions and actively engaging in the attainment of health goals (Crawford-Shearer, 2009). This process benefits multiple individuals and subgroups within an organization and creates an environment that considers all health aspects of an individual and the support of others involved. Empowering individuals in PCC is diverse and includes individuals of different status that comprise a healthcare facility. PCC at the residential level fosters an atmosphere that is trustworthy and respectful, allowing older people to have autonomy and participation in direct care services. Relationships with staff members are caring and appreciative so that the recipient can continue to live in a way that is meaningful to him or her. Staff members that demonstrate PCC create strong relationships with both care recipients and family members and spend time getting to know the individuals, so the proper care is accounted for. Employees that demonstrate this kind of organizational behavior are surrounded by a culture that responds accordingly to changes in care recipient's conditions and has high staff retention that supports a better quality of care (National Nursing Home Quality Improvement Campaign, 2017).

It is equally important for all members to be directly or indirectly involved with the provision of care to facilitate empowerment by effectively communicating and expanding knowledge of the availability of resources and information needed to enhance the quality of life.

In order to break down the cultural strictures of ageism and age segregation in long-term care settings, care recipients, family members, and medical employees must learn how to collaborate effectively as a functioning unit to improve the quality of life and well-being of older

individuals. The diffusion of power and control in an active aging environment allows all three subgroups to feel more valued and respected within long-term care institutions, which ultimately affects the quality of care each resident receives (Shura, Siders, & Dannefer, 2011).

At the individual level, it is important for patients to have self-efficacy, autonomy, and feel empowered in the decision-making process (Small et al., 2013). This feeling of empowerment caters to the individual as well as in group settings because those who work closely with one another share common interests in supporting a similar cause (Fisher & Gosselink, 2008). Empowerment within a family context is increasing the knowledge, motivation, self-esteem, and self-efficacy of all members who are involved in the caretaking process to promote positive health and improve the quality of life among older individuals.

Next to families, employees in long-term care facilities are considered to be an important factor in the culture change movement to promote better quality of care. As the U.S. population continues to age, the need for personal care services and the demand for long-term healthcare workers continue to be an ongoing battle. The inadequate supply of workers, inefficient work structures, and ineffective managerial and leadership practices all contribute to a higher turnover rate which affects the quality of care given to the care recipients (Barry, Brannon, & Mor, 2005; Butler, Brennan-Ing, Wardamasky, & Ashley, 2014; Sikorska-Simmons, 2006).

The relationship between the quality of care provided to clients and the environment of staff in long-term care facilities was further explored by Sikorska-Simmons (2006). Organizational behavior and perceptions of work culture are strongly influenced by the employee's attitudes and relationships towards the care recipients. It is crucial that staff members work in an environment that values employee empowerment, teamwork, and participation in decision making to help improve job satisfaction and organizational commitment (Sikorska-

Simmons, 2006). Those that focus on having adequate resources, collaborative relationships, and competent management are creating an atmosphere that is supportive, which in turn, increases the active involvement of all individuals, including the care recipient, family members, and medical personnel, in the decision-making process (Choi, Flynn, & Aiken, 2011). This type of cultural interaction acknowledges the intellectual and functional capacity of all individuals involved in the delivery of healthcare services. The assurance of patient safety and improving quality in the continuum of healthcare requires a more person-centered approach shifting from the traditional, hierarchical model of care. PCC seeks to individualize care by engaging patients and family members in the healthcare process and creating an environment where all individuals with diverse roles feel empowered and respected (Bucknall et al., 2016; Caspar & O'Rourke, 2008).

2.2.4.2   Care Recipient Empowerment in Healthcare

Relationships that are built off empowerment recognize supportive social networks, stimulate client participation, and facilitate quality management in order to strengthen the role of care recipients. Interventions have been designed and implemented to create stronger relationships between care recipients and staff to increase active participation and autonomy in the decision-making process (Morrow-Howell & Van Geen, 1997). Care recipients in these interventions are looked to as facilitators, or experts, in the solution towards the improvement of quality of care.

Parrish, O'Malley, Adams, Adams, and Coleman (2009) further explored the implementation of a transitional care intervention to determine factors attributing to an organization's ability to sustain long-term patient care improvements. Project management and administration leadership were found to be critical factors in care transitions intervention.

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Leaders that facilitated organizational change established a consistent direction, reiterated

expectations, and demonstrated an authentic passion towards the organization's new goals

(Parrish et al., 2009). This offers a structural outline for healthcare agencies to maintain

alignment between organizational goals and individual interests while reinforcing behaviors

autonomy and empowerment when working towards a shared purpose of delivering quality

healthcare services (Crawford-Shearer, Fleury, Ward, & O'Brien,2012).

Several authors have conceptualized empowerment from a theoretical perspective which

has brought attention to the effectiveness of multi-level interventions concerning cultural,

contextual, and sustainability issues (Shearer, Fleury, Ward, & O'Brien, 2012). The framework

for empowerment is centered around the influence and control of decisions that affect one's life.

Next to the individual, attention is drawn to relationships with others that are directly or

indirectly involved in the decision-making process (Angelelli, 2006). Theoretically,

empowerment is a social-contextual process which includes all relationships and social forces

that are capable of regenerating self-control and feelings of power to that individual. When

considering empowerment programs and intervention strategies that strive to increase the care

recipient's intellectual and psychosocial skills, Shearer et al. (2012) stressed the importance of

implementing an effective self-care plan that seeks to improve overall health and quality of life

through education and emotional support. Despite the attention to theory and specification of

intervention strategies outlined in this body of literature, findings revealed several limitations

that could influence the overall expected outcome of empowerment interventions for older adults

(Shearer et al., 2012). In order to address issues related to low levels of perceived empowerment,

an organizational change should originate at the smallest level, starting with an individual's

strengths and abilities, and moving fluidly in a projective direction that targets individual

strengths within a governing body. This allows stronger connections to transpire among older individuals and others that are striving to achieve both personal and organizational goals (Crawford-Shearer et al., 2012).

The impact of group involvement on older individuals was presented in a study that analyzed several aspects related to collective efficacy and empowerment through social engagement (Fisher & Gosselink, 2008). Efficacy, considered a precursor to empowerment, inspires both individuals and groups to participate in social action to attain goals. The achievement of goals in this setting, not only empowered individuals, but also increased the efficacy in groups thereby encouraging social engagement and action (Fisher & Gosselink, 2008). Individuals that worked collectively as a functioning unit experienced a level of empowerment and confidence that led to goal-oriented actions of social engagement. This concept of empowerment takes into consideration the social context in which older adults can have control over their lives by actively participating and engaging in conversation that relates to medical care (Kane et al., 1997).

If the goal is to include and effectively collaborate with older individuals in the process of self-care, then recognition of individual strengths needs to be acknowledged to promote the well-being of older patients as well as others involved with providing care. Fotoukian, Shahboulaghi, Khoshknab, and Mohammadi (2014) illustrated several attributes that pertain to older adults with chronic diseases which help the individuals regain power over their lives. Awareness promotion, sense of control, development of personal abilities, autonomy, and coping all focus on the aging population. It is important that they are aware and educated on changes to their health so proper action is taken on both parts to address those needs. Giving individuals the freedom and control to perform tasks maximizes a person's personal, physical, and social

capacity to be involved and essentially manage health decisions that cater to successful aging. Older individuals want to feel confident and satisfied with the surrounding people and environment when faced with responsibilities or health challenges (Fotoukian et al., 2014). These characteristics of empowerment place individuals in an environment that is thought provoking and collaborative paving the foundation for a culture that supports organizational change.

Care recipients engagement, along with effective leadership practices, can work to address many of the fundamental problems associated with the aging process that benefits the goals of a cultural change movement. Shura et al. (2011) advanced the notion of culture change within a LTC community by addressing care recipients' lack of structural opportunities to overcome helplessness and instead, allowing these individuals to be more directly involved in community change. Decision-making in a decentralized LTC setting emphasizes cross-age relationships with elders, placing these individuals in a leadership role that stimulates creative reform ideas and new change initiatives. Care recipient participation and a shift in the balance of power given to older individuals is striving towards an environment of social engagement and relationship connectedness that goes against the institutionalized and incompetent roles that recipients are deemed to have in the traditional medical model of care (Shura et al., 2011).

2.2.4.3   Family Empowerment

Relationship building, diffusing power, sharing knowledge, and stimulating physical and intellectual engagement are all attributes for improving the delivery and quality of care received from older individuals (Bucknall et al., 2016). When considering the quality of care on elders, family support systems and healthcare professionals carry a strong influence on the empowerment process. Family members/caregivers and health experts need to be aware of health

conditions as well as services that assist in the quality of care. Family-based empowerment models suggest that families be more aware and educated on the health conditions that affect older individuals as well as the type of care suited to fit the individualized needs of older adults (Rabiei, Mostafavi, Masoudi, & Hassanzadeh, 2013). Family participation in the care for older individuals has increased self-efficacy, self-esteem, perceived threats, and quality of life of those who receive care, which has largely contributed to the improvement of care in the health system (Rabiei et al., 2013). Empowerment, in this context, not only affects the older individual, but also radiates to different realms within the environment that have an influence on the individual's well-being. From an organizational perspective, the fundamental aspects of empowerment affect the entire structure of the healthcare system and the extent to which care is being given, which includes the dynamic between family caregivers and staff members and the quality of care associated with each party (Kane et al., 1997).

On a socio-environmental level, family members devote a substantial amount of time interacting and providing care to individuals who do not have the functional or mental capacity to do so. With the aging process, family caregivers take on several complex roles that can range from assisting with ADL, to administering medication, or managing healthcare decisions for family members who are unable to do so. Those tasks can become quite daunting and very challenging to uphold given the unpredictability of health conditions and lack of guidance on how to handle these health matters. Inadequate knowledge or communication on the delivery of care, lack of guidance or instruction from healthcare providers, and feelings of uncertainty with how to provide care are all problems that caregivers face in the healthcare system. Many times, family caregivers are unfamiliar with the type of care and the amount of care needed to maintain an individual's health. Next to the quality of care, many members are unaware of community-

based resources or services that are available to help with the aging process. This puts family members in a vulnerable position of caring for individuals without having the proper understanding or resources that could otherwise be available to older individuals. In a healthcare environment, it is important for family members/caregivers to have concrete information and support from providers to ensure competent and effective care that does not put the older individual or any member of the family at risk.

One of the greatest challenge's family members are faced with is the fractured relationships and ineffective communication between nurses and staff members. Oftentimes nurses and caregivers are in conflict over the specific needs or situations that occur during hospital admission or discharge (Reinhard, Given, Petlick, & Bemis, 2008). Miscommunication, ambiguity, and lack of understanding of patient's needs interfere with the quality of care provided to older individuals (Nguyen, Pachanal, Beattie, Fielding, & Ramis, 2015). The researchers further reported the transition from direct care to more indirect, supportive interpersonal care caused added stress on family members who already felt uncertain about providing care (Nguyen et al., 2015).

Reinhard, one of the authors of *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*, noted that stress not only projects externally to other members, but also internally, increasing a caregiver's risk for fatigue, sleep deprivation, low immune functioning, and cardiovascular disease (Reinhard et al., 2008). Many of the risk factors associated with stress can be reduced with proper communication, education, and support from members directly and indirectly involved with care. When effective communication is exhibited, behaviors of staff and family members improved, less conflict occurred, and staff members were less likely to quit (Nguyen et al., 2015).

2.2.4.4   Staff Empowerment in Healthcare

The inadequate supply of healthcare workers, inconsistent income, and high turnover rates in the long-term care system has become a focus for gerontologists and healthcare researchers. As the population continues to age, worker retention in long-term, in-home, and community-based services is an important determinant in the quality of care (Butler et al., 2014). Given the financial setbacks in this realm, organizations must work to structure an environment that enables all stakeholders to participate and collaborate effectively in diverse dimensions. Tayab and Narushima (2015) reiterated the integration of PCC as an approach that views the quality of care through a holistic perspective and from that level of understanding, customize care based on the individual's needs. Individuals in these healthcare settings strive to be more culturally competent by respecting and prioritizing patient's needs, which equates to better quality of care (Tayab & Narushima, 2015). The theoretical and conceptual implications of empowerment in PCC extend to and from multiple levels within an organization. Empowerment functions is an individual's ability to take control and have confidence in decision-making or to be viewed as a shared process in which care recipients, family members, direct care workers, and managers collaborate in information exchange to achieve organizational outcomes (Yeatts, Shen, Yeatts, Solakoglu, & Seckin, 2016). Active involvement and responsive listening among all members, along with effective communication and management or leadership practices is crucial to the sustainability of healthcare in successful aging.

Empowerment not only resonates at the individual level, but also resides in the structure and cultural behavior of healthcare organizations. The structures provide an opportunity for advancement and resources to enhance the knowledge and skills of workers striving towards a culture that is both sustainable and effective. Workers are more willing to perform in an

environment that fosters autonomy and a greater sense of control over working conditions. An atmosphere in this setting, directly affects staff stability and the relationship used to empower both employees and patients within a healthcare system (Barry et al., 2005). Within an organization empowerment is internalized by staff members at the individual level that translates into a relationship among other individuals on a community level. Facilities with lower employee turnover rates and higher retention influence the strength of relationships between people, which is directly affected by the level of social engagement and care being given in such organizations (Barry et al., 2005). Staff members with greater job satisfaction view empowerment, teamwork, and participation in decision-making more positively (Sikorska-Simmons, 2006). Employees perceptions in the work environment are highly shaped by job satisfaction which caters to the overall quality of care put out by workers. Organizational cultures that value staff participation is more likely to instill positive work-related behaviors and effective services which older individuals seek (Sikorska-Simmons, 2006). Investing time on communication and interpersonal skills can improve the social interaction between individuals within an organization. That, next to the experience, highly influences the quality of care provided to care recipients.

Promoting vocational advancement and interpersonal skills in the work environment was further explored in staff workers who cared for dementia-specific patients. It was determined that those factors had a tremendous impact on employee turnover and burnout (Coogle, Parham, & Rachel, 2011). Researchers in the study investigated the relationship between job satisfaction and career commitment through empowerment interventions specifically designed to enhance self-efficacy, career planning, and job satisfaction by instilling values of recognition, responsibility, and respect among care providers. Effective communication, peer mentoring, and the implementation of problem-solving and stress management skills suggested an increase with job

satisfaction in a work environment that encourages opportunities for professional development. Job satisfaction plays a critical role in the quality of relationships between care workers and supervisors within an organization (Anderson, Corazzini, & McDaniel, 2004). The attention brought on relationships between direct care workers and supervisors has suggested an increase in job satisfaction, performance, and work-related outcomes, which has helped to reduce the likelihood of quitting (Brannon, Barry, Kemper, Schreiner, & Vasey, 2007). In order to improve retention rates within organizational practices, more altruistic approaches that focus on relationship building, care recipient-employee matching, recognition, and active participation planning are needed to enhance individual and facility development (Brannon et al., 2007).

Strategies, or initiatives, that allowed caregivers to provide quality care were examined by Caspar and O'Rourke (2008), whose objective was to establish a connection between care-provider access to structural empowerment and the provision of individualized care in LTC settings. The amount of power, information, and access to resources healthcare providers had catered to the level of empowerment that was shown in order to provide care effectively (Caspar & O'Rourke, 2008). Choi et al. (2011) illustrated five dimensions in the nursing organization and outcomes model used to comprehend the organizational context where care takes place. The conceptual framework of this model considers facility participation, adequate resources, effective managerial practices, collaborative relationships, and foundations for better quality of care. Active participation, supportive supervision, and the availability of resources were found to be strongly related to job satisfaction within these work environments (Choi et al., 2011). Active involvement of staff members facilitates open, receptive feedback, and offers input in the decision-making process. Supervisors and managers should work to be more considerate of employees concerns and respond in a manner that is respectful and caring towards workers'

needs. Organizations that recognize opportunities and enhance the strengths of individuals can attain goals and achieve organizational outcomes in a productive manner (Banaszak-Holl & Hines, (1996).

2.2.4.5   Diversity among Caregiving Issues

The growth rate of older individuals is a pivotal focus for health care professionals and individuals who need long-term health care services. The delivery and financing of long-term care garnered considerable attention in the 1900s when more than 11 million Americans with chronic conditions needed prolonged care and approximately 7 million of those individuals were older adults who had a long-term care dependency (Scanlon, 1988). Most adults over 65 years have had or are experiencing one or more chronic health issues that negatively affect an individual's well-being. Community-based services and programs are one form of support that significantly affects older populations with diverse needs. Older individuals with functional limitations and are isolated benefit greatly from these services in order to regain autonomy and improve quality of life (B. Kim, Park, Bishop-Saucier, & Amorim, 2017).

Given the number of chronic conditions associated with aging it is important that services and programs support the physical, social, and psychological well-being of older adults. The Centers for Disease Control and Prevention, the National Center for Health Statistics, and the National Health Interview Survey, 2013-2014, illustrated the percentage of both men and women 65 and over who had one of the following chronic health conditions - heart disease, hypertension, stroke, asthma, chronic bronchitis, cancer, diabetes and arthritis. The data showed over 50% of the population for both men and women having hypertension and 43% of men and 54% of women having arthritis. Different types of dementia, including Alzheimer's disease, are also commonly seen in older adults. Approximately 24% of individuals ages 75-84, and 54% of

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adults 85 years and older have dementia in the non-nursing home population (Federal Interagency Forum on Aging-Related Statistics, 2016).

2.2.4.6   Caregiving Issues

Informal and formal caregivers play the roles in caregiving for people who need long-term care services. In California, more than 6 million informal caregivers including family members, friends, or neighbors were providing care for a long-term illness or disability during 2009 (Hoffman & Mendez-Luck, 2011). In California, about 57% of the caregivers are women, and about 47% of the caregivers are adults between 18-44 years old. About 16.7% of the households have one informal caregiver taking care of their loved one age over 50 and older. Of the Californians who are playing the informal caregivers' roles, 73.2% are taking care of their family members (Scharlach et al., 2003). According to the data from the Alzheimer's Association, in 2011 more than 1.5 million Californians provided unpaid caregiving services to people with Alzheimer's and other types of dementia (Alzheimer's Association, 2012). About one-third of the informal caregivers live with the care recipients and 52% of the caregivers have a full-time job outside the house. The average caregiver who lives away from the client spends 21 hours per week on average. Those who live with the ones they are caring for average 36 hours per week (Hoffman & Mendez-Luck, 2011).

2.2.4.7   Quality Assurance and Self-Assessment

Self-assessment is an important and valuable component in developing, maintaining, and improving the quality of care in a healthcare system (Harrington, Woolhandler, Mullan, Carillo, & Himmelstein, 2001). Per Bose, Oliveras, and Edson (2001), self-assessment is a cost-effective approach to measure the quality of care and maintain the professional competence, but questions came up for its validity. Early in 1977, Levine (1980) mentioned that there were three processes -

self-observation, self-judgment, and self-evaluation reaction - which can be an early theory of

the self-assessment process. "A comprehensive, systematic, and regular review of an

organization's activities and results referenced against a model of business excellence" is the

definition from the European Foundation of Quality management based on the TQM literature

(Mohr-Jackson, 1998, p. 13).

In the healthcare settings, the self-assessment process using the performance model can

be easily incorporated into the individual self-assessments practice with the action plan to fulfill

the role with the guidelines (Bose et al., 2001). The benefits from self-assessment in terms of the

quality assurance include low-cost, increasing compliance with standards (Adamow, 1982),

helping professional development (Ouslander, Bonner, Herndon, & Shutes, 2014), empowering

the participants, improving communication between managerial and front-line staff (Harris &

Schaubroeck, 1988), and helping to identify the skills for transferability (Mayall & Maze, 1985).

2.3   Summary

As a result of the review of literature about PCC and translational models, a paucity of

research was found on the best practices of care in ADHC/CBAS programs. This is unfortunate

since organizations are struggling to identify successful PCC models that are impacting

communities with a high concentration of poverty and people of color that could be replicated to

meet the changing requirements of state and federal officials. In the review of the literature, I

also found a dearth of social science research on CBAS/ADHC centers in the U.S. and

California. This may stem from the lack of interest and fiduciary investment by state and federal

stakeholders in PCC CBAS/ADHC programs or the lack of interest in research applicable to this

population.

The current literature review was conducted to identify the body of knowledge surrounding the efficacy of integrating a PCC model into ADHC/CBAS programs. The secondary purpose was to identify best practices for translating the PCC model into ADHC/CBAS programs in the community. It provides a critical view that significantly augments knowledge about the contemporary crisis in community-based programs for frail elderly seniors.

