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### Publication Date

2021-04-01

### DOI

10.1016/j.apnr.2021.151395

Peer reviewed



## Experiences and needs of family support for HIV-infected Asian Americans: A qualitative dyadic analysis

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### ARTICLE INFO

#### Keywords:

Asian American  
HIV  
Family support  
Dyadic analysis  
Qualitative study

### ABSTRACT

**Background:** When coping with HIV-related challenges, family support is the first line that Asian Americans living with HIV (AALHIV) lean on; however, few studies have explored the dyadic aspects of family support among AALHIV. We aimed to explore the dyadic aspects of family support among AALHIV and their family caregivers. **Methods:** From September 2017 to January 2020, we recruited 18 dyads among AALHIV and their caregivers in Los Angeles and New York City by the purposive sampling method. Using qualitative dyadic analysis of semi-structured, in-depth interviews, we explored dyadic aspects of family support among participants based on Fitch's Supportive Care Framework.

**Results:** We found that AALHIV obtained support from family caregivers to cover the domains of their physical, psychological, spiritual, informational, social, and practical supportive care. This dyadic analysis indicated congruence in most supportive care; however, there were also dissimilar in the support perceptions.

**Conclusions:** Our findings exemplify the physical, psychological, spiritual, informational, social, and practical support from AALHIV and their family caregivers. When developing a culturally sensitive intervention for AALHIV, we need to consider the different aspects of the support. Especially, family support can enhance patients-providers' relationships as well as health engagement with HIV care.

## 1. Introduction

Asian Americans are one of the rapidly growing populations in the United States (Budiman et al., 2019). Issues related to the care of HIV-positive Asian Americans have been reported (Tang & Chen, 2018). Among different ethnic groups in the U.S., Asian Americans are the only ethnic group that is incurring a continuous increase in HIV infection, with increases from 4.9 per 100,000 people in 2011 to 5.5 per 100,000 people in 2016 (Kim & Aronowitz, 2019). With the advent of antiretroviral therapy (ART), HIV has become a chronic condition (Xu et al., 2017), and poses new challenges for people living with HIV (PLHIV), including HIV-related stigma, limited access to care, treatment engagement, ART adherence, symptoms and conditions related to HIV,

side effects from HIV and chronic diseases and quality of life (QOL) (Chen et al., 2018; Turan et al., 2017; Xu et al., 2018; Zhu et al., 2019). Furthermore, cultural factors can also affect HIV care for Asian Americans living with HIV (AALHIV), treatment and management, such as acculturation stress, serostatus disclosure, and continuation of family obligations (e.g., afraid of losing face and bringing shame to the family, the pressure to marry or carry out the family line) (Chen et al., 2014; Li et al., 2006; Tang & Chen, 2018).

When coping with the HIV-related challenges, family support is usually the first line to provide care (Kohli et al., 2012; Li et al., 2006), especially in collective cultures in which many Asian Americans are immersed (Chen et al., 2018). Although AALHIV encompasses diverse backgrounds and populations, such as Chinese, Filipino, Indian,

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<https://doi.org/10.1016/j.apnr.2021.151395>

Received 16 July 2020; Received in revised form 21 September 2020; Accepted 31 December 2020

Available online 7 January 2021

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Vietnamese, Korean, Japanese, many of them devote their lifestyles to the original cultural norms as their families make decisions and offer support, especially health-related issues (Kim & Aronowitz, 2019; Chen et al., 2014).

Relationship closeness and support provided within networks are important factors in different cultural backgrounds (Amiya et al., 2014). For example, peer support plays an essential role among HIV-positive men who have sex with men (MSM) in the United States (Bor et al., 2004), but HIV-infected MSM in China are rely more on their family members (Li et al., 2006). Also, the acculturation levels in immigrated Asian American populations was leveraged on AALHIV dependence on family support. Some of the AALHIV strongly adhere to their cultural heritage and rely on family support and some of them, who are independent for making decisions, fully embrace American culture (Tang & Chen, 2018).

