Self Concept in Adolescent Lesbian Living with HIV: A case Study

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Abstract

This research objective are studying self-concept, lifestyles, parenting styles and social support in 4 cases study of adolescent lesbians who are HIV infected from maternal, clinical and antiretroviral follow up at Srinagarind Hospital, Khon Kaen University, Khon Kaen province, Thailand. A self-concept questionnaire was developed from Anchalee Soodsane 's self-concept questionnaire, and a parenting style questionnaire was developed from Pannawadee Chantharach's parenting style questionnaire, and other data was collected by in-depth interviews and used Atlas.ti computer program for arrange data for analysis.

Research result found in a part of life style, positive self-actualizations related to relationship and supportive. Negative self-actualization was found related to HIV infected status but in health responsibility that found not awareness in healthy behavioral and poorly stress management skill. Parenting styles perception was democratic parenting style but some point not consistent with their perception. For social support found the important emotion support and information social support especially counselling was from friends and their fans supportive. Appraisal and instrumental social support was most found in their family. But about HIV and illness issues if not found in their family or medical team there are not found in other group. Self-Concept in academic value, almost were in positive direction. Self- Concept in interpersonal relationship that found almost of them has difficulties in establishing relationships with others. And emotional adjustment self-concept, positive emotional related good relationship with friends and their fan. Negative emotional that related with HIV infected status. Self-image that also found related to self-concept.

Keywords: Self-concept, adolescent lesbian, adolescent with HIV, case study

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Introduction

In 2014 Thailand had 34,000 adolescents with HIV/AIDS and 13,600 cases were maternal infections (Bureau of epidemiology, 2014). Even today, there is no way to eradicate HIV away from human body but there is an effective antiretroviral and standard treatment that developed system to care HIV people. As a result, HIV can control and not has opportunistic disease however they have to have good adherence. Now HIV infected is not terminal illness like in the past but it is called chronic illness. (Center for Disease Control and Prevention : CDC, 2015)

Children who infected HIV grow up to be a adolescents. They may have a difficult with chronic illness and in addition they will have difficulties to adapt themselves to be adolescents. (Sucha Chanem, 1986 cited in Neungruthai Khorphonklange,2009) In this period they try to find self-identity including sex role. (Sharinporn

Machara,2009). Particularly in the way of sexuality or sexual orientation, may affect the self-concept because self-concept is thinking, feeling and attitudes toward themselves in various fields. It is related between persons and environment; they have a perception to compare themselves with another and get information and feedback from the others. And they also want to know the others' feeling about themselves. (Kantha Umbhud, 2007, Thaweesitha Jaihaw, 2007) Factors are influence directly to self-concept, that are self- image, health status, intellectual, family's influences, parenting style, status and role in family, life style. (Pannee Jenchit, 1983 cited in Pimol Thanma, 2002). Thus, it can be seen caused and the ways to make a better selfconcept that are role and influence of family and society around adolescent. Family and society like a supportive network around adolescents. After review literature, met family, parenting style, social support in family and society around adolescent related to direction of their self-concept (Murphy DA, Moscicki AB, Vermund SH, & Muenz LR., 2000) thus, if an individual's self-concept is different likely due to factors related such as family, parenting style and social support.

The in-depth study on self-concept in adolescent lesbians living with HIV and explore related factors, first is life style explain with a self-actualization, health responsibility, exercise, nutrition, interpersonal relationship and stress management. Second factor is parenting style and last factors to explore social support. This study will make guideline and promote essential social support and will develop counseling in these adolescents to have more positive self- concept. In this study, the definition of "adolescents" is people which age between 18-24 years old and they are maternal HIV infection. The definition of "lesbians" is women who have sex at birth as female but love and/ or sexual preferences with the same sex; in this study has two words in a part of lesbian that are "*Tomboy*". Its definition is a word that calls a female who has characteristics and behaviors like a boy or a man and love or attracted to a girl or a woman like their girlfriend. And "*Lady*" its definition is a word that calls a female who has characteristics and behaviors like normally women or girl but love or attracted to a tomboy like their boyfriend.