CHAPTER 3

RESEARCH DESIGN AND METHODS

In this study, I utilized a mixed-methods approach to assess the readiness and determine the necessary operational and organizational culture modifications required for implementing a PCC model in a Southern California ADHC. The layout of this chapter includes the research design, including an overview of the sequential explanatory mixed-methods two-phase design of quantitative via survey followed by qualitative via focus groups; the study population description, sampling procedures, and ethical considerations relevant to the inclusion of participants for study are also included. The chapter concludes with the focus group protocols and method for analysis as well as the descriptive statistical analysis utilized for the quantitative data.

3.1   Statement of Purpose

The purpose of this study was to determine the readiness of a CBAS/ADHC program's practices and operations to implement a PCC model to meet the new standards for certification and licensing requirements by the California Department of Aging (CDA) and California Department of Public Health (CDPH).

3.2   Research Design

3.2.1   Mixed Methods

Both descriptive statistical analysis of quantitative - numeric data followed by qualitative data analysis - descriptive/text/graphical images was employed (Sandelowski, Voils, & Knafl, 2009). Recognizing the complexity of current social work issues, a mixed-methods approach was selected for this study because many social scientists and gerontologists believe these types of studies warrant a multifaceted research design. Additionally, there is growing interest in mixing

qualitative and quantitative methods to both thoroughly understand social welfare policy

decisions and interventions in PCC programs. As the research literature recommends, this was a

triangulation study that integrated data from multiple sources for the best interpretation and

conclusion.

3.2.2 Triangulation

The majority of social science research is grounded on a single research method and, as

such, may suffer from the limitations associated with that method or from the specific

application of it. Triangulation offers the opportunity for testing multiple effects with the

prospect of enhancing confidence in the research results. It is the use of multiple methods

whereby the strengths of one method compensates for the weaknesses of the other (Tashakkori &

Teddlie, 1998). This method was used to confirm results from the simultaneous application of

multiple methods, multiple investigators, multiple datasets, or multiple theories. Using the results

from the qualitative face-to-face one-on-one interviews and focus group sessions along with the

quantitative questionnaire ensured that data triangulation was achieved as a sampling and

validation strategy.

Taylor and Bogdan (1998) contended the manner for validating insights gathered from

different sources of data and participants is triangulation. Hale, Treharne, and Kitas (2008) and

Jonsen and Jehn (2009) advised when an issue is explored from several perspectives,

triangulation enhances the methodology and validity of the study. Shank (2008) concluded that

when different strands are woven together, stronger evidence of the validity of the findings

achieves higher confidence. Thus, the use of triangulation in the present study involved mixing

methods and sources of data (Shank, 2008) to ensure the reliability of findings.

3.2.3 Quantitative Research

Quantitative research gathers data with exacting measurements and provides conclusions concerning how many, who, and when (Cooper & Schindler, 2003). Cooper and Schindler (2003) suggested that a standard instrument employed in quantitative studies is the survey questionnaire. The researcher selects what to study, then presents questions designed to provide numerical results that can be analyzed statistically providing explanations that can be provided without bias and couched in objectivity (Creswell & Plano Clark, 2010). A questionnaire was deemed appropriate for the quantitative portion of this mixed methods study assessing an ADHC's readiness for implementing a PCC model program.

Questionnaires comprising a battery of Likert scaled questions concerning self-reported opinions, attitudes, and feelings were completed by program participants, their family members, and staff (Nemoto & Beglar, 2014). Some advantages for utilizing Likert scales involve,

- Collecting data can be relatively quickly for large sample sizes

- Sameness in cohorts can provide a high reliability amongst binary groups: comparing and contrasting can be interpreted with quantitative and qualitative research studies

- Validity of the interpretation of the data can be made from a variety of means

To address the research questions and hypotheses that guided the quantitative portion of the study the following null and alternative hypotheses testing were employed. With the first two hypotheses, I examined relationships between background variables, co-variates, and PCC with state and federal regulations. Using the third hypothesis, I examined group differences.

3.2.4 Qualitative Research

Qualitative researchers are more concerned with seminal research, specifically, from the phenomena of observing then describing having immersed themselves in the environment (Savenye, 2001) as an observer and participant. Outlier comments were more readily captured in

this research; the concern with de-conflicting narratives is the humanistic element of social behavior where voices of marginalized participants are rarely heard and their personal narratives are often left-out or avoided in qualitative research. Furthermore, it allows researchers to draw on cultural history (Gutierez, 2016), especially in non-dominant communities, and allows for the decolonization of marginalized perspectives. A notable focus of this study was to advance quality research that produces fresh insights into PCC models using constructs from both datasets that were analyzed simultaneously.

3.2.5   A Phenomenological Approach

A phenomenological qualitative approach was used in this study. Maxwell (2005) points to this approach as a process of eclecticism; "there is no right way" (Tesch, 1990, p.153), or "systematic way" (Becker, 1993, p. 219) of conducting a study. This type of research is *naturalistic* suggesting that there are actual settings, whereby the researcher enters and spends considerable time in "schools, families, neighborhoods and other locales" (Bogden & Bilken, 2006, p. 4). In addition, naturalism is an old tradition of qualitative research (Babbie, 2016) with the intent of the researcher to naturally observe and report "what really is" happening (Gubrium & Hostein, 1997, p. 81). Similarly, Best and Kahn (2006) define naturalistic inquiry as "studying the real world as they unfold naturally; non-manipulative, unobtrusive, and non-controlling; openness to whatever emerges with a lack of predetermined constraints and outcomes" (p. 241).

Bogden and Bilken (2006) defined the phenomenological approach to refer to an "attempt to understand the meaning of events and interactions to ordinary people in particular situations" (p. 43). As a research methodology, phenomenology is both descriptive and qualitative (Polkinghorne, 1989). The focus is on subjective experiences, instead of descriptors of covert actions or behaviors (Polkinghorne, 1989). It consists of "reflectively bringing into nearness that

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which tends to be ambiguous or to evade the intelligibility of our natural attitude of everyday life" (Van Manen, 1984, p .41). The phenomenological analyses reported by Van Manen (1984) may be a dynamic interplay of six research activities.

a. Turning to a phenomenon that seriously interests us and commits us to the world

b. Investigating an experience as we live it rather than as we conceptualize it

c. Reflecting on the essential themes that characterize the phenomena

d. Describing the phenomena through the art of writing and rewriting

e. Maintaining a strong-oriented relationship to the phenomena

f. Balancing the research context by considering parts and the whole (p. 39)

3.3 The Study Participants and Setting

The goal was to sample the "entire range of the population and capture the representativeness of the individuals, settings, and activities selected" (Creswell & Plano Clark, 2010, p. 89). Patton (1990) contended *purposeful sampling* allows the researcher to engage in "information-rich cases for in-depth study" (p. 169). Patton asserted that these "cases are those from which one can learn a great deal about issues of central importance to the purpose of the research" (p. 169).

3.3.1 The Study Sample

The study group was recruited from the population of an ADHC program located in the City of West Covina, CA. Located 19 miles east of Downtown Los Angeles in the Eastern San Gabriel Valley and part of Greater Los Angeles County, the City of West Covina encompasses a diverse population of 106,098 comprising 53% Hispanics or Latinos, 42% Caucasians, and 25% African American of which almost 2.3% (2,402) were people 60 years old and over. This agency

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was selected for study based on the researcher's familiarity with the participants who live and attend the ADHC.

3.3.2   Demographics of the Study Population

To qualify for study, the participant had to be engaged in the center 3-5 days per week. Involvement entailed current membership, regular attendance, and participation in PCC activities by both themselves and their family.

All program participants (100%) enrolled in the ADHC program August 1, 2017-July 31, 2018, their family members, and the ADHC staff, during the same period, was included for study. All were residents of West Covina and the surrounding areas of Los Angeles County.

A distribution of the demographic characteristics of study participants can be found in Table 3.1. As shown, the largest group of the active participants (54%) were between 75-84 years of age; more than 34.7% were over 85 years of age. A large proportion (63%) were females and 52% reported being widowed while 47% were still married. The entire group (100%) were Chinese immigrants of which the majority (66%) were from Mainland China and have lived in the U.S. for at least 10 years or more. Slightly more than half of the group (53.9%) were living with their children, 25.7% said they lived with their spouses, and 19.5% reported living alone. Over 39% have attended an ADHC center for at least 1-5 years while more than 46% reported attendance at the ADHC study center for at least a year.

Table 3.1: Demographic Characteristics of Study Participants

	Characteristics	%	#
	From 65 to74 years	10.55	27
Age	From 75 to 84 years	54.69	140
	85 years and older	34.77	89
Gender	Male	36.72	94
	Female	63.28	162

Characteristics		%	#
Marital Status	Single	0.39	1
	Married	46.88	120
	Widowed	51.56	132
	Separate/divorced	1.17	3
Country of Origin	Hong Kong	7.81	20
	Mainland	66.02	169
	Taiwan	18.36	47
	Others	7.81	20
Living Status	Alone	19.53	50
	With spouse	25.78	66
	With children	53.91	138
	With roommate	0.78	2
Number of Years Lived in the U.S.	1-10 years	16.02	41
	11-20 years	36.33	93
	21-30 years	22.66	58
	30 + years	25.00	64
Number of Years Lived in the Community	1-5 years	24.22	62
	6-10 years	22.27	57
	11-15 years	23.05	59
	16 + years	30.47	78
Number of Years Attending an ADHC	1-5 years	39.06	100
	6-10 years	16.41	42
	11-15 years	32.42	83
	16+ years	12.11	31
Number of Years Attending This ADHC	1-5 years	46.88	120
	6-10 years	21.48	55
	11-15 years	28.13	72
	16+ years	3.52	9

3.3.3 Health Conditions of the Study Population

All of the study center participants had medical or physical conditions and more than

three functional disabilities or challenges that require assistance or supervision level of care. For

example, as seen in Table 3, more than 87% needed assistance accessing resources and the majority (94.5%) required aid preparing meals and cleaning their home. Additionally, more than half of the participants required care with hygiene (56.6%), money management (48.9%), transportation (57.2%), and using some assistive device (63.2%).

Close to one-third of them had diagnoses of dementia or related cognitive issues, and more than 20% had a mental health diagnoses, such as depression, anxiety, or schizophrenia with or without medication. As across all ADHC/CBAS program populations, the study group comprised older participants with disabilities that needed around-the-clock care, while others managed with a limited number of personal care hours each week at home. This ADHC PCC program is able to provide both these types of services along with support for appropriate utilization of prescription medications.

Table 3.2 describes the center participants' service utilization during the time this study was conducted; a comparison of three 6-month periods that they were enrolled in the study is shown.

Table 3.2: Comparison of Diagnoses, Conditions, and Services Provided by the ADHC During Three 6-Month Time Periods

Portfolio of Participant by 6-Month Period	As of					
	31 Dec 2016		30 June 2017		31 Dec 2017	
Total # of Participants	239		251		273	
	#	%	#	%	#	%
Diagnoses/Conditions						
Dementia	68	28.45	68	27.09	79	28.94
Intellectually/Developmentally Disabled	1	0.42	1	0.40	1	0.37
Mental Health Diagnosis	46	19.25	52	20.72	64	23.44
Health Status/Needs						
Psychiatric Medications	19	7.95	23	9.16	28	10.26
Behavior Symptoms	1	0.42	2	0.80	0	0.00
Ambulation Assistance	26	10.88	20	7.97	22	8.06

Portfolio of Participant by 6-Month Period	As of					
	31 Dec 2016		30 June 2017		31 Dec 2017	
Total # of Participants	239		251		273	
	#	%	#	%	#	%
Bathing Assistance	71	29.71	76	30.28	81	29.67
Dressing Assistance	59	24.69	67	26.69	62	22.71
Toileting Assistance	2	0.84	3	1.20	2	0.73
Self-Feeding Assistance	1	0.42	0	0.00	0	0.00
Transferring Assistance	19	7.95	15	5.98	15	5.49
Accessing Resources	206	86.19	213	84.86	245	89.74
Hygiene Assistance	137	57.32	141	56.18	154	56.41
Mean Preparation Assistance	232	97.07	232	92.43	253	92.67
Medication Management	17	7.11	35	13.94	50	18.32
Money Management	114	47.70	117	46.61	143	52.38
Transportation	126	52.72	140	55.78	172	63.00
Fall risk	65	27.20	57	22.71	67	24.54
Uses walker/cane/wheelchair	147	61.51	150	59.76	186	68.13
Hearing/Vision Deficits	212	88.70	217	86.45	172	63.00
Communication Deficits	0	0.00	0	0.00	1	0.37
Speaks English	14	5.86	7	2.79	0	0.00
Services Provided						
Special Diet	138	57.74	113	45.02	132	48.35
Group/Individual Psych Services	51	21.34	51	20.32	53	19.41
Speech Services	3	1.26	6	2.39	5	1.83
Prescribed Meds Administered at Center	0	0.00	7	2.79	14	5.13
Self-Administered Meds at Center	4	1.67	12	4.78	36	13.19
Restorative PT and/or OT	198	82.85	199	79.258	216	7912
Skilled Nursing Services	87	36.40	87	34.66	92	33.70

3.3.4 Study Participants' Family Members

The second study group comprised family member(s) of the research participants such as, daughters, sons, grandchildren, and non-relative caregivers living with or close to the study

participant and saw them regularly. As described in Table 3.3, most of these individuals were

between 41 and 55 years of age (56%) and almost all were 41 years and older (98%).

Table 3.3: Demographic Distribution of Study Participants - Family Members

Characteristics		**%**	**#**
Age	From 18-25 years	0	0
	From 26-40 years	2	1
	From 41-55 years	56	28
	56 years and older	42	21
Gender	Male	54	27
	Female	46	23
Marital Status	Single	8	4
	Married	84	42
	Widowed	0	0
	Separate/divorced	8	4
Relationship to Study Participant	Son	50	25
	Daughter	40	20
	Legal Rep.	0	0
	Others	10	5
Living with Study Participants	Yes	62	31
	No	38	19
Frequency of Visits with Study Participant	Daily	66	33
	Every week	28	14
	Every month	4	2
	By year	2	1
Employed	Yes	80	40
	No	20	10
Provides Direct Care to Study Participant	Yes	66	33
	No	34	17

As many as 80% were regularly employed of which 66% were providing direct care to

their loved ones in the study. Over 66% reported visiting the study participants daily another

28% said they saw them on a weekly basis.

3.3.5 The ADHC Study Center's Staff

The third study group is composed of the ADHC center staff including consultants. Of the 32 total staff members that were working at the center at the time of the study, a sample of 20 completed the questionnaire. As seen in Table 3.4, all study staff were 26 years of age and older; the majority were married (70%) females (75%) with 13 or more years of education and had been working at the study ADHC for 1-5 years (65%).

Table 3.4: Demographics District of the ADHC Staff Study Participants

Characteristics		%	#
Age	From 18-25 years	0	0
	From 26-40 years	30	6
	From 41-55 years	35	7
	56 years and older	35	7
Gender	Male	25	5
	Female	75	15
Marital Status	Single	25	5
	Married	70	14
	Widowed	0	0
	Separate/divorced	5	1
Years of School	1-5 years	0	0
	6-9 years	0	0
	10-12 years	15	3
	13+ years	85	17
Years Lived in the U.S.	From 1-10 years	15	3
	From 11-20 years	30	6
	From 21-30 years	25	5
	Above 30 years	30	6

3.3.6 The ADHC Program

The ADHC Center used in this study had been providing medical and social services support to elders and disabled individuals Monday through Friday from 9:00 AM to 1:00 PM as

a fully licensed and certified program since 2002.

3.3.6.1 Program Services

The Center provides care in a specialized setting that fosters and promotes individuals'

psychosocial and physical well-being in a protective environment. It was designed specifically to

- Assist in the transition from acute care to rehabilitation

- Prevent inappropriate or premature institutionalization in a long-term care facility

- Provide supportive services and respite to families and caregivers of the participant

- Provide participants with a safe, fun and stimulating environment under constant responsible care

- Enhance the daily quality of life and independence of participants by enabling them to continue living at home and in a community

Advantages to this program include

- Allows time for respite care, self-renewal, and attending to other family needs

- Activities encourage interaction and stimulate physical, mental, social and spiritual wellness

- Consultation services provide information and emotional support to both individual and family

- Qualified assistance available for participants with special needs

- Each individual is assessed to develop their own plan of care

- A friendly ear is available for day-to-day problem solving

- Transportation provided based on each individual's assessment

- Nutritional services - two meals a day

3.3.6.2 Program Costs

The services provided by the ADHC program are paid on a fee-for-service cost

reimbursement schedule by managed care plans. The ADHC is contracted with 11 managed care

plans and is compensated an average rate of $71.17 per person/per day as shown in Table 3.5. The Centers multi-disciplinary staff of health care professionals and program aides provide services to program participants as authorized (a minimum 2 days to a maximum of 5 days/per week; an average of 3 days/per week) on- and off-site. These services range from transportation, medical care. skilled nursing, personal care, psycho-social support, dietary to nutritional consultation, physical therapy, occupational therapy, therapeutic activity as well as speech therapy, professional consultation services and mental health, psychiatric and psychological services as needed, along with three meals a day -- breakfast, lunch and snacks.

Table 3.5: The ADHC Contracted Managed Care Plans and Payment Information

Managed Care Plan	# of Members	Rate for Services	Other Services Offered to Participants
Health Net	132	$76.88	Dental Cal program
LA Care	53	$75.51	Respite care, caregiver support and training programs, medical transportation
MOLINA Health Plan	26	$68.64	Medical transportation, caregiver support
Inland Empire Health Plan	4	$68.64	Medical transportation, caregiver support
Anthem Blue Cross	17	$68.64	Medical transportation; Medicare Advantage
Kaiser Permanente	1	$68.64	Medical transportation; training program
Cal Optima	1	$68.64	Not known
SCAN	2	$76.27	Research project
Blue Shield	8	$68.64	Not known
Care More	0	$68.64	Medicare Advantage

3.4   Procedure and Human Ethics

3.4.1   Institutional Review Board (IRB)

Approval from the University of North Texas Institutional Review Board (IRB) was sought and received on February 15, 2017, before any part of the study was conducted. A copy of the approval is in Appendix A. The study was deemed minimal risk to participants as

determined by the U.S. Federal Government of Health and Human Services (2019) regulation CFR subsection 46.10, which states the probability and magnitude of harm or discomfort anticipated in the research should not be greater in and of themselves than any ordinarily encountered in daily life, or during the performance of routine physical or psychological examinations or tests. Eligibility for study was determined by participants' enrollment in the ADHC program.

To protect their identity, all study participants records were de-identified and unique case numbers were assigned to the responses - interviews and surveys - of individuals and their family members as well as program staff. Although participants were referred to by their given names during the interviews absolutely no first or surnames was reported in the results or discussion of this study.

3.4.2   Consent Form and Scripts

All participants were given a Consent Form to read and sign prior to study implementation. A copy of the consent form is in Appendix B. The conditions of the study were communicated to all participants at the start of the research where they were informed of their right to refuse or withdraw at any time from the study without penalty. The consent form explained the purpose of the study and informed the participant that no identifiable information would be kept; all identifiers, such as first and surnames, were not kept in any manner. Anything shared during the study would be used solely for the researcher's dissertation and scholarly and professional publications such as peer-reviewed journals and/or conference presentations.

All consent forms were signed by center participants, family members, and staff then scanned and emailed to the research supervisor for central storage in the University of North Texas Department server. All interview notes, data sets, and analyses are retained in a locked

cabinet or secure cloud where it will remain for 3 years after the publication of this dissertation, after which time all materials will be deleted or destroyed.

The research scripts were designed in English and Chinese versions in order to assist opening the conversation with the research participants. In the script, the researcher gives a general introduction of the researcher, the purpose of this research, the length of the research process for the survey and interviews, and explained there were no foreseeable risks involved in this study. In the research scripts, the research also mentioned this research is a volunteer based and the research participants will get a cloth grocery bag in gratitude for the participation. At last, the contact information was written at the end of the script for the participants to keep for communication purposes. A copy of the script is in Appendix C.

All communication was conducted in either English or Chinese depending on the participant's preference. Extra care was taken to ensure that respondents understood the nature of the study and that participation was voluntary. No sanctions nor incentives were employed to encourage participation, nor were any applied if the participant declined or withdrew from the study. In gratitude for study participation, those who completed their interview received an imprinted, cloth grocery bag valued at $2.00.

3.4.3   Participant Selection Criteria

There were NO exclusions from study; all program members of the ADHC were eligible for the study regardless of their gender, race, religion, or sexuality.

3.4.4   Participation Recruitment

Initial contacts were made on site; flyers and recruitment materials approved by the IRB were posted throughout the facility, on program buses, and personally distributed to program participants to take home and share with their family members. The recruitment materials are in

Appendix D. Opportunities were taken throughout daily activities to explain the purpose of the study and answer any questions.

