

Barriers to HIV Treatment Adherence among Thai Youth Living with HIV/AIDS: A Qualitative Study

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Abstract: Globally and in Thailand there are growing numbers of youth living with HIV/AIDS and they face challenges to HIV treatment adherence that can lead to treatment failure and drug resistance. This qualitative study explored the needs and concerns about adherence to HIV treatment among youth living with HIV/AIDS using a technical collaborative action research approach. Participatory activities and in-depth interviews were conducted among 25 youth living with HIV/AIDS in northern Thailand. Data were analyzed by content analysis. Findings show that participants did not adhere to HIV treatment and engaged HIV risk behaviors. There were five themes related to experiences regarding HIV treatment adherence, namely: lack of drug knowledge; boredom, discouragement, and denial; fear of disclosure; not managing medication, and risk-taking. We concluded that the participants needed psycho-social support and counseling to enhance HIV treatment. Nurses can play a critical role in developing and implementing effective programs and strategies that involve youth living with HIV/AIDS, giving them support and helping them, their families, and other health care providers to achieve HIV treatment success.

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Introduction

Globally, five million youths aged 15–24 years-old are living with HIV/AIDS.¹ In Thailand, despite the stable and slightly declining trend of HIV prevalence among other people generally, the highest number of sexually-transmitted infections (STIs) occur in the 15–24-year-old age group, aggravated by risky behaviors such as having multiple sex partners

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and engaging in unprotected sexual intercourse.² According to evidence from the Bureau of Epidemiology³, more than 31,000 youth living with HIV/AIDS (YLWHA) between 15 and 24 years of age in Thailand represent the increasing HIV/AIDS epidemiological rate among youth groups. While Thai government's efforts have focused on increased access to antiretroviral therapy (ART), an increasing rate of ART non-adherence is an important cause of HIV treatment failure, leading to the development of drug resistance.^{4, 5}

Optimal management of ART has resulted in substantial reductions in morbidity, mortality, and the need for extensive use of health care.⁶ Existing studies show that YLWHA have failed to adequately adhere to ART, resulting in increased viral load and the development of HIV resistance.⁷ The reasons for this non-adherence include pill burden, life-style burden, youths' denial and fear of their serostatus, lack of knowledge about the availability and effectiveness of ART^{5, 8}, the complexity of the ART regimens, resulting in regimen fatigue⁹, as well as the stigma that YLWHA suffer.^{10, 11} Additionally, YLWHA continue to engage in multiple risk behaviors, especially unprotected sexual intercourse and drug use, that place them at risk of transmitting HIV.^{4, 12} Alcohol and substance use by youth are linked to early sexual debut and increased risky sexual behaviors such as inconsistent condom use and multiple partners.^{13, 14} Consequently, both non-adherence to ART and HIV risk behaviors place this population at high risk of poor health, diminished quality of life and length of life.

Although, HIV treatment adherence is a challenge among YLWHA in other countries, the barriers related to HIV treatment non-adherence among YLWHA in Thailand needed to be identified.

Review of Literature

Treatment adherence is defined as the ability of the patient to develop and follow a plan of behavioral and attitudinal change that ultimately serves to

empower them to improve health and self-manage a given illness.¹⁵ The objective of HIV treatment with ART is to suppress viral replication as much as possible, thereby reducing the likelihood of resistance and reducing HIV-related morbidity and mortality.

Antiretroviral drugs (ARVs) are substances capable of suppressing duplication of the HIV virus. They increase the survival rates of persons living with HIV/AIDS and promote their quality of life.¹⁶ A high degree of ARV drug-taking (>95%) is necessary for successful treatment.¹⁷ Although taking ARVs decreases the HIV duplication rate, poor adherence to the ARV regimen causes drug resistance and increases the amount of the virus circulating in the blood, which results in treatment failure.^{17, 18} YLWHA have a higher likelihood of HIV resistance and virologic failure when compared with adults because they have many additional obstacles to ART adherence emerging during puberty. Transition to youth leads to changes in lifestyle involving growing independence, separation from parental involvement, increased peer pressure and fear of stigmatization, increased risk-taking behaviors, psychiatric problems and substance abuse.^{19, 20, 21, 22} Previous studies have shown YLWHA prevalence to HIV treatment non-adherence. The barriers to ART adherence include having unstable housing,²³ depression and anxiety,^{24, 25} medication-related adverse effects,⁵ forgetting to take medication,²⁶ the complexity of the ART regimens resulting in regimen fatigue,⁸ as well as the stigma that YLWHA suffer.^{10, 11, 22}

Existing research also indicates that YLWHA struggling to maintaining good HIV treatment adherence may face more than a single barrier. Health care providers need to appreciate the barriers of HIV treatment adherence within the whole context of their lives. Additionally, previous research indicates that psychosocial factors such as depression and anxiety were most consistently associated with poor adherence across studies.