In general, family support starts after the serostatus disclosure; the support includes a broad range of physical, psychological, spiritual, informational, such as sharing and providing up-to-date information about the disease and practical support, such as financial or medical assistance, or support in daily routines (Mohanan & Kamath, 2009; Poudel et al., 2015). Studies have shown that greater family support is associated with positive changes in physical and mental health, and decreases self-isolation (Amiya et al., 2014; Poudel et al., 2015; Shrestha et al., 2014), better access to HIV care (Liu et al., 2013), higher ART adherence (Poudel et al., 2015; Xu et al., 2018), reduced risk behaviors (Li et al., 2006; Tan et al., 2018), and enhanced quality of life (Xu et al., 2018) among PLHIV. Additionally, family support also assists PLHIV to develop a sense of responsibility as well as self-efficacy; thus, PLHIV can regain hope for their future and develop a positive attitude toward life after HIV diagnosis (Li et al., 2006).

Interestingly, some studies that focused on family support declared that there is no benefit or a negative association between family support and well-being of PLHIV (Poudel et al., 2015; Ushie & Jegede, 2012). For example, one study found that where families provided only instrumental support (e.g., the assistance of tangible material) without emotional support, the ART adherence decreased (Ciambrone, 2002). Also, negative family interactions with frequency in family-inflicted physical harm and emotional distress were associated with an increase in ART non-adherence (Poudel et al., 2015). Although caregivers might want to be as supportive as possible, their values with immorality and HIV stigma can contradict their intentions, which can impose undue stress on the PLHIV (Brown et al., 2010). These findings highlight the double-edged sword of family support, which can be positive or negative to PLHIV. Thus, to maximize the positive effects of family support, we need to better understand the experience of family support from PLHIV and their caregivers, as well as the possible discrepancies between them.

Currently, few studies are exploring the dyadic aspect of family support among AALHIV (Liu et al., 2013; Tan et al., 2018). Qualitative dyadic analyses can capture both sides of the views, especially the dyadic interaction among PLHIV and their family caregivers. Therefore, elucidating the dyadic aspects of family support experience and triangulating the results between the two parties are desperately needed (Liu et al., 2013; Tan et al., 2018).

In this qualitative study, we aimed to explore the dyadic aspects of family support among AALHIV and their family caregivers. Specifically, we would like to understand the following: (1) the perceptions of AALHIV regarding their experience of the family support they received, (2) from a caregiver's perspective, what kind of care did they provide to the HIV-positive family members? And (3) whether perceived family support obtained by the AALHIV was expected. These questions are particularly important in cultures where limited HIV-related resources are available (Lin et al., 2005). Then, a culturally specific intervention geared toward AALHIV and their family members can be developed.

## 2. Methods

### 2.1. Participants and settings

From September 2017 to January 2020, we recruited 18 dyads of AALHIV and their caregivers from the Chinese-American Planning Council, Inc. (CPC), the Asian/Pacific Islander Coalition on HIV/AIDS Community Health Center (APICHA Community Health Center), and the Asian Pacific American AIDS Intervention Team (APAIT) in two cities (Los Angeles and New York City). Inclusion criteria for study patients were as follows: (a) self-identified as Asian or Pacific Islanders, (b) confirmed HIV serostatus, (c) willing to participate in the interviews, and (d) at least 18 years old. Inclusion criteria for the caregivers were: (a) identified as the primary family caregivers by patients; (b) willing to participate in the interviews, and (c) at least 18 years old.

### 2.2. Data collection

The ethical review boards at the involved institutions approved the study. After securing the informed consent, bilingual researchers conducted in-depth interviews with HIV-positive Asian Americans and their family caregivers. All of the in-depth interviews were audio-recorded and conducted in English or Asian languages (Mandarin, Cantonese, or Japanese) according to the study participants' preference. Each interview took about 60–90 min and was conducted in private locations (a private conference room, the participant's house, or other locations of choice). Also, the in-depth interviews with AALHIV and their caregivers were conducted separately in two different private spaces or at different times when the AALHIV or the family caregivers were available. All study participants received small stipends in exchange for their participation. Specific questions for AALHIV included the following: "what support are you getting from family members?", "Which support is the most helpful?" For family caregivers, sample questions are "what support did you provide to the patients?", "What support did your family member need the most?"

### 2.3. Data analysis

Throughout this study, we followed the Standards for Reporting Qualitative Research guidelines (O'Brien et al., 2014). All the in-depth interviews were transcribed verbatim for data analysis. The transcriptions which were not in English were translated into English. First, two researchers independently analyzed the data in the individual and dyadic levels using an inductive approach based on the Fitch's Supportive Care Framework (Fig. 1). This theoretical model described the supportive care needs of patients with chronic disease including physical, psychological, spiritual, informational, social, and practical support needs (Fitch, 2008). Second, researchers compared and contrasted each individual's experience and needs of family support that of the caregivers by using the qualitative dyadic analysis approach (Eisikovits & Koren, 2010). This process discovers overlaps between individual narratives and identifies points of collaboration and contradiction between dyads, which form the "unit of analysis." Third, researchers cross-analyzed significant statements, sentences, and quotes, to formulate themes based on both AALHIV and caregivers' perspectives on their supportive care received/provided. Comparing dyad perspectives allowed triangulation to derive a fuller, more contextualized understanding of the nature of family support. In the end, all quotes and themes were summarized in an Excel document.

