

Caregiving Experience Among Asian American Families of Individuals With Serious Mental Illnesses



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Source: <https://www.hortihands.com/en/disclaimer-en>

Disclaimer:

Today's presentation is part of the work of the 'Ohana AANHPI Behavioral Health Center of Excellence. Today's webinar focuses on Asian Americans, especially Chinese and Vietnamese Americans, and does not present information on Native Hawaiians and Pacific Islanders.

Agenda

- I. Overview of Family Caregivers of Persons with Serious Mental Illnesses**
- II. Voices of Chinese and Vietnamese American Family Caregivers: Study Findings from Chinese and Vietnamese American Family Caregivers of People with Serious Mental Illnesses in the San Francisco Bay Area**
- III. Discussions**
 - What We Have Learned and What We Need To Do
 - Things to consider
- IV. Available Resources**
- V. Questions and Answers**



OVERVIEW

Source: <https://www.dreamstime.com/illustration/overview.html>

I. OVERVIEW OF FAMILY CAREGIVERS OF PERSONS OF SERIOUS MENTAL ILLNESSES

- ❖ The Well-being of Family Caregivers of People with Serious Mental Illnesses (SMIs)
- ❖ Asian American (AA) Family Caregivers of People with SMIs



Caregiving For Family Members with SMI

- In 2020, 5.6 % of adults aged 18 or older (or 14.2 million people) had SMIs (SAMHSA, 2021).
- SMIs, such as schizophrenia, bipolar disorder, and major depression, can be treatable and full recovery is possible (Gruhl, 2006; Salzer et al., 2018; SAMHSA, 2019).
- SMIs are often accompanied by impairments and have been recognized as a significant source of disability: Necessitating temporary or permanent reliance on family members for support (Bond & Kukla, 2011; Mueser & Cook, 2014; National Alliance for Caregiving, 2016).
- SMIs are usually diagnosed later in adolescence or young adulthood (NAMI, 2015).
- The vital role of family members in the recovery process (Han et al., 2018; Mueser & Cook, 2014; Rahmani et al., 2015; Zhou et al., 2016).



Spirce: <https://aanhpi-ohana.org/>



Caregiving Challenges Among Family Caregivers of People with SMIs

	Caregivers of an adult person with a mental illness	Average US Caregiver
Length of caregiver role	8.7 years	4 years
Hours of care per week	31.8 hours	24.4 hours
Rate of co-residence	45%	34%

Source: National Alliance for Caregiving (2016)

- Negative impacts of caregiving on family caregivers' well-being (Adelman et al., 2014; Crowe & Lyness, 2013; Crowe et al., 2015; Han et al., 2022; Hsiao, 2010; Kaye, 2011; Kishor et al., 2018; McCann et al., 2015; Perlick et al., 2016; Zauszniewski & Bekhet, 2014).
 - Poor mental health and quality of life
 - Physical ailments
 - Financial stress
 - Social isolation
 - Impaired family dynamics
- Stigma and compounded distress (Hinshaw, 2007; Mak & Cheung, 2012; Perlick et al., 2011)
 - For example, between 40% and 79% of family members of people with mental illnesses reported feeling devalued/undervalued by other members of society.
- *Relatively limited empirical studies and resources are available.*



Rising Mental Health Concerns among Asian Americans

- Very limited research on the caregiving experience with AAs (Li Verdugo et al., 2023).
- Culture shapes the caregiving experience.
- AAs are the fastest-growing ethnic minority in the U.S.: Between 2000 and 2019, AA experienced the highest population growth rate compared to all other racial and ethnic groups. During this period, the Asian population increased by 81% (Pew Research Center, 2021).
- The AAs are often perceived as a "model minority." (Leung et al., 2010; Park, 2012).
- According to the 2021 National Survey on Drug Use and Health,
 - About 16% of AAs reported experiencing any mental illness.
 - SMIs rose from 2.9 % to 5.6 % in AAPI people ages 18-25 between 2008 and 2018.
 - Major depressive episodes increased between 2015 and 2018
 - from 10 percent- to 13.6 percent in AAPI youth ages 12-17,
 - from 8.9 percent to 10.1 percent in young adults 18-25,
 - from 3.2 percent to 5 percent in the 26-49 age range.
- Underutilization of mental health services (e.g., 5.1% compared to the national average of 14.4%; SAMHSA, 2020.)