Research Objectives

To study self-concept, lifestyles, parenting styles and social support in adolescent lesbians who are HIV infected from maternal.

Participant

Four cases study of adolescent lesbians who are HIV infected from maternal and their range age between 18-24 years old, clinical and antiretroviral (ARV) follow up at Srinagarind Hospital, Khon Kaen University, Khon Kaen province, Thailand. Participant was enrolled by proposing if meet all criteria and has inform consent to be case study.

Research Methodology

This research was mixed method; research tools were in-depth interview and two questionnaires were used to collected data. Questionnaire developed from Pannawadee Chantharach's parenting styles and Anchalee Soodsane's self-concept questionnaires. It was used to collected data in first time of interview. After that there had an appointment for 30-40 minutes in-depth interview a time, average appointment was 3-5 times a case study until data was saturated. Data was collected between December 2015 and February 2016 then collected data was content analysis and used Atlas.ti to arrange all data. Data from questionnaire was analyses by frequency in whole and in each item that related points to data from in-depth interview.

Research Result

Case study No.1

Demographic data: she is 22 years old. Study in high vocational. Her parent was passed away by AIDS since she was 8 years old after that her relative send her to the government orphanage. At the orphanage, she has treated HIV with ARV and good adherence. In last year, she was discharged from the orphanage. She is supported by Non-Governmental-Organization (NGO) about living expense, she was treat by nurse staff who is supported from that NGO.

She defines herself as a tomboy; her girlfriend stays at the same orphanage and college. They have relationship like lover more than 5 years ago.

About treatment information, she is transferring to infectious adult clinic, healthy, good adherence and not has opportunistic disease. Her current ARV is Tenofovir,

Lamivudine and Efavarenz but about white blood cell (CD4) and viral load (VL) level cannot remember. She has taken ARV more than 13 years ago.

Life Style:

Self-actualization It related two dominants, first related her acceptation in HIV, after she had changed her attitude toward HIV due to she had connected with HIV peer group and there were discussed, sharing and supported together. As a result, she has positive attitude toward herself. Second relation is supportive from other; not only scholarship from sponsor but she also got helping from friends, girlfriend and medical team about to be counselor. Moreover her friends treat like she is value friend. A negative self-actualization related to a dominant and other minor. A dominant point is about infected status. She concerns about relationship with friends and other if disclose. She gains the esteem of peers in the group. Other concerns are about selfimage; her height. She thinks that is the result of an infection and ARV. And worthless feeling related to the not attention from her relatives as expected. **Health Responsibility** found a healthy behavior is associated with good understanding in HIV infected and the concern in illness which may make people know that they are infected with HIV. As a result, she has a strictly good behavior in health care.

Personal Relationship the data found that friends and girl friend relationship are the most important impact to healthy behavior, by providing the instrument support, information and emotional support. And she has a good relationship with the medical team who providing instrument and information supportive. Simultaneously, the HIV peer network is associated a part in changing the perspective on the illness and more positive attitude toward HIV.

Stress management found three dominant problems that met in daily life. Those are HIV related problem, relationship problem and insufficient expense. The handle on the problem has two forms, first trying to prevent problem situation, second trying to change perspective about problem.

Parenting Style

The scores from the questionnaires showed the most score parenting style was democratic, second was authoritarian and the last was uninvolved parenting style. That consistent with results from in-depth interview. After she admitted to the orphanage since nine years old therefore she stayed in there over 10 years. At the first, she was treated with ARV and HIV status was disclose so she was take care in closely by orphanage staff; during take ARV in everyday after took it she got a reward, As a result, she did not feel bad for taking ARV. Moreover it not only caring in her health, they like be a counselor when she had any problems. She usually had opportunities to join in the activities in the orphanage. Her closely care giver took care her warmly and reasonable.