Clarifying HIV stigma, non-disclosure, caregiver stress, and peer relations are essential to understanding how to improve HIV treatment adherence for YLWHA within their specific contexts.^{5, 27, 28} Despite, the growing body of literature on the complex factors of HIV treatment adherence among YLWHA, existing studies lack qualitative data on the barriers, needs and concerns regarding HIV treatment adherence from the perspective of YLWHA's in the Thai context.¹¹ Deep understanding is needed to develop an enhanced HIV treatment adherence program specific for the needs and concerns of Thai YLWHA. Therefore the purpose of this qualitative study was to explore the needs and concerns about adherence to HIV treatment among YLWHA in Thailand.

Design: A qualitative design using a technical collaborative action research approach²⁹ with focus group discussions and in-depth interviews was conducted over a five-month period with YLWHA. This approach was chosen because it focuses on investigating specific and localized solutions, and promotes more efficient and effective data gathering by encouraging personal participation in the process.

Participants

The 25 YLWHA consisted of 14 males and 11 females aged 14–21 years who were diagnosed as HIV-infected, and willing to participate in this study. Through purposive sampling health care providers and AIDS networks recruited study participants from

YLWHA who came to receive treatment at the HIV clinics of community hospitals in Chiang Mai province, Thailand. Eligibility criteria were that the youth were aged 14–25 years; had been diagnosed as being HIV-infected; and received HIV services from community hospitals in Chiang Mai province, Thailand.

Data collection

After obtaining approval from the Institutional Review Board of the Faculty of Nursing, Chiang Mai University, potential participants were recruited for the study between October 2010 and May 2011. Initially, four focus group discussions were conducted among the 25 participants using participatory activities. These activities engaged participants by allowing them to take part actively and respond verbally in games, and allowed them to form small task groups to share perspectives about HIV treatment adherence. A semi-structured interview guide was used to explore their needs and concerns about adherence to HIV treatment. Each group had a moderator and a note taker to facilitate and manage communication within the group. Then, in-depth interviews were conducted with the YLWHA, following a semi-structured interview guide that encouraged participants to speak more freely and comfortably about their perspective on HIV treatment. The types of questions asked of the participants can be seen in Table 1. Interviews lasted 60–120 minutes, and were tape-recorded, transcribed verbatim and checked by two co-researchers for accuracy.

Table 1 Examples of the Questions in the Interview Guide:

Questions for YLWHA:

- (a) What are barriers of HIV treatment adherence among youth living with HIV/AIDS?
- (b) In the past, how have youth living with HIV/AIDS engaged in HIV risk behaviors?

Ethical considerations

After obtaining approval from the Institutional Review Board of the Faculty of Nursing, Chiang Mai University, permission was also obtained from the community hospital administrators. All participants were informed in advance about the purpose and the research processes of this study, including that participation was voluntary. Participants were assured that none of the information gained in the study would affect their treatment, daily living or job. All data were treated as group information, with no personal identifiers. Individuals who agreed to participate were asked to sign a consent form. In accordance with their rights, the participants were verbally informed that they had the right refuse to answer any of the questions at any time during the interviews and also to stop the recording at any time they chose and that all data would be keep secure. A token of appreciation was given to each participant at the end of the study.

Data analysis

Qualitative data were analyzed iteratively using content analysis.³⁰ Transcripts from each group were read and categories were reviewed several times in order to ensure that the concepts pertaining to the same phenomena were placed in the appropriate category. The themes and the content of the data throughout the data collection and analysis processes were identified by the primary author and subsequently verified by two co-authors for coding consistency, emergence of

main themes, and extraction of statements to support the themes. Coding, themes, and key findings were discussed by the co-authors until consensus was reached.