3.5   Data Collection

Survey and interview questionnaires were developed to collect data from program participants, participants' family members, and program staff and consultants. Electronic web-based versions in both English and Chinese were implemented for the data collection (Couper, Traugatt, & Lameias, 2001; Kaplowitz, Haddock, & Levine, 2004). and were distributed and collected via SurveyMonkey®; an online web-based software that allows the creation and distribution of surveys through virtual mechanisms.

3.5.1   Quantitative Instrument - The Surveys

Three versions of the survey to collect data from program participants, participants' family members or caregivers, and program staff and consultants were developed in both English and Chinese. All three versions of the questionnaire were divided into three sections:

- Section 1: Basic information
- Section 2: PCC-related activities
- Section 3: Program operations

Each survey question was designed to provide the evidence required to address the CDA self-assessment tool for re-certification.

3.5.1.1   Section 1 of the Survey Instruments

The purpose of this section was to collect demographic/background information. Study participants were asked about their age, gender, origin, marital status, education, years of living in the U.S. and the West Covina community, years in attendance at ADHC Centers, and

attendance at the study ADHC program. Included were questions concerning relationship of participant to family member, utilization of in-home support services (IHSS), and, who pays for and provides the services.

The participants' family members in the study were asked about age, gender, marital status, relationship with loved one, education, work status, years living in the U.S. and the West Covina community. They were also asked:

- If they live with their loved one

- If not, how often they visit them

- If they have regular jobs or receive IHSS paychecks from the State

The ADHC staff were asked about age, gender, marriage status, education, length of stay in the U.S., tenure in healthcare profession and at the facility, current positions, and plans for education during the next five years.

3.5.1.2   Section 2 of the Survey Instruments

Section 2 contained the 23 questions replicated from the CDA's self-assessment tool and extended an additional 27 that fall under six categories for ascertaining participants, families, and staff members' assessment of the study's ADHC - PCC program concerning:

- Access to resources in the community

- Choices of setting, rights, autonomy, and independence

- Choice of services and supports, and accessibility

Figure 3.1 reflects the subject areas of the questions asked contained in the self-assessment tool.
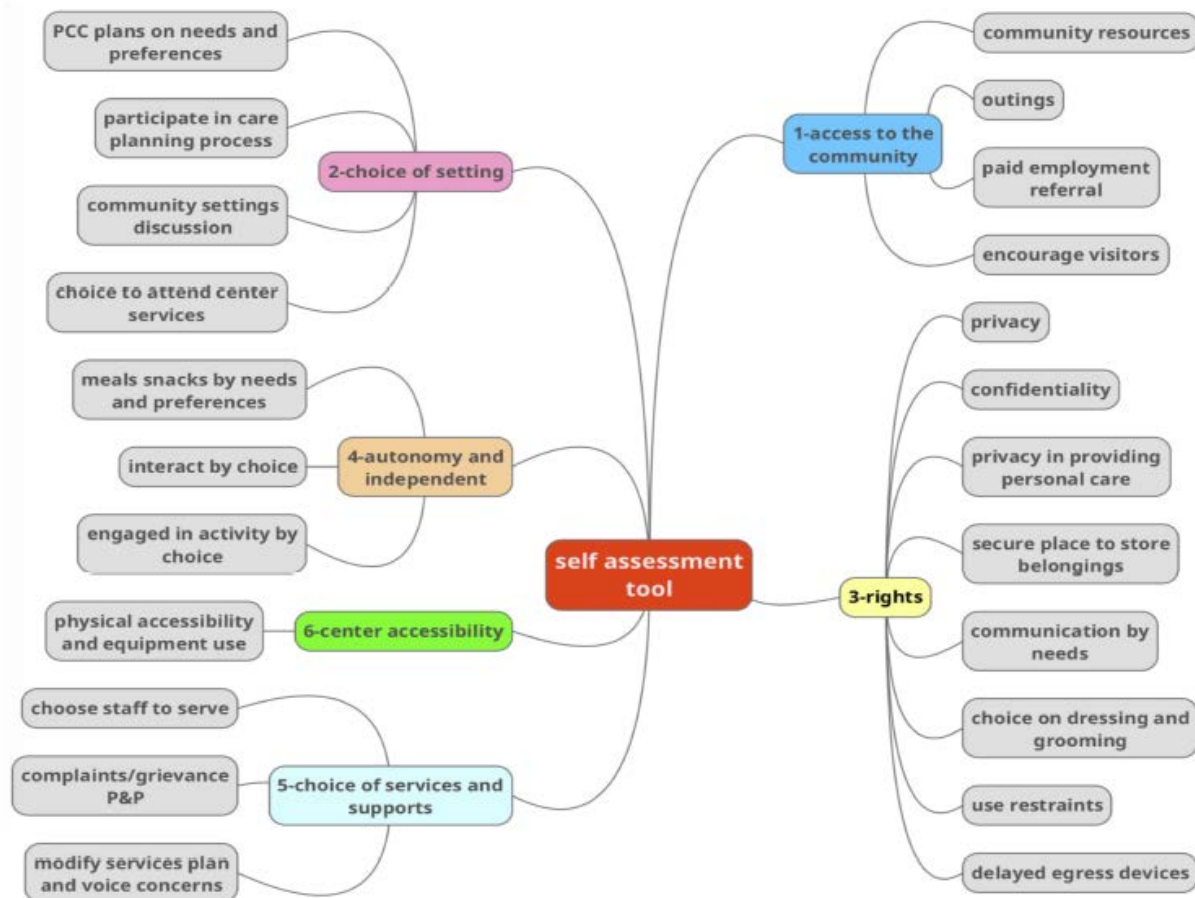
Figure 3.1: Self-assessment questions by categories.

3.5.1.3   Section 3 of the Survey Instruments

In the final section, respondents reported on the organization's culture, mission, program operation, and management. Program participants were asked 20 Likert-scale (a 6-point scale with 1 = *not known,* 2 = *strongly agree,* 3 = *agree,* 4 = *neither agree nor disagree,* 5 = *agree,* 6 = *strongly agree*) questions concerning program operations and management, decision-making, feelings, trust, privacy, respect, care, and the home-like environment. To account for multiple caregivers, questions were modified to include the phrase "focus caregiver" to help participants remember to answer the survey items concerning the caregiver who fit the research criteria. The participants' family members were asked similar questions. Program staff and consultants were asked 25 Likert-scale questions related to the ADHC study organization's mission, management

satisfaction, leadership effectiveness, team performance, management performance, manager effectiveness, job satisfaction, career goals, and work-life balance.

3.5.2 Pilot-Test of the Survey Instruments

Pilot studies refer to implementation of the data collection on a very small sample of a similar population to test the utility of a research instrument such as the questionnaires developed for this study. The purpose is not only to test validity and reliability of the instrument but to identify misspelled words and inappropriate skip patterns of the electronic survey.

The survey questionnaire was pilot-tested by a convenience sample of 10 participants who were selected based on availability; the results were not included in the total study sample data. This pilot study identified issues with clarity of the questions; to test the applicability of the survey in addressing the primary research study questions and to test the efficacy of the procedure (Creswell & Plano Clark, 2010). Ten participants were drawn from the list of respondents to the letter of invitation and consent form. Because no amount of intellectual application can substitute for testing a procedure or the questions contained within that procedure (Creswell & Plano Clark, 2010), pilot-testing of the content and procedure is required. Results of the pilot study ensured clarity, user-friendliness, appropriate wording, and meaning of the questions.

3.5.3 Reliability/Credibility

To yield more reliable results and valid interpretations, in-depth interviews with probing, and self-reflective iterative processes by which the interviewer and the study participant explored deeper issues to make sense of truths were completed by the entire study group (Denzin & Lincoln, 2000). These types of interviews offer a distinct way of gathering data essential to understanding the participant's, their family members', and the staff's attitudes and perceptions

of the ADHCs PCC approaches (Denzin & Lincoln, 2000). Credibility and trustworthiness of these data were enhanced by "the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexplained preconceptions and presuppositions" (Bogden & Biklen, 2006, p. 43).

Different terms are used in qualitative research to describe validity, for instance:

- Krefting (1991) and Lincoln and Guba (1985) described it in terms of trustworthiness

- Maxwell (2005) described it as a "goal rather than a product; it's some that can never be proven" (p. 105)

- Guba and Lincoln (1989) contended each piece of information in the study should be expanded by at least one other source, such as a second interview or another method

For this study, member checking was employed to verify participant responses. This entailed each participant review the transcript of their in-depth interview then given an opportunity to discuss the integrity of the results of the first interview then make modifications - additions or subtractions as appropriate. Member checking as a technique decreases the chances of any misrepresentation by the researcher.

3.6   Qualitative Data Collection Procedures

Participants completed interviews during the survey process where in-depth questions on their experiences of and the necessity for PCC. Open-ended questions with follow-up probes were employed to understand the perspectives and nuances of a PCC model from a holistic perspective. Table 3.6 shows the interview questions.

Table 3.6: Open-Ended Interview Questions

Category	Open-Ended Questions
Access to the community resources	What are the barriers of the participants accessing the community resources?
Choice of setting	How does the center do to respect participants' choice during the process of PCC Planning?

Category	Open-Ended Questions
Rights	What are the issues for the participants to excise their rights?
Choice of services and supports	How would you like the center do to empower the participants making choice of services and supports?

The interview and survey process appropriated about 30 minutes along with another 30 minutes for the each of the three focus groups. All were conducted in both Chinese and English. The focus groups as well as the interviews were audio-taped and transcribed then uploaded to the University of North Texas server. When a participant refused to be recorded, reflective notes were taken instead. Issues, concerns, or discoveries were all recorded and documented (Bogden & Biklen, 2006).

3.7   Analysis of Data

3.7.1   Analysis of Qualitative Data

Qualitative research requires deep analyses and gives validation to participants. Thus, comparing and contrasting of participants can be made through analysis. Common themes were identified, analyzed, and used to guide translation of PCC model best practices into the current systems of care. The qualitative data analysis method of theme discovery is appropriate to respond to the questions: "who says what, to whom, why, how, and with what effect" (Babbie, 2016, p. 309). To search for themes and patterns, participant responses were separated into categories. Patton (2002) argued data collection should be followed by inductive reasoning and a process for developing conclusions and generalizations. Farber (2006) suggested phenomenological data needs to be interpreted and organized into categories to enable construction of a picture by using coding into themes, patterns, concepts, jokes, or similar features.

3.7.2 Analysis of Quantitative Data

Pearson product moment correlation (hereafter referred to as the Pearson correlation) was utilized to analyze the survey data. It is a statistical procedure that allows researchers to determine the extent of an association or relationship between two variables. Background variable scores were examined in relationship to self-assessment questions by categories. The strength of combining Likert scale survey data with reflective notes collected during in-depth one-on-one interviews provides validity, omitting any potential biases, and allows for "repeated observations" (Maxwell, 2005, p. 145).

3.8 Summary

Chapter 3 was a discussion of the constructs of both the qualitative and quantitative mixed-method study for assessing an ADHC's readiness for integrating a PCC model into their systems of care. Chapter 4 contains the results of the quantitative portion of the research findings. Chapter 5 contains the qualitative results from the study divided into two parts: Parts A contains the results of the individual interviews and focus groups and Part B contains the results of the documents reviews of the cooperation self-assessment results from the ADHC in 2016 and 2018 self-assessment results from another CBAS center with a similar background. The research results from Chapter 4 and Chapter 5 will answer the questions in Chapter 1 designed specifically for this dissertation.

CHAPTER 4

RESEARCH FINDINGS

The purpose of this study was to determine the readiness of a CBAS/ADHC program's practices and operations to implement a PCC model to meet the new standards for certification and licensing requirements by the California Department of Aging (CDA) and California Department of Public Health (CDPH). A mixed-methods approach using both qualitative and quantitative strategies were employed for assessing the necessary operational and organizational culture modifications required for implementing a PCC model in a Southern California ADHC. The layout of this chapter includes results of the quantitative analyses from the data collected from surveys to test the model in Figure 4.1:
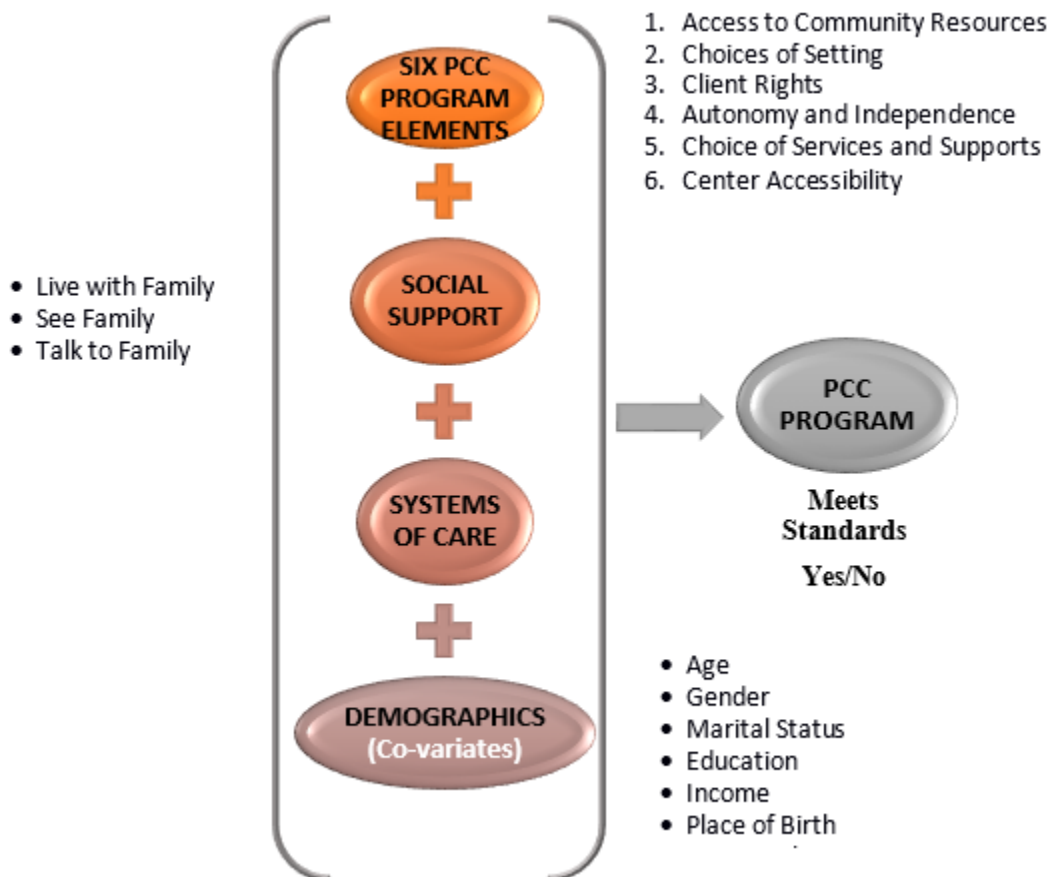
Figure 4.1: Research model.

4.1   Quantitative Research Question and Hypothesis

Statistical analysis using both Excel and SPSS version 25 to explore the following

questions and test the hypothesis.

RQ1:   How do the study participants' health statuses compare to the rest of ADHC
       program participants throughout California ADHC programs.

RQ2:   What is the relationship between 6 PC elements, social support, system of care
       (administration) and co-variates (age, gender, education, marital status, location.
       income, country of origin, and years in the U.S.) and implementing a successful
       person-centered care ADHC program?

H_1:   There is a relationship among 6 PC elements, social support, system of care
          (administration) and co-variates (age, gender, education, marital status,
          location. income, country of origin, and years in the U.S.) and implementing
          a successful person-centered care ADHC program.

H_0:   There is no relationship among 6 PC elements, social support, system of
          care (administration) and co-variates (age, gender, education, marital status,
          location, income, country of origin, and years in the U.S.) and implementing
          a successful person-centered care ADHC program.

4.2   Characteristics of Research Participants

As reported in Chapter 3, all program participants (100%) enrolled in the ADHC program

between August 1, 2017-July 31, 2018, their family members, and the ADHC staff during the

same period were included for study. One-hundred percent completed the survey and in-depth

interview; a sample were interviewed two or more times as part of the reliability/credibility

check. As shown in Table 2 in Chapter 3 over half of the study participants (54%) were between

75-84 years of age; and more than 34.7% were over 85 years of age. The entire group (100%)

was comprised of Chinese immigrants; the majority (66%) was from Mainland China and has

lived in the U.S. for at least 10 years or more.

4.3   Characteristics of Research Participants' Family Members

At least one family member, such as an adult child or grandchild living with or caring for a study participant agreed to be involved in the study. One-hundred percent were interviewed and completed the survey questionnaire.

As seen in Table 3, over half of the family group (56%) ranged from 41-55 years of age while most reported being married (84%) and 50% were sons of the participants. As many as 80% maintained a regular job, and at least 66% were providing direct care to their loved ones.

4.4   Person-Centered Care Self-Assessment Tool

The PCC model has been broadly regarded synonymously with the best quality of care. This tool is being used to measure the extent to which participants, family members, and staff rate the study ADHC a success in implementing a person-centered program. In addition, the CBAS assessment tool will provide guidance concerning community characteristics and agency capacity to implement best practices at the study ADHC. I believe that assessment is an integral part of the planning process, as it will allow the study ADHC center to prepare for integration of a PCC model. Results from this determine evidence concerning the extent of readiness for compliance to the new Federal requirements under the Center for Medicare & Medicaid Services (CMS).

As mentioned in Figure 4.1, research model, six components were used to detect the level of implementation in the PCC program including

- Access to the greater community
- Choice of setting
- Rights of privacy
- Dignity, respect, and freedom from coercion and restraint

- Autonomy and independence

- Choice regarding services and supports and center accessibility

The questions are guided by CMS guidelines and public input from the Statewide Transition

Plan. All answers need to be supported by evidence throughout the system of care including:

Policies and Procedures, In-service Training Records, Employee Records, Participant Health

Records, and Information Materials. 'No' responses suggests that the center needs to take action

and improve in deficit areas to achieve compliance with the federal requirements and regulations.

More importantly, the psychometric scale should find stability and be reliable and applicable for

further use. The results in this section showed that the study ADHC supports embracing person

choice and autonomy for people receiving social-medical model services.

4.5   Study ADHC PCC Research Findings Overview

From Figure 4.2, the independent variables are PCC defined by the six components,

requirements related questions to Q1-Q50 are being tested for their utility in assessing an

agency's current service practice by a participant, one of their family members, and staff at an

ADHC.

Results show that among the three groups of survey participants (the center participants,

their families, and staff) more than 8% agreed on Q29 - that the center ensures participants have

privacy when being assisted with personal care. In Q30, participants overwhelmingly felt that the

center ensures that participants have privacy when being assisted with personal care. In Q36,

respondents reported that the center communicates with participants based on needs and

preferences through sign language, and in Q37, 97% said the center supports participants in

dressing or grooming as described in Federal Requirement Category 3: Rights, and Q42 from the

Federal Requirement Category 4: Autonomy and Independence. One promising approach, that is

evident by the reported data, is that PCC models can be operationalized and tailored to participants' needs. Another consistent theme on PCC for participants at the study ADHC, was that the old approach of traditional ADHC did not consider individual preferences and diverse needs of frail elderly seniors with chronic illnesses and functional limitations. Therefore, to serve this population better, it is evident that new person-centered approaches to care are required that are responsive to the diverse and multi-needs in which health care plays a vital but not exclusive role.
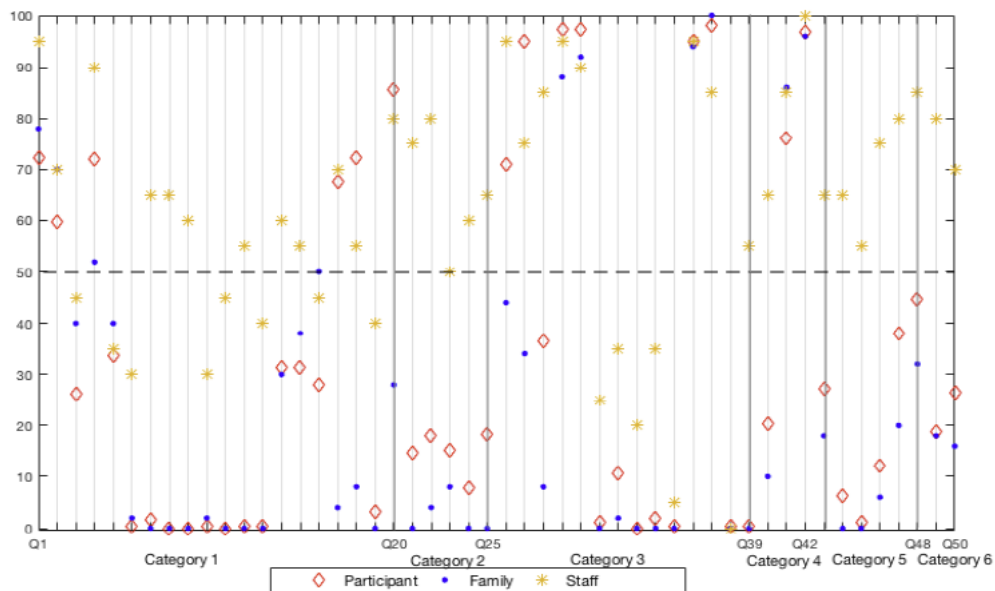
Figure 4.2: Overview of participants, families, and staff responses.