Social support

In this case study, it is from four principles as friends, girlfriend, medical team and NGO from abroad. Friends like be an emotional and an appraisal social support and could found that in girlfriend and included HIV issue and illness. Information and instrumental social support like supported by medical team. Scholarship and daily expense are supported by NGO. In her daily life, friends are the most important and have influence to this case study.

Self-Concept

For first, self-concept in academic value in this case study, it likes to be positive direction. She thinks she has a moderate intelligence, an appreciated writing and reading skill but weakly in calculated. In a part of learning behavioural she likes to learn by demonstrated in each step, likes to fixation and creative. Then, self-concept of interpersonal relationship also to be positive direction. She has good relationship with friends, has a closely friend group and to be loved and friendly. Girlfriends relationship is good, a mutual understanding and can encourage when has any problems. But she often unconvinced because of fearing that girlfriend turn away to love a better men. This case study has positive attitude toward working with other, a

personality trait like assertive, socialize and friendly. And last about emotional adjustment self –concept that found all emotional depend on relationship with friends and girlfriend. Not confident feeling in relationship makes a negative mood. HIV issue might relate boring and anxiety emotional and it is a principle cause of unconvinced. Although until now she never discloses her infected status to friends.

Case study No.2

Demographic data: she is 21 years old. Her parent passed away since she was only 2 years old after that her relative send her to the government orphanage with her older sister who was only 5 years old. At the orphanage, she has treated HIV with ARV. After she finished primary school, she has psoriasis symptoms. It often appeared so she was drop out from school then studied in informal education and occupational training about sewing and cooking. She moved out from the orphanage with her older sister when she was 18 years old. She had worked with friends near the orphanage but when symptom of psoriasis shown she had been laid off. So she needs to stay with her older sister. And find a job again, now she works in convenient store near Bangkok and her salary is 8,000 THB.

She defines herself as a tomboy; her currently girlfriend like tomboy too but just has relationship about one month.

About treatment information, she is transferring to adult infectious clinic, healthy, good adherence and not has opportunistic disease. Not has psoriasis symptom. Her current ARV is Zilavir and Efavarenz but about CD4 and viral load level cannot remember. She has taken ARV more than 15 years ago.

Life Style:

Self-actualization that found she has negative self –actualization there were data that support more than positive self –actualization. It is her social support, there is only from her older sister. Other supportive is from her friend from the same orphanage and same work place. The supported data with negative self-actualization like when she has neither any trouble in daily life nor one to be beside. She concerns about illness especially psoriasis symptom, self-image that she though it is a cause of short relationship with her girlfriends and it also affected when she finding any job.

Moreover, her problem arrangement that often not success to solve might be a cause of negative self-actualization such as when she had insufficiency expense in each month she likes to starve.

Health Responsibility in this case that found only good adherence, it is good behavioral for healthy but other behavioral in daily life like to be not, such as one meal a day in regularly, starve due to insufficiency money, regularly sleep late, drink alcohol and do not exercise. Although now her health is good but she stills nervous in psoriasis symptom that cannot forecast.

Stress Management found two principle problems, first that is insufficiency expense. Second is anxiety in self-image because of her height only 138 centimeter and usually affected to relationship with her girlfriends and works application. In the part of problem solving, about insufficiency she has chosen starve. Self-image problem just only has consulted her older sister; she thinks this problem cannot change anything just only release negative feeling when met disappoints situation.

Interpersonal Relationship in her daily life, it related with family and workplace. She is supported by only two groups. According to her positive self-actualization due to usually has sister supportive in her daily life such as to be consultant and took care when she was sick. Relationship with colleague, she was trained about job and when she will go to a hospital for get antiretroviral, they usually loan for transportation expense and medicine expense.