## 3. Results

The participants' ages ranged from 36 to 72 years, with the mean age of 56.81 years old ( $SD = 11.02$ ). Twelve were male (66.70%) and six were female (33.30%). Average years of living with HIV was 20.47 ( $SD = 5.30$ ). Regarding ethnicities, thirteen AALHIVs (71%) were Chinese,

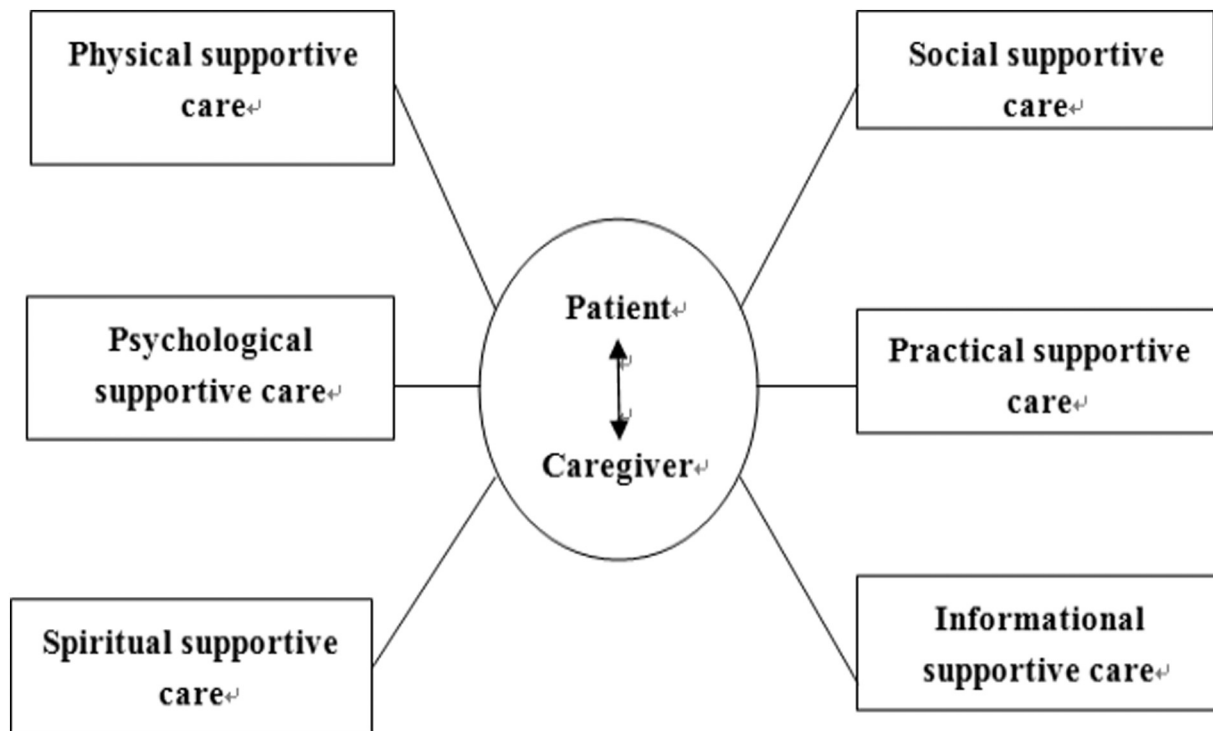


Fig. 1. Fitch's supportive care framework.

one AALHIV (6%) was Japanese, two AALHIVs (12%) were Malaysian, and other ethnicities, respectively. For caregivers, the ages ranged from 23 to 69 years, with an average age of 51.53 years old ( $SD = 14.56$ ). Within caregivers, four were male (22.20%) and fourteen were female (77.80%). The majority of family caregivers were spouse/partners ( $N = 14$ ), others were parents ( $N = 1$ ) and children ( $N = 3$ ). More than half (82%) caregivers were Chinese, one was Malaysian, Vietnamese and other ethnicity, respectively. Table 1 shows the details of sociodemographic characteristics of the participants and their caregivers.

