

Article

Spirituality and Dignity of Thai Adolescents Living with HIV

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Abstract: (1) Background: Adolescents are a key asset and resource for the social and economic development of any country, with the potential to make a significant contribution to their families, communities and countries. Healthy and educated adolescents are important. However, there are still significant rates of death, illness and disease among adolescents in some countries, where HIV is one of the most prevalent causes of death in this group. Adolescents living with HIV may experience and encounter social restrictions and physiological limitations. Therefore, this investigation explored whether the concepts of spirituality and dignity had any relevance to participants sense of meaning and purpose and whether these had any impact upon their health and well-being (2) Methods: A qualitative descriptive design was used involving twenty-two adolescents living with HIV attending one regional hospital in Southern Thailand. One to one interviews and descriptive diaries were used to collect the data and thematic analysis enabled the identification of attributes of spirituality and dignity. (3) Results: The findings revealed that spirituality and dignity were present in the lives of Thai adolescents living with HIV expressed in the main category of living life responsibly. This comprised of six themes: (a) Understanding the disease and accepting the truth about life, (b) Maintaining hope for a cure, (c) Focusing on life's purposes, (d) Making life choices, (e) Caring for oneself and (f) Responsibility towards other. (4) Conclusions: The findings provide helpful insights for parents, nurses, and other health professionals supporting adolescents living with HIV to obtain a holistic, dignified approach to care that includes attention to the spiritual dimension.

Keywords: adolescence; HIV; dignity; spirituality; qualitative research

1. Introduction

Adolescence is a phase in life where health is often good and future patterns of adult health are established. Adolescents are a key asset and resource for the social and economic development of societies and nations with great potential to contribute to their families, communities and countries (World Health Organization (WHO 2014)). Adolescents' evolving capacities affect how they think about their health and future, and how these may influence their decisions and actions. However, adolescence is a time of considerable risk. The physiological, emotional and social changes in adolescence may influence the choices they make and behaviors they engage in. Therefore, this transition may affect the spectrum of diseases and health-related behaviors, experienced by

adolescents. The WHO (2014) suggests they are responsible for the epidemiological transition that takes place during the second decade from infectious diseases to no communicable conditions. This means there are still significant rates of death, illness and disease among adolescents. There is a need to focus more on the deaths that occur during adolescence because no adolescent should die from a cause that is preventable or treatable.

1.1. Prevalence of HIV in Adolescents

HIV is one of the most prevalent causes of death among adolescents (WHO 2016). Although the overall number of HIV-related deaths worldwide is down 30%, estimates suggest that HIV deaths among adolescents are rising (WHO 2014, 2016). In 2015, an estimated 36.7 million [34.0 million–39.8 million] people were living with HIV and the annual number of new infections among adults remained static at about 1.9 million [1.7 million–2.2 million]. Importantly, adolescent girls and young women aged 15–24 years are at high risk of getting HIV infection (UNAIDS 2016), “accounting for 20% of new HIV infections among adults globally in 2015, despite accounting for just 11% of the adult population” (UNAIDS 2016, p. 8). In the Global Summary of the AIDS Epidemic in 2015, nearly 2 million adolescents (aged 10–19) were living with HIV (UNICEF 2016) and more than 40% of new HIV infections globally were recorded in adolescents and young adult populations (12–24 years) (Kim et al. 2014).

Thailand is a global leader in HIV prevention and treatment. It has a strong commitment to achieving the 90-90-90 goal by 2020, having developed comprehensive and proactive strategies, which has meant that the epidemic is now in decline (Siraprapasirin et al. 2016). In 2015, Thailand was ranked as having the fourth largest HIV prevalence in Asia and the Pacific, accounting for 9% of the region’s total HIV population (UNAIDS 2014). It has been estimated that there are approximately 445,504 people living with HIV/AIDS in Thailand and 7,816 individuals became newly infected with HIV, while the estimated HIV prevalence among adults is 0.83% aged over 15 years (Siraprapasirin et al. 2016). In particular, the rates of Thai adolescents infected with HIV are rising, with approximately 35,000 young people aged 10–24 years infected with HIV in 2014 (Ministry of Public Health 2014). This increase may also reflect the fact that although more children with HIV survive into adolescence, some still do not receive sufficient care and support (WHO 2016).

HIV-related stigma has a detrimental impact on a variety of health-related outcomes in people living with HIV (Rueda et al. 2016). HIV-related stigma and discrimination continue to occur in all national settings, and frequently work to entrench existing social inequalities and intersect with other forms of stigma. Similar to other western countries, stigma attached to HIV infection and AIDS is a common phenomenon as experienced by persons living with HIV/AIDS, families and health care providers in Thailand. The report from the rollout of the People Living with HIV Stigma Index (PLHIV Stigma Index) in nine countries in Asia and the Pacific including Thailand showed that HIV-related stigma is pervasive in the lives of people living with HIV (UNAIDS 2011). Stigma marks people as being different attaching to them an element of disgrace (Goffman 1986). It denies an individual’s dignity; respect and right to participate fully in their community. Stigma manifests in discriminatory and sometimes violent treatment of people living with HIV, their families and others affected by HIV. It can have a negative impact and impose restrictions on education, work, and healthcare (Churcher 2013; Turan et al. 2017; UNAIDS 2011). It may restrict travel, prevent participation in religious or cultural ceremonies, and trigger verbal or physical violence, isolation or complete ostracism. It may also affect personal and family life, including the opportunity to marry and to bear and raise children (UNAIDS 2011).

Stigma may be internalized and experienced as shame or guilt, or externalized as discrimination. It may lead to reduced self-confidence, loss of motivation, withdrawal from social contact, avoidance of work and health-based interactions, and abandonment of planning for a positive future (UNAIDS 2011). People living with HIV may experience more cognitive impairment and more depression (Akena et al. 2010). A life crisis such as living with HIV can inhibit an adolescent’s ability to mature and reach their full potential enabling them to experience a meaningful life including Thai adolescents. The study in the Thai context found that diagnosis with

HIV was life threatening for Thai adolescent. Some of them dropped out from school because they felt worried that their HIV status would be disclosed. They experienced stigmatization and discrimination (Balthip and Purnell 2014). In the case of Thai adolescents living with HIV, a diagnosis can interfere with all dimensions of their life—body, mind, and spirit. Their life becomes characterized by challenges and restrictions which some may have encountered from birth (Balthip and Purnell 2014). Life restrictions may result in some adolescents living with HIV developing psychiatric disorders and attempting suicide (Musisi and Kinyanda 2009).

Recently, advances in combination antiretroviral therapy (ART) and treatment provide hope of long-term stabilization of the infection transforming the lives of people living with HIV. In addition, although the WHO (2015) guidelines stated that ART should be provide for all adolescents living with HIV, adolescents face significant barriers accessing and remaining in HIV treatment and engaged with care services. These complicated new treatment regimens present difficulties related to medication adherence. A systematic review and meta-analysis conducted by Kim et al. (2014) found that only 62% of adolescents and young adults were adherent when taking ART. Moreover, the current WHO and UNAIDS (2015) guidelines for HIV mainly focus on physical and psychological health. Providing physical care alone such as access to ART may not be enough to improve the quality of care, and promote adherence and compliance.

1.2. Spirituality and Finding Meaning and Purpose in Life

Spirituality is a broad concept comprising of several key attributes, meaning and purpose, transcendence, connectedness, relationships and religiosity (Puchalski et al. 2014). There is a growing body of evidence suggesting that spirituality can play a key role in nurturing good health, healing, and well-being (Koenig et al. 2012) because spirituality confers inner strength, comfort, peace, wellness, and wholeness (Narayanasamy 2001). A systematic review exploring the impact of adolescents' religiosity/spirituality and mental health found that most studies (90%) showed that higher levels of religiosity/spirituality were associated with better mental health in adolescents. Adolescents who reported higher levels of religiosity/spirituality were more likely to report having better mental health (Wong et al. 2006). Similarly, a study of spirituality and religion in patients with HIV/AIDS found that patients with a spiritual and religious belief had greater optimism, greater self-esteem, greater life satisfaction, and they drank less alcohol (Cotton et al. 2006). An exploratory qualitative study, focused on the meanings older adolescents aged 16–19 attach to spirituality (Spurr et al. 2013). The findings suggested that the majority of participants agreed that spirituality significantly affects their sense of wellness. They believed that spirituality is an important dimension of wellness that lead to an increased self-esteem providing a set of rules that assisted them to live a better or healthier life (Spurr et al. 2013). In adults living with HIV, spirituality helped them to cope with side effects of ART and increased adherence (Kremer et al. 2009).

1.3. The Four Notions of Dignity

McSherry (2016) claims that spirituality and dignity are intimately related and inherent in every human being since to ignore the role of spirituality in the health and wellbeing of the individual could lead to a violation of their dignity. Nordenfelt and Edgar (2005) in their four notions of dignity model suggest dignity is something we all possess as human beings. Dignity relates to moral stature linked to self-respect and respect for others. Dignity is related to the identity we attach to ourselves as integrated and autonomous individuals with a history and; the dignity of merit (formal and informal) often associated with rank, office, position and recognition of achievement or contribution to society. The four notions suggest that the preservation of human dignity is a priority for all societies and the responsibility of each person; it seems especially pertinent for those providing healthcare. The validation of human dignity can lead to positive attitudes, behaviors and life choices. This has relevance for adolescence living with HIV because their own self-identity and worth may be threatened through fear, and the attitudes of others towards them within society from the stigma and discrimination they can encounter.

Currently, the influence of spirituality and dignity on adolescents living with HIV in particular in the Thai context is undocumented. There is little evidence exploring adolescents' understandings of spirituality and dignity. Moreover, how these concepts may influence their life style choices and health behaviors. Crucially, many of the insights of spirituality and dignity have been developed with adult populations, Christians and Western cultures in particular the U.S. (Wong et al. 2006). To date, existing knowledge associated with spirituality and dignity amongst adolescents living with HIV does not provide health professionals with sufficient depth of understanding about the pivotal role of spirituality and dignity in enhancing the well-being of adolescents living with HIV.

This study is timely in light of the increasing availability of and effectiveness of antiretroviral therapy, which means many adolescents are surviving into adulthood. These positive outcomes necessitate the development of services that offer a holistic approach including psychological and spiritual support. The paper presents the findings from a qualitative descriptive study that explored how adolescents living with HIV in Thai context achieved meaning and purpose in life. Thematic analysis was used to identify whether the concepts of spirituality and dignity had any relevance to participants sense of meaning and purpose and whether these had any impact upon their health and well-being.

2. Methods

2.1. Design

A qualitative descriptive design explored how Thai adolescents living with HIV established meaning and purpose in life. The concepts of spirituality and dignity are not used explicitly in Thai culture because these are seen as integral to the delivery of holistic care; these two terms/words were not used directly with participants in the interviews. Thematic analysis enabled the identification of attributes of spirituality (Puchalski et al. 2014; Royal College of Nursing 2011) and dignity, as defined in Western healthcare (Tranvåg et al. 2016) in the participants' responses to gain an understanding of how these may support adolescents living with HIV to achieve meaning and purpose in life.

2.2. Participants Selection and Recruitment

Data were gathered from 22 adolescents living with HIV attending one regional hospital in Southern Thailand. Participants were selected according to the following inclusion criteria: they had lived with HIV for 3 or more years, aged 15 to 19 years, were able to communicate well in the Thai language, and were willing to participate. Participants aged less than 18 years were required to have a guardian. At the outset of the study, 34 adolescents living with HIV were notified about the study and of these 25 met the inclusion criteria. Of the 9 adolescents who did not meet the criteria, 2 were younger than 15 years, 5 were older than 19 years, and 2 had difficulty reading and writing in the Thai language. Of the 25 participants who met the criteria, three were subsequently excluded because follow-up interviews could not be conducted to validate (clarify, expand, or confirm) data from the first interviews because they had moved. This was because the quality of the response in the first interview was very superficial and insufficient to be included in the analysis.

2.3. Participant Demographics

Participants included 12 female and 10 male. Three participants identified themselves as gay men and infected with HIV from sexual transmission. They had not disclosed their HIV status to anyone including their family members. None of the participants had publically disclosed their HIV status except one female participant who, because she receives a monthly allowance of 600 baht from the local authority, had to disclose to them her HIV status. (Table 1).

Table 1. Participant Demographics ($n = 22$).

| Information | Number |
|---------------------------------------|---------------|
| Gender | |
| Male | 10 |
| Female | 12 |
| Marital Status | |
| Single | 17 |
| Married/cohabited | 4 |
| Separated-divorced | 1 |
| Education | |
| Primary school or less | 2 |
| Secondary school | 7 |
| High school/college | 10 |
| Bachelor | 13 |
| Religion | |
| Buddhist | 21 |
| Islam | 1 |
| Living arrangements | |
| w/spouse/partner | 4 |
| w/family | 16 |
| Alone | 2 |
| Employment Status | |
| Student | 12 |
| Student and work a part time job | 5 |
| Employed as unskilled worker | 1 |
| Working in rubber garden | 2 |
| Unemployed/no permanent job | 2 |
| Means of Transmission | |
| Sexual intercourse | 4 |
| Mother-to-child | 15 |
| No identify causes | 3 |
| Duration of infection with HIV | |
| <5 years | 5 |
| 5–10 years | 2 |
| >10 years | 15 |

2.4. Ethical Considerations

The Human Ethics Committee, Faculty of Nursing, Prince of Songkla University, Thailand (Protocol number 0521.1.05/2308), approved the study. Permission to access participants was gained from the director of the hospital. Participants received detailed information and a description of the study from the nurses who cared for them. Participants were informed participation was voluntary and all information would be kept confidential for example any information that might identify participants was removed. Data were stored securely and destroyed after analysis and a pseudonym used. Informed and written consent