Parenting Style

As questionnaire score that found the most score parenting style was democratic, second was an authoritarian and last was uninvolved parenting style. But the score that found from questionnaire like similar, that consistent with results from the indepth interview, she admitted to the orphanage since two years old therefore she stayed in there over 15 years. She was changed a care giver many times and they have an individual characteristic therefore they have different parenting styles. Moreover she likes to talk with her sister since when they stay together in the orphanage, not trust in a caregiver and friends.

Social support

In her daily life found most of them were related family members such as emotional, appraisal and information social support but after evaluated of family supportive found it was less and inefficient, this may be the reason for lack skills in problem-solving strategies in life and negative attitude toward herself. Social support from colleague is only instrumental supportive, they usually loan for transportation expense and medicine expense.

Self-Concept

As analysis data that found academic value self-concept is negative direction, data from questionnaire and in-depth interview was compatibility. She thinks she has a low intelligence, an unappreciated writing and reading skill and weakly in calculated. She likes to learn about occupational training not academic. Interpersonal relationship self-concept, she has not good relationship and does not has a closely friend. Former girlfriends' relationship was good when communicated via social network like LINE chat programme or FACEBOOK programme but when they met her in realistic, relationship had changed and break contact in finally. She was encouraged only from family member when has any problems. About working with other, she thinks she can work but not like friendly with colleague; her personality trait like introvert and less social skill. And last about emotional adjustment self –concept that found positive emotional depend on relationship with girlfriend, like to be protector and leader that fulfill her self-esteem.Negative emotional; boring and anxiety emotional that related insufficiency expense and psoriasis illness. In this case HIV is not affected to her emotional, she not disclos infected status anyway.

Case study No.3

Demographic data

She is 21 years old. Her parent passed away when she was primary school age, after that she has stayed with grandmother. Her grandmother was a Thai dessert street vender, low income and insufficiency expense in each month but her aunt has supported until she finished primary school, she and her grandmother moved to stay with her aunt in downtown. She was treated by ARV as result her health was good, no had an opportunistic disease, she could studied until finish high school and now she is forth year university student. She often joined in activities that organized by HIV peer network, she had been elected to lead the youth camp, art camp in regional and national but after she enrolled to be a university student, she quits from all activities. She was supported by her aunt 2,000 THB and loan from student loan fund 2,200 THB a month. In case if not insufficiency she could ask her aunt more. There are five family members, her aunt family's income more than 50,000 THB a month.

She defines herself as a lady. Now she has a boyfriend and their relationship more than one year. But she not discloses her infectious status. Her boyfriend is an office staff. Now they are stay together at her aunt's house.

About treatment information, she is transferring to adult infectious clinic, but she never go to adult infectious clinic after has transferred more than 1 year. Her health still good but has Pruritic Papular Euption (PPE), not has serious opportunistic disease. Her current ARV is Tenofovir, Lamivudine and Lopinavir. Her CD4 and viral load level cannot remember. She has taken ARVmore than 13 years ago.

Life style:

Self-actualization a positive self-actualization related to family supportive, she has opportunity to attend school until study in the university, living with independently not authoritarian treat like other teenage. About HIV issue, she think it is fortunately that the disease not rapidly progress if take ARV in good. It will be healthy like a normal person. Now her perception about health it is still good although she not goes to hospital for follow up her clinical more than 1 year ago and last for positive selfactualization, she satisfied in currently love status, be loved and treated by her boyfriend although she thinks love among lesbian is not long period. For negative self-actualization related to HIV issue and ARV, she does not want to disclose her infected status because people around her not understanding and acceptable to HIV and infected people. Moreover she has fear and anxiety about her illness but also bored to usually take ARV. She has negative attitude toward ARV due to its side effect. Illness made her likes different from friend, she likes to be normally life same as her friends, does not considerate with illness thus she tried to be passive personality among friends, tried to avoid conflict at all, accept things as friends are and avoid upsetting others.

Health Responsibility as data was analysed that found causes of irresponsible behavioural related to her health perception, she thought her health still good and disease not rapidly progress and no symptoms thus she attempts to refused her reality

illness status by laboratory; CD4 count and Viral load level and not aware to health promote and symptomatic prevention.

Stress Management found her stress strategies like to be escaped a problem, not faced with a stressful situation, usually release pressure by diary. And in her daily life, stress caused by relationship with friends and her grandmother but a principle caused by HIV and infected status disclosure.

Parenting Style

As data from questionnaire that found the most score is democratic, second was uninvolved and the last was an authoritarian parenting style. The score that found from questionnaire that consistent with results from in-depth interview, her aunts treated her like their daughter, accepted her opinion and also her sex orientation. They gave opportunities to do in favorite things, about studying she could choose by herself and to be a counselor if she has any problems.

Social Support

In this case study was derived from three main groups; family members, friends and boyfriend but a dominant social support in all part is family supportive that are emotional, instrumental and information support. Friends supportive are appraisal support and assisted her study but social support that found not related to health promote and take ARV with continuity.

Self-Concept

First, self-concept in academic value in this case study that data found her attitude toward her academic value in positive direction, related to data from questionnaire. Then, interpersonal relationship self-concept, analysis data that found she think, she has good relationship with friends because of her personality trait like assertive, socialize and friendly so easy to make relationship with other but not deep relationship related to data from questionnaire. And last about emotional adjustment self –concept that found negative direction toward emotional adjustment, because of happiness in life is unclear but attitude toward negative mood found related with illness, ARV taking which has been unable to arrange the problem and negative feelings as they occur.

Case study No.4

She is 21 years old. Her parent passed away by AIDS when she is a toddler after that she stayed with adopted father; he is her uncle. Now she did not attending school after she finish high school she could enroll to be a government university student but when she is studying in 2^{nd} year she dropped out, although she tried to be a private university student she also dropped out.

Presently, she has online business with her boyfriend; cosmetic and fashion cloth on internet that has income about 3,000 -5,000 THB and she usually gets monthly expense from her adopted father 8,000 THB; he has owner business.

Her family is 6 members; adopted father, aunt, aunt in law and their 2 twin daughter and her adopted mother works at the United States.

She defines herself as a lady. Now she has a boyfriend and stays together in downtown private apartment did not stay at her adopted father house like a past because she likes to be independent. Her boyfriend is similar age; known through social media Tom Lady Online chat program and their relationship is more than 2 year, but she not discloses her infectious status.

About treatment information, she is transferring to adult infectious clinic, but she never go to adult infectious clinic after has transferred more than 1 year. Her health still good but has Pruritic Papular Euption (PPE), not has serious opportunistic disease. Her current antiretroviral (ARV) is Tenofovir, Lamivudine and Lopinavir and about CD4 count and viral load level cannot remember. She has taken ARV more than 13 years ago.

Life Style

Self-Actualization as data was analyzed that found self-actualization in both positive and negative, first for positive self-actualization related to independent life; now she does not stays with family so not limited teenage life by strictly family rule and she thinks she can take care herself. And negative self-actualization that related about she stills remain depend monthly expense from her adopted father she likes to has a full time job, and negative self-actualization also related to HIV and infected status disclosure including her illness is a chronic disease; uncured. She should take a medicine in everyday but frustrated that she cannot so concern about AIDS symptom that might be appear and finally other will know about her illness.

Responsibility Health in this case study as data was analysed that not found any behavioural which promote healthy like as regularly exercise, eating every meals and nutritious foods and behavioral for treatment like regularly take medicine and clinical follow up also not found. It may be caused by several factors such as her perception in health is still good, lack of strong social support because of now she stays with her boyfriend similar age; might not awareness in health promoting.

Personal Relationship that found relationship that happens in her daily life are friends relationship and boyfriend relationship like information, encourage and counseling supportive but excluded HIV and illness issue but family relationship that found only instrumental supportive more than counseling and encourage.

Stress Management that found three main problems that happen in her daily life, there are HIV and illness issue, boyfriend relationship and concern about job; likes to have a full time job. Problem strategies are two patterns; first she likes to try solving a problem by herself such as trial and error method, second pattern if a difficulty problems she likes to ignore until had a new idea.

Parenting Style as parenting style questionnaire score that found the most score is democratic, second was an authoritarian and the last was uninvolved parenting style. The score that found from questionnaire is related to data from the in-depth interview, after she moved from uncle house and stayed with adopted father, parenting style

changed from authoritarian style to be democratic style; from family strictly rules to be flexible rules when stayed with her adopted father felt not frustrated and she had more freedom to decision about her life otherwise she is supported in expense and other instrumental.

But after she moved to stays with her boyfriend, relationship with family not closely like a past, there are only budget supportive. And a point that not like democratic parenting style is attending time might not enough for attending and counselling, most of daily life she usually stays with her aunt family; they are characteristics like authoritarian, strictly rules and not accepted her opinion.

Social Support

That found social support in her daily life is her boyfriend supportive, she has emotional, information and instrumental supportive but excluded HIV and illness issue. Social support from a few closely friends including a friend who HIV infected that found emotional and information supportive. Family relationship that found emotional, appraisal and instrumental supportive but not found information supportive like counselling and encourage. Although she has sufficiency in the living factors but social support that found not related to health promote and take ARV with continuity.

Self-Concept

Self-concept in part of academic value that found trend to positive direction, her perception in intelligence is moderate level. She has ability about art but weakness in calculated. Self-Concept in a part of personal relationship, her perception like a negative direction, she has introvert personality so hardly and take a time to make a new relationship but she likes to make it via social network as a Chat program more than in a normally society. Self –Concept in a part of emotional adjustment that found illness issue affected to negative emotion and moreover related to anxiety emotion about relationship with boyfriends and friends if they know about infected status, for positive emotion related to good relationship with boyfriend and supportive from family.

Conclusion

As content analysis that from in-depth interview data, frequency score counting in whole questionnaire and each item analysis from parenting style questionnaire and self-concept questionnaire. That found life style is comprised self- actualization, health responsibility, exercise, nutrition, interpersonal relationship and stress management. In four cases study found positive self-actualization caused was related with relationship and supportive between their fan, friends, family and a medical team. A negative self-actualization was found related with HIV infected status concerns; not want to disclose. In addition, issues related self-actualization is the problems in daily life and not success solving. In health responsibility that found only one case has healthy behavioral and good adherence to taking antiretroviral but in three cases found they are not aware in good behavioral for healthy. Its cause may from case no.1, she has a scholarship and she is closely monitored by staff.

Parent Style: As analyzed data from questionnaire that found four cases parenting styles perception is democratic but when considered and analyzed from in-depth interview data found some point not related to their perception they lack support in the consultation for information on the decision. And in addition, a not clearance rules in the family that found some case study could go to pub or bar in lately night; not necessary to ask for permission and they also could drink alcohol.

For social support that found the important emotion support is supportive from friends and their fan; accepted in their individual that made they feel valuable, received love, trust and care. Appraisal social support, most found in their family. They can get feedback in both positive and negative data for evaluated themselves. Instrumental social support was found from family and some friends. Information social support especially counselling was found from friends and fan, only one case usually consulted her sister. HIV and illness issues if not found in their family or medical team there are not found in other group.

Self-Concept in academic value, almost are in positive direction; they could study in the university and they knew about their ability and aptitude. Self- Concept in interpersonal relationship that found almost of them have there are difficulties in establishing relationships with others due to introvert personality and not trust other. Emotional adjustment self-concept that found all, there are positive emotional related good relationship with friends and their fan. Otherwise it related with supportive from other. There are negative emotional that related HIV infected status not like to disclose. They always concern about their illness symptoms other might know their infected. Self-image that also found related to self-concept; their physical had effected by HIV and serious illness when they were young. Now their body weight and height lower than Thai standard. Self-image also related to relationship problem.

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