As shown in Table 2, AALHIV obtained family support from their caregivers to cover the domains of physical, psychological, spiritual, informational, social, and practical supportive care. This dyadic analysis showed congruence in most supportive care; however, there were also dissimilarities in support perceptions.

Table 1  
Sociodemographic characteristics of participants ( $N = 18$ ).

Variables	AALHIV $N$ (%)	Family caregiver $N$ (%)
Gender		
Male	12 (67%)	14 (78%)
Ethnicity		
Chinese	13 (71%)	15 (82%)
Japanese	1 (6%)	
Malaysian	2 (12%)	1 (6%)
Vietnamese	–	1 (6%)
Other	2 (12%)	1 (6%)
Education		
11th grade or less	12 (67%)	9 (50%)
High school or GED	3 (17%)	6 (33%)
2 years of college/AA degree	3 (17%)	2 (11%)
Masters degree	–	1 (6%)
Currently working status		
No	4 (21%)	7 (40%)
Part time	10 (57%)	5 (27%)
Full time	4 (21%)	6 (33%)
Legal status		
Yes	12 (69%)	14 (77%)

AALHIV: Asian Americans living with HIV.

### 3.1. Physical support

Some AALHIV described that their caregivers support patients to manage physical symptom by providing daily care, caring for them during hospitalization, and taking herbal medicine. Congruent with AALHIV, caregivers expressed that they supported the family members through verbal persuasion and practical action. For example, caregivers remind AALHIV to practice good health (e.g., no smoking, healthy diet, rest) and encouraged them to see a doctor when they felt ill. However, many of the AALHIV did not follow the caregivers' suggestions. One 23-year-old wife of an AALHIV stated, "I keep telling him to see a doctor, but he refuses to do so. He ignored me and didn't go."

Besides, caregivers provided AALHIV daily and physical care.

My husband has joint pain, bone pain, and his eyes are not good because of his diabetes. The doctor suggested that we should warm a towel every morning to put on his joints. Every morning, I prepare the towel for him. Also, I prepare eye drops to moist his eyes five times a day.

(63-year-old, female, spouse)

### 3.2. Psychological support

We found 18 dyads of AALHIVs and caregivers reflecting these psychological support as follows: (1) Providing psychological support AALHIV during difficult times (e.g., assist in disclosure to other family members); (2) Assisting AALHIV to cope with psychological stresses and to reduce anxiety; (3) Comforting and encouraging the family member with HIV, and (4) expressing love. By providing this psychological support, caregivers also bore great psychological distress.

I told my parents that I had this disease, and then my parents said ah. What they thought was, don't worry about it. They told me that this disease does not need to worry. With the development of new medicine, it (HIV) will be controlled. People with this disease will

**Table 2**  
Dyadic aspects of family support among HIV-positive Asian Americans and their caregivers.

Domains	Definition	Congruence themes	Examples quotes
Physical support	Support for physical comfort and freedom from pain, optimum nutrition, ability to carry out one's activities of daily living	Care for AALHIV during hospitalization	"She doesn't like the hospital food, which are mashed potatoes, oatmeal, milk, and bread. I always bring something she likes for her, usually some snacks from hometown, such as cakes and noodles. During her 2 months of hospitalization, I went to the hospital every day to take care of her." (23-year, female, partner)
		Provide food	"I took him home, and provide get food. You know, to nourish him, so he can heal faster. Uh, uh. I also research of vegetables, fruit, juice can help him. When he began the treatment, the nutrition is more important." (58-year-old, female, partner)
		Persuade AALHIV to take care of health	"Because my dad has a lung cyst, I advised him not to smoke, take care of his health, and drink less Red Bull..." (30-year-old, male, son) "We took him to the hospital's emergency room. Three times. After that, I told him, "You better not to work because you are so sick now!" (58-year-old, female, partner)
		Provide physical care	"My husband has joint pain, bone pain, and his eyes are not good because of diabetes. The doctor suggested that we should warm a towel every morning for him for a few minutes, so that there would be liquid in his eyes and the eyes would become moist. So we do that every morning." (63-year-old, female, spouse)
		Use Chinese traditional medicine or materials	"When I make soup, I usually add some traditional herb materials, such as Angelica, lily, wolfberry, which are better for health. Especially when his hypertension is out of control, I will make soup for him. He