Asian American Family Caregivers of People with SMIs: Cultural & Contextual/Structural Factors

- Caregiving-related challenges and their consequences for well-being tend to be even greater for AA family caregivers.
 - Asian culture generally echoes the Confucian values of strong family ties, mutual obligation, loyalty, and collective responsibility (Chien, 2008; Lee, 1997; Leung et al., 2010; Li et al., 2019; Paik et al., 2016; Yeh et al., 2016).
 - This sense of **familism** can drive Asian American caregivers to persevere despite difficulties.
 - **A sense of duty/responsibility** towards one's family and more involvement in a caring role.
 - **Co-residency** (Han et al., 2019; Pishori, 2015; Snowden, 2007).
 - The concept of **saving face**, which is directly related to the negative stigma associated with mental illness
 - Mental illness resulting from bad thoughts, a lack of willpower, personality weakness, possession by spirits, and/or karmic repayment for their ancestors' misdeeds or their own previous lives (Chen et al., 2013; Chu & Sue, 2011; Hsu et al., 2008; Lee et al., 2009).
 - A great deal of secrecy and concealment for those struggling with SMIs – Not seeking mental health help.



Asian American Family Caregivers of People with SMIs: Cultural & Contextual Factors Ctn'd.

- Many Asians tend to rely on self-control or informal support networks before seeking professional help (Chien et al., 2008; Chung et al., 2001; Han et al., 2015; Lee, 1997; Zhao et al., 2016)
- Significant stigma among AAs is related to heightened fear and shame that further negatively impact mental health, and delayed treatment that can lead to a downward cycle of worsening symptoms (Hsiao et al., 2005; Hsu et al., 2008; Kung et al., 2019).
- Immigrant status factors include a lack of familiarity with systems, limited social support, and acculturation factors, such as limited English proficiency (Office of Minority Health, 2019).
- Preferences to seek help from the same ethnocultural backgrounds (i.e., Asian American professionals), yet limited AA bicultural/bilingual mental health professionals (Fraga et al., 2014; Han & Pong, 2015; Lee et al., 2011).
- *The underutilization of mental health services and co-residency could increase the caregiving burden among AA family caregivers.*
- AA family caregivers may not seek help for themselves either and become “hidden” patients/clients needing protection from potential health/mental health consequences.



Protective Factors for Well-Being



https://www.researchgate.net/figure/Visualization-of-some-indicative-risk-and-protective-factors-across-various-stages-of_fig1_351558309



<https://cerebral.com/care-resources/social-support>

- The positive role of self-care on stress (Hedman, Ljotsson, & Lindefors, 2012; MacNeil & Jagers, 2013).
- The positive role of social support on well-being among family caregivers (Lai & Thomson, 2011; Sangalang & Gee, 2012).
- Positive family caregivers' beliefs and attitudes toward well-being (Crowe & Lyness, 2013; Gharavi et al., 2018; Terrill et al., 2018; Rahmani et al., 2015; Redlich et al., 2010; Seligman, 2011; Zheng et al., 2016).
- The significant role of self-efficacy
 - Self-efficacy is an individual's belief in their capacity to confidently handle difficult situations (Bandura, 1994).
 - Enhanced service utilization (Chenoweth et al., 2016; Karst & van Hecke, 2012; Mulyanti et al., 2017; Wingerden et al., 2018)
 - Well-being among family caregivers (Chenoweth et al., 2016; Pedrazza et al., 2013; Ramzani et al., 2019).
- Roles of service utilization in promoting positive attitudes and self-efficacy, which can promote well-being among family caregivers (Dixon et al., 2001, 2004; Gharavi et al., 2018; Redlich et al., 2010; Toohey et al., 2016).



Family Caregivers of PSMIs During/Post the COVID-19 Pandemic.