Rigor and trustworthiness

Strategies to enhance trustworthiness were devised to ensure the rigor of this study.³¹ Credibility was strengthened by using multiple methods of data collection (methodological triangulation) to compare the variety of all data sources and methods in order to confirm the accuracy of the findings. The researcher observed the participants' behavior, expressions and the surrounding environment, and then recorded these observations in field notes at the end of each meeting. The researcher also used participatory activities and in-depth interviews in order to confirm the accuracy of these findings. Member-checking, that is some participants being asked to validate and give feedback on the data they provided, was one strategy to confirm credibility.³² Further, the findings were shared with the co-authors for verifying the accuracy of the interpretation. A clear audit trail showed all finding were derived directly from the data, ensuring conformability.

Results

Five themes emerged from the interviews reflecting YLWHA' perspectives, and are described below and summarized in Table 2.

Table 2 Themes and subthemes regarding needs and concerns of HIV treatment adherence

Theme	Subtheme
Lack of drug knowledge	Not knowing the adverse effects of ART Not knowing about reducing the adverse effects of ART
Boredom, discouragement and denial	Being bored with taking medicine repeatedly Feeling discouraged by their incurable disease Denial

Table 2 Themes and subthemes regarding needs and concerns of HIV treatment adherence (Continued)

Theme	Subtheme
Fear of disclosure	Losing friendships Disclosure of infection
Not managing medication	Forgetting to carry the medicine Not taking medicine on time
Risk taking	Lack of negotiation skills Curiosity Poor safe sex planning skills

Lack of drug knowledge

Some YLWHA did not know the details of the ART regimens they were taking regarding name, action, and adverse effects of ART, especially among those who received new regimens. They were able to remember only the appearance of the ART they took, including the tablet size and capsule characteristics. As one stated:

When I take a new medicine, I don't know what formula it is. It's a big tablet. (Male youth)

Some of them did not know about the action of ART in the body and how the drugs control viral activity within the body. They did not understand why they had to take the drugs.

I don't really understand about taking medicine. I didn't know how the drugs acted. (Male youth)

I knew that my viral load was high, but I don't know why I had to take medicine. (Female youth)

Another issue brought up was that participants lacked understanding about the side effects of ART—specifically: 1) not knowing the adverse effects of ART, and 2) not knowing about reducing the adverse effects of ART.

Data indicated that participants did not have adequate knowledge about the adverse effects of ART, such as fat redistribution.

I changed my ART regimen but my tendon did not get better. Are there side effects? I wanted the nurse to check why this happened. (Female youth)

Another said:

I have changed the ART regimen I have been taking for a while. Now I don't know what to do. (Female youth)

Boredom, discouragement and denial

Because of the long treatment time, the YLWHA felt bored and discouraged with taking antiretroviral medicine. Some YLWHA were tired of taking ART repeatedly and felt discouraged because they had was an incurable disease. They did not comply with HIV treatment requirements. This issue was caused by: 1) being bored with taking medicine repeatedly, 2) feeling discouraged by the incurable nature of the disease, and 3) being in denial.

Most YLWHA felt tired of taking ART because they had to take the same medication with every meal for a long time:

I feel bored because I take it every day. One will get bored when doing something repeatedly. (Male youth)

YLWHA felt discouraged about the pathogenic condition of AIDS because they thought that as it was

an incurable disease they would finally die of it anyhow. One YLWHA, infected by her mother, bemoaned her life with HIV infection, wondering why this had happened to her and not others. As one female youth put it:

I felt it couldn't get any worse. This disease couldn't be cured. Why did this happen to me? Why didn't this happen to others? (Female youth)

Most YLWHA were infected by their mothers. Caregivers had to determine the readiness of youth regarding informing them about their blood tests. After taking their blood test, some YLWHA did not accept their positive sero-status. They showed resentment, anger and said that they could not accept their positive sero-status. In addition, some blamed their parents for causing them to be infected. As they said:

I can't accept that I'm infected. (Female youth)

I want to blame my mother for giving me this. I curse my mother in my mind. (Female youth)

Fear of disclosure

YLWHA were fear of being rejected by their friends. Although society currently accepts patients with HIV living among healthy people, it is noticeable that YLWHA do not let their friends and other people know that they have HIV, perhaps fearing discrimination and bias. They take the medication behind their friends' backs. The qualitative results indicated that two were concerned about disclosure. They did not want people to know that they were HIV-infected, and were afraid of being rejected by others, so they concealed their HIV infection. Losing friends and disclosure of infection are considered here:

When their friends knew about their HIV infection, they showed diverse behaviors, including not accepting them as friends, teasing them about the infection, and mocking them by saying that their mothers were dead because of AIDS. Furthermore,

their friends' rejection made participants not want to go to school. Consequently, they exhibited a lack of discipline in taking ART.