**Table 2 (continued)**

Domains	Definition	Congruence themes	Examples quotes
Psychological support	Support related to the ability to cope with the illness experience and its consequences, and a sense of comfort, belonging, understanding and reassurance in times of stress and upset	Provide psychological support during PLHIVs experience difficult times	would take two cans of soap to go to work." (62-year-old, female, spouse) "My parent saw my husband humiliate me for several times. Last time, when he hit me, my mom also has a heart attack. My mother, who immigrate to the U.S. for four years, and saw my situation. So she said to my husband, 'how could you do that? You need to talk about this to me!'" (38-year-old, female, AALHIV)
		Help AALHIVs coping with psychological problems and reducing stress	"What I really care about is that I hope my daughter can be less stressed. I will do anything to reduce her stress, and help take care of the grand kids." (61-year-old, female, mother) "I gave him all the support. he needs a lot of emotional support. Yea, he needs a lot of that, so. I was talking to him all the time and hug him. You know, to make him feel better. Just let him know that he is going to get better. Even that will take a long time maybe a few months to six months, or even eight months. So we deal with that situation until he gets better." (61-year-old, female, mother)
		Comfort, respect and encourage AALHIV	"Well, I didn't know what to do ay the first time, believe me. It was something new for me. I mean, you don't know how to approach somebody in this situation. The only thing I told him, 'Don't worry. You're young. You're, going to get over it. You're going to get better. Just do things right. Eat right. Exercise, go to the doctor. Um, and take care of yourself.' I was helping him like that." (58-yea-old, female, partner)
		Express love to AALHIV	"I want her to have the best of everything before I die. I want her to be able to walk

(continued on next page)

Table 2 (continued)

Domains	Definition	Congruence themes	Examples quotes
Social support	Support related to family relationships, community acceptance and involvement in relationships	Accompany AALHIV to attain kinds of social activities	out and have the job she wants. And do what she wants no matter who she is." (57-year, female, spouse) "The medicine would help me to control the illness. But the spouse's support is also important. She waiting for me in China for last 8 years. With her waiting for me, it provided the motivation and supports when I was down." (47-year-old, male, AALHIV)
			"We travel together, such as hang out at the beach, go out on bike ride. And we also shop and eat out together. Each year, we talk about where to go on the next trip..." (47-year, male, AALHIV) "In general, I often attend the gathering with his younger brother and sister. When I have free time, I call them, get together for tea. They all say, the family should get together often! In general, at least once or twice a week." (62-year-old, female, spouse)
		Keep relationship with each other	"I didn't want to make the situation worse, so I just said 'okay I'll be your friend, I'm not going nowhere, I'm still going to help you' 'I'll be here, I'm not going nowhere' That's how the friendship started. Then, we bonds a little better, then we separated. But the friendship was still there, that was the good part." (36-year-old, male, AALHIV)
			Visit or contact AALHIVs regularly "Because I lives in Florida, and I go back to see mom and dad once or two a month regularly to make sure they were OK." (30-year, male, son) "Because we can only see one day a week, we usually contact through instant message..." (26-year-old, female, AALHIV)
Spiritual support	Support related to the meaning and		"He went with me to the Buddhist temple.

Table 2 (continued)

Domains	Definition	Congruence themes	Examples quotes
Practical support	Support for direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person (e.g., homemaking services, financial assistance)	purpose in life to practice religious beliefs	Go to Buddha hall and church activities Pray for AALHIV Inside the Buddhist temple, we are all brothers and sisters. We all sit together and listen to lectures." (62-year-old female, spouse) "I often ask him, 'If I die, what are you going to do?' [Laughs] When I go to sleep, I just pray to God. 'God help me up? Keep me strong, keep me healthy, so I can help him.' I need to help and my dogs. We have two dogs." (58-year-old, female, spouse)
		Childcare	"She is my only child, and I need to help her to take care of the kids. I'm responsible for pick up the kids, their food, and tutor some simple homework..." (61-year-old, female, mother) "In this family, I do everything inside the house, such as buying grocery, cooking, laundry, etc. In general, I send the child to school at 7:30, I came back to cook for her, but also do her dishes! Then, she carried the lunchbox on the backpacks. After She went to work, I would clean up, mop the floor, do the laundry. I do laundry two or three times a day. In the evening we did the laundry only for the baby. She came home late and I did her laundry the next day. It is harder than I was young." (61-year-old, female, mother)
		Daily chores	"When he didn't have the strength to walk, and I will send him to the hospital and ask for examination and possible treatments..." (23-year-old, female, partner) "I used to accompany my father to go to the hospital and be a translator for my father." (30-year, male, son)
		Access to healthcare service	"If we g travel, I often prepare the medicine. I afraid that if he
		Provide translation support	
		Medical care	