All the above is noteworthy and provides evidence for replication of models in all CBAS programs and other day programs, such as when more than 70% of participants agree (Q1) on centers' ability to provide information on transportation services such as public bus, light rail, taxi, van services, or special transportation, this is significant. Currently, participants are using the transportation from the county, city, and local level providers to come to the center and return home, or some of the center participants live in the senior housing projects. In sum, the findings

indicate that PCC is increasingly recognized as central to health care especially in community-based programs.

4.6   Study Participants Compared to California Statewide Participants

To assess the generalizability of the results of this study a comparison analysis was conducted between California statewide data to the study population their functional status of ADL and functional Status of IADL.

Figure 4.3 compares study participants' ADL needs with those from CBAS/ADHC centers throughout California. As can be seen, the study groups' needs were lower than the state as a whole in all six areas. This indicates that the study participants have higher functions than the rest of the State in these programs.
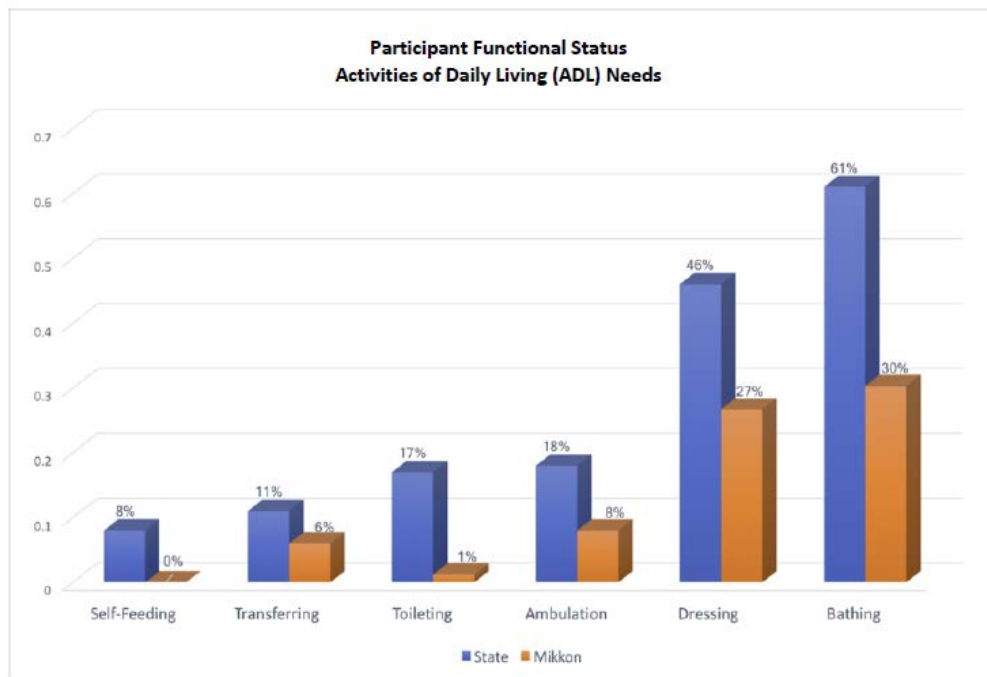
Figure 4.3: ADL of study participants compared to the state of California as a whole.

Figure 4.4 compares the IADL needs among study participants' to that among the rest of California and again, the study group had significantly lower levels of required assistance for

medication management, money management, and transportation. However, the results also indicate a high demand among participants in both groups (close to 90%) for assistance in accessing community resources.
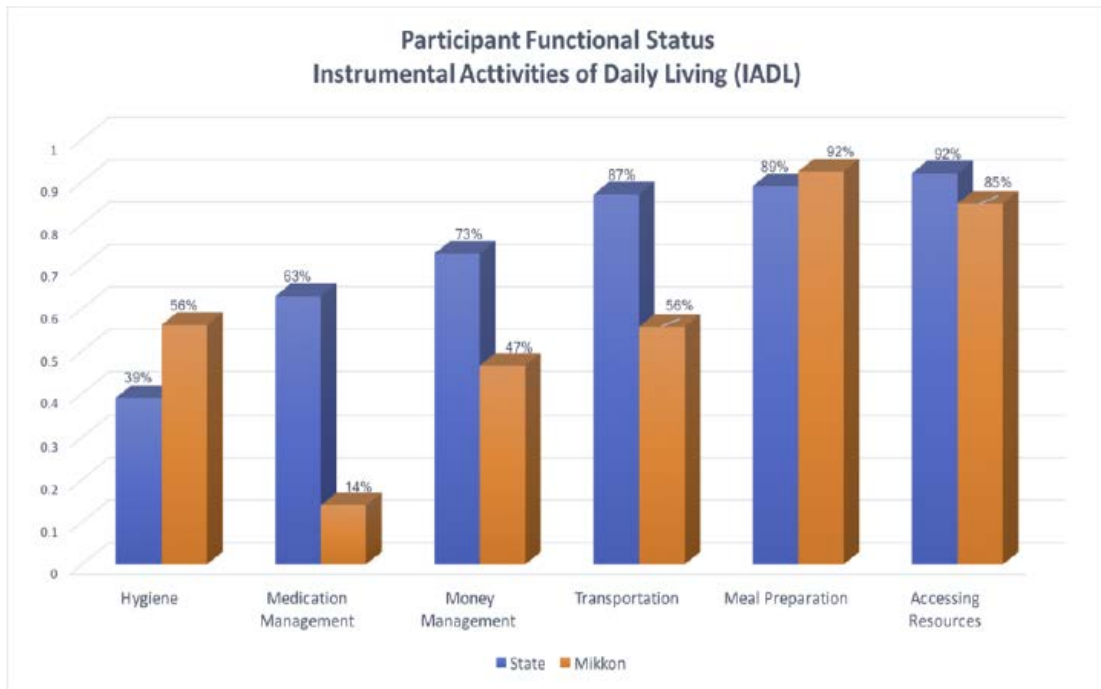
Figure 4.4: IADL of study participants compared to California.

4.7   Six Elements of the ADHC PCC Program

To determine the current status of the ADHC PCC model implementation in meeting the federal and state standards, the following are results of the analyses on each of the six elements comprising a PCC program:

- Access to community resources

- Choices of setting

- Client rights

- Autonomy and independence

- Choice of services and supports

- Center accessibility

4.7.1 Access to Community Resources

The scatter plot in Figure 4.5 presents all three groups of research participants who

reported less than 50% feel that the center provides information to participants about other adult

day services, Alzheimer's specialized programs, enrichment centers, home health and hospice

care providers as well as family caregiver support employment programs and providers. Included

in this category are questions concerning legal assistance programs along with health insurance

counseling and advocacy programs. This information is part of the Federal requirement

"Category 1: Access to the Community" entails information concerning full access to these

programs and supports in the greater community be integrated throughout the program.
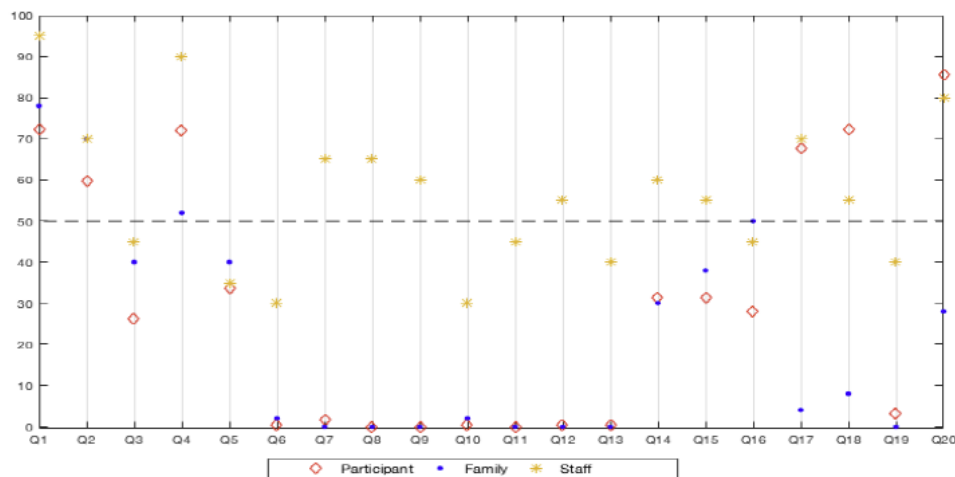
Figure 4.5: Access to the community resources by study group.

It should include opportunities to seek employment and work in competitive integrated

settings, engage in community life, control personal resources, and receive services in the

community, to the same degree of access as individuals not receiving Medicaid HCB Services

(DHCS, 2018).

4.7.1.1 Community Resources: Transportation Services, Senior Housing Options, and IHSS

Over 70% of the participants and families and more than 85% of the staff members

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responded that the Center always provided information about transportation services such as public bus/rail, taxi/van services, and special transportation providers. Nearly half of all participants receive LA County ACCESS services with scheduling assistance by program staff and typically coordinated by family members. Center social workers help the participants with their ACCESS applications and local Dial-A-Ride applications.

Approximately 60% of participants and 70% of family members and center staff believe information regarding senior housing options, such as the senior apartment, assisted living, board-and-care, and skilled nursing providers is provided. One-third of the study participants live or are in the process of applying for senior housing projects such as senior apartment and affordable housing projects. Nearly 74% of the participants self-reported receiving the IHSS.

4.7.1.2   Community Resources: Seeking Paid Employment

Responses show that 83.2% of participants, 94% family members, and 35% staff are unaware of this community-related resource.

4.7.2   Choices of Setting

The results showed a larger percentage of participants and family members are unaware of the PCC care planning process, which focuses on an individual's needs and preferences. On average, 61.88% of participants and 94.4% of family members responded with "not known" to all five questions related to the choice of setting. Nearly 30% of staff members are unaware that the center follows a care plan that not only focuses on the individual's needs but also encourages active involvement from all three subgroups in the care planning process. One-hundred percent of family members are completely unaware that the center has a person-centered plan on file and that the center is documenting whether or not participants are choosing to attend and receive services.

4.7.3 Participant Rights

Figure 4.6 concerns how the center encourages participants' families to participate in the care planning process. The result shows less than 50% of all three study groups were aware of and/or participated in a person-centered plan that was on file for all participants, based on the their needs and preferences although 60% of the staff had contributed.
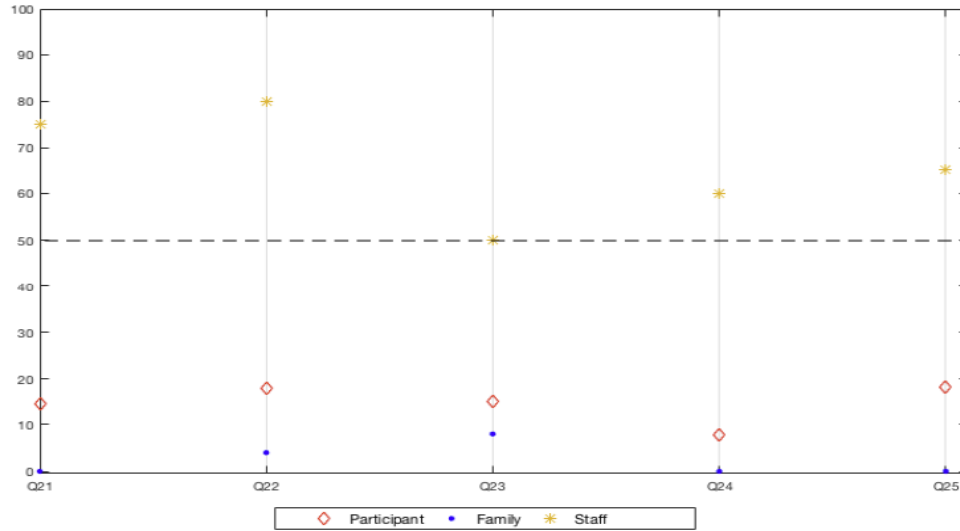
Figure 4.6: Overall rights of the program participant.

4.7.3.1   The Right to Privacy and Dignity

Results of two questions focused on participant's rights to privacy, dignity, respect and freedom from coercion and restraint and whether the center posts participants' rights in a prominent location were used to assess this element. At least 83% and higher for both participants and staff agreed that the center informs and posts the participants' rights.

4.7.3.2   Rights to Privacy of Personal Information

The participants are assured personal information, such as medical conditions and financial situation, is in a place where privacy and confidentiality are important. Q29 ensures that participants have privacy while using the restroom. Q30 states whether participants have privacy when being assisted with personal care. Higher percentages were seen in the "agreed" category

for all three subgroups in comparison to all other columns. This research contradicts responses recorded from the interviews, where more participants believed there is not enough privacy when discussing medical conditions and financial matters at the Center. More staff members than participants and family members believed participant's personal information had been discussed privately and in confidence. What is interesting to note however, 18% of family members disagreed with these questions, which is higher than participants (13.41%) and staff members (5%).

4.7.4 Choice of Services and Supports

Federal regulations require participants to have "Choice of Services and Supports" by program staff facilitating individual options regarding services and supports, and who provides them (DHCS, 2018). Only 50% of the staff agreed that the Center supports participants in choosing center staff to provide their care to the extent that alternative staff is available. Less than 50% reported that the center has a complaint or grievance policy and informs participants how to file a grievance as shown in Figure 4.7. Q45 is about how the center instructs participants how to file a grievance. Q47 is about how the center enables participants to voice their concerns about the services received.
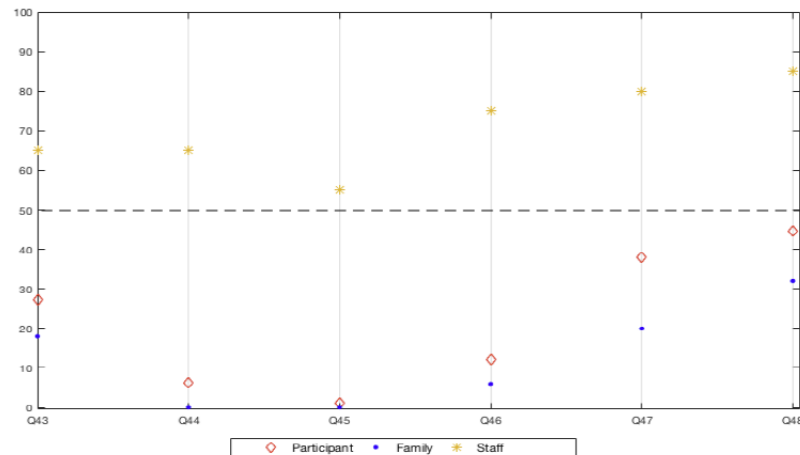
Figure 4.7: Choice of services and supports by groups.

4.7.5   Autonomy and Independence

Active involvement and positive encouragement of activities are needed to be in compliance with the PCC model of care. Q41 specifically asks if the center encourages participants to interact with whomever they choose and Q42 asks if the center encourages participants to engage in whichever activities they choose. At least 85% of participants, family, and staff members all "agreed" that ADHC provides this well. Findings indicate that the majority of members associated with the study ADHC believe it facilitates autonomy and a sense of independence in all members involved as shown in Figure 4.8.
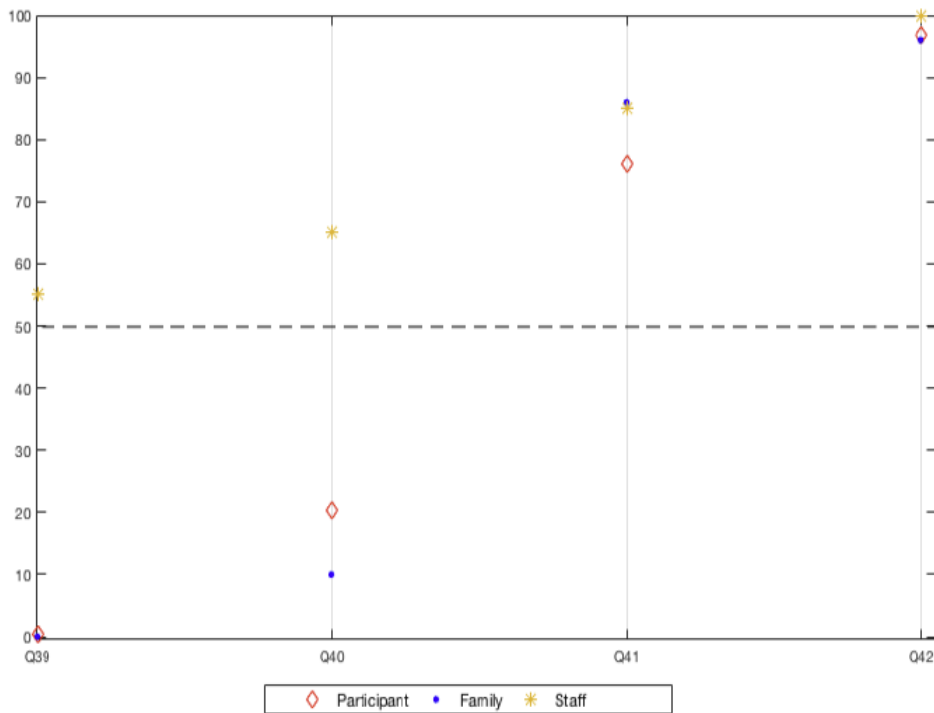
Figure 4.8: Active involvement and positive encouragement of activities.

4.7.5.1   Meals and Snacks Served at the Center

It is a federal requirement that the center provides participants with meals/snacks to meet their needs and preferences. About 50% of participants and families disagreed that the center provides participants with meals/snacks to meet their needs and preferences. Over 50% of

participants and family members disagreed with the food choices provided by the Program. Staff

members, however, agreed with the food services provided and recommend participants to eat

during their stay

4.7.5.2   Communications Styles related to Center Participants Needs and Preferences

These questions addressed participant's needs and preferences for different

communications styles including assistive technology, Braille, large font point print, sign

language, and other languages next to English. Almost 100% of staff are bilingual English and

Chinese Mandarin, Chinese Cantonese, Taiwanese, Cambodian, Vietnamese, and other

languages and dialects. On the other hand,only 10% found support because some participants at

the center use smartphones and ipads to communicate with center staff through the Chinese

popular app WeChat. The center provides iPad training class two times per week at the center

teaching participants how to use the iPad for communication. Q33, Q34, and Q35 got very low

scores because the center never has Braille, large font print, sign language, and alternative

method to use for communication in between staff and participants.

4.7.5.3   Use of Restraints, Delayed Egress Devices, or Secured Perimeter

The study group was asked if the Center uses restraints in compliance with ADHC/CBAS

regulation (Title 22, CCR, and Section 78315). All participants, families, and staff either

disagreed with or unaware of the Center's policy as a restrain-free facility and people have

limited knowledge about the regulation, policy, and procedures about the restraints. The same

was true for Q39 concerning the center's use of delayed egress devices or secured perimeters by

ADHC/CBAS law (FindLaw, 2019).