Source: <https://www.medicare.com/newsroom/blog/2021/05/mental-health-during-covid19-how-to-recognize-when-you-or-a-loved-one-may-need-help>

- Heightened Caregiving Challenges During the COVID-19 Pandemic (De Hert et al., 2022; Brown et al., 2020; Eckardt, 2020; González-Blanco et al., 2020; Gorden, 2022; Leggett et., 2021; Park, 2020; Wang et al., 2020).
 - Caregiving challenges worsened during the COVID-19 pandemic as caregivers worry about their own health and experience stress regarding various pandemic-related public health measures (e.g., social distancing) and their consequences.
 - Critical mental health services had been disrupted, especially at the beginning of the pandemic.
 - People with SMIs have reported experiencing exacerbated symptoms and higher rates of relapse.
 - Family caregivers experience a double burden.
- While caregiving-related challenges during COVID-19 were stressful, AA caregivers were even more challenged because of the anti-Asian sentiment and violence against Aas.
- Important to focus on enhancing the well-being of everyone, especially family caregivers, particularly AA family caregivers.





Source: <https://www.mcleanhospital.org/essential/why-asian-americans-dont-seek-help-mental-illness>

II. VOICES OF CHINESE AND VIETNAMESE AMERICAN FAMILY CAREGIVERS

- ❖ Study* Findings from Chinese and Vietnamese American Family Caregivers in the San Francisco Bay Area, California

**Funding: The Silberman Faculty Development Fund from the New York Community Trust [Grant number P13-000547] to Drs. Meekyung Han (PI) and Sadhna Diwan (co-PI).*



Main Goals of the Original Study

- To explore the caregiving experience among AA family caregivers of people with SMIs within a cultural context.
- To provide insights for culturally responsive intervention/prevention programs for mental health scholars, policymakers, and professionals.
- Implemented a mixed-method design involving three ethnic groups: Whites, Chinese Americans, and Vietnamese Americans.
 - What are the overall caregiving experiences among family caregivers?
 - How do cultural values influence caregiving experiences?
 - To what degree do protective factors mitigate the impact of caregiving-related distress on their well-being?



Source: <https://aaci.org/healthy-living-blog-caregiving-concerns-within-the-sandwich-generation-part-1/>



Study Participants*

*A non-probability sampling: Neither representativeness nor generalizability.

Focus Group

A total of six focus groups were conducted (two per each ethnic group) with 78 family caregivers:

- 27 Whites
- **30 Chinese Americans**
- **21 Vietnamese Americans**

Survey

- 48 Whites
- **61 Chinese Americans**
- **55 Vietnamese Americans**

Survey: Chinese and Vietnamese American Family Caregivers (N=116)

Characteristics	Chinese	Vietnamese
Gender		
Male	55.7%	62.7%
Female	44.3%	37.3%
Average Age	57.87	42.35
Marital Status		
Married/living with partner	83.6%	60.8%
Single/Widowed/Separated	16.4%	39.2%
Education Level		
High school and lower	9.6%	33.3%
Associate's degree	83.6%	31.4%
Bachelor's and higher	6.6%	35.3%
Relationship to a Person with a SMI		
Parent	70.5%	23.5%
Other family caregivers	29.5%	76.5%
Living with a Person with a SMI	82.0%	68.6%

Average 75%



Caregiving Experience among AA Family Caregivers of People with SMIs

	Main themes	Sub-themes
Overall Caregiving Experiences	Caregiving related challenges	<ul style="list-style-type: none"> • Experience of intense emotion • Negative impact on caregiver’s mental health • Negative Impact on Social Relations and Family Dynamics • Social stigma attached to mental illness
	Hope for Recovery and Independence	<ul style="list-style-type: none"> • Hope for Recovery • Hope for Independence
Roles of Culture on Caregiving	Culture Matters: Similar Yet Different Caregiving Experience	<ul style="list-style-type: none"> • Chinese American FCs: Family obligation, Shame, lack of understanding about SMI, & (over-)protection • Vietnamese American FCs: Family obligation, Roles of religion (Buddhism, Christianity/Catholicism, or Taoism)
		<ul style="list-style-type: none"> • <i>White FCs: advocacy & teamwork</i>