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Table 2 (continued)

Domains	Definition	Congruence themes	Examples quotes
Informational support	Support for information to reduce confusion, anxiety and fear, to inform the person's or family's decision-making; and to assist in skill acquisition.	Financial support	didn't take medicine on time, his condition would get worse." (60-year-old, female, spouse) "My sister and I usually give my father pocket money and living expenses every year..." (30-year, male, son)
		Help PLHIVs to communicate with children.	"The relationship between the son and his father was interesting. He communicated less with our sons, but he concerns the sons' situation. Thus, sometimes, he would asked me to call our sons, and let me communicate with them, for example to rush them to get married..." (62-year-old, female, spouse)
		Get the information of AALHIVs' health status	"When I aware my dad's condition, I started searching and getting more HIV information...After my father saw the doctor, I also double check with the doctor with the information." (30-year-old, male, son)
		Provide family members information on how to make them more healthy	"So take care of yourself.' I told him you. Especially when he eats a lot of spicy food, I'll say, 'You can't eat that because your stomach is acting out!' He got a lot of stomachache. So I told him to take care of himself." (58-year-old, female, spouse)

AALHV: Asian Americans living with HIV.

live for a long time. After my parents comfort me, the rock in my mind was falling.

(38-year-old, female, PLHIV)

Comparing to her mother, this 61-year-old caregiver shared,

When she told me that she had HIV, my mind went blank, and I had a panic. Just felt like that she has cancer and will die soon!

(61-year-old, female, mother)

However, some dyads share their experiences of intimate partner violence between the AALHIV and their spouses. One 42-year-old female living with HIV described after her spouse knew her serostatus, he constantly yelled, beat and humiliated her and also disclosed her status to all of their social networks. She said, "even in front of my own parents, he just grabbed me and hit me into the wall. I ended up in the emergency room with concussion".

Similarly, one 72-year-old female caregiver also shared "After my

husband knows that he has HIV, he is always in bad mood. Many times, he threatened me that he will jump out of the window as we were living on the 5th floor! Also, when he doesn't like the food that I cooked, he just threw those dishes on the floor!"

### 3.3. Spiritual support

A few of the interviewed AALHIV had religious beliefs such as Christian or Buddhism and went to church for their spiritual needs. Usually, caregivers accompanied AALHIV to the temple to worship Buddha or to Sunday fellowships for a church gathering. Most of the caregivers' praying was focusing on curing HIV and the health of the AALHIV. Most likely, caregivers understand the disease better and can provide support to the AALHIV.

Uh, even when I go to sleep, I pray to God. Just asked, "God help me up? Keep me strong, keep me healthy, so I can help. I can, I can, I can keep helping him, and take care of my dogs."

(57-year-old old, male, MSM caregiver)

### 3.4. Social support

These dyads were actively involved in different social activities to enhance family and social relationships. The dyad activities included meal gatherings with family members, grocery shopping and family traveling, keeping the relationship with other friends and families is important for both AALHIV and caregivers. Some example quotes are presented in Table 2.

### 3.5. Practical support

Most couples expressed congruent perceptions in practical support, including childcare, daily chores such as cooking, shopping, cleaning, washing, access to healthcare service, providing translation support, medical care, and financial support. Detailed quotes are shown in Table 2.

### 3.6. Informational support

Some caregivers described that they helped AALHIV communicate with children, doctors, and case managers. The caregiver also provided AALHIV information on how to take care of the HIV-related symptoms such as, by persuading AALHIV to take rest while fatigued, reduce work, eat a healthy diet, and take care of themselves. Besides, to provide better family support, caregivers also learned more about the disease. However, in the dyadic analysis, we found some dissimilar perceptions regarding dietary restrictions. For example, one AALHIV demanded to use his own set of eating utensils and to eat from separate dishes, while caregivers thought it unnecessary.

I got updated knowledge about HIV, thus, I often tell my dad that he doesn't need to separate dishes, just share with us. But he insisted and worried that he will transmit the virus to us.