4.7.6   Center Accessibility

More than 50% agreed on both questions as shown in Figure 4.9: asking about if the center ensures that all public areas are physically accessible to the participants and if the center provides equipment to meet their needs.
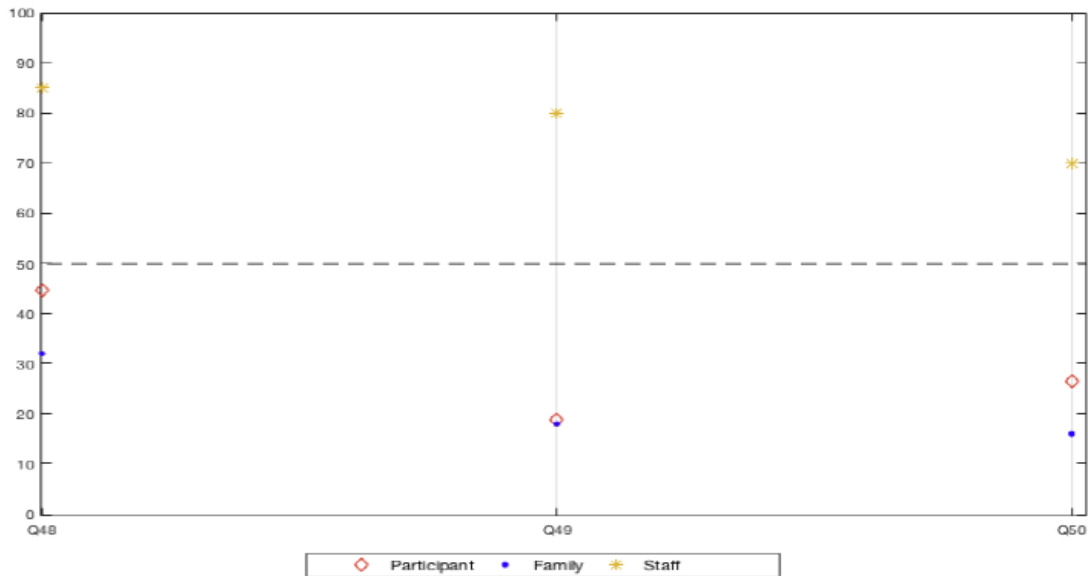
Figure 4.9: Center accessibility by study.

4.7.6.1   Physical Accessibility in Public Areas and Equipment Provided

Q49 ensured that all public areas are physically accessible to participants to meet their needs. Q50 asks if the center provides equipment to meet participants' needs. From the data in Appendix E, 23% of the participants, 17% of the families, and 75% of the staff members agreed that the center is physically accessible and has the equipment available to meet the participants' needs.

4.7.6.2   Operation and Management of the Center

Questions relating to care implementation throughout the program operations surrounding their feelings about safety, happiness, helplessness, decision-making, and protocols

for bringing their concerns to the attention of the staff while receiving the services at the center were used to assess current status of operations and management.

A majority of the participants feel safe (91.01%), happy (83.20%), and enjoy the time (78.52%) at the center. More than half of the participants reported that they can make their own decisions (77.35), the staff care about me (69.53%), and they rarely feel helpless at times (62.11%) at the center. However, less than half of the participants feel comfortable bringing concerns to staff members (47.65%).

4.7.6.3   Family Members

Nearly all of the respondents, 94%, agreed or felt neutral about sending their loved ones to the study ADHC. Over 70% felt comfortable bringing concerns to the staff and trusted the professional team of the program. Unfortunately, more than 60% of the family members reported rarely visiting the Center to see their loved ones, thereby limiting their knowledge about any problems or needs they may have and have seen only limited information about the services the center provides to them.

4.7.6.4   Staff and the Center's Operations and Management related to PCC

Almost all of the staff (90%) responded they felt positively concerning a strong feeling of teamwork and cooperation within the study organization. They reported that communication is encouraged, and that at the end of a typical day, they felt they had contributed to the quality of life of program participants. The majority of staff (80%) agreed on the mission of the organization, trusted the people they worked with, and felt value about themselves at work. Most, 70%, agreed management is interested in the staff, they were treated fairly, and that poor performance is effectively addressed throughout the organization. However, in contrast, less than

half agreed they were paid fairly and only doing the job because they needed the money, and would choose another center if the same job was offered or will re-apply to this job again.

4.7.7   Responses in Choosing Center Staff

Q43 stated the center supports participants in choosing which center staff provides their care to the extent that alternative staff is available. From the data in Appendix E, the results from the study show only 27% of participants and 18% of the family members agreed with the center supports participants in choosing which center staff provides their care to the extent that alternative staff is available at Center. The data shows that almost the same proportion, slightly more than 30% of participants, family members, and staff feel neutral about this issue. About 37% of the staff and 50% of the family members disagreed or do not know about this question. Staff members, however, agreed that the participants can choose whoever of the staff they like to provide services to them as long as the one they choose is available.

4.7.7.1   Responses to Complaint/Grievance Policy

From the data in Appendix E, Q44 and Q45 asked if the center has a complaint/grievance policy, which informs participants how to file a proper grievance, on top of instructions to support the requirements of providing the choice of services and supports.

Among the 256 participants and 50 family members, almost 90% disagreed or was unaware of the complaint/grievance policy. However, 60% of staff members agreed on these matters. Results indicate a difference of perception between staff members and participants/family members. Communication needs to occur between these two parties in order to understand the individual's needs and preferences.

4.7.7.2   Participant's Ability to Modify Services and Voice Concerns

Q46, Q47, and Q48 state whether participants are able to modify their services, voice their concerns regarding services, and ask questions regarding the services received. The data shows that an average of 31.5% participants, 19.33% family members, and 80% of staff agreed to the ability of service and supports. On the other hand, 44% of participants, 46% of family members, and 8% of the staff disagreed or did not know how to answer the following questions. The number of participants and family members had mixed feelings about all three questions. A higher proportion in both participants and family members shared the opinion of negative responses related to voicing their concerns, asking questions, and enabling to modify the services they receive at the center.

4.8   Cross Analysis

4.8.1   Living Condition and Relationship between Participants and Adult Children

The descriptive analysis data reviewed the relationship between the participants' living condition and the relationship between their adult children. Table 4.1 shows more than half of the participant live with their children, and 64% of the participants feel that they are very close to their children, which is much higher among those living with their children than those not living with them. According to the data, the total number of the participants living with their children is 138. Over 80% reported they have very close relationships with their children as shown in Table 4.2.

Study participants are older adults who often need social support, and their family are the closest people to support them in their social network. If they do not have a close relationship with the family, they may need more social support from the center.

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Table 4.1: Living Conditions and Relationship with Children

Who to live with	%	Relationship with Children	%
Alone	19.53	Very close	64.06
With spouse	25.78	Close	25.78
With children	53.91	Fair	8.59
With roommate	00.78	Not Close	0.78
		Not close at all	0.78

Table 4.2: Relationship between Participants and Families Living Together

Live with children and their relationship (n = 138)	%	#
Very close	83.33	115
Close	9.42	13
Fair	5.07	7
Not Close	0.72	1
Not close at all	1.45	2

4.8.2   Relationship between Participants with IHSS and the Length of Years Staying in the U.S.

As shown in Table 4.3, about 41% of the participants using IHSS have been in the U.S. between 11 to 20 years. The number of participants not receiving IHSS increases as the length of time in the U.S increases.

Table 4.3: Relationship between Participants Receiving IHSS and the Length of Years Living in the U.S.

IHSS	1-10 years	11-20 years	21-30 years	30+years
Have IHSS	16.00	77.00	43.00	53.00
Do not have IHSS	26.00	16.00	14.00	11.00
Have IHSS (%)	8.46	40.74	22.75	28.04
Do not have IHSS (%)	38.80	23.88	20.89	16.41

The result indicated that two variables are positively correlated as it is shown in Figure 4.10, the longer the participants is in the U.S., the more likely they are to have IHSS. One can clearly see that among the group of people that have stayed in the U.S. between 11-20 years,

more than 40% of the participants have IHSS services. Less than 10% of the participants have

IHSS in the group between 1-10 years length of stay in the U.S. IHSS is the service model

providing personal care and domestic services to persons with disability and live in their own

homes. The person most likely to receive the services are aged, blind, and disabled. This is also

the most cost-effective way of helping older adults aging in place in their own communities.

IHSS program is an oversight by the California Department of Social Services and administered

on the local county level of government (CDA, 2018).
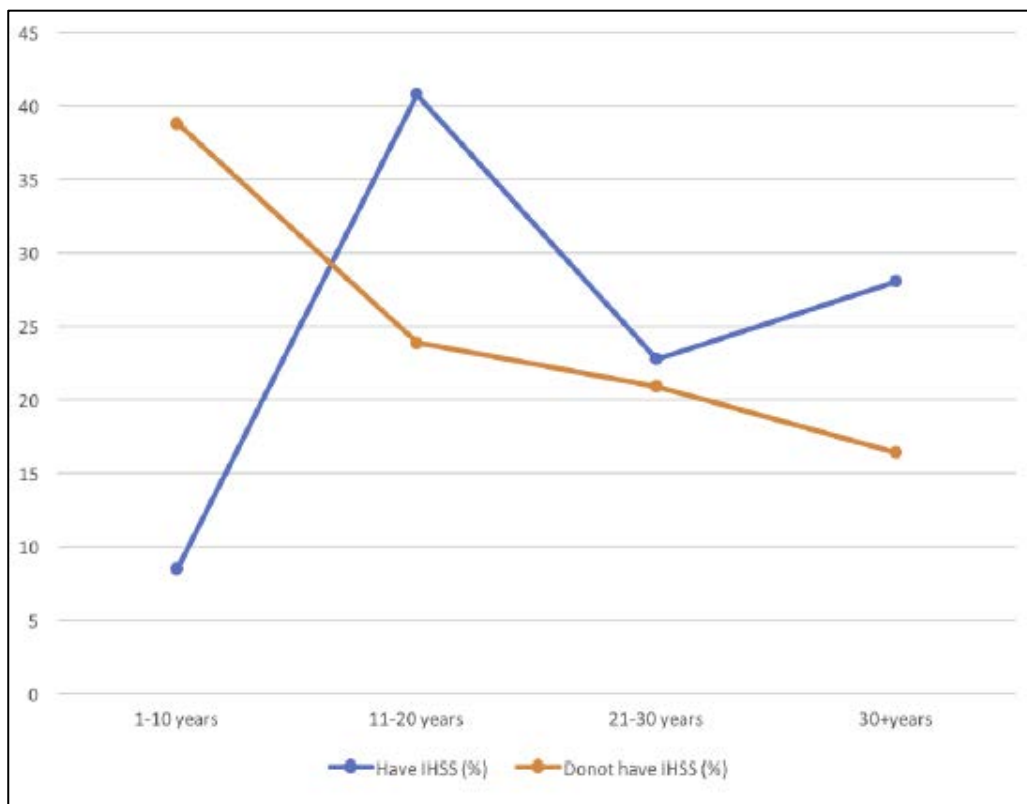
Figure 4.10: The relationship between participants IHSS and number of years living in the U.S.

4.9   Further Analyses

The next steps are to conduct chi-squares, *t*-tests, and correlations to identify significant

differences among the three study groups and regressions to test the study model.

CHAPTER 5

QUALITATIVE RESEARCH FINDINGS

5.1   Qualitative Research Findings

A qualitative design employing face-to-face interviews and focus group methods was

conducted in addition to the survey data. The purpose was to ascertain salient themes with which

to "explore," "process," and find "meaning" of the study participants' perspectives concerning

the ADHC program's extent of involvement in the PCC model (Creswell & Plano Clark, 2010, p.

146). Qualitative inquiry "begins with the assumption that human behavior is made up of

thoughtful, meaningful responses to stimuli in the world. What something means to someone

affects how the person will respond to the thing" (Taylor, 1992, p. 3). Qualitative methods in the

broadest sense are descriptive research (Creswell, 2010; Taylor & Bogdan, 1998) because the

researcher is interested in "people's own written history or spoken word and observable

behavior" (Taylor & Bogdan, 1998, p. 5). In addition, Creswell and Plano Clark (2010)

contended that descriptive research is "interested in meaning, processes, and understanding

gained through words and pictures" (p. 145).

5.1.1   Interviews

All survey responses from the center participants, their families, and center staff were

collected by face-to-face interviews conducted by the Investigator. Detailed information on

interviews and focus groups questions can be found in Appendix F. As the interview data began

to accumulate, inductive analyses recognized recurring themes across individuals and groups

materialized (Moustakas, 1994). Note: when necessitated, interviews were used to explore these

areas further.

The interview findings were classified into four groups of study participants: (a) center

participants, (b) family members, (c) center staff; and (d) Administration from other CBAS centers.

5.1.2   Qualitative Research Questions

The following questions guided the qualitative analyses:

RQ1:   What are the experiences of the facility's staff, participants, and family members with person-centered care?

RQ2:   What are the specific practices and strategies currently employed in the center to support person-centered care development?

RQ3:   What are the operational challenges, if any, for implementation of person-centered care practice in the facility?

RQ4:   What recommendations do administrators and program directors from other agencies have for implementing person-centered care in their ADHC programs?

5.1.3   Center Participants' Interview Findings

Among the responses, the majority of the study participants (more than 75%) feel safe, happy, and enjoy the time they spend at the center. Five of the respondents expressed loneliness at home while their adult children and grandchildren were out working or at school.

Miss. Chin, a participant who attends the ADHC program 5 days a week, said very solemnly, "I have nobody to talk and I get bored at home watching TV."

Mr. Chu who has a son and daughter, said he was worried if an emergency happened to him or his wife; they would not know what to do. He further stated in a high pitched voice, "We cannot even call 911 because we don't speak English."

These narratives are a testament to the center's focus on PCC - ensuring participants feel needed and valued is important as is maintaining relationships with individual's in their respective homes and assisting them in getting out into the community is an important outcome and recommendation for future PCC ADHC practitioners. With this study, I also discovered the

proportion of men expressing or indicating any degree of loneliness was similar for other men in the comparative centers. Women in study maybe only mentioned or accounted for loneliness less than 10%.

Although participants suggested more types of activities they need to attend. Attendees in the study still felt very good about socializing with people who they share the same culture with them and speak to the people who can speak the same language. Overwhelmingly, participants reported that they can make their own decision on certain activities they would like to attend, and decisions related to their health care and wellness (Angelelli, 2006). However, they also mentioned the barriers of not knowing what options and resources that are out there in their communities and their children are too busy to help them to reach the services or programs they need or desire to get from the community. Mr. Nguyen said that he would like to know more about the resources in West Covina but he is also afraid of getting lost. He clearly states, "If I knew how to take dial-a-ride to get my medications or where there is a nearby pharmacy - I would go on my own so that I would not have to wait on my son or daughter. Waiting on them I get anxious." For future program planner, ensuring the provision of affordable transportation, barrier free transportation, and the elimination of language barriers could be a mechanism to allow older adults to be more independent without the need of a loved one. Mr. Nguyen story is also testimony in establishing several apparatuses or future inventories that could measure the elimination of ageism.

Close to two-thirds of the participants stated "the staff cares about me and I don't feel helpless when I attend the center." Some participants complained about the attitude of some staff member. Specifically, staff often do not show much patience when they ask questions or request services from them. About 50% of the participants felt comfortable bringing concerns to the staff

members; but they also reported, they have already received so much benefit from study and they do not want to give staff hard time. The lack of and inappropriateness of services for participants may, therefore, also contribute to a participant experience and isolation at the center and even more at home. The most common complaint that the participants gave is about food and transportation. In terms of PCC practice, meeting the needs and the reasonable expectation is very critical at all CBAS centers and the most challengeable task for the staff to achieve.

5.1.4   Participants' Family Interviews Findings

The discussion at the interviews focused on family members. The topics about their loved one's safety, loneliness, helplessness, trust, grievance, as well as their caregiving roles and issues were discussed at length.

More than 90% of the respondents felt comfortable and were willing to send their loved ones to study ADHC and they hoped that the program hours were more than 4 hours per day of what the state required. Participants hoped their loved ones could come back home but not until after they arrived home. One participant's daughter told us that she had to hire a caregiver to watch her mom for at least 4 hours every day after her mom comes back from study. Because her mom is a new immigrant, she came to this country less than 5 years, so she is not qualified to receive IHSS services. Financially, the daughter and her family feel this a burden for them and also it is not easy for them to find a good caregiver who is loving, gets paid reasonable, and speak the same language that her mom speaks. Some family member felt comfortable to bring concerns to the staff and trust the professional team of study ADHC. Unfortunately, more than half of the family members reported not visiting the center seeing their loved ones, do not know about the problems and needs of their loved ones, and have very limited information about the services the center provided to their loved ones. The reason they gave is that they are too busy at

work, some family members have younger children, some are not living with the participants, and believe that their loved ones are doing fine with study's services. Almost all the participants' families hoped that study could do more for their mom and dad because they need this type of setting of services. Moreover, study as a community program and service has in place respite to support families providing care for participant's family members and to help alleviate caregiver distress (Anderson et al., 2005). All that has been said by the interviewees, family caregivers did report enhanced levels of well-being, reduced feelings of burden and stress, and delayed placement of their loved one being institutionalized. It is noteworthy to mention; the results of this study suggest that many factors must be considered if respite care is going to assume a credible and significant role in ADHC/CBAS programs. Participant and families summed it nicely, the short relief that respite programs provide meets only one of many needs of caregivers. To be an effective PCC model, study must also address the many other frustrations and stresses often accompanying caregivers' experiences.

5.1.5   Center Staff Interviews Findings

During the interviews, the staff was not only asked about the PCC and PCC Planning but also asked if they have a good understanding of the organizational mission, vision, and management of the center. Specifically, this PI probed how management treats them? How management handles poor performance? Questions also probed teamwork, communication, trust, and how they felt about their own value to participants.

Almost all staff believe in the spirit of teamwork and working collaboratively in this organization. Most agree that communication is encouraged at study. The staff also felt that they have contributed to the quality of life of the participants being served; but, wished and hoped that they could do more. Most of the staff agreed strongly and indicated that they understood the

mission of the organization and trust their coworkers. A little more than half of the staff agreed when asked if the management is interested in the staff and being treated fairly in this organization, as well as if poor performance is effectively addressed throughout this organization. Fifty percent of the staff complained about low pay and they did not feel they were being paid fairly. They stated they only do the job because they need the money and this job cannot reach their potential and if they would choose another center if the same job offered or will reapply this job again. The reasons for them to quit their job and move to another job include better pay, staff burnout, and staff morale (Banaszak-Holl & Hines, 1996).

In sum, staff who work in ADHC/CBAS programs can experience similar stressors as participants. As demonstrated by the staff, there are a number of factors that have been shown to affect staff stress and levels of job satisfaction. More broadly, organizational factors seem to play an important role in the development of staff morale, with issues such as role clarity and conflict, task autonomy, and supervision and social support taking a predominant role in the organization. These issues are of significant importance in PCC programs but also in the gerontology field, not only because they have been shown to be closely related to the emergence of positive or negative staff morale, but additionally because they are a part of the service that can actually be scalable or redesigned accordingly, for a better quality of life for both staff and clients.

When asking about the PCC implementation, the staff seems not ready and most of the staff would like to follow the flow, some staff do not want to make a change and a few staff are against the change.

When the participants and the family members were asked if the staff cares about them and if they feel respected, more than 80-90% of the respondents agreed and some felt uncertain as to what this question was asking. On the other hands, a really important theme was mentioned

by nearly one-third of the participants and 50% of the family respondents reported not trusting their primary care physician (PCP) at the center. The main reasons are because they only spend 2-3 minutes with the patients, the participants do not have a chance to tell the PCP their problems. Also, participants did not believe their family doctors can fix their problems and guide them in their health care needs. To conclude, primary care and holistic care must be an integral piece of the puzzle for the success of a PCC ADHC model in terms of personnel, family, and patients. It should be noted, that physician practice in a PCC model differs from traditional other fee-for-service care and practice in a health maintenance organization. The physician working in ADHC/CBAS must be able to work within a framework of an MDT team, which requires both better clinical and communication skills and personal comfort with the team approach. Unfortunately, PCP cannot give as much time as they need to with participants and families. The study ADHC attempts to enhance physician-patient interactions in all aspects of care. It should also be noted, physicians in an ADHC setting often have difficulty in setting aside enough time to interview and assess a participant with multi-system illnesses. Future PC models should emphasize collegial collaboration of physicians with patients and family members which enables chronic conditions to be followed closely and any exacerbations to be treated promptly, usually avoiding long and costly hospital stays which is the goal of CBAS/ADHC models.

5.1.6   Administrator and Program Director from Other CBAS/ADHC Centers Interview Findings

An administrator from another CBAS center and a program director from a different CBAS center were interviewed. Questions were focused around barriers in accessing resources, respecting participants' choices in the PCC care planning process, exercising participants' rights, and empowering participants.

According to the other program director, she revealed that respecting the participant's

decision to include family members of their choice as well as if they opt to decline their family's involvement as well. She further states, "If family members are included in this process, it is noted accordingly in the respective disciplines initial and reassessment documentation" (J. Yuen, 2018). In Chinese culture, participants and family members believe that the family has a crucial role to play in health care decision making, even when participants can make their own medical decisions. Chinese scholars have agreed that both patients and families agree that medical decision-making should be done in good collaboration with physicians.