Intense Emotion & Mental Health Problems

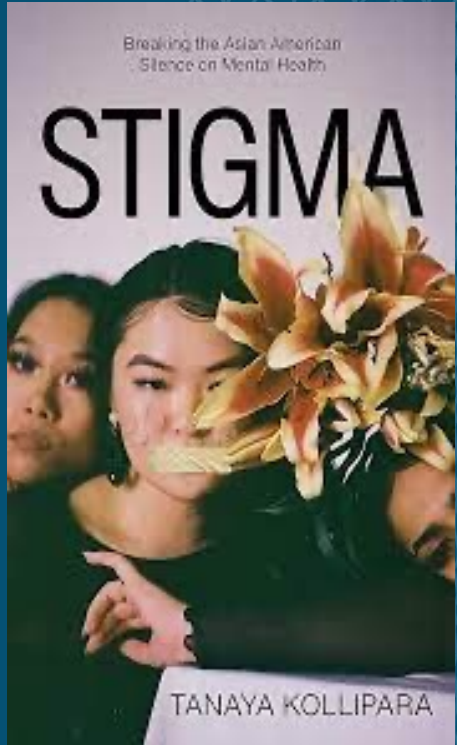
- “A lot of times, we feel a sense of powerlessness. In daily living, there is nowhere to gain strength. It feels that our whole life stops and does not move forward. Like there is no way to keep moving forward.”
- “I’ve had some traumatic stress responses from those experiences”
- “I was constantly in crisis mode. I felt post-traumatic stress disorder constantly”.
- “I’ve been wanting to find a psychologist.... I’ve been thinking about it for at least five or six years. I am afraid that I may fall apart and break down at any time.”

Negative Impact on Social Relations and Family Dynamics

- “Our social life becomes nonexistent. For us, there is no more. In the past, people would come over every week... but now no one has come to our home.”
- “In the past, for example, the whole family would attend the school potluck, but now...one of the family cannot go. Sometimes you will think, oh, they’re not going, then might as well the whole family not go”.
- “I frequently get angry at my wife and young daughter. I yell at them. This frequently occurs, but sometimes, I cannot control myself [due to stress caused by caring for an ill member]”.



Social Stigma Attached to SMIs



Source:
<https://www.amazon.com/Stigma-Breaking-American-Silence-Mental/dp/1637304447>

- “[Due to stigma] When a problem [like mental illness] arises in the family, they may not go get it checked out early. They may wait until it is very serious and to the point where there is nothing that can be done anymore.”
- “I think in the Chinese culture, this is very difficult because from the time we were little until now, we always called people shen jing bing (crazy person).”
- “Our Vietnamese is all about *saving face*, worried about the humiliation that our kid got sick. We didn’t let anyone know.”
- “Vietnamese people are really reluctant to mention or talk about the term ‘tâm thần’ (means *mental* in English), because that means crazy. And being a crazy person is a stigma in our culture.... So, ‘tâm trí’ (means *mind* in English) is better.”



Hope for Recovery and Independence



Source: www.hope4-recovery.org

- “At first, it was pretty serious, but now, I feel that she has recovered to about 90%.”
- “When we see them have some sort of improvement, or seem a little happier, then we see some light again. Then it feels all worth it.”
- “I think another aspect is needing them to be independent..”
- “I always think one day, if I die, what’s going to happen? So, you have to help him be independent.”
- “We always wish for them to go to work, to be independent and be able to take care of themselves... You must help him be independent, and he is slowly improving.”





<https://media.spokesman.com/photos/2023/03/31/63f01898b7139.image.jpg>

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Chinese Participants: Family obligation, Shame, lack of understanding about SMI, and (over-)protection

- “In American culture, it seems easier to talk about it [SMI], but in Chinese culture, it is not as open, not even to your close family members.”
- “Chinese people still don’t have enough knowledge about mental illness...when a problem arises in the family, they may not go get it checked out early.”
- “Our (non-Asian) counselor told me that my son, who is already in his early 30’s... he [the counselor] said that I shouldn’t allow him to live at home But if we kick him out, then where is he going to go? If I cannot support him, what is he going to do?”





Source:
<https://voiceofoc.org/tag/vietnamese-american-federation-of-southern-california/>