(30-year-old, male, son)

## 4. Discussion

In this study, we presented a series of the dyad analyses for AALHIV and their caregivers by their support needs in physical, psychological, spiritual, informational, social, and practical support. AALHIV participants and their family members shared their experiences of the support received/provided; however, some discrepancies were also reported as presented in our analysis (Table 3).

The study has shown that positive psychological family support has a



**Table 3**  
Similarities and dissimilarities in family support perceptions between HAALHIV and their caregivers.

Domains	Incongruence themes	Examples quotes from AALHIVs	Examples quotes from caregivers
Physical support	Caregivers encourage AALHIV to see the doctors, but AALHIV didn't follow	"I feel like American doctors are putting me off. They don't care what you tell them, they just tell me to do. Then the report came out, and I was asked to make an appointment to see the report. Can the doctor just tell me my result then? I don't want to see a doctor right now. Doesn't help and waste money." (30-year, female, AALHIV)	"I keep telling him to see a doctor, but he refuses to do so. He ignored me and didn't go." (23-year-old, female, partner)
	Whether use Chinese traditional medicine or not	"When I was pregnant, my mother told me to use the herb medicine to protect the fetus. However, my infectious doctor told me that the drug I used now should not be taken with other alternative medicine." (38-year, female, AALHIV)	"When she was pregnant, I told her that you can use traditional Chinese medicine to protect your fetus...." (61-year-old, female, mother)
	Caregivers persuade AALHIV to take care of health, but AALHIV didn't follow	"I smoke whenever I want. I often smoke when there is nothing to do." (60-year, male, AALHIV)	"My dad had a lung cyst before, luckily, it was benign. His blood sugar was also high. We were always concerned about his health and tell him not to drink Red Bull. He likes to drink red Bull all the time. We tried to persuade him not to smoke, but he wouldn't listen." (30-year-old, male, son)
Psychological support	When providing psychological supports, caregivers also bear great psychological distress.	"I told my parents that I had this disease, and then my parents said ah. What they thought was, don't worry about it. They told me that this disease does not need to worry. With the development of new medicine, it (HIV) will be controlled. People with this disease will live for a long time. After my parents comfort me, the rock in my mind was falling."	"When she told me that she has HIV, my mind went blank, and I had a panic. Just felt like that she has cancer and will die soon!" (61-year-old, female, mother)

**Table 3 (continued)**

Domains	Incongruence themes	Examples quotes from AALHIVs	Examples quotes from caregivers
Informational support	Caregivers express love to AALHIV in their way, but AALHIV feel it as a burden.	(38 years, female, AALHIV) "Previous she did not touch my mobile phone, now always look at my mobile phone. She was afraid that I was seeing someone. She looks at me very closely, wants to know my whole life, and she wants to know all my friends. She wants to know everything now, I feel so annoyed." (26-year, male, AALHIV)	"After 2-month, we decide to live together. I like him. It would be convenient to live together so I can take care of him. It's a relief to see him every day." (23-year-old, female, partner)
	Dissimilar perceptions regarding the dietary restrictions.	"I was worried. It would be safer to eat separately..." (60-year, male, AALHIV)	"I got updated knowledge about HIV, thus, I often tell my dad that he doesn't need to eat separately, just share with us. But he insisted and worried that he will give the virus to us." (30-year-old, male, son).

AALHV: Asian Americans living with HIV.

protective effect for PLHIV. However, negative family interactions presented with bidirectional effects toward positive and negative coping (Amiya et al., 2014). Our in-depth interviews also displayed similar reports as many AALHIV obtained physical and psychological support from family members. However, some AALHIV participants hesitated to disclose their status for a while until it could no longer be hidden, e.g., hospitalized or accidental exposure. Especially for caregivers who were the child of an HIV-infected participant, the role as the caregiver is not only providing physical and psychological support, but also served as the translator and liaison (informational support) between the family and the healthcare facilities. The study suggested, however, that children should not be used as translators since many complicated and sensitive issues can be discussed in the office visits (Clough et al., 2013; Cohen et al., 1999).

Many dyads shared their psychological support from each other. To some extent, psychological support became a burden for each other. For one dyad, the HIV-infected man needed his girlfriend constantly for care when he was new to access the healthcare system. After he used the system and made online friends to get more information, he no longer needed his girlfriend's support. He said, "She is so annoying and asked me every single detail of my life!" Then, the frustration from the caregivers was also shared with the researcher. She described that "I did so much for him, now he is only playing his cell phone and doesn't want to talk to me." This is echoed with other studies focusing on HIV-infected caregivers (Pirraglia et al., 2005). Depression and caregiver burdens are highly associated (Pirraglia et al., 2005). Due to this study design, we did not quantitatively measure the caregiver burden, therefore, we do not know whether the caregiver burden was higher compared to the general population. However, many caregivers in this study shared that religion was very important for them. As one caregiver stated, she needed to go to the temple at least once a week for a whole afternoon. That was the only chance that she could be on herself to talk and



socialize with others besides her HIV-infected spouse.