Some YLWHA were afraid that their friends might know about their HIV infection and reject them, refusing to play with them and making friends with others. One said:

I'm afraid that my friends will find out. If they do, nobody will be my friend. I'm afraid that others will know. If they do, they will never play with or talk to me. (Male youth)

Different perspectives revealed how YLWHA try to hide their HIV infection from other people. They mentioned secretly taking ART, to avoid suspicion by friends or lovers who would ask about their medicine. Two said:

I didn't tell. I was afraid I wouldn't have any friends. Sometimes I went to the toilet to take my medicine. (Female youth)

I had a girlfriend. I was afraid that she would know about my infection, so I didn't tell her. (Male youth)

Not managing medication

Participants did not have medication plans that fitted in with their daily lives. They learned and followed examples from friends in both thought and behavior so that their friends would accept them. These included hanging out, staying overnight at friends' houses, playing with friends, and traveling. These activities made many forget to carry and take their medicine while they were out.

I forgot to carry the medicine, so I didn't take it. For example, going out, staying at my friend's home, doing things with friends outside, like playing music, playing with friends, travelling to other provinces. I sometimes forgot when carried away by music. (Male youth)

I studied in the city. Sometimes I did not take the medicine. I went out to sketch and paint on the Walking Street. I had to go to work early sometimes, too. I just played with my friends. I returned to the city every evening. I slept at my friend's dormitory. Sometimes I left my medicine at home, so I didn't take it. (Male youth)

Because some participants did not always take their ART at the correct time, this affected the level of medicine in the blood circulation and the therapeutic action of the medication. Such behavior was the result from participants being teenagers. At this age, they wanted to be independent and they liked their freedom. They did not want to follow rules, and they wanted to be accepted by their friends. When YLWHA were doing other activities, they did not take their medicine on time. Sometimes it was because they got up late. Although participants knew that they must take ART on time, their mothers came to wake them up, yet they still do not get up to take ART.

Two said:

I sometimes didn't take the medicine on time. I woke up late. (Female youth)

I rarely took the medicine on time. Sometimes my mother woke me up but I didn't want to get up. (Female youth)

Risk-taking

Participants admitted that they had many risk behaviors, including: having sex without using condoms, having many sexual partners, participating in nightlife activities, drinking alcohol, and using narcotic drugs. They lacked constraints and consideration. They followed their sexual desires. Sometimes they were under the influence of narcotic drugs. According to the qualitative data, teenage-hood was a critical period of sexual development, psychosocial and emotional change that lead to HIV

risk behaviors. Moreover, external factors, such as the social and cultural context, and peers, parents, and neighbors, all might have a bearing on the HIV risk behaviors of the YLWHA. This caused them to be at greater risk from HIV infection. The three subthemes in this section are: lack of negotiation skills, curiosity, and poor safe sex planning skills.

Although YLWHA knew about safe sex, they either could not or did not use appropriate explanations in order to counter the persuasion of friends to engage in risky behavior. They could not negotiate with their sexual partners to use condoms while having sex. They had friends and hung out together, and were becoming adults and were at the age when friends' acceptance was important:

I had new friends. I smoked and drank, so I got a little naughty. When I was in Grade 5, I was very close to my friends. I went everywhere that my friends persuaded me to go. (Male youth)

Most of my friends stay in dormitories. They said we should go there. They asked me to drink with them. (Female youth)

Sometimes I used a condom and my girlfriend asked me if I didn't trust her. (Male youth)

Since YLWHA were becoming young adults, they were very curious, and when they saw the risky behaviors of their friends and parents, they wanted to do as they did. In addition, they might be challenged by their friends to try narcotic drugs. After trying and enjoying them, they could get addicted to such drugs easily, and three said:

I didn't know. I just wanted to try. When you're young you just want to try. Marijuana makes people go crazy. I smoked half a package of cigarettes a day; ten cigarettes. I did what my father and my grandfather did. My father and my grandfather smoked. I stole some to try. (Male youth)

I went out to drink alcohol. I went with friends. I wanted to be with them. I tried this and that. After that, I didn't use amphetamines any more. (Male youth)

I followed my naughty friends. They tried things and I wanted to try, too. (Male youth)

The YLWHA were poor in the skills used in preventing the spread of disease and infection from viruses during sexual intercourse. They did not carry condoms to prevent getting more viruses when having sex. During this period, the age of high sexual emotion, they are interested in sex and the opposite sex and they practice sexual behaviors leading to sexual intercourse. At this age they lack restraint, consideration, and deliberation in action and behavior, resulting especially in unprotected sex, for example:

I didn't use a condom. My girlfriend didn't know (about my condition). I didn't have any condoms. I forgot about them. (Male youth)

I didn't protect myself. I didn't prepare. (Male youth)

I slept with someone I didn't know, and I didn't prepare. (Female youth)

Discussion

The findings from this qualitative study highlighted the fact that most YLWHA did not fully adhere to HIV treatment because of cognitive and psychological factors, especially those associated with their teenage development. Even though knowledge about ART has spread rapidly through Thai society and the government has initiated efforts to expand the use of ART, YLWHA apparently still lack proper knowledge of ART. This might be due to the impact of perinatal HIV infection on their cognitive functions as they grew up, which caused them to have compromised learning ability, poor self-expression,

and less communication skills than healthy children.³³

However, educational methods have the potential to increase medication adherence self-efficacy and the perceived importance of taking ART close to the right time among the YLWHA.³⁴ The results of this study indicated that the YLWHA required knowledge about the benefits of ART in their lives and about management of the side effects of ART. These findings are consistent with another study that found similar results in youth in Nepal.³⁵

Study results also indicated that YLWHA felt discouraged about the pathogenic condition of AIDS. They faced ART problems such as the pill burden that includes the dosing schedule, dosing complexity and adverse drug effects. Lipodystrophy, especially face lipodystrophy, was a common long-term adverse effect of d4T, and PIs that was a likely cause of loss of YLWHA's quality of life and may lead to poor ART adherence.^{18, 36, 37} Our findings suggested that YLWHA were concerned about disclosing their HIV status because they expected a negative reaction from others. Females did not disclose their illness to their communities due to fear of negative reactions and discrimination from friends.¹⁰ They also faced social stigma from both their communities and their families.^{9, 38} These impacts could affect the accuracy of communication with health care providers for HIV treatment adherence. They needed society's understanding and education in order to reduce stigma and improve their mental health.¹¹

The YLWHA in our study, by forgetting to take medication, showed that they could not follow medication planning.³⁹ Based on their psychosocial and cognitive developmental trajectories, they needed their autonomy and independence, but were preoccupied with self-image and the need to fit in with their friends. The adherence to complex regimens was particularly challenging at a time of life when youths did not want to be different from their peers. It was difficult for them to take ART when they were asymptomatic, particularly regarding doing it on time.

These findings show the influence of parenting and peer behaviors on the sexual and drug use risk taking behaviors of YLWHA. In keeping with Thai social and cultural contextual conditions, their parents were not aware of their sexual behaviors because of their tendency to keep their sexual stories secret for fear of being scolded, blamed, and punished.⁴⁰ Parental disapproval of sex, lack of knowledge and skills in avoiding sexual risk-taking behaviors are associated with precoital behaviors, intentions and sexual initiation practice among Thai youths.⁴¹ Additionally, Thai YLWHA had lower sexual self-efficacy, which was associated with having multiple sex partners,⁴² difficulty refusing sex, and increased likelihood of unprotected sexual intercourse. Not surprisingly, the findings indicated that the link between the use of alcohol and drugs in sexual relationships increases the dangers therein. Alcohol was seen as a permissive or mediatory pathway enabling YLWHA to more easily break with traditional norms of sexual behaviors. Substances such as amphetamines were being used to increase sexual pleasure. Furthermore, this study indicated that peer norms including families and friends were a powerful influence on risky behaviors among YLWHA.⁴³ However, there was little data about the impact of family influence on HIV risk behaviors. These findings suggest that families of YLWHA may have negatively impacted the youths' risky behavior because parent-youth relationships played a significant role in youth development and attainment of autonomy. YLWHA lacked the knowledge that comes from experience and parent-child communication to guide them away from risky behavior.

Limitations

This study had several limitations. It was conducted with YLWHA living in Chiang Mai province, and therefore was unable to fully capture the cultural diversity across Thailand or to represent a larger population of YLWHA. Additionally, as this

study included only YLWHA who have accessed health care services, it did not provide data regarding different demographic and non-disclosed groups.

Conclusions

The qualitative results demonstrated rich findings about the phenomenon: that YLWHA are especially vulnerable to adherence problems and HIV risk behaviors due to increasing rate of drug resistance and opportunistic infection. Our results provide information and understanding about barriers to HIV treatment adherence among YLWHA for developing nursing guidelines and nursing care for YLWHA in nursing practice and nursing education. This should be of great benefit to the future quality of life of YLWHA in Thailand. YLWHA demonstrated an understanding of adherence and non-adherence to HIV treatment. They should be involved in planning comprehensive programs required to serve both the ART adherence and the psychosocial needs of YLWHA who are rapidly changing in physical maturation, cognitive processes, and life styles.

Future research: There is an urgent need for effective programs and strategies for enhancing HIV treatment adherence and reducing HIV risk behaviors. The YLWHA, together with their families and multidisciplinary care providers, should be engaged in the design and implementation of such research to guarantee relevance of such programs, so as to achieve HIV treatment success.

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อุปสรรคของควมมีวินัยเกี่ยวกับการดูแลรักษาเอชไอวีในกลุ่มเยาวชนที่ติดเชื้อเอชไอวี/เอดส์

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บทคัดย่อ: เยาวชนที่ติดเชื้อเอชไอวีต้องเผชิญความท้าทายกับการมีวินัยในการดูแลรักษาเอชไอวี ซึ่งส่งผลให้เกิดความล้มเหลวในการรักษาและทำให้เกิดการติดเชื้อ การศึกษาเชิงคุณภาพครั้งนี้เพื่อสำรวจความต้องการและความตระหนักเกี่ยวกับความมีวินัยในการดูแลรักษาเอชไอวีในกลุ่มเยาวชนที่ติดเชื้อเอชไอวีโดยใช้วิจัยเชิงเทคนิคแบบมีส่วนร่วม การทำสนทนากลุ่มและการสัมภาษณ์เชิงลึกในกลุ่มเยาวชนที่ติดเชื้อเอชไอวีจำนวน 25 รายที่อาศัยในภาคเหนือของประเทศไทย การวิเคราะห์ข้อมูลใช้วิธีการวิเคราะห์เนื้อหา ผลที่ได้แสดงให้เห็นว่าเยาวชนที่ติดเชื้อเอชไอวีขาดวินัยในการดูแลรักษาเอชไอวีและมีพฤติกรรมเสี่ยงเกี่ยวกับเอชไอวีโดยจัดกลุ่มเป็น 5 หัวข้อที่เกี่ยวข้องกับประสบการณ์ความมีวินัยเกี่ยวกับการดูแลรักษาเอชไอวีดังนี้ การขาดความรู้เกี่ยวกับยา, เปื้อนน้อย ท้อแท้ และปฏิเสธ, กลัวการเปิดเผย, ไม่ได้จัดการกับการรับประทานยา และการมีพฤติกรรมเสี่ยง ข้อมูลดังกล่าวสามารถสรุปได้ว่าผู้เข้าร่วมต้องการการสนับสนุนทางด้านจิตสังคมและการให้คำปรึกษาเกี่ยวกับการดูแลรักษาเอชไอวี พยาบาลเป็นผู้ที่มีบทบาทสำคัญในการพัฒนาโปรแกรมและกลยุทธ์ที่มีประสิทธิภาพที่เกิดจากการมีส่วนร่วมของเยาวชนที่ติดเชื้อเอชไอวี ครอบครัวและเจ้าหน้าที่ในทีมสุขภาพเพื่อให้การดูแลรักษาเอชไอวีประสบผลสำเร็จ

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