


The Patient–Provider Continuum of Care: Narratives of People Living With Comorbid HIV and Diabetes in Northern Thailand

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Abstract

Background: Among South-East Asia Region countries, Thailand has a high prevalence of HIV with an increasing significant comorbidity of diabetes mellitus (DM). **Objective:** Guided by syndemics, the purpose of this qualitative study is to develop insight into the experience of patients living with comorbid HIV and DM in Northern Thailand for quality improvement. **Methods:** Interviews were conducted in 2 groups for content analysis: (1) people living with comorbid HIV and DM and (2) health-care staff providing care to patients living with the comorbidity. **Results:** Participants' (N = 12) ages ranged from 42 to 56 (mean = 49). Health staff (N = 12) generated complementary narratives. All participants reported onset of diabetes after discovering they were HIV infected. Content analysis revealed emergent themes regarding (1) knowledge and perceptions and (2) management framed by syndemics and chronicity. **Conclusion:** Findings suggest routine training for patient education and provider integration of care. Macrosocial factors such as limited access and resources and biological factor such as drug interactions are noted as key considerations for future interventions and alterations in the care for patients with comorbid HIV and DM.

Keywords

Thailand, diabetes, HIV, comorbidity, patient perspectives/narratives, quality improvement, qualitative methods, global health

Background

Among South-East Asia Region (SEAR) countries, noncommunicable diseases (NCD) such as diabetes mellitus (DM) account for more than half of all deaths (1,2). In Thailand, DM has become more prevalent *and* comorbid with communicable diseases such as HIV (1,3). Although HIV rates are declining, Thailand has a higher regional prevalence compared to other SEAR countries (3). Antiretroviral therapy (ARV) is effective (4), but long-term use is associated with health complications, including DM onset (5–7). The aging HIV+ population shows health issues such as insulin resistance, impaired glucose tolerance, DM, and other metabolic syndromes (8,9). Thus, it is imperative to optimize care for people living with comorbid HIV and DM (PLWCHD).

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Thailand implemented a 100% condom use program among sex workers, becoming the first nation to reverse an HIV epidemic (10). In 2002, Thailand implemented a Universal Health Care (UHC) policy (11), and in 2006 to 2007, issued compulsory licenses for the import/local production of ARV to meet program costs, despite punitive economic measure (12). Chiang Mai, a northern province of 1.6 million people, encompasses 25 hospitals (1 general, 1 university, and 23 community), with 266 health centers (13). This study examines health care for PLWCHD; it explores the district setting, where community hospitals are located because it is the most accessible comprehensive level of health care for patients without private insurance, where most people seek care, despite the absence of resources such as on-site blood testing (13).

Syndemics, a theoretical construct originating in social science that uses the biopsychosocial context to consider macrosocial reasoning for behavior and outcomes, provides a framework for this study (14–16). Although research has explored syndemics and chronicity with PLWCHD in African countries (17–19), limited scientific investigation has extended to Asian countries. Currently, DM and HIV clinics are operated independently in Thailand. While screening for DM is common among older adults living with HIV at HIV clinics, screening for HIV in DM patients is rare. There is no dedicated medication adherence clinic for either diseases. Adherence is addressed on a case-by-case basis if the problem is severe. Nurses play an important role as educators and counselors for both DM and HIV patients, followed by pharmacists. Therefore, this study explores patients' knowledge of diseases and perceptions surrounding comorbidity management with narratives from health staff provide additional context to develop insights into patient-centered care for PLWCHD in Northern Thailand.

Methodology

Design

This study used semistructured interviews with patients and health-care staff to produce reliable, comparative data (20) using a narrative health messages model—a new strategy for research design and exploration (21). Model principal components include (1) narrative characteristics, (2) mediators, and (3) outcomes/responses. Narrative characteristics require engaging participants across personal and sociocultural levels via realistic and appealing techniques as crafted in the data collection instrument (21). For example, the data collection instruments included interactive questions about patients' and providers' personal experience to encourage them to share their own stories of health and health training, respectively. Additionally, the data collection procedures were culturally embedded through conducting interviews in Thai with exchanges that were culturally resonating (ie, the 2 research personnel present at time of the interviews both greeted participants with a “*wai*,” the traditional form