Also, several dyads mentioned that they experienced intimate partner violence before and after HIV diagnosis. One caregiver described that she was so frightened because her HIV-infected spouse was threatening that he was going to kill himself, and several times that she saw him hanging on the window of their 5th-floor apartment window. While asking for help from her children, she got pushed several times. Other participants also shared their experiences of violence. One female HIV-infected participant shared that after she was diagnosed with HIV, her husband physically and sexually abused her, even in front of her caregiver (mother). In this discordant couple, she became the victim of an unfaithful marriage. Due to the language barrier, participants were so afraid to call the police and could only hide while the spouse was at home. Her caregiver also shared that as the mother of a woman living with HIV, she was not only taking care of her grandchildren, but also needed to prevent her daughter from getting hurt by the son-in-law. She shared that she could have a good retired life in her hometown, but because of the responsibility as a mother, she needed to take care of her daughter no matter how old she is.

Studies have shown that HIV-infected women in discordant couples experienced higher (86%) intimate partner violence (IPV) (Mashaphu et al., 2018). In addition, Asian women in the United States who were in an abusive relationship experience higher rates of mental health problems, HIV risk behavior, and substance use (Hahm et al., 2017). However, limited research has focused on the IPV situation in Asian American populations, especially in HIV-infected populations (Hahm et al., 2017; Pengpid & Peltzer, 2013). In the present study, many female HIV-infected individuals and female caregivers all shared different degrees of violent experiences. IPV is associated with health inequalities as well as minorities and immigrants (Stockman et al., 2015). Future studies should explore more on the experiences of HIV-infected Asian Americans and how their coping strategies can shed light on how to provide a culturally sensitive intervention to prevent and escape from IPV situations.

#### 4.1. Limitations

There are several limitations to this project. First, we recruited study participants from two metropolitan areas in the United States. The resources and networks might be different from other U.S. locations. Therefore, the study results might not be generalizable to other U.S. regions. Second, the sample size was small because HIV is a highly stigmatized topic. Many of the study participants did not disclose their HIV status to anyone yet; therefore, inviting their family caregivers to join the study was challenging. However, since this is one of the first projects focusing on HIV-infected Asian Americans and their family caregivers, this dyad analysis will move the science forward to shed light on the real conditions in HIV-infected Asian American's lives. Third, in this project, first and second generations of AALHIV participated in this project. The first and second generation of AALHIV might have different perspectives and needs of support from family members. For example, first-generation AALHIV might need more informational support because much of the health information is in English and they need more assistance to understand the content of the disease prognosis and management. Second-generation AALHIV might need more psychological support because letting a family members accept an ill child again is the most important task for them. Therefore, the next research study should recruit more participants in different generations to enrich the information of AALHIV.

#### 5. Conclusion

In this project, we tried to understand the support from AALHIV and their family caregivers in different aspects of physical, psychological, spiritual, informational, social, and practical support. To appropriately respond to the healthcare needs of AALHIV, it is necessary to consider

this support in different aspects and barriers (e.g., IPV, language barriers, caregiver burdens) to patients–providers relationships and help-seeking behaviors related to HIV care—all of which will influence health outcomes and quality of life.

#### CRedit authorship contribution statement

WTC conceptualized the study. WTC and CSS conducted the in-depth dyadic interviews. FFH and WXS transcript and analyzed the in-depth interviews. JC, BVL, and JAY oversaw implementation of the study and data collection. FFH and WTC prepared the draft manuscript and managed subsequent revisions. All authors have read and approved the final manuscript.

#### Funding

This publication resulted (in part) from research supported by NINR under Award Numbers [K23NR14107], NIMHD [R03MD012210] and NIMH [P30MH058107] & [R25MH087217]. The contents of this article are solely the views of the authors and do not represent the official views of the National Institutes of Health.

#### Declaration of competing interest

The authors declare no conflicts of interest.

#### Acknowledgements

We gratefully acknowledge all the study participants, without them, it is not possible to complete these projects.

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