5.1.7   Accessing Community Resources

When asking about the barriers for the participants to access community resources, Directors mentioned social isolation and language barriers as major issue participants' experience. Social isolation is atypical and reflected in some aspects of Chinese norms and values, such as the strong sense of self-reliance and reluctance to use formal services. With more than 46 million people in the U.S/ that do not speak English as their primary language, and more than 20 million speak English less than "very well." It is common that most health care organizations provide either inadequate interpreter services or no services at all, participants who have limited English standardization do not receive needed health care or quality healthcare. In a PCC model, much-improved data is needed to allow them to make informed choices about the care that they receive.

The administrator also mentioned participants' origin of home countries. She points out that participants came to this country through their adult children and they all went through the different life span changes in their native country. Specifically, the expectations are different. For example, some of them are very easy to be satisfied and they are blessed for what they have. It is very rare that they ask for additional assistance from the government. Some people have higher

expectation, they are trying to get as much as they can whether they need it or not. Overall, participants who are foreign-born, are well aware that ADHC/CBAS improve their well-being, meet their needs, enable them to establish social relationships with other predominant language groups, and alleviate their family caregivers burden.

The access to information about the community resources mainly from their "friends" at the city's senior centers, adult day health care centers, their family members, and their children's friends' parents. The program director who is a credentialed social worker discussed barriers for the participants including transportation and their family's availability, responsibility, ability, willingness, and communication as well as the relationship between the older adults and their adult children. She also mentioned about when the participants would like to receive the community resources mostly likely when they have some problems not only the health issues but some family relations, legal, financial, mental health, or addiction to gambling or substance abuse and opportunity seeking.

As providers, we need to find out what the reason that causes them up into a certain situation and they do not have the resources or capacity to solve the problems so that we can provide support on linking the community resources as much as we could. Both CBAS administrator and the program director mentioned the reality is, they only come to the center for 4 hours receiving the services, we all have an average of over 100 people to serve every day, we can do what we can within our capacity. They both feel that we will not be able to help all of the participants with all the problems they have at the center during the program hours to meet their expectations.

5.1.8   Respecting the Choice of Settings for the Participants

The administrator stated that it is important to involve the participants in the entire PCC

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planning process and always ask them what their goals are. And, make sure the IPC follows the

person. The issues they are trying to implement with the PCC process is how to deal with their

unexpected expectations. For example, there is a participant who likes to gamble, his wishes are

to win the lotto, his preference is to go out and buy lotto every morning. His goal is to sneak out

of the center and go to the corner store to buy lotto. She believes that was a kind of unexpected

expectation in terms of PCC.

The program director also mentioned that the goals of the participants have to be realistic

and the multidisciplinary team (MDT) might need to provide the suggestive goals to the

participants according to their physical, mental, and cognitive condition. In order to understand

the participants' needs, desires, and preferences, motivational interview techniques are extremely

important for all professionals to use. The MDT members also need to have close

communication with the participants' family members and Primary Care Providers and also to

see if the center has the resources to help them to achieve their goals with their 4 hours of

services time and the staff on board.

5.1.9   Exercising the Participants' Rights

The administrator thinks that it is easy to exercise the participants' rights by having an

open-door policy to receive complaints. From her own experience, Chinese culture teaches

people to take what they are given and they do not complain too much. Also, during the initial

assessment process, the social workers review the participant's rights in English and Chinese

with them and let them take them home to read carefully with their family. The copies of

participant's rights are also posted on the wall of the center in the English and Chinese

languages.

The program director believes that the "Participation Agreement" contains the basic and

very important contents of the rights of the participants. This document is mandatory, reviewed and signed by the participants upon their initial enrollments and reassessment occurs every 6 months. The participants' rights are only reviewed one time upon their enrollment and most of the time, the participants were asked to take it home and review it with their families, but they are always welcome to come back to discuss it whenever they have questions.

5.1.10 Empowering the Participants to make Choices of the Services and Supports

The administrator stated the importance of having the participants always know the importance of teamwork between the center staff, consultants, participants, and family members. They are always welcome to voice their concerns and making the choices of receiving and declining the services they are receiving.

The program director believed the strength-based empowerment to the participants can benefit them and the center by using their previous skills to participate in the new programs to the PCC therapeutic activity programs that the Director created. The challenges include the limitation of time, space, and staff. With the implementation of new IPC starting May 1, 2019, new policy and procedures and new programs need to be modified and created meeting the needs of federal and state requirements under the Statewide Transition Plan.

5.2 Focus Groups

Focus groups were conducted at the center during the program hours for the participants, business hours after the program hours within the MDT meeting session for the center staff, and on one of the weekends for family members. Four questions were asked guiding the group discussion about the barriers of accessing the community resources, respecting participants choice during the PCC planning process, the issues for exercising participants' right, and how to empower the participants making choices of their services and supports.

5.2.1 Center Participants Focus Group

For the center participants' focus group, I recruited six people, four female participants and two male participants. Table 5.1 shows the focus group participants' basic demographic information.

Table 5.1: Basic Demographic Information - Center Participants Focus Group

Center Focus Group Participant	Age	Sex	Years in Study	Years in the U.S.
1	86	M	12	40
2	82	F	6	35
3	79	F	8	13
4	84	F	3	4
5	88	F	7	5
6	76	M	2	3

The focus group was conducted in a training room in the study ADHC after the group maintenance exercise session from 10:20-11:40 am. The discussion was following the designed questions covering the four areas of accessing community resources, respecting participants' choice on PCC planning, exercising participants' rights, and empower participants on making choices.

5.2.1.1   What are the Barriers of the Participants Accessing the Community Resources?

When talking about the barriers to access the community resources, the six focus group participants all agreed that language is the biggest issue for them to understand the flyers, government programs, health plan benefits, and health promotion disease prevention materials. Participant 6 stated that people around him have no idea about what services they can get from the community and also, they are not sure which services they need to pay for and which services they do not need to worry about the payments. Participant 4 and Participant 5 agreed with the

issue of the language is the biggest barrier that they have in accessing community resources, which really affects their community involvement and their quality of life in the local community. Participant 4 added that they sometimes receive some health promotion and services materials containing language they can read, but they have a hard time understanding the meaning of it because the language translated is not the style they are familiar with back in their home country.

Participant 2 stated the center social workers are too passive on delivering the community resources information to the participants. Participant 1 agreed with her and mentioned that some of the center social workers are nice and patient, but they have limited knowledge and resources to help them locate as much information as they needed.

5.2.1.2   What Does the Center Do to Respect Participants' Choices During the Process of PCC Planning?

Participant 3 mentioned that he was asked a lot of questions by the center nurses, social workers, therapist, and dietitian and even the psychologist about his conditions, addressed his problems, reviewed his medication and health records, and told him what to do but nobody ever asked him how he felt about doing it or not. Two other group participants told Participant 3 that they all should trust the professional staff and they all believe all they want them to do is good for them. Participant 2 stated the staff at study ADC are all very friendly. They always check on Participant 2 and see if she has new medications, hospitalizations, got falls or any pain but she did not know what they were going to write on the IPC until the review of the IPC with the program director before signing the "Participation Agreement." Participant 3 added that she did not remember that she was involved in any care planning process.

5.2.1.3   What are the Issues for the Participants to Exercise Their Rights?

Four out of the six focus group participants mentioned the biggest issue to exercise their rights is to understand the rights fully. They all remembered that they signed the agreement and also remember the program director announced that the Participant Rights is posted on the wall of the front desk. Participant 4 and Participant 5 remembered that the program director went through the rights and also gave them a copy of the Participant Right but now they do not remember what is in it. Participant 5 and Participant 2 suggested the Participants Right should be reviewed and learned periodically in order for them to remember what is in it. Participant 1 added that he trusts the center staff and they would not do anything to hurt us. He told the whole group that they need to trust the center staff and he does not need to read line-by- line of the Participants Rights. Participants did not know where the Participants Rights was posted.

5.2.1.4   What Would You Like the Center to do to Empower the Participants Making Choices of Services and Supports?

Participant 1 stated the services from the center are already planned and they do not need to make the choice of the services. Participant 2 and Participant 4 mentioned the center needs to provide more options for the activities to meet the needs of a small group of special needs participants. Participant 1 and Participant 3 complained about the music being too loud and they feel anxious and nervous when the music is on for the dancing group. Participant 6 told the group the center needs to give the participants' the right to choose the social workers they would like to read the letter for them because the social worker assigned to him has no patience. Participant 5 and Participant 4 also agree that the center needs to make more options available on choosing the staff they would like to receive the services from.

5.2.2 Family Members Focus Group

The family focus group was conducted on a Saturday afternoon from 2-4 pm in study ADHC. Fruits, cookies, trail mix, hot tea, soft drinks, and crackers were served to the family focus group participants. Three female participants and two male participants were the current study ADHC's participants' family members who attended the focus group. Basic demographics for this group are in Table 5.2.

Table 5.2: Basic Demographic Information - Family Focus Group Participants

Family Focus Group Participant	Age	Sex	Lives with Participant	IHSS Receiver
1	57	F	Yes	Yes
2	56	F	Yes	Yes
3	54	M	Yes	No
4	67	F	No	No
5	49	M	Yes	No

5.2.2.1 What Are the Barriers of the Participants Accessing the Community Resources?

Participant 3 from the family focus group stated the center should be responsible to provide information to the participants about community resources. That should be the center social workers' job to let the participant know what kind of benefits they can get and help them to apply for that.

Participant 2 and Participant 5 immediately agreed with Participant 3 and mentioned that they are too busy, and they rarely see and get chance to talk about the participants and almost no time for them to find out what the services and support programs in the community where they live. Participant 4 told us that she sees her mom in a couple of weeks and she believed that her mom is doing fine in her senior apartment and she is fine with where she is at right now. Participant 1 also mentioned that she has limited understanding and access to the county

resources. She told us that once she listened to the 1300 radio station, the program director talked about the services and support programs in the long-term care system, which really opened her mind. This is the first time for her to know there are so many programs that can help the older adults when they need help. The other participants asked if they can get the recordings and hoped the center can provide more information to the families too because they need to get educated and understand where to get help when they need it. Participant 1 also stated that kind of information is not only good for their parents but could benefit them as well.

5.2.2.2   What Does the Center Do to Respect Participants' Choices During the Process of PCC Planning?

Participant 3 mentioned that he was asked by one of the Nurses about his mom's discharge summary from the hospital, but he has not been invited to the MDT meeting at the center. When the facilitator asked around to see who attended the center's MDT meeting, nobody in this group had ever attended the MDT meeting. Four of the participants in this group have no idea what a MDT meeting is. Participant 6 stated he believes that the center staff are professionals and know better about his parents' condition because his parent always told him that the center nurses are very nice to them and gave them good information on health promotion tips. Participant 3 also agreed with Participant 6 and told us that they need to let the center staff and their parents make plans which are good for their health. The family needs to support them by getting the information to the team.

5.2.2.3   What Are the Issues for the Participants to Exercise Their Rights?

When the facilitator asked if the families have ever read the Participant Rights, four out of the six family focus group participants had not seen their parents bring the documents back home. Participant 5 mentioned that his parent brought an envelope back home on the first few

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days of attending to the program, but he did not pay attention to what was in that envelope and did not open it. Participant 3 told the group that he did not think the participants understand what their rights are. They have attended the center services, but he did not think that was a problem. Nobody in this focus group has ever paid attention that the center has the Participant Rights posted at the center and they did not seem to care about it.

5.2.2.4   What Would You Like the Center to Do to Empower the Participants in Making Choices of Services and Supports?

When talking about empowering the center participant in making choices of the services and supports, family focus group Participant 3 suggested the center needs to give them more options for them to work on their problems not only on the health side but on the mental and emotional sides as well. Participant 6 does not think the center participants understand what choices they have to choose from at the center. Participant 2 agreed and she did not think that the center has more special programs for them to choose. Participant 4 shared a different opinion. She thinks that the participants should be blessed to receive so many benefits from the center and everything is free. She did not think that she can receive this kind of services and support after she paid her taxes all her life in this country. She also stated that she would not be qualified to enroll in this program and she cannot afford to pay for it even if there is a similar program available for her to attend.

5.2.3   Center Staff Focus Group

The focus group from center staff was conducted after program hours within one of the MDT meeting room including MDT members and invited one-MDT staff to attend. A total of 12 people attended the meeting, their ages ranged from 29-66 years old, and their years of working

at the study ADHC is from 2-18 years. Simple demographics for the center staff focus group is

shown in Table 5.3.

Table 5.3: Basic Demographic Information - Center Staff Focus Group Participants

Staff Focus Group Participant	Age	Sex	Years in ADHC	Years in the US
1	66	M	18	40
2	45	F	17	22
3	53	F	3	23
4	54	F	4	21
5	44	F	16	20
6	39	F	7	18
7	29	F	2	5
8	34	M	2	29
9	60	F	2	12
10	33	F	2	7
11	32	F	3	11
12	42	F	12	30

5.2.3.1   What Are the Barriers of the Participants Accessing the Community Resources?

The PCC implementation was the hot topic brought out although the question asked

about the community resources. Focus group Participant 9 stated the government reinforced the

PCC because they have nothing to do but make changes for them to keep their jobs. Participant 1

supported her point and expressed unwillingness of making changes by stating they already

make the participants happy and do not think the center needs to make any changes.

When talking about the barriers to access the community resources, focus group

Participant 12 stated that if the center actively introduced the services and resources to the

participants it would cause too much work for the social workers and they are already too busy to

handle the work right now. If the participants asked the social workers to apply the benefits for

them she did not think there would be enough time for them to handle it because they only have

4 hours to receive services at the center and the center's average daily attendance is 140. Some focus group participants who have the social worker background would like to at least do something about it by making a binder, posting information, and providing education session.

5.2.3.2   What Does the Center Do to Respect Participants' Choices During the Process of PCC Planning?

Focus group Participants 2 and 3 stated that they speak to the participants' family members all the time during the assessment process. Sometimes, they have to invite the family to the center for the interviews when the center participants have no capacity to describe their condition or the participants speak the languages they do not understand. Participant 5 stated that she did the same to communicate to the participants, but as the therapy consultant she does not have much time, she would rather be communicating with the nurses to get the information. Group Participant 10 mentioned about the MDT meeting involvement, she would like to invite the families and participants, but she did not think the center should invite them because the limitation of the time and room make it so difficult sitting in the MDT meeting. Focus group Participant 6 expressed her experience of communication with the family members is unpleasant sometimes because the families sometimes cannot give the information needed rather than that they are judgmental and very demanding. Participant 10 thinks that we should respect the center participants' choices and allow them to change the services in the IPC because sometimes they are afraid of talking to the professionals, but they will tell the CNA and LVN about their true feelings and their concerns.

5.2.3.3   What Are the Issues for the Participants to Exercise Their Rights?

Participant 4 and Participant 5 believe the biggest issue to exercise the participants' rights is for them to understand their rights fully. They do not think that the participants know about

their rights at the center while they are receiving the services. At least they do not remember there is a right that they can exercise. The rest of the focus group participants have the same concern about helping the participants to understand the rights and reminding them to check the copy of the Participants Rights posted on the wall by the front desk. Participant 8 suggested the center needs to put this topic in the education to the participants and also the in-service for the staff members at the center at least on a quarterly basis.

5.2.3.4   What Would You Like the Center to do to Empower the Participants Making Choice of Services and Supports?

Participant 7 agreed with empowering the participants making their choice of the services and supports but she questioned about how to accommodate their request if the request is not reasonable and their goal is unreachable. For example, the center participants always complaint about the food, we can arrange the food according to their conditions needs but there is always no way to accommodate their preference of the taste and special desire for 140 people daily covering breakfast, snacks, and lunch. Now the center receives food from different vendors, she believed that no vendors will do business with the center if they are asked to do 140 different types of food. Another social worker background focus group Participant 7 stated that the participants should have the choice of choosing or switching social workers, but the reality could happen like the social worker who does not do a good job gets less workload than the social workers who do a great job with patience, love, and help. Some focus group participants asked about what the center can do to meet the participants' wishes and desires but the center does not have the capacity or resources to provide the services and supports to them during the program hours.

CHAPTER 6

DISCUSSION AND CONCLUSION

The purpose of this study was to determine the readiness of a CBAS/ADHC program's practices and operations to implement a PCC model to meet the new standards for certification and licensing requirements by the California Department of Aging (CDA) and California Department of Public Health (CDPH). A secondary goal was to propose an evidence informed Person-Centered Adult Day Health Care operational model for further study. Findings may benchmark the profiling of related ADHC/CBAS programs throughout California as well as the rest of the nation.

In Chapter 6, I discuss the research findings under five themes related to the participants' family and staff's perspectives and suggests federal and state standards compliance; influences of language proficiency and social isolation, immigrant status and social support, health literacy, and changes in role and social status. These factors are considered in the next sections.

6.1   Low English Proficiency and Social Isolation

Almost all of the center participants had limited English proficiency. Language could be the most significant barrier when they are accessing community resources, understanding the terms about their health, participating in the care planning process, their rights expressing their wishes and needs, and making their choices. For instance, W. Kim and Keefe (2010) mentioned the language barrier is the major issue that blocks their access to the community resources in their research on Asian American immigrants. Lower English language proficiency leads to social isolation which could be a barrier to accessing services. Although most of the participants live with their children, most of the adult children held full time jobs or multiple jobs which limited opportunities for English language learning by the seniors. S. L. Friedman and

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Kalichman (2014) described the family caregivers' burden from workload, which would add to communication barriers for the seniors.

6.2   Immigration Status and Social Support

Immigration status explained the senior people's experience of person centered care in that the longer the center participants resided in the U.S., the more likely they were to have IHSS benefits from the State of California Social Services Department with PCC. Newly admitted immigrants lower social support and limited access to social workers were reported with lower PCC. Also, social workers may be perceived to have an extra burden working with newly admitted immigrants compared to those with longer stays, especially since participants and family may not be willing to share the information actively because of concerns about overburdening the social workers. Moreover, newly arrived immigrants from mainland China may have a sense of cultural guilt for accessing services they perceive to be undeserving since they have never paid any taxes to the U.S. government.

6.3   Low Health Care Literacy

Chinese background seniors may lack in health care literacy skills for accessing care services independently and the effects of health care illiteracy may be compounded by age-related declines in vision, hearing loss, function, and cognition. Low health care literacy is prevalent among older aged immigrant Chinese who may prefer alternative or traditional Chinese medicine, such as the services of acupuncturists. For instance, Chesla, Chun ,and Kwan (2009) reported immigrant Chinese families struggle in managing type II diabetes from low health care literacy and over-reliance on special diet. Shaw, Huebner, Armin, Orzech, and Vivian (2009) also reported cultural beliefs held by immigrant Chinese hampered their adherence to health care providers' instructions. However, these two studies were conducted in medical and clinical

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setting and not in CBAD services and home health care settings. The findings of this study

extend those from clinical settings to CBAD services and home health care settings.

6.4   Change of the Role and Social Status

With immigration to the U.S., most elderly Chinese may experience multiple losses of

control, power, financial assets, good health, and role change, which could lower participating in

their PCC planning process (Matthews, Stanhope, Choy-Brown, & Doherty, 2018). For instance,

they may be feel helplessness choosing the staff for services, or requesting modification of the

services (Hsu, Cheung, & Ong, 2006; Lieu, 2014). For instance, older Chinese immigrants hold

to the traditional values of filial piety, harmonious process, and being productive. This might

translate into lower willingness to requested social services from self-perceptions of being

powerless, useless, and helpless (Shin, 2002; Tsoh et al., 2016). From these findings, it would

appear that a working PCC model for older Chinese immigrants would be as in Figure 6.1.
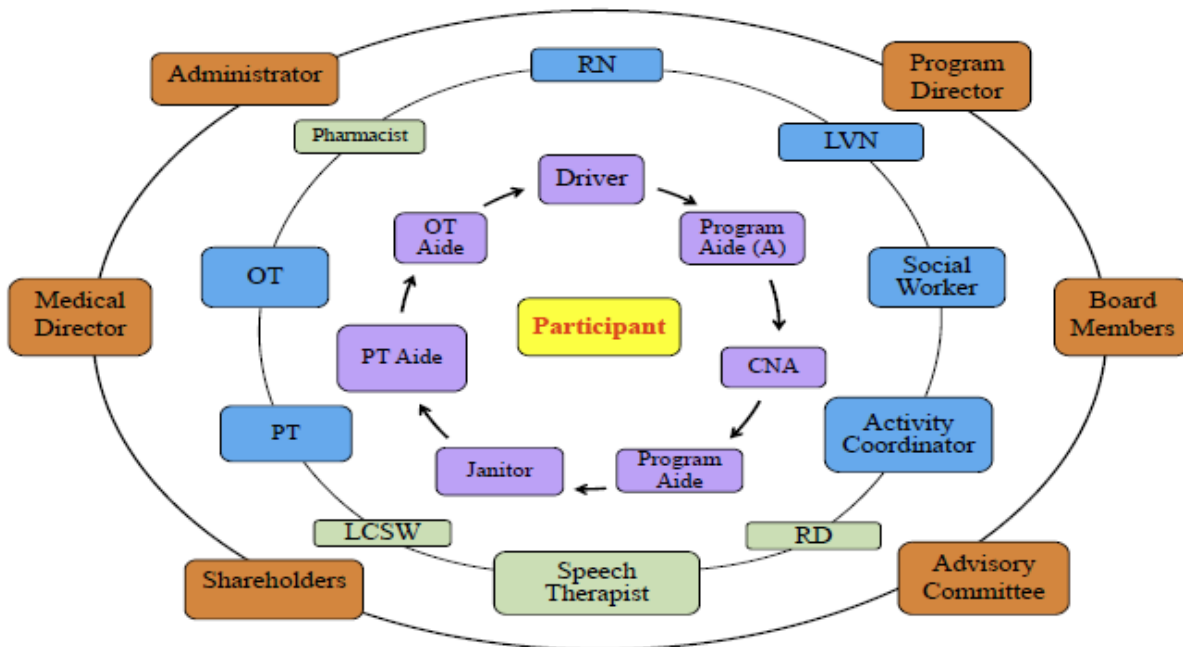
Figure 6.1: Best practice operational model of PCC in CBAS/ADHC with elderly immigrant Chinese.

