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Familial support in integrated treatment with antiretroviral therapy and medications for opioid use disorder in Vietnam: a qualitative study

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Abstract

Background: Patients report that familial support can facilitate initiation and maintenance of antiretroviral therapy (ART) and medications for opioid use disorder (MOUD). However, providing such support can create pressure and additional burdens for families of people with opioid use disorder (OUD) and HIV. We examined perspectives of people with HIV receiving treatment for OUD in Vietnam and their family members.

Methods: Between 2015 and 2018, we conducted face-to-face qualitative interviews with 44 patients and 30 of their family members in Hanoi, Vietnam. Participants were people living with HIV and OUD enrolled in the BRAVO study comparing HIV clinic-based buprenorphine with referral to methadone treatment at 4 HIV clinics and their immediate family members (spouses or parents). Interviews were professionally transcribed, coded in Vietnamese, and analyzed using a semantic, inductive approach to qualitative thematic analysis.

Results: Family members of people with OUD and HIV in Vietnam reported financially and emotionally supporting MOUD initiation and maintenance as well as actively participating in treatment. Family members described the burdens of supporting patients during opioid use, including financial costs and secondary stigma.

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Author contributions: PB performed the final thematic analysis and wrote the initial draft of the analysis. DT designed the qualitative data collection. NH and PM performed the qualitative interviews. DT, AE, NH, PM, and KH performed the initial qualitative analysis, consisting of data coding and synthesis in code summaries. TK, GB, and LG designed and oversaw the BRAVO trial, including the qualitative data collection. All authors edited the manuscript critically for content and agreed with the final manuscript.

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Conclusions: Describing the role of family support in the lives of people living with OUD and HIV in the context of Vietnam enriches our understanding of their experiences and will support future treatment efforts targeting the family unit.

Keywords

Vietnam; HIV; Opioid Use Disorder; Qualitative

Introduction

Heroin injection drug use is an important source of new HIV infection and a barrier to timely diagnosis and effective treatment among people with HIV.[1–5] In Vietnam, HIV infection is more prevalent among people who inject drugs (PWID) than any other at-risk group, which represents an opportunity for healthcare integration.[6,7]

Integration of methadone maintenance therapy (MMT) with HIV care is preferred by patients receiving methadone in Vietnam.[8] Patients attending integrated clinics express greater satisfaction than those receiving HIV care and medications for opioid use disorder (MOUD) separately.[9]

Family dynamics are critical to the success of anti-retroviral therapy (ART) and MOUD. PWID in Vietnam report receiving multiple types of support from their families, but conflicting with them around drug use.[8] Family conflict and lack of family support are associated with continued heroin use among MOUD patients in Vietnam, while hope for improved family relationships motivates MOUD retention.[9–13] Family members also support ART adherence through reminders; lack of family support predicts ART non-adherence.[14,15] Family is so tightly connected to HIV care in Vietnam that some ART clinics require a family member to be present when care is established.[16]

Families encourage PWID with HIV in Vietnam to engage with services, assist with treatment costs, and mitigate stigma.[11,17,18] However, extension of stigma to family members can cause harms and compromise support.[19,20] Family members of PWID report increased care burden, financial conflict, existential threats to the family, and decreased quality of life.[21–24] MOUD may positively affect family relationships, reduce stigma, and increase treatment success.[25,26]

Because family members promote treatment success for PWID with HIV in Vietnam, therapeutic approaches may benefit patients by involving supportive family members. This is especially true in Vietnam, which is transitioning from an isolating, detention-based model of addiction treatment to a community-based model.[27] Most data on family support in addiction comes from PWID; qualitative studies of family members are scarce, and focus on harms and coping in the setting of untreated addiction rather than mechanisms of support. Exploring these mechanisms of support and opposing barriers through triangulation with family members is important to inform interventions that include the family in treatment of PWID with HIV. The current study uses interviews with Vietnamese PWID with HIV and supportive family members to describe family members' roles in aiding patients and challenges faced in doing so before and during integrated HIV/MOUD treatment.

Methods

Setting

Qualitative data were collected as part of the "Buprenorphine to Improve HIV Care Engagement and Outcomes" (BRAVO - NCT01936857) study, a multisite, open-label, randomized, flexible-dose trial of buprenorphine/naloxone prescribed in HIV clinics versus referral to MMT in Vietnam.[28–30] BRAVO was a collaboration between Hanoi Medical University (HMU), the Provincial AIDS Control authorities of Hanoi, Thanh Hoa, and Bac Giang, the Vietnam National Institute of Mental Health, and Oregon Health & Science University. All procedures were approved by Institutional Review Boards at Oregon Health & Science University and Hanoi Medical University.

Respondent Selection

Semi-structured interviews were conducted with a subset of BRAVO participants receiving care at four outpatient HIV clinics in Hanoi and their family members. Research staff purposively sampled participants to ensure a sample balanced across sites and treatment arms, with diverse marriage and employment status, and family structure. Recruitment occurred during clinic visits within one month of study enrollment. Participants were asked to identify the family member most supportive to them in MOUD treatment. Not all participants had a paired family member; they either did not identify a supportive family member, the family member declined participation, or the family member's health status prevented their participation. All participants and their family members were consented for interviews.

Interviewers

Interviews were conducted by two full-time researchers with prior training and experience with qualitative interviewing and Masters-level qualifications.

Interviews

Between 12/30/2015 and 04/27/2018, 74 private, in-person interviews were conducted in Vietnamese using a semi-structured interview guide (44 patients, 30 family members). The family interview guide focused on engagement with the participant and their care, support provided, and burdens experienced; the participant interview guide included some questions about family support, but also covered a wide range of topics, such as stigma and medical care. Interview duration was between 30 and 60 minutes.

Participant and supportive family member interviews addressed the impact of patient drug use on family members, and family support during use and treatment. Respondents received 200,000₫ for each interview. Following each interview, respondents had an opportunity to explain or add to earlier statements.

Analysis

Digital interview recordings were professionally transcribed in Vietnamese. Qualitative thematic analysis identified themes relating to family burden and family support. Three researchers created a preliminary code list, grouped into themes, after reviewing interview

transcripts. Though researchers were likely implicitly influenced by knowledge of pre-existing literature, a semantic, inductive approach was used. An inter-coder agreement check was performed between two coders using Atlas.ti 7.1 Software (ATLAS.ti Scientific Software Development GmbH, Berlin), with differences resolved by a third coder. An intercoder reliability rate of 85% was calculated for 10% of transcripts. Code summaries underwent team review.

Selected quotations related to family burden and family support were translated into English. Major themes and minor themes on these topics were summarized, as were counterexamples to major themes.

Results

Respondent characteristics

Participants enrolled in this qualitative study (n=44) were 95% male, 36% married and 41% employed. All invited participants agreed to be interviewed. 52.3% of interviewed participants received buprenorphine/naloxone and 47.7% received methadone. 63.3% of interviewed family members were related to participants receiving buprenorphine/naloxone and 36.7% were related to participants receiving methadone. Family members (n=30) were 77% female and included parents (47%) and spouses (50%). (Table 1)

Thematic analysis

Three themes emerged around the role of family in the lives of patients: 1) Family members were engaged participants in the treatment process, 2) Families incurred financial and time costs providing patients with practical support, and 3) Family members lost social status due to secondary stigma.

Family members were engaged participants in the treatment process

Family members were the primary source of emotional support and highly involved in MOUD treatment. They encouraged participants to start MOUD, emphasizing its benefit for the participant and their family, and supported them in their treatment by learning about and reinforcing the treatment process. This was seen as essential to treatment success by both participants and their family members.

Suggesting MOUD

Family members were sometimes the first to learn about MOUD and introduced the idea to participants. One wife described helping her husband initiate treatment.

> "*He told me that they had Methadone treatment for free here and he asked me if he should register for the treatment…It would not take too much time, so I encouraged him to try his best with his treatment.*" (Spouse)

Family members were major drivers of treatment initiation, gathering information and addressing administrative hurdles so participants could receive treatment.

"*I knew [about MOUD treatment] first from [the doctor], then I brought my son up here for him to meet the doctor. After that visit, [he] helped with my son's administrative procedures for the addiction treatment.*" (Parent)

Family monitoring of patients

Family members discussed keeping participants close during early MOUD treatment. One respondent asked his son to move in during treatment initiation, so family members could provide encouragement and monitor his progress.

"*[He had a house in Linh Nam] but we had to make him live here so that we could monitor him during the start of his treatment period…The family wanted him to live close so that they could talk with him to help boost his spirit as well as to comfort him.*" (Parent)

Some participants continued to use heroin while receiving MOUD, necessitating close supervision from family members who became intimately involved in treatment.

"*I tried to encourage my husband a lot. I went with him every day when he went to the clinic. I was afraid that he would go somewhere else instead of the clinic. I had to watch him carefully. After he had his sublingual tablets, we went home. [I know] he had not completely quit heroin; he still missed it, so I had to watch him.*" (Spouse)

One respondent gave her son money to buy heroin early in treatment, when he was still experiencing withdrawal symptoms. She stopped later in treatment when she saw his methadone treatment preventing withdrawal.

"*At the beginning of my son's addiction treatment, he still missed using heroin because at that time [the doctor was adjusting his doses] his dose was not enough, so I gave him some money for heroin. However, when his dose was enough, I did not give him any more money.*" (Parent)

This level of monitoring was not always welcomed. Family members sometimes found giving participants autonomy more effective in motivating treatment.

"*If I asked my son to do this or that, it seemed I tried to impose this or that on him, so he did it in order to get over with what I asked him. Therefore, when he raised the idea of [going to treatment], and I already had the phone number of the research assistant (RA), so I gave the number to my son and he contacted the RA himself. After that, he decided to come here to register for the treatment.*" (Parent)

Family members became knowledgeable about the MOUD treatment process. They served as confidants for participants, who frequently shared the ups and downs of recovery. They were often aware of dosage changes and side effects.

"*My daughter confided in me that at the beginning when she took the medication, she felt so sleepy and always felt like she was not completely awake…She told me everything. She did not hide anything from me.*" (Parent)

Emotional support was impactful for participants. A desire to be present for family members was a key motivator for both MOUD and ART.

"*I think a lot about my son. I don't want him to lose his father early. He's only twenty-four, twenty-five. He is not married yet. I don't want him to lack paternal love.*" (Participant)

Families incurred financial and time costs providing participants with practical support

Participants depended on support from family members during their heroin use and treatment, and providing this support came at considerable cost to families. Much of the financial and emotional burden on families was directly associated with participants' heroin use, but families also paid for participants to access medical treatment and to visit participants in rehabilitation centers.

Financial costs

Many participants relied financially on their family for their heroin use and daily necessities. This placed families in financial difficulty, sometimes requiring them to borrow money. A few participants stole items for which family members had to pay. Tension between familial obligation and the high degree of financial support participants required led to profound stress for family members. One parent reflected that the participant's financial reliance on them was overwhelming.

"*In my thoughts, I did want to let go of him. Sometimes, I wanted to die so that I did not have worry about anything, but they were just my thoughts. If I let go, whom my son and my grandson relied on…even I had diabetes, but I had to bear all these.*" (Parent)

Refusing did not diminish the burden on family members, and often resulted in threats. Conflicts over money or attempts to prevent participants from using drugs could escalate to violence and strained relationships.

"*In terms of finance, 80% of the time, the family depended on me. Therefore, when my husband asked for money, I had to hide from the kids to give it to him. My oldest son reminded me all the time not to give his father even a penny and he got upset when his father only threatened me just a little, but I already gave in.*" (Spouse)

Participants were aware of their financial impact on family members. They discussed their families paying for multiple courses of detoxification and giving them money to discourage them from obtaining money illegally.

"*My life has been always good even when I am addicted to heroin. I do not have to steal for money and always have money to spend. I do not have to wander around on the streets to steal for money. Talking about good [life], I always own it. My friends have to try to earn a living, but I am 40 and my mother still takes care of me. In the morning when I wake up and there will always be money for me. No one can have a comfortable life like me. Other people have to earn money to take care of their families as soon as they wake up.*" (Participant)

Childcare

Constant stress across multiple domains sometimes led to complete dissolution of relationships and breakdown of family structures. This could lead to further demands on participants' parents to care for grandchildren.

> "*[My son and my daughter in law] were separate for a while. I told my daughter in law to get married to another man. Since they got separated, their son came to live with me when he was 7 years old and now, he is 14 years old.*" (Parent)

Providing childcare was an important way families supported MOUD treatment. One respondent discussed how her mother-in-law took care of her baby so she could attend her husband's induction session.

> "*When he came [to the clinic] to take sublingual pills, I was asked to be here for counseling session. Today was his induction day, so family member was required to be present. Because I had a baby, so I asked him to go ahead, and I waited for my mother-in-law to come to take care of my baby, then I could go.*" (Spouse)

Medical needs

Family members provided financial support for complications of substance use. Many participants required hospitalization, medications for HIV and Hepatitis B and C, and supplements recommended by their physicians. Family members often helped pay for health insurance, which covered ART. These costs could be substantial, and sometimes represented a major financial burden.

> "*Now my son had to take [HCV] medication and I was told that this medication was not covered by health insurance, and it was expensive, so I was a little concerned…It was said that the fees were about 25 million vnd at first, but after the program sponsored, it would be 20 million vnd ($860).*" (Parent)

Family members directly cared for participants at home for less serious acute health concerns or to maintain their general health.

> "*My son felt tired when he just started taking this medication. Our family tried to make the best environment for him. My wife usually bought milk for him, and he ate really well.*" (Parent)

Participants echoed the importance of family members supporting them in day-to-day expenses and medical treatment.

> "*Each month my parents gave me two million vnd (~$85) or when I was sick and had no money, then my parents also gave me money for medications…All of my medications were paid by my older sister and also my wife.*" (Participant)

> "*We lived with my mother-in-law. We took care of our living expenses. Other expenses like electric bills my mother-in-law paid for it. We paid for our child's educational expenses and our living expenses. My mother also helped out with paying for our food.*" (Participant)

Support and challenges during detention

The burden of caring for a person with addiction in their home was so great, family members sometimes supported participant detention in state-run compulsory rehabilitation centers (06 Centers).

> "*This time, if [the 06 Center] opened slots again, [I would send her off]. I could not stand her any longer because she was really a burden. It was too much. If she focused on working, everything was fine. However, [heroin] was in her brain.*" (Parent)

Families still experienced significant risks and costs when participants were in 06 Centers. They had to frequently travel long distances to visit participants. Family members described these visits as dangerous, time-consuming, and expensive.

> "*I did not want to visit him at all, but my wife pushed me to do that. Each month the money I had to spend two million vnd (~$90) to visit my son and it was almost the same as the amount of my monthly salary.*" (Parent)

Participants described how families visited them in 06 Centers several times a year, brought HIV medications, and provided funds to buy food.

> "*[My family] visited me once every two or three months. Each time they came they brought canned foods (meat, fish) and peanuts because there was nothing to eat with white rice there.*" (Participant)

Assistance in day-to-day matters

Participants identified families as a safety net throughout their lives. Even extended family assisted with childcare and bought necessities for participants in some cases.

> "*When my aunts buy clothes for my mom and for their children, they buy some for my son too.*" (Participant)

This practical, day-to-day support was important to the participants as they struggled to become, in their words, "normal" again.

Family members lost social status due to secondary stigma

Stigma toward participants extended to family members. As a result, family members, especially men, experienced a loss of status in their community, which reduced their ability and willingness to engage social supports. One father, previously the head of his extended family at gatherings and ceremonial events, drew back from this role due to stigma.

> "*The idea of having an addicted son affected me. Since my son was like that, I became more reserved.*" (Parent)

This loss of status was internalized and even affected relationships with social supports unfamiliar with participants' addiction. Withdrawal from these relationships increased the burden upon families through isolation.

> "*My high school friends called me to go out to relax. They did not know my son was addicted because they did not live close by. I told them that I was tired, but*

actually now my son was [like this] I felt ashamed, so I did not want to meet people." (Parent)

While families experienced some stigma because of participants' addictions, their HIV status was far more stigmatized. Families reported being treated differently by neighbors, extended family, and doctors. Some family members hid participants' HIV status to avoid this. One respondent talked about how neighbors began to treat her differently when her HIV-positive son returned from an 06 Center.

"*They treated [him] totally different, and they even looked at me with different eyes…when people knew about his HIV infection, they avoided [us] more; they did not want to have any contact. Close to our house, there were neighbors who I really liked. They had lived there more than 10 years. Our relationship was really good. However, since my son returned from a rehabilitation center, they stopped coming to my house.*" (Parent)

Families were sometimes ostracized by relatives and could be isolated during important cultural events such as Tet or a death anniversary. Discrimination in healthcare sometimes forced families to seek care further away, increasing expense. While hiding the diagnosis could protect families from stigma and exclusion, it also resulted in emotional isolation, as families were left to cope with the emotional challenges of HIV and addiction alone.

"Interviewer: Did you have anyone support you emotionally? Around the neighborhood, or unions?

Respondent: No, because we hid it. Only within the family, people know. With this kind of illness, we hid it from other people." (Parent)

Some participants described stigma, especially from family members, diminishing as they grew accustomed to participants' HIV diagnoses. One respondent stated that self-stigma improved as well, enabling her husband to receive combined ART-MOUD treatment near their house without concerns about encountering neighbors. While stigma indirectly affected HIV-negative family members, spouses who were also HIV-positive experienced the greatest social burden.

"*Friends who knew about [our HIV status], they felt reluctant to be in contact with. They tried to avoid [us]… When we met, they said hello normally, but sitting down and talking with each other hardly happened; not close like normal people.*" (Spouse)

Participants shared their experiences of self-stigmatization. Some saw social avoidance as a strategy to protect themselves from criticism. A sense of inferiority prevented one participant from asking for help.

"*I do everything by myself. I don't ask anyone for help. I feel reluctant doing so. It's not that they avoid me but I avoid them. I feel kind of inferior.*" (Participant)

Loss of status by both participants and family members limited their willingness and ability to seek assistance. As a result, they bore the twin burdens of HIV and heroin use disorder alone.

"*[I thought] at general hospitals there would be no stigma because doctors were supposed to be counselled or learn basic knowledge to prevent [HIV] infection, so why they still felt afraid, or they still showed clear sign of stigma toward people like us… Because of being afraid to be stigmatized and the way people looked at him he did not go to the hospital and now this bone tuberculosis cannot be cured.*" (Spouse)

Discussion

Supportive family members' attempts to engage with rather than withdraw from participants is consistent with behavior described in Greece.[31] Dissolution of family relationships was rare. Outside of families, participants' social networks were limited by years of addiction and incarceration. This was compounded by shame and social avoidance, preventing participants from accessing other supports and further increasing reliance on family.

Family members' ability to rely on others was also limited by stigma, mostly related to participants' HIV status. Previously-published literature describes HIV disclosure leading to increased stigma, while disclosure within families can lead to reduced stigma and increased support, consistent with the supportive family context focused on in this study.[18] Prior studies have also reported that HIV and injection drug use contribute independently to layered stigma.[19–21] However, the central role of HIV in stigma towards families of PWID in Vietnam has not been previously articulated.

Prior studies have highlighted the role of family members' approval in starting MOUD.[11] In this study, family encouragement and awareness of the impact of their use on family motivated participants to pursue treatment. Financial support continued during treatment; emotional support increased as family members engaged with treatment – a behavior not previously described. Family members were involved through information-sharing, attending appointments, and sometimes monitoring treatment success, though others found that less scrutiny facilitated recovery. Tension between control and support has been highlighted previously among family members of people with substance use disorders.[32,33] Interestingly, family encouragement in MOUD treatment paralleled how family members support patients in ART treatment.[14,15]

Families provided practical support to participants during treatment despite significant costs, crucial for a population with a high rate of catastrophic health expenditure.[17] This support allowed participants to focus on MOUD treatment, as has been shown with ART adherence, likely contributing to their success.

This study is limited by selection of a treatment-seeking population; family members of PWID not interested in treatment may experience greater burdens. Not all study participants had a paired family member interview, often due to factors that might have affected family member responses. Some family members were not able to attend interviews due to poor health while others declined to participate. This study also intentionally selected supportive family members for interviews to protect participant confidentiality and safety; unsupportive family members are not represented in this study. While these results likely do not reflect the

experiences of unsupportive family members, supportive family members are more likely to be a resource for PWID and participate in interventions and are an appropriate focus.

Systems of care in Vietnam serving people with comorbid MOUD and HIV must consider the role families play. Supportive family members were shown in this study to be engaged participants in MOUD/HIV care and assisting them may facilitate further engagement in the treatment process. Interventions including family members of PWID in Vietnam have been shown to improve relationships.[23–24] In combination with integrated ART/MOUD treatment, similar approaches may be effective in reducing the impact of substance use on family members of PWID with HIV in Vietnam, allowing them to provide support for patients' recovery.

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Table 1.

Respondent Characteristics

	Patient Interviews	Family Interviews
Total Participants	**44**	**30**
Gender		
Male	42	7
Female	2	23
Marital Status		
Single	16	1
Married	16	28
Divorced/Separated/Widowed	11	1
Employment status		
Employed	18	16
Unemployed	26	0
Retired	0	14
Treatment		
Buprenorphine/Naloxone	23	19
Methadone	21	11