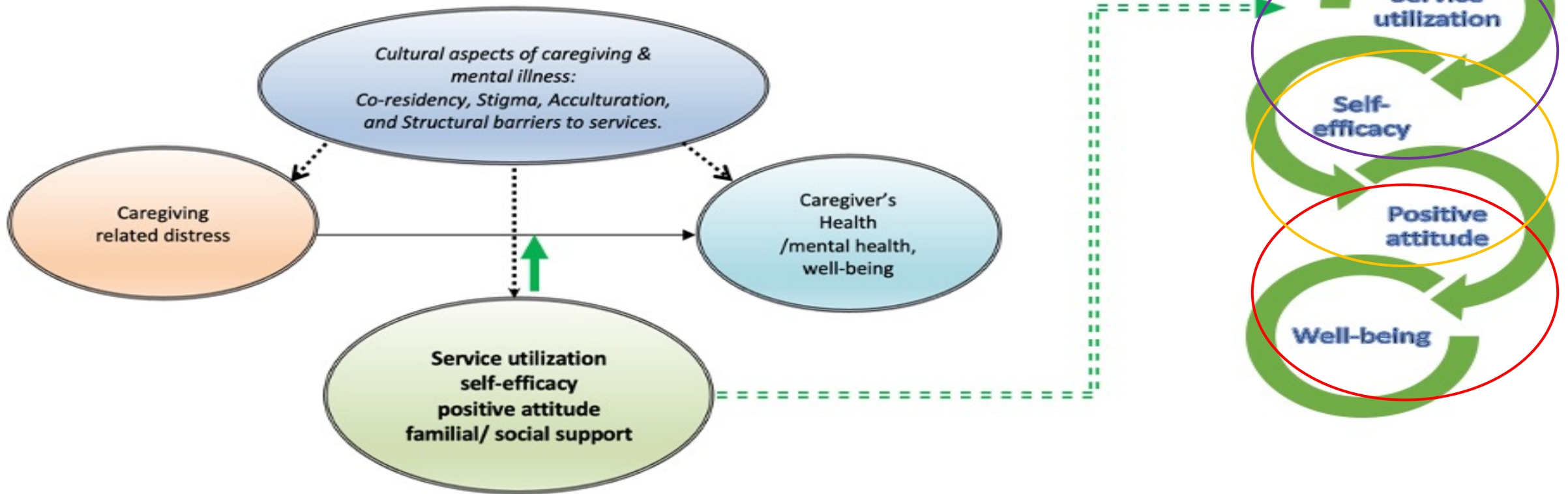
Vietnamese Participants: Family obligation, Roles of religion (Buddhism or Christianity/Catholicism)

- “Based on Buddhism, it’s Karma. A person did some bad things in one incarnation/past life; thus he has to suffer in his current incarnation.”
- “We keep praying, then God gave us a special method.”
- “He got sick by nature, so it’s our responsibility to take care of him.”
- “The major reason was due to genetics, but sometimes it was also caused by a family problem. It’s caused by the way the surrounding people behave and treat you.”



Key Survey Results: Importance of Positive Attitude, Self-Efficacy, Service Utilization on Well-being among AA Family Caregivers of People with SMI

Sociocultural Stress and Coping Model (Knight & Sayegh, 2010)



A photograph of a green chalkboard mounted on a wooden wall. The chalkboard has white text written on it in a casual, slightly slanted font. The text reads: "So ... What have we learned so far ???".

*So ...
What have we
learned so far ???*

<https://simplydukebasketball.wordpress.com/2015/11/25/757/>

III. DISCUSSIONS

- ❖ What We Have Learned
 - ❖ Things To Consider



What We Have Learned: From Our Study

- AA family caregivers experience considerable caregiving-related stresses.
- The culture of each group plays a vital role in influencing how caregiving impacts the family caregiver's well-being.
- Protective factors like positive attitude, self-efficacy and service utilization can promote AA family caregivers well-being.
- By recognizing that family caregivers are at risk for developing mental health issues themselves (e.g., anxiety, depression, emotional overload, and PTSD), yet service utilization can mitigate the adverse effects, mental health professionals must proactively provide services/resources to family caregivers within the cultural contexts.
- Stigma was found to be significantly present and detrimental: There is an ongoing dire need to de-stigmatize SMI on a societal level through advocacy and education.