This model may depict what a CBAS/ADHC PCC service should seek to address. This prospective model would replace the current operational medical care as in Figure 6.2.

| Stakeholder 20% | Stakeholder 20% | Stakeholder 20% | Stakeholder 20% | Stakeholder 20% |

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Figure 6.2: Medical model of CBAS/ADHC with elderly immigrant Chinese.

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In order to achieve the PCC CBAS/ADHC with elderly immigrant Chinese as in Figure 18, the following suggestions are made for the organization best practice in terms of PCC practice.

1. Manage stakeholder activities regularly at the center inviting staff, participants, families, and community resources.

2. Create a PCC Operations manual including the organization's mission, vision, and strategy as the guidance for best practices and develop an advisory committee with the composition of professionals of researchers and practitioners.

3. Review the center's Policy and Procedure in all areas, and more attention needs to be paid on participant's choice, rights, autonomy and independence, privacy, and legal aspects of affairs as well as access to community resources.

4. Develop a Quality Strategy for the center to include principles, competency tools, an evaluation process, and create a Quality Advisory Committee with leaders in the healthcare field to maintain the best practice at all time by conducting self-assessments in all departments on a quarterly basis including an internal audit every year.

5. Promote electronic health records and go paperless by purchasing the most advanced application and equipment as well as implementing staff recruitments and related training.

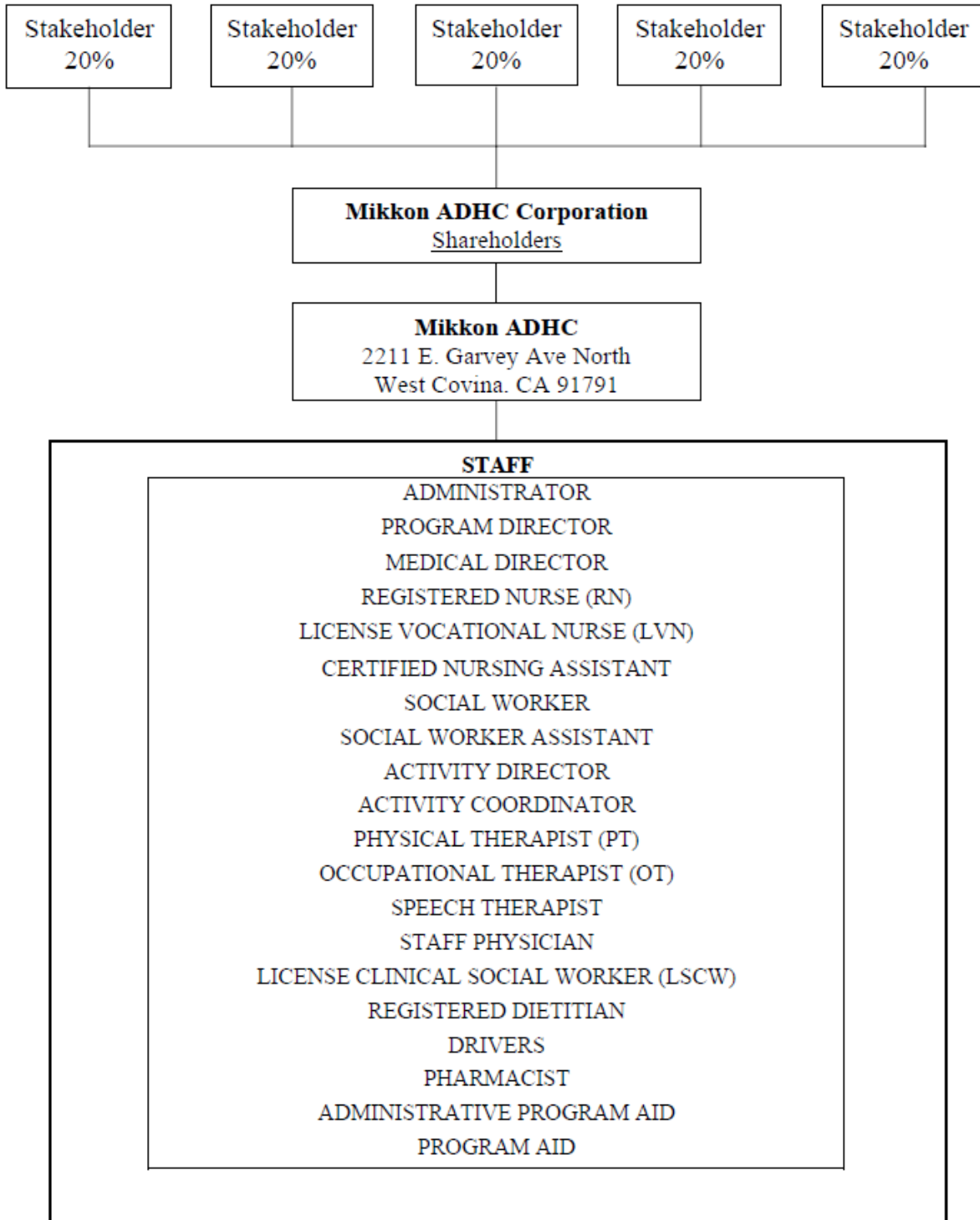6. Extend the capacity of the center's availability by applying to open 7 days per week instead of 5 and by moving to a bigger place, as well as an extension of the service hours from 4 to 6 in order to accommodate the needs from the participants and their families. Hire more program aides to cover the floor during the program hours.

7. Create internal staff development programs and provide opportunities for staff to get trained, promoted, and compensated for their good performance.

8. Explore more opportunities to the funding resources by signing up for Medicare Advantage program, Palliative Care Program, increasing private pay attendance, working with the Regional Centers and Veterans Administration, Board, and Cares, Residential Care Facility for the Elderly, and community homes.

Figure 6.3 illustrates the main qualities of a person-centered (Upper part) as compared to a medical care focused (lower part) services regimen.
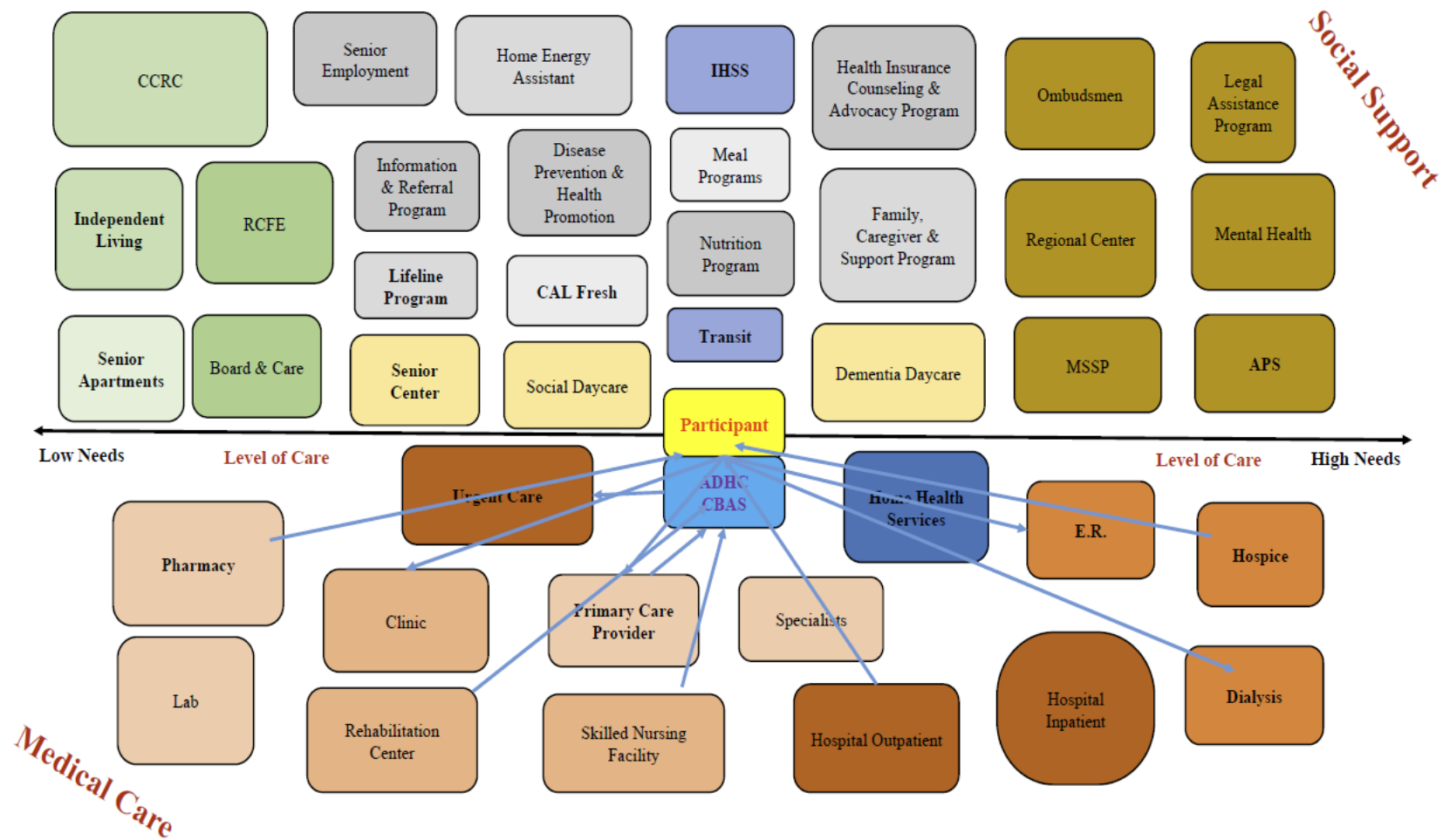
Figure 6.3: Person-centered care versus medical care centered models.

The average MIKKON enrollee has limitations in almost one-third of ADLs. For example, participants at MIKKON require ambulation assistance, transferring assistance, and less than 1% of the participants can feed themselves or use the toilet on their own. Furthermore, the generality of program characteristics associated with functional outcomes suggests the MIKKON program may be able to choose different routes to improve care. Furthermore, my findings suggest that having a full-time PT/OT/ST/RD may be associated with better outcomes. Smaller programs may have a difficult time employing full-time contracted professional. "High Touch Communication Program" creating a strong bond between participant, family, and staff and community service providers as needed by assigning the staff communicating and checking the participants' condition on a regular basis, collecting data, and documenting information for future records (Mehrotra & Wagner, 2008).

"Caregiver Support Program" will be designed for supporting the family members by providing the education on geriatric and gerontology as well as information about community resources and supportive services. The support group will meet on a monthly basis and the center will invite experts and professionals to the group discussion and training sessions.

External experts in medical, nursing, occupational therapy, physical therapy, psychosocial services, therapeutic activity, and nutrition service might be invited to train the center staff on the PCC approach related knowledge, skills, and experience. This should be designed into the strategic plan with annual continuing education and an in-service training plan. The training should serve as staff orientation, continuing education training, and PCC special training. The training can be conducted internally working with university professionals. The topics of the training should include organizational culture, policy and procedures, skills, community resources, safety and concerns, abuse reporting, specific medical needs, social needs,

and hands-on instruction under each department requirements. The training will also be delivered by different methods such as webinars, documentation, videos, shadowing, coaching sessions, and classroom training at the center. In-service training for professional and frontline staff needs to be provided with constant reminders to follow the federal and state laws and regulations and to empower them to work with the participants and their families towards improving participants' quality of life (Matthews et al., 2018).

The following efforts need to be taken to strengthen accessing community resources for the participants and their families and creating strategic planning on the programs involving the communities to work together for the services recipients and their families.

1. Working closely with the Health Plans on communication, coordination, creating a partnership, and building a good relationship to support the needs of introducing benefits, services, and programs to the center participants and support the families and staff at the center.

2. Encourage center staff going out to explore the community resources and conducting outreach for the center and make it part of the center's strategic plan as well as the policy and procedures. The center participants and their families are also invited and encouraged to explore the opportunities to the access of community resources which can help themselves and help other participants at the center.

3. Create outings are a very important therapeutic activity, partnering with community older adults and health care programs, also inviting them to the center to promote collaborative activity programs, and working closely with the center staff and the participants.

4. Working with government agencies such as the Area Agency on Aging, and local city departments, local not-for-profit aging service organizations and services providers such as transportation providers, senior-related services program, low-income supportive programs to help participants to access the state and local resources for services and support.

5. Working closely with the healthcare providers such as participants' primary care physicians and specialists, hospitals, clinics and urgent care, rehabilitation facilities, and home health care agencies.

6. Collaborate with local adult day programs such as senior centers, enrichment centers, and create collaborative activities involving their participants and staff and also

encourage visitors and inviting local community resources to the center to attend managed activity programs.

7. Upgrade physical environmental features to the center by adding brail and color light reflection, adding Chinese characters to the signage, and enlarging the letters of the posts at the center.

Figure 6.4 presents a model of empowerment in PCC in CBAS/ADHC settings.
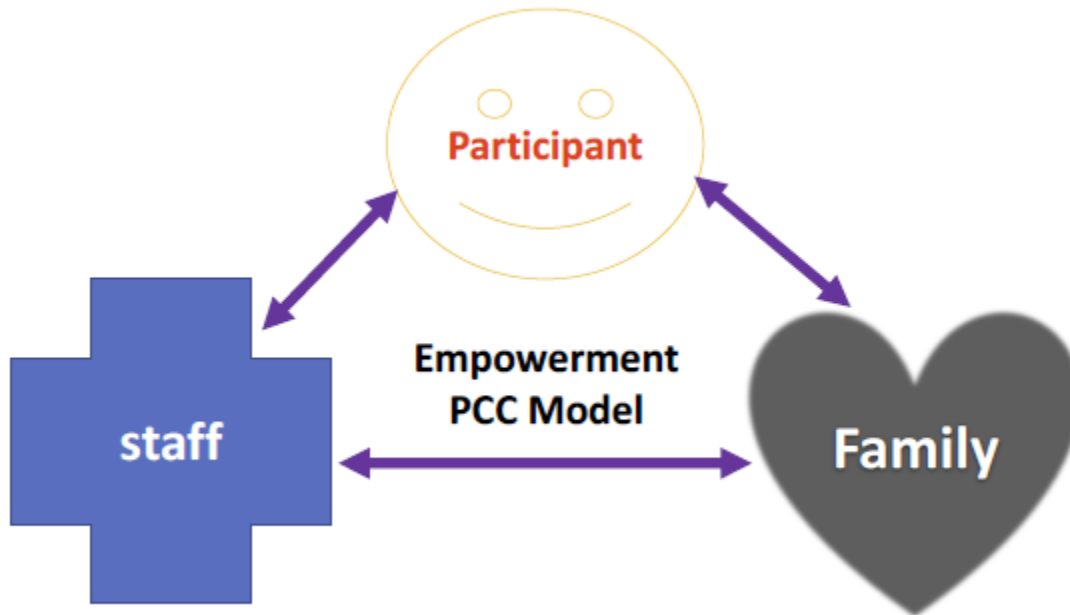
Figure 6.4: Model of empowerment.

According to the empowerment theory, participants and their families make their own decisions regarding services they require. Center staff would like to have a policy and Procedure to follow in order to provide assistance as needed.

Beneficial outcomes participant empowerment at the MIKKON include decreased risk for adverse drug reactions, improved compliance at home, and decrease costs related to prescription drugs if the participants have a use for less medication.

For instance, while the center's meal services are part of the California food program, Chinese food is the major meals provided to the participants who are of the Chinese cultural background.

The MIKKON center could also empower clients educating them on how to file a grievance as elderly Chinese immigrants are less likely to complain for cultural reasons. Others may perceive to have been ignored by the administrators after they filed the complaints. A complaints or "Grievances Box Program" managed by the administrative staff and opened every week may be of assistance.

6.5   Implications Policy Practice, Education, and Research

Green and Glasgow (2006) indicated practice-based evidence is needed for responsive care models. These considerations are discussed in the following sections.

6.5.1   Policy-Practice Level

More policies and operations manuals with detailed instructions should be completed to guide the CBAS/ADHC caregivers to provide for cultural diversity among participants and families. Policies should be written in Chinese for participants and family facing linguistic barriers (Miyawaki, 2015). Moreover, participants and their families may need help with information on community resources. On the California state level, close to 90% of the center participants indicated a high demand for assistance in accessing community resources. In this regard, collaboration would be key to successful person centered (Eilers et al., 2007). PCC is about giving consumers and family caregivers choices about the services and care they require.

6.5.2   Education I

Formal and informal healthcare related education plays a very important role in CBAS/ADHC programs seeking to be person-centered. This would require redesigning the CBAS/ADHC programs to provide appropriate education as part of quality care (Institute of Medicine, 2000, 2001). However, CBAS/ADHC programs' administrators and program directors

may not have training in educating consumers and family caregivers in PCC services and how to access them. Also CBAS/ADHC program staff with very limited knowledge, skills, experience, and motivation implementing PCC are less likely to provide consumers with the education they need.

6.5.3 Research

PCC research is a new research topic in CBAS/ADHC for LTC services and support (Kogan et al., 2016). The aim of this exploratory study was to determine the readiness of the current CBAS/ADHC programs operation practice in terms of the implementation of a PCC model. Future studies should seek to replicate and extend the findings from this study.

6.6 Conclusion

This exploratory, descriptive case study explored an adult day health care center's readiness for integrating a PCC model with participants who are elderly Chinese and their family caregivers. Findings suggest an empowerment model to be a best practice with this population. The findings of this study show preliminary evidence for future follow-up studies that could benefit CBAS/ADHC facilities throughout California and adult day programs in this country.

APPENDIX A

IRB APPROVAL AND APPROVAL FROM STUDY SITE

UNT

UNIVERSITY OF NORTH TEXAS™
A green light to greatness.

August 1, 2017

Dr. Keith Turner
Student Investigator: Min Cole
Department of Rehabilitation & Health Services
University of North Texas

Re: Human Subjects Application No. 17-273

Dear Dr. Turner:

As permitted by federal law and regulations governing the use of human subjects in research projects (45 CFR 46), the UNT Institutional Review Board has reviewed your proposed project titled "Modeling the Transition from a Medical to Person-Centered Care Model in CBAS/ADHC." The risks inherent in this research are minimal, and the potential benefits to the subject outweigh those risks. The submitted protocol is hereby approved for the use of human subjects in this study. **Federal Policy 45 CFR 46.109(e) stipulates that IRB approval is for one year only, August 1, 2017 to July 31, 2018.**

Enclosed are the consent documents with stamped IRB approval. Please copy and use **this form only for** your study subjects.

It is your responsibility according to U.S. Department of Health and Human Services regulations to submit annual and terminal progress reports to the IRB for this project. The IRB must also review this project prior to any modifications. **If continuing review is not granted before July 31, 2018, IRB approval of this research expires on that date.**

Please contact The Office of Research Integrity and Compliance at 940-565-4643, if you wish to make changes or need additional information.

Sincerely,

Chad Trulson, Ph.D.
Professor
Chair, Institutional Review Board

CT:jm

MIKKON ADULT DAY HEALTH CARE CENTER

2211 East Garvey Ave. North, West Covina, CA 91791
Tel: (626) 967-0812 • Fax: (626) 967-9286 • Toll Free: (888) 888-1281
E-mail: wecare@mikkon-adhc.com • Website: www.mikkon-adhcc.com

MIKKON ADHC

Letter of Approval for Person-Centered Care Research

February 15th, 2017

To Whom It May Concern:

This is to approve Min Cole working with Dr. Keith Turner and Dr. James Swan from University of North Texas conducting Person-Centered Care related research in MIKKON ADHC.