of salutation in the Kingdom of Thailand, although 1 personnel was not Thai). Transportation, the act of getting absorbed in the narrative, was used as a mediator (21). For instance, participants were gradually stimulated to impart their perspective through first requesting general health information in a survey format, then inviting them to respond to questions about their knowledge/perspectives, and further welcoming their commentary on management from individual to communal scopes. Following the model culturally grounded narratives by Larkey and Hecht (21), outcomes/responses included attitudes and beliefs such as arriving at the ideal of disease prevention where study personnel solicited participants' suggestions on how to help people living with HIV avoid the onset of DM. Through the data collection instrument, constructed with narrative model principal components, results may provide the opportunity for patients to offer historical information that better elucidates their experiences, which can help providers improve care. The study protocol was approved by the Chiang Mai University (CMU) Faculty of Medicine (#REC-25580701-04674) and California State University, Fullerton (CSUF, HSR15-0263), Institutional Review Boards.

Data Collection

Participants were PLWCHD and health staff identified and recruited using convenience sampling at HIV and DM clinics via CMU connections with HIV coordinators at Sarapee, Sansai, and San Kamphaeng community hospitals. Notably, comorbidity is a complex experience and is analyzed in this article through 2 main chronic conditions in order to focus inquiry aligned with the study aim: explore the continuum of care for PLWCHD. HIV and DM were particularly selected given their synergistic dynamic where ARV may prolong one's life span, yet also induce onset of DM and DM rates are rising (5–9). Interviews were conducted with (1) PLWCHD and (2) health-care professionals managing PLWCHD. Participants were 18 years or older, including 12 patients and 12 providers, divided equally across hospitals. Verbal consent and interviews were conducted and audio-recorded in Thai without identifying information and then translated and transcribed for content analysis. Following the interview, patient participants received 100฿ (approximately US\$3) in cash and a pen and notepad; health-care participants received a CMU tote bag. Debriefing included reiteration of confidentiality procedures and answering questions.

Analysis

Qualitative analysis techniques were used (20). Data were arranged in transcripts by interviewee and then reduced into themes by coding and consolidating transcripts into meaningful categories. Two coders reviewed transcripts separately and then produced 1 uniform codebook through an iterative process (20). Transcripts were coded; authors

corroborated emerging codes with 91.82% agreement. Data triangulation with patients and providers, and prolonged engagement in the field, provided additional validation (22). Finally, data were reorganized into a synchronized format and represented by summarizing the observations of coded transcripts.

Results

Sample

Of 12 patients interviewed, there were 9 females, 2 males, and 1 unreported. Ages ranged from 42 to 56 years (mean [M] = 49). Ten reported Buddhist and 2 reported Christian beliefs. All reported onset of DM after discovering their HIV+ status. Two reported no formal education. Of the 12 health-care staff, 7 were females and 5 males. Ages ranged from 25 to 57 years (M = 46). All reported Buddhist beliefs, and their roles included hospital director, HIV coordinator, NCD manager, pharmacist, nurse, and physician.

Patient perception and awareness of health status and provider communication. Upon completion of the sociodemographic portion of data collection, patients were prompted to describe their current health status. Their insight provided clarity on their knowledge and perceptions of living with comorbid HIV and DM. Notably, patients' responses varied with the several reports of poor health predominantly reported. For instance, patients reported:

I was healthy, but after . . . diabetes, sometimes when I wake up, I feel weak on this leg, I feel dizzy. (Female, 56)

I feel tired, exhausted, I am unable to do heavy work. (Female, 44)

Patients were also requested to share their opinion regarding the amount of information they receive from health-care staff about living with comorbid HIV and diabetes. Several patients reported satisfaction with the health-care information they received. Some also wanted to learn more about medicine, safe sex education, and health preservation. For instance, one participant described receiving information on medicines:

[The staff] take good care of me. At the beginning, when I came to receive services here, I was asked whether I wanted to take ARV drugs or not. They didn't force me to take the drugs. I decided to take the drugs and they have taken care of me. When I was sick, nurses and nurse assistants took good care of me. I've never been discriminated by them. (Female, 44)

Regarding safe sex education, one participant said that health-care providers instructed them:

. . . not [to have] sexual relation with others. (Male, 47)

Another reported receiving instruction on:

Prevention of sexual transmission of HIV, and prevention of getting more HIV infection from others, [using a] condom every time when having sexual intercourse even with my husband. (Female, 44)

Some patients described receiving information about maintaining their health such that:

[Doctors suggest] doing some exercise [and adhering to prescribed] drugs. I should eat food that has no sugar and fat. (Female, 46)

[Doctors have told me] about taking care of myself and reducing [the amount of sweets I eat]. (Female, 56)

Provider preparation for treating PLWCHD. Providers were questioned about their training in how to treat PLWCHD to better ascertain their knowledge and perceptions of caring for PLWCHD. Only some (4/12) reported specific training to treat PLWCHD. For instance:

Yes, I've received training in how to take care of HIV patients and about ARV drugs because here is a small hospital and not many staff. . . We . . . attend HIV training at the nation and region level. For diabetes, we attend training here at the hospital. The hospital has refresh trainings for staff periodically. We also provide diabetes training for health volunteer at the health stations. (Female, 57)

However, most providers (8/12) reported no training. For example,

. . . I'm responsible for patients living with HIV who take ARV drugs and have high blood sugar level. But, I never had any trainings in diabetes. I was trained on how to treat patients living with HIV who have side effects after taking ARV drugs. . . (Male, 51)

When asked about their confidence in treating PLWCHD, health staff expressed clear belief in their capacity of treating PLWCHD. Although most reported no specific training for PLWCHD, providers felt self-assured in providing care to such patients with responses including:

Ok, I can say we have strong confidence because we have . . . clinical practice guidelines to treat the patients with diabetes and HIV together. (Female, 40)

Only a few providers expressed moderate confidence. For instance, one noted:

I'm confident to a certain extent. . . They have criteria to evaluate patients, and also to measure the results for both HIV and diabetes. (Female, 40)

Additionally, staff reported that consulting with other physicians was helpful. One health staff member said:

We're pretty confident because we don't take care of patients alone, we send patients to other related clinics, like NCD. There are doctors at the NCD. (Female, 49)

Staff expressed interest in learning more about the relationship between HIV and DM and in taking preparation courses. For example,

I want to know more information about drugs as I'm a pharmacist. I want to know about the side effects of HIV drugs that may induce diabetes or increase blood sugar and cholesterol level, because mostly when patients have diabetes, they will have hyperlipidemia, hypertension. By having HIV, they have to take many kinds of medicines that have effects on . . . patients' bodies. (Female, 40)

One noted that training on diabetic wound treatment may help prevent complications, stating:

Yes, I want to have training courses because I have diabetes patients with necrotic wounds and [need information on how to] control the medications from HIV, too. Yes, we want to learn about this course for prevention . . . Maybe we have short courses, you know? Control blood sugar by themselves for 7 days or 3 days for control in hospitals, and then we have to adapt the education (ie, pills or injection). For some cases we have problems because [it is hard to regulate] when [patients go] back to community or to work. (Female, 46)

Staff also described obstacles in treating patients adequately, including limited budget and overall lack of resources. For instance, one participant noted:

Lack of budget and not having a good welfare in Thailand, because we have some people [without] ID and [unaccounted in our] welfare systems and then some case will pay by herself or himself only, and then not have money [to] take care themselves for every visit in hospital. Welfare is not [a] good system for all people in my country. (Female, 46)

Limited health staff was also a challenge reported by providers. Notably, one participant said:

Maybe lack of experts for treating PLWCHD . . . There [are] limited staff and resources as we are a community hospital. For some laboratory testing, we draw patient's blood, but we cannot conduct laboratory testing at the hospital, so we have to send the blood to another hospital . . . for laboratory testing. (Female, 49)

Another articulated challenges related to complications arising from delayed HIV diagnosis:

The main problem is, [HIV] is still not common to check in every patient . . . so some of my patients with diabetes, [may] have HIV but they don't know, so [then there is a delay in detection]. (Female, 40)

Patient management of comorbidity. Notably, all patients reported receiving separate appointments for HIV and DM care. Patient discussion included the belief that the same level of care or greater was needed for patients with comorbidity compared to solely HIV infection. Some participants suggested a more precise form of care was needed for comorbid patients. For instance:

It would be great if we [comorbid patients] had special care. (Male, 47)

Yes [more care is needed], I have two diseases! (Female, 44)

A patient who described the perception that more resources are not necessary to treat comorbidity mentioned:

I think [my current care] is ok now. I'm given knowledge and good care every time I come here . . . if within 1-2 months, my blood sugar level is still high, then the doctor will change the medication and help me to change my eating attitude. If I have problems and I want to see the doctor, I can see the doctor any time. The clinic is good . . . They call to remind me of my visit, and they do follow up. I'm happy here. (Male, 42)

Additionally, patients shared that care depends on the patient and stated:

It depends on the doctor's suggestion and how patients take care of themselves . . . If we don't love and take care of ourselves, many diseases will come, and our health will be bad. If we love and take care of ourselves, our body will get better and better. (Female, 46)

I think it is not different, whether having more care or not. It depends how we take care of ourselves. If we know we have diabetes, we take good care of ourselves. I feel like I'm healthier than people without diabetes. (Female, 41)

When asked how hospitals can improve care for PLWCHD, patients discussed patient-provider communication, privacy, and workforce. For instance:

I think if the hospital can separate HIV patients from [others] to make it more private, it'll be good. (Male, 42)

Sometimes, there were not enough doctors and staff outside the examination rooms. (Female, 54)

However, some participants noted previous improvements in care for PLWCHD including:

I have seen that the hospital continues to improve its services for 5-6 years. (Male, 42)

Provider management of PLWCHD. Providers were asked about their opinions of the current health-care service for PLWCHD at their respective hospitals. Most (9/12) staff described the current quality of health services at the hospital

as good or shared satisfaction with services provided. For instance:

I am quite satisfied with it. In the past, we didn't have a clinic, but now we have a clinic . . . and we can also strengthen capacity of the clinic in the communities. Right now, we send some patients to receive care at Tambon Health Promoting Hospital, so there are groups of patients here and there with the same standard of the healthcare services. (Female, 41)

However, one participant expressed dissatisfaction with current health services for PLWCHD, stating:

No, I don't like. I am trying to talk to people who are taking care of this. But it's hard because we cannot force or ask patients to see doctors at HIV or DM clinic if they don't want. (Male, 46)

Participants described separate clinics for HIV and DM or specialized programs as unnecessary due to the low number of available staff and PLWCHD. For instance:

There are only 15 patients living with comorbid HIV and diabetes. To set up a special clinic for them is not worth it . . . especially for the community hospital; nurses have to help doctors care for patients because there are so many. Right now, we don't have enough space and staff for the comorbid clinic, and it's unnecessary because there's not only comorbid HIV/diabetes. HIV patients also have many diseases such as hypertension. Do we need to set up a clinic for every comorbid HIV [case]?-No. (Female, 57)

We don't [have specific clinics for comorbid HIV and diabetes patients], and I don't think any other health-care services do because it's too specific. Normally, HIV patients also come here with other problems such as alcoholism, hypertension, diabetes. Some patients have many diseases but mainly they have HIV. (Male, 25)

However, when describing potential programs, one stated:

It should be like one stop service to me . . . this clinic has specialists and also leaders of patients . . . such as volunteers who are also HIV patients . . . so, they can take good care of other HIV patients and . . . check them instead of [a] doctor. At the same time, these volunteers can [share their experiences with] new patients for both [physical and mental support]. But, for those who decide to go to DM clinic with HIV, it's quite hard to get [timely service]. (Male, 46)

Discussion

This research examined patients and providers to obtain a more comprehensive understanding of care for PLWCHD in Chiang Mai, Thailand. Semi-structured interviews allowed participants to share narratives regarding knowledge and perceptions of health status and management/delivery of care for HIV/DM comorbidity, while health staff provided

insight into quality improvement (21). Results highlight the utility of applying a syndemics lens to investigating health, behavior, and outcomes (14–16).

Knowledge/Perceptions

Self-reported health status varied, with several patients describing poor health as a result of comorbidity; however, patients also described receiving information from health staff on topics that enhanced their knowledge about PLWCHD (eg, medication adherence and safe sex). Although staff predominantly received training for HIV and DM care separately, patients believed they received enough information about PLWCHD from providers, validating health staff's confidence in providing treatment. Health staff, nonetheless, desired more training to better understand PLWCHD. Particularly, to improve delivery of quality health-care information, providers expressed interest in better understanding drug pathology and side effects that may induce comorbidity or further complications.

The efforts of the Thai government, specifically the Ministry of Public Health (MOPH), in providing UHC for HIV+ patients may play a role in patient reports of wellness. The government has issued compulsory licenses for the import or local production of ARV to meet the expenses of its program and ensure continued access (12). Furthermore, the 2002 UHC reform of the Thai health system helped advance access to health for all citizens (23,24). Utilizing a “framework for assessing the performance of health systems” (25), the Thai health system functions ably, despite being underresourced. Moreover, health-care staff participants reported satisfaction with current health care for PLWCHD. Their satisfaction may be due to several factors, including patient-reported satisfaction with the quality of service; availability of both HIV and DM clinics in these institutes; and local HIV programs provided by the MOPH for community hospitals (eg, providing ARV).

Management

Although patients were familiar with management regimens, the high number of complications in PLWCHD showed there is still room for improvement. Given the complexity of chronicity for PLWCHD, it is important to note patients reported general support from health-care staff as beneficial. Although the majority reported not receiving training to treat PLWCHD specifically, training in managing PLWCHD is nonetheless critical, as ARV drugs have been linked to the onset of DM (26,27). In concordance, both participant groups suggested that community hospitals may benefit from more home health staff. In addition, increased funding may also allow for private space, a concern of PLWCHD.

Established literature specifies 3 common models for managing health in patients living with comorbid HIV/NCD in low- and middle-income countries throughout sub-Saharan Africa and South East Asia which include (1) integrating services for NCD into centers initially providing HIV care; (2) integrating care for HIV into centers initially providing

NCD services; and (3) synchronized integration of both HIV and NCD care and services (28,29). The majority of such models stand as unsustainable, isolated initiatives, which ultimately fade due to absence of institutionalized longevity with support of local government entities (28,29). In Thailand, the health-care process is not streamlined with a singular point of medical contact for PLWCHD, and health staff participants described several obstacles to achievement. For instance, limited budget, health-care staff, and resources may delay early HIV diagnosis, increasing complications. Thus, a single point of medical contact may help allocate resources more effectively. Alternatively, health staff reported concerns with cost-effectiveness for streamlined health care for PLWCHD, suggesting it may not be advantageous in this context. The projected increase in PLWCHD, however, may require a systematic consideration of cost-effective and efficacious care (1). Additionally, cross-sectional, patient-centered care may provide a strategic point of contact for disease diagnosis, circumventing delayed diagnosis.

Strengths and Limitations

This study included 3 community hospitals to obtain a more well-rounded view of integrated care for PLWCHD. Additionally, both patients and health staff were interviewed to allow for triangulation of perspectives and experiences to validate findings. Data collection provided participants an opportunity to share and reflect on this growing global health concern. The study was limited to Chiang Mai, Thailand, and was exclusive to community hospitals serving patients with low socioeconomic status. More research should be conducted involving general hospitals and patients from different socioeconomic backgrounds. Additionally, future studies should consider how culture may inform health in order to develop competent programming for prevention.

Conclusion

Overall, findings suggest establishing routine training for health staff to ensure familiarity with current treatment and ongoing education for patients. Particularly, health staff articulated concerns of comorbid health complications and unanimously desired to learn more about the intersection of HIV and DM care. As posited by syndemics constructs, patients living with HIV may be at higher risk of DM due to macrosocial factors such as limited access and resources as well as lack of training for comorbid disease management; biological factors include drug interactions and shifts in quantity and quality of life, and socioenvironmental factor persist such as endemic HIV rates in SEAR countries (14–17). The Thai MOPH may consider continuing their approaches to economic restructuring to support resources (ie, space, staff) in district-level hospitals. Overall, this study may help guide interventions and alterations in the integration of care for PLWCHD. Finally, this study may provide a basis for future research on PLWCHD.

Appendix

MHIRT Interview Patient Version

General Information

1. What is your age? _____ years
2. What is your sex: Male = 1 or Female = 2 or Other = 3
*Note: if other, please briefly explain _____

Religion

3. What is your religion?
 - Buddhist
 - Christian
 - Islam
 - No religion
 - Other (specify _____)

Education

4. Have you gone to formal school (including from grade school and college)?
 - a. Yes
 - b. No
5. How many years did you attend school? _____

Household

6. Are you married?
 - a. Yes
 - i. If yes, are you living with your spouse?
 1. Yes
 2. No
 - b. No
7. What is your occupation? _____

Health

8. How long have you been diagnosed with HIV? _____
9. How long have you been diagnosed with diabetes? _____

Health Part II

Knowledge/Perceptions:

10. Please describe your current health status.
11. In your opinion, do you receive enough information from health-care staff such as doctors and nurses about living comorbid with HIV and diabetes?
 - a. If Yes: What have you been told?
 - b. If No: What would you like to know more from the health staff about your health?

Management

12. In your opinion, what are health-care services that the patients who have both HIV and diabetes need in addition to care for patients who have HIV alone?
13. When you get care from the hospital, do you have one appointment or separate appointments for HIV and diabetes? If yes, please describe the combined service you receive?
14. As a patient, how can the hospital improve their healthcare for you?

Prevention

15. If you wanted to share your story to help HIV-infected persons avoid diabetes what would you say?

MHIRT Interview Staff Version

General Information

1. What is your age (in years)?
2. Sex of the respondent: Male = 1 or Female = 2 or Other = 3
*Note: if other, please briefly explain

Religion

3. Check off all denominations that have had an impact on you
 - Buddhist
 - Christian
 - Islam
 - No religion
 - Other (specify _____)

Education

4. What is your specialty? _____

Health

Knowledge/Perceptions:

5. Have you received training in how to treat patients living with comorbid HIV and diabetes? If yes, please describe the contents or curriculum.
6. How confident are you in treating patients living with comorbid HIV and diabetes?
7. Please specify what you would like to know more about comorbid HIV and diabetes.

Management:

8. How do you like the current health care service for people living with comorbid HIV and diabetes at your hospital?
9. Does your hospital have any specific health-care programs and/or interventions for people living with comorbid HIV and diabetes (eg: special clinic or one-stop service)?
 - a. If Yes: please share more details?
 - b. If No: please share your ideas of how it should be.
10. In your opinion, what are the major obstacles in order to develop or improve care for HIV/diabetes patients?
 - a. If Yes: please share more details and speak about any (eg: lack of resources? Lack of staff? Lack of physical space?)
 - b. If No: *continue with questions below*

Prevention:

11. If you were asked to design a program to help HIV-infected persons avoid diabetes, what would you suggest?


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Bilikisu Reni Elewonibi leads the work for the Willows Impact Evaluation in Tanzania as a research associate at the Harvard T. H. Chan School of Public Health in the Department of Global Health and Population. Dr Elewonibi holds a PhD in Health Policy and Administration and Demography from the Pennsylvania State

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Marcelo E Tolmasky has studied the problem of antibiotic resistance and possible solutions for over three decades. Although during the beginning years his research was confined to molecular biology aspects, his interests keep growing encompassing aspects of causes and consequences of the growing menace of resistance to antimicrobials. He also became involved student training practicing the “learning through research” concept. The combination of widened research interests and involvement with training led Dr Tolmasky to become familiar with numerous diseases and the different ways they can be tackled, such as educating the

population, developing preventive, diagnostic, and therapeutic interventions, studying how different behaviors can influence the incidence and progress of disease, performing epidemiologic studies to identify risk factors for various diseases, especially in disparity populations.

Michele M Wood holds a doctorate in Community Health Sciences from the School of Public Health at the University of California, Los Angeles, with a minor degree in Sociology. She also holds a Master’s degree in Community Psychology. She teaches graduate and undergraduate courses in Research Methods, Statistics, and Program Design and Evaluation. Dr Wood’s research interests include preparedness messaging and risk communication for disasters, HIV/AIDS among high-risk populations, and program evaluation. Dr Wood has served as a subject matter expert and advisor for USGS and FEMA, and is currently serving as Principal Investigator on earthquake early warning research. In addition, Dr Wood has participated in multiple workshops on mobile alerts and warnings organized by the National Academy of Sciences.