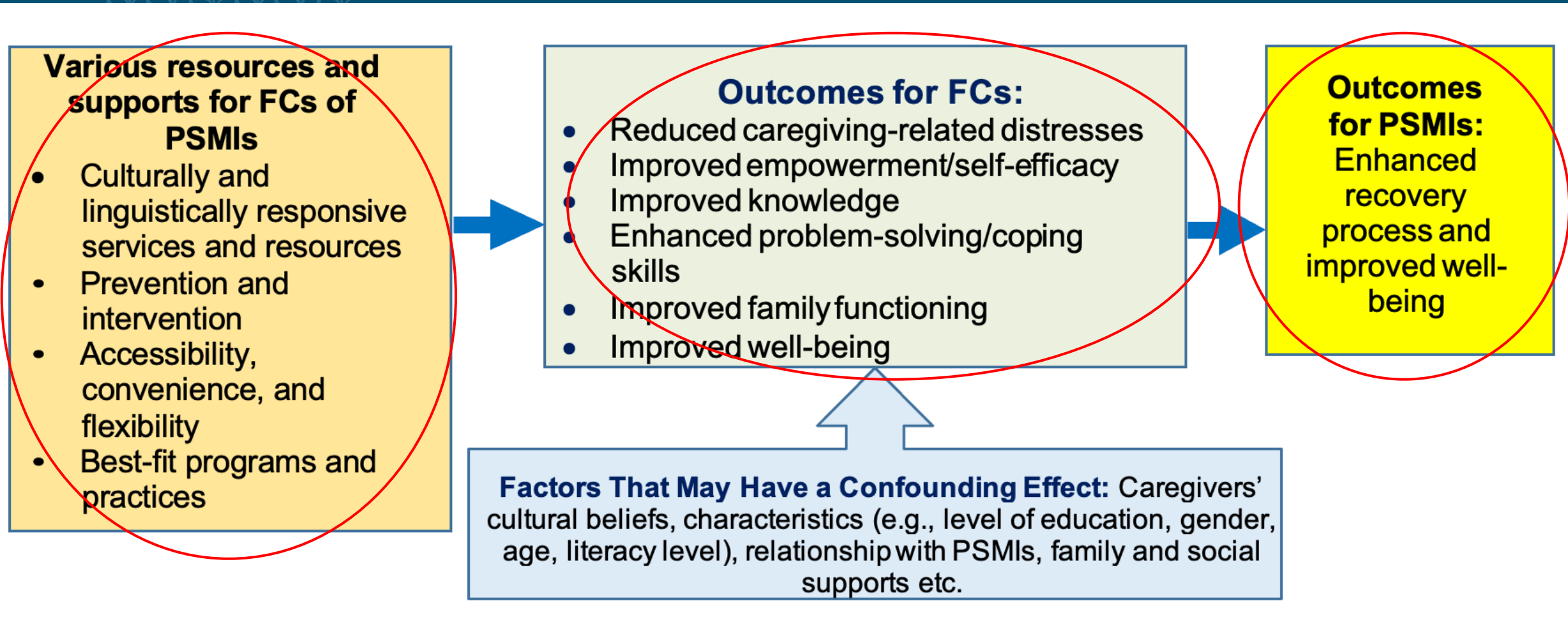


What We Have Learned: Promising Resources/Services

- Given the limited resources and knowledge, increasing research efforts and funding for behavioral health providers and agencies is essential.
- AA Family caregivers need resources and services.
 - *For their family members with SMIs* (e.g., reliable background information on the illness and its treatment); for the family (e.g., family therapy or family counseling); and for themselves (e.g., a psychoeducation program, individual counseling services, and peer support groups).
- Positive connections between service utilization and well-being (Dixon et al., 2001, 2016; Gharavi et al., 2018; Jansen et al., 2017; Lucksted et al., 2008; Moghbel et al., 2019; Peng et al., 2022; Smith et al., 2014; Toohey et al., 2016).
 - Psychoeducational and supportive services assist the caregivers of people with SMIs in coping with caregiving challenges and promote self-efficacy and empowerment of family caregivers.
 - Family therapy, including conflict resolution skills, has also proven helpful.
 - Various intervention modalities to enhance positive cognition, such as cognitive therapy, cognitive behavioral therapy, mindfulness-based cognitive therapy, and acceptance and commitment therapy, are also promising for caregivers.



Proposed Schema for the Expected Effects of Supporting Family Caregivers: “Healthy Family Caregivers, Healthy Family, and Better Recovery”



Things to Consider

- **Trajectories of Caregiving Challenges and Coping Practices among AA Caregivers**
 - Examining the caregiving trajectory and the key stress points over time is essential to understanding the impact of various critical events/stressors on caregivers' coping abilities, support, and use of resources within and outside the ethnic community.
 - This could yield valuable information on the types of support that may be most effective at various points in the caregiving trajectory.
- **Considering Similarities and Diversity within the AA Communities**
 - Each sub-ethnic group has a distinct culture, tradition, religious beliefs, and language.
 - AAs experience considerable differences in healthcare, education, and socioeconomic status within sub-ethnic groups.
 - Each AA subgroup has a uniqueness that impacts their caregiving attitudes, experiences, and coping practices.
 - Avoid grouping them and give equal attention to each subgroup as distinct entities.



- Use of eHealth (i.e., health and mental health care delivered through the Internet) & mHealth (i.e., health or mental health care through mobile phone networks) Services and Resources



<https://www.healthitoutcomes.com/doc/the-rise-of-mhealth-0001>

- *From our study: Specific obstacles regarding in-person services include time constraints, lack of transportation, child care, employment obligations, and reluctance to disclose their situation to others.*
- During the pandemic, most of these formal support resources have been offered through eHealth (Garfan et al., 2021; Inse et al., 2015; Haddock et al., 2014).
 - Internet-based telehealth is becoming vital for providing easy-to-access mental health care and promoting help-seeking behavior.
- Mobile health can provide unique advantages to caregivers by providing helpful tools when users face in vivo stressors (Garfan et al., 2021; Lecomte et al., 2020; Sin et al., 2019).
- Recent studies established the effectiveness of eHealth and mHealth interventions for people with informal/non-professional caregivers in general (Ferré-Grau et al., 2021; Sala-González et al., 2021).
- Such autonomy, anonymity, flexibility, and self-paced design can help AA family caregivers engage in content to promote well-being.



WHAT WE OFFER

We are your source for empowerment, education, and support for individuals seeking behavioral healthcare, including mental health and substance use resources.



IV. AVAILABLE RESOURCES

- ❖ Selected Resources Through SAMHSA's Website
- ❖ *'Ohana CoE: Upcoming Resources and Training*



Family Matters!

“Equipping Behavioral Health Systems & Authorities To Promote Family Recovery From Mental Health Conditions & Addiction”
(SAMHSA, 2012)

Selected Resources Available Through SAMHSA

➤ SAMHSA Family Support Guide

https://www.samhsa.gov/sites/default/files/samhsa_families_family_support_guide_final508.pdf

➤ Honoring Family Caregivers:

<https://www.samhsa.gov/blog/honoring-family-caregivers>

➤ Parent and Caregiver Resources:

<https://www.samhsa.gov/families/parent-caregiver-resources>

➤ Taking Care of You: Self-care for Family Caregivers:

<https://www.samhsa.gov/resource/dbhis/taking-care-you-self-care-family-caregivers>



Example: California's Behavioral Health Support for Families

Website: <https://www.dhcs.ca.gov/Pages/Treatment-Resources.aspx>

Find Local Treatment Options

1. [Shatterproof Treatment Atlas](#): Evidence-based addiction treatment providers, based on location and specific treatment needs.
2. [Choose Change California](#): Information about opioids and treatment options, searchable by location.
3. [Find a Treatment location by ZIP code](#)
4. [SAMHSA Treatment Locator](#)
5. [Injectable Naltrexzone](#)
6. [Google Recovery Resources locator](#)
7. [SAMHSA Buprenorphine Treatment Practitioner Locator](#)
8. [DHCS NTP Directory](#)
9. [SUD Recovery Treatment Facilities](#)
10. [Interactive NTP Locator Map](#)
11. [SUD Non-Emergency Treatment Referral Line](#)
12. [Substance Use Disorder County Access Lines](#)

- ✓ Not always focus specifically on family caregivers of individuals with SMI's.
- ✓ Sometimes may not be quite culturally responsive.
- ✓ Finding federal, state, and local resources can still be difficult for some family caregivers.



‘Ohana CoE Workshops, Training, Resources & Technical Assistance

- “The AANHPI ‘Ohana Center of Excellence is your source for empowerment, education, and support for individuals seeking behavioral healthcare, including mental health and substance use resources. We center (w)holistic and cultural approaches to serving the needs of the Asian American, Native Hawaiian, and Pacific Islander communities.”
- Serve as the central location for the Asian American (AA) Native Hawaiian (NH) Pacific Islander (PI) behavioral health community. This includes resources for behavioral health, such as research-informed online seminars (both live and archived), community tool kits, and links to behavioral health resources.
- **Please join us & subscribe to our email list: <https://aanhpi-ohana.org/>**



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Caregiving Experience Among Asian American Families of Individuals With Serious Mental Illnesses



**Thank You!!
&
Any
Questions??**

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