This research is designed to measure the production of culture change in adult day health care setting of Long-Term Care. More specifically, we are going to look at the Person-Centered Care and Participant-Directed Care concepts & practice for staff, family and participants in MIKKON ADHC. The sponsor of this research is Quality of Life Group, a not-for-profit organization dedicated to improving quality of life in older adults.

We hope the research can be a beneficial to us towards a better practice of ADHC/CBAS and HCB settings of Long-term Care to serve better a diverse population of older adults helping them aging in place in their communities with their loved one. This is just the very first step from the long journey of "Participant-Directed Care" in Home and Community-Based Services Adult Day Health Care setting. We understand that our journey Culture Change in ADHC has not even started yet and will never end. Thank you for choosing us as the research partner, we will work together to the better quality of life for the people we serve.

For additional information, please feel free to contact me.

Regards,

Jack Liang
Administrator
MIKKON ADHC
pdirector@mikkon-adhcc.com

APPENDIX B

CONSENT FORM

University of North Texas Institutional Review Board

北德克萨斯大学研究审核委员会

Informed Consent Form and Authorization to Use and Disclose Health Information for Research

以研究为目的的了解和使用医疗信息的知情同意书

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the purpose, benefits and risks of the study and how it will be conducted. Signing this form also gives permission for use and disclosure of your health information as part of this research study.

在用于参与本研究之前，对于此研究的目的，受益和风险以及对该项目将如何进行的说明的之情和理解非常重要。 仔细阅读。

Title of Study: <u>"Modeling the Transition from Medical to Person-centered Adult Day Health Care".</u>

研究课题： 实现以社区为基础的成人日间保健中心的照护模式从医疗型过渡到人为本的照护模式的转变。

Investigator: 研究调查员

Student Investigator: <u>Min Cole.</u> University of North Texas (UNT) Department of <u>Rehabilitation and Health Services.</u>
学生研究员： MIN COLE，北德克萨斯大学（UNT）大学，康复和卫生服务系

Principal Investigator: K. Whisnant Turner, Ph.D., University of North Texas (UNT) Department of <u>Rehabilitation and Health Services.</u> Department of <u>Rehabilitation and Health Services.</u>

监督研究员：K. Whisnant Turner, Ph.D., 特纳博士，北德克萨斯大学（UNT）大学， 康复和卫生服务系

Purpose of the Study: To create a model to gauge compliance with the federally mandated and California state-regulated transition from a Medical Model of service delivery to a Person-centered Care model for Adult Day Health Care programs. The research will be based on new State of California Department of Aging requirements for CBAS/ADHC centers.

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研究的目的是因为我们需要从提供服务的医疗模式过渡到以参与者为中心和为主导的照护模式，以遵守和服从联邦政府和加利福尼亚州政府对于加州成人日间保健中心的法律法规的强制性要求。

Study Procedures: Study participants, or their representatives, will be asked how strongly they agree with each survey statement. The interview will take about 15 minutes.

研究程序： 您将被回答调查调查问卷中的一些问题，这些问题需要您给出对每个陈述的认可程度，这将大约需要 15 分钟的时间。

Foreseeable Risks: There are no foreseeable risks involved in this study.

可预见的风险： 本研究无可预见的风险。

Benefits to the Subjects or Others: Those who participate in center programs may experience preservation of dignity and respect through greater opportunities for choice, autonomy and independence. MIKKON ADHC staff will gain a greater awareness of their roles in the transition process and clarity of purpose. Administration will have a map of the transition process and clarity on the programmatic goals and outcomes. Family members can gain a better appreciation and inclusion in the care-planning process.

该项目优势： 您和其他参与者以及明康保健中心的工作人员还有家人都会参与研究。 你们的帮助会使我们的照护和提供服务的过程更具人性化和符合您的期望和需求。这项研究还可以帮助其他成人日间保健中心项目去实现以人为主导的照料实践，帮助他们的参与者保持尊严和尊重，实现自我选择，自主和独立的高品质的生活方式。

Compensation for Participants: In gratitude for their participation, those interviewed will receive an imprinted, cloth grocery bag valued at $2.
参与者报酬：为感谢您的参与，您将收到一个价值 2 美元的购物袋。

Procedures for Maintaining Confidentiality of Research Records: Research participants will only be identified by code numbers. An electronic research template will be created through Survey Monkey to be used by the Student Investigator to gather data. The PI will store the information on a secure server in the UNT Department of Rehabilitation and Health Services. Consent forms will also be scanned and stored in a separate folder on the server. Names and specific identifications of participants will be in another password-protected file in that location. The University of North Texas will use the study results for the completion of a

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dissertation and other professional publications.

研究记录和保密程序：所有参与研究的人员都会在使用编号的情况下进行研究。学生研究员会利用 Survey Monkey 这个系统来收集数据。 监督研究员会将收集到的数据存储在 UNT 大学康复和卫生服务系的保密硬盘中。被研究人员的姓名和编号会在一个用密码保护的加密文件中体现并单独保存在保密硬盘中。我们让您签署医疗健康信息的保护授权表和您自愿参与研究的授权表会用扫描的方式储存在保密硬盘的文件夹中。北德克萨斯大学讲使用研究结果完成博士论文的研究和相关文章的出版。

Use and Disclosure of Health Information: If you sign this document, you give permission to Min Cole at University of North Texas (UNT) Department of Rehabilitation and Health Services to use or disclose or release your health information that identifies you for the research study described in this document.

了解和使用您的医疗信息：您签了这个文件，是为了研究的目的，愿意给 Min Cole，美国被德克萨斯大学康复和卫生服务系学生许可使用您的医疗信息的权利。

Health Information to be Used or Disclosed: The health information that we may use or disclose or release for this research includes your physical evaluation include diagnosis, medication and treatment, Multidisciplinary team assessments, progress notes indicating his/her physical and mental condition.

医疗信息的使用和分享：我们使用您的医疗信息的内容包括您的身体检查，包括诊断，服药和处方，专业评估和关于您身体和精神状况的笔记。

Who may use or disclose the information: The health information listed above may be used by and/or disclosed or released to University of North Texas (UNT) Department of Rehabilitation and Health Services.

谁会使用您的医疗信息：上述的医疗信息会在北德克萨斯大学康复和卫生系研究使用。

Who may receive the information: Min Cole is required by law to protect your health information. By signing this document, you authorize Min Cole to use and/or disclose or release your health information for this research. Those persons who receive your health information may not be required by Federal privacy laws (such as the Privacy Rule) to protect it and may share your information with others without your permission, if permitted by laws governing them.

Min Cole 作为研究人员需要已发保护您的医疗信息。签署此文件的意义是您给予 Min Cole

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许可使用您的医疗信息来做研究。根据联邦政府隐私保护法授权人在没有经过您的允许的情况下把您的医疗信息告诉其他人。

Expiration of the authorization: This Authorization does not have an expiration date and ends of this research study.

这个授权没有特定的日期限制，直至研究结束截止。

Right to revoke authorization: Please note that you may change your mind and revoke this Authorization at any time, except to the extent to University of North Texas (UNT) Department of Rehabilitation and Health Services. To revoke this Authorization, you must write to Min Cole at min.cole@qolg.org or K. Whisnant Turner, Ph.D. at keith.turner@unt.edu.

您要明白，您随时都有权利改变您的意愿，通知北德克萨斯大学康复和卫生系。如果您撤销次授权您必须用通过以下的方式与 Min Cole 联系。 Min Cole 的邮箱是 min.cole@qolg.org. Dr Turner 特纳博士的邮箱是：keith.turner@unt.edu 联系。

Questions about the Study: Contact Min Cole at min.cole@qolg.org, or K. Whisnant Turner, Ph.D. at keith.turner@unt.edu.

如果您对本研究有任何疑问，可以通过以下的方式与 Min Cole 联系。 Min Cole 的邮箱是 min.cole@qolg.org. Dr Turner 特纳博士的邮箱是：keith.turner@unt.edu

Review for the Protection of Participants: This research study has been reviewed and approved by the UNT Institutional Review Board (IRB). The UNT IRB can be contacted at (940) 565-4643 with any questions regarding the rights of research subjects.

关于研究的问题： 本研究报告已经得到北德克萨斯大学研究审查委员会的审查和批准。关于研究对象的权利的任何问题，请与大学的研究审核委员会联系。他们的电话是（940）565-4643。

Research Participants' Rights:

Your signature below indicates that you have read or have had read to you all of the above and that you confirm all of the following:

- Min Cole has explained the study to you and answered all of your questions. You have been told the possible benefits and the potential risks and/or discomforts of the study. You

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University of North Texas
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have been told how your health information will be used and disclosed for the study.

- You understand that you do not have to take part in this study or authorize use and disclosure of your health information, and your refusal to participate or your decision to withdraw will involve no penalty or loss of rights or benefits. If you decide to withdraw from the study, the study personnel may only use and disclose your health information already collected. If you decide to revoke your authorization to use and disclose your health information, you may not be allowed to continue in the study. The study personnel may choose to stop your participation at any time.
- You understand why the study is being conducted and how it will be performed.
- You understand your rights as a research participant and you voluntarily consent to participate in this study. You also consent to use of your health information in this study.

You have been told you will receive a copy of this form.

研究参与者的权益：

您在下面的签字表示您已经阅读和收到上述所有信息，并且您同意一下所有的内容：

- Min Cole 已经对我介绍了此研究病回答了你所有的疑问。您已经被告知该研究的好处和风险。您已经了解到在此研究中将使用和如何使用您的医疗信息。
- 您已经懂得了我可以有权利不参与这个研究，不透露和授权使用我的医疗信息。如果我不参与这个研究我不会遭到惩罚或丢掉我的权利和好处。如果您同意授权使用医疗信息，这些信息只限于已经收集到的信息。 同样研究人员可以在任何时候取消我的参与。
- 您已经了解到该研究是如何进行的。
- 您知道研究参与者的权利， 而且是自愿参与这个研究。您同时也知道您的医疗信息有可能会被使用。
- 我有可能要一份我签署文件的复印本。

_____

参与者姓名 Printed Name of Participant

_____   _____

参与者签字 Signature of Participant   日期 Date

For the Investigator or Designee:

I certify that I have reviewed the contents of this form with the subject signing

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above. I have explained the possible benefits and the potential risks and/or discomforts of the study and the use and disclosure of health information. It is my opinion that the participant understood the explanation.

我的签字表示保证收到以上信息，我已经得到对于此研究的好处和预期危机的解释，并且了解我的医疗信息有可能被使用。参与此研究和懂得关于此研究的解释是我的意愿。

_____   _____
调查员签字 Signature of Investigator or Designee   日期 Date

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University of North Texas Institutional Review Board

Informed Consent Form and Authorization to Use and Disclose Health Information for Research

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the purpose, benefits and risks of the study and how it will be conducted. Signing this form also gives permission for use and disclosure of your health information as part of this research study.

Title of Study: "Modeling the Transition from Medical to Person-centered Adult Day Health Care".

Investigator: Student Investigator: Min Cole, University of North Texas (UNT) Department of Rehabilitation and Health Services.

Principal Investigator: K. Whisnant Turner, Ph.D., University of North Texas (UNT) Department of Rehabilitation and Health Services.

Purpose of the Study: To create a model to gauge compliance with the federally mandated and California state-regulated transition from a Medical Model of service delivery to a Person-centered Care model for Adult Day Health Care programs. The research will be based on new State of California Department of Aging requirements for CBAS/ADHC centers.

Study Procedures: Study participants, or their representatives, will be asked how strongly they agree with each survey statement. The interview will take about 15 minutes.

Foreseeable Risks: There are no foreseeable risks involved in this study.

Benefits to the Subjects or Others: Those who participate in center programs may experience preservation of dignity and respect through greater opportunities for choice, autonomy and independence. MIKKON ADHC staff will gain a greater awareness of their roles in the transition process and clarity of purpose. Administration will have a map of the transition process and clarity on the programmatic goals and outcomes. Family members can gain a better appreciation and inclusion in the care-planning process.

Compensation for Participants: In gratitude for their participation, those interviewed will receive an imprinted, cloth grocery bag valued at $2.

Procedures for Maintaining Confidentiality of Research Records: Research participants will only be identified by code numbers. An electronic research template will be created through Survey Monkey to be used by the Student Investigator to gather data. The PI will store the information on a secure server in the UNT Department of Rehabilitation and Health Services. Consent forms will also be scanned and stored in a separate folder on the server. Names and

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University of North Texas
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specific identifications of participants will be in another password-protected file in that location. The University of North Texas will use the study results for the completion of a dissertation and other professional publications.

Use and Disclosure of Health Information: If you sign this document, you give permission to Min Cole at University of North Texas (UNT) Department of Rehabilitation and Health Services to use or disclose or release your health information that identifies you for the research study described in this document.

Health Information to be Used or Disclosed: The health information that we may use or disclose or release for this research includes your physical evaluation include diagnosis, medication and treatment, Multidisciplinary team assessments, progress notes indicating his/her physical and mental condition.

Who may use or disclose the information: The health information listed above may be used by and/or disclosed or released to University of North Texas (UNT) Department of Rehabilitation and Health Services.

Who may receive the information: Min Cole is required by law to protect your health information. By signing this document, you authorize Min Cole to use and/or disclose or release your health information for this research. Those persons who receive your health information may not be required by Federal privacy laws (such as the Privacy Rule) to protect it and may share your information with others without your permission, if permitted by laws governing them.

Expiration of the authorization: This Authorization does not have an expiration date and ends of this research study.

Right to revoke authorization: Please note that you may change your mind and revoke this Authorization at any time, except to the extent to University of North Texas (UNT) Department of Rehabilitation and Health Services. To revoke this Authorization, you must write to Min Cole at min.cole@qolg.org or K. Whisnant Turner, Ph.D. at keith.turner@unt.edu.

Questions about the Study: Contact Min Cole at min.cole@qolg.org, or K. Whisnant Turner, Ph.D. at keith.turner@unt.edu.

Review for the Protection of Participants: This research study has been reviewed and approved by the UNT Institutional Review Board (IRB). The UNT IRB can be contacted at (940) 565-4643 with any questions regarding the rights of research subjects.

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Research Participants' Rights:

Your signature below indicates that you have read or have had read to you all of the above and that you confirm all of the following:

- Min Cole has explained the study to you and answered all of your questions. You have been told the possible benefits and the potential risks and/or discomforts of the study. You have been told how your health information will be used and disclosed for the study.
- You understand that you do not have to take part in this study or authorize use and disclosure of your health information, and your refusal to participate or your decision to withdraw will involve no penalty or loss of rights or benefits. If you decide to withdraw from the study, the study personnel may only use and disclose your health information already collected. If you decide to revoke your authorization to use and disclose your health information, you may not be allowed to continue in the study. The study personnel may choose to stop your participation at any time.
- You understand why the study is being conducted and how it will be performed.
- You understand your rights as a research participant and you voluntarily consent to participate in this study. You also consent to use of your health information in this study.
- You have been told you will receive a copy of this form.

Printed Name of Participant

_____   _____
Signature of Participant   Date

For the Investigator or Designee:

I certify that I have reviewed the contents of this form with the subject signing above. I have explained the possible benefits and the potential risks and/or discomforts of the study and the use and disclosure of health information. It is my opinion that the participant understood the explanation.

Signature of Investigator or Designee   Date

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University of North Texas   8/1/2017 – 7/31/2018
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APPENDIX C

SCRIPTS TO INTRODUCE THE STUDY TO POTENTIAL PARTICIPANTS

RESEARCH SCRIPTS

Good morning Mr./Mrs. Participant,

My name is Min Cole. I am from University of North Texas (UNT) Department of Disability and Addiction Rehabilitation. I am working with Dr. Keith Turner to conduct a research on Modeling the Transition from a Medical to Person-Centered Care Model in CBAS/ADHC.

The purpose of the study is because we need to make the transition from Medical Model of service delivery to Person-Centered Care model to maintain compliance with federal and California state regulations per State of California Department of Aging mandatory requirement for all CABS/ADHC centers in California.

You will be asked to response how strong you agree with each of the following statement in the survey questionnaires that will take about 15 minutes of your time.

There are no foreseeable risks involved in this study.

You and other participants and staff from MIKKON ADHC as well as family members can help make our care planning process more inclusive. This research can also help other Adult Day Health Care programs to achieve Person-Center Care practices that help their participants preserve dignity and respect by providing greater opportunities for choice, autonomy and independence.

In gratitude for your participation, you will receive an imprinted grocery bag.

We are going to keep all your personal and health information confidential by signing the "Authorization for Release of Protected Health Information" form and give the researcher authority to access your data. We will maintain all identified information confidential and secured in MIKKON ADHC. The University of North Texas researcher will use your deidentified data to conduct the research on behalf of MIKKON ADHC. Your personal information will not be identifiable in any publications or presentations.

If you have any questions about the study, you may contact Min Cole at min.cole@aol.com, phone number (626) 290-2228 or Dr. Keith Turner at keith.turner@unt.edu.

Thank you for your cooperation. Now let's start our interview.

研究开场脚本

早上好，

我是 MIN COLE，我来自北德克萨斯大学（UNT）大学。我将与 Dr.Turner 特纳博士一起要在明康保健中心进行一个主题为将成人日间保健中心从医疗模式过渡参与者为主导的照护模式的研究。

研究的目的是因为我们需要从提供服务的医疗模式过渡到以参与者为中心和为主导的照护模式，以遵守和服从联邦政府和加利福尼亚州政府对于所有加州成人日间保健中心的法律法规的强制性要求。

您将被回答调查调查问卷中的一些问题，这些问题需要您给出对每个陈述的认可程度，这将大约需要 15 分钟的时间。

本研究无可预见的风险。

您和其他参与者以及明康保健中心的工作人员还有家人都会参与研究。 你们的帮助会使我们的照护和提供服务的过程更具人性化和符合您的期望和需求。这项研究还可以帮助其他成人日间保健中心项目去实现以人为主导的照料实践，帮助他们的参与者保持尊严和尊重，实现自我选择，自主和独立的高品质的生活方式。

为感谢您的参与，您将收到一个有品质生活集团自助的购物袋。

我们还要让您签署医疗健康信息的保护授权表和您自愿参与研究的授权表以保护您的所有个人和健康信息和对您权利的尊重。我们研究是在明康保健中心的认证并保护所有信息的前提下进行。您的个人信息将不会在任何出版物或演示文稿中公布。

如果您对本研究有任何疑问，可以通过以下的方式与我联系。 我的电话是（626）290-2228， 我的邮箱是 min.cole@aol.com。 特纳博士的邮箱是 keith.turner@unt.edu

本研究报告已经得到明康成人保健中心和北德克萨斯大学研究审查委员会的审查和批准。关于研究对象的权利的任何问题，请与大学的研究审核委员会联系。 他们的电话是（940）565-4643。

感谢您的合作，我们就开始访谈了。

APPENDIX D

RECRUITMENT MATERIALS

MODELING THE TRANSITION FROM A MEDICAL TO PERSON-CENTERED CARE MODEL

UNIVERSITY OF NORTH TEXAS
QUALITY OF LIFE GROUP
MIKKON ADHC
MAY 2017

This research is designed to measure the production of culture change in MIKKON adult day health care center in Southern California. The purpose of the study is because we need to make the transition from Medical Model of service delivery to Person-centered Care model to maintain compliance with federal and California state regulations per State of California Department of Aging mandatory requirement for all CABS/ADHC centers in California. This research will benefit to all CBAS centers in the States of California. The main researchers are Min Cole and Dr. Keith Turner from the University of North Texas.

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实现以医疗照护模式到
以人为中心照护模式的转型

北德克萨斯大学
品质生活集团
明康成人日间保健中心
2017 年 5 月

这项项目是研究南加州明康成人日间保健中心文化变化的现状。研究目的是为了遵守和服从美国联邦政府和加利福尼亚州政府对以社区为基础的医疗型成人日间保健照护项目的要求，我们需要从以医疗服务模式为主体的照护模式转变为以人为中心的照护模式。这项研究将有益于加利福尼亚州的所有成人日间保健中心。 主要研究人员来自北德克萨斯大学的 Min Cole 和 Keith Turner 博士。

APPENDIX E

INTERVIEW AND FOCUS GROUP QUESTIONS

Category	Open-Ended Questions
Access to the community resources	What are the barriers of the participants accessing the community resources?
Choice of setting	How does the center do to respect participants' choice during the process of PCC Planning?
Rights	What are the issues for the participants to excise their rights?
Choice of services and supports	How would you like the center do to empower the participants making choice of services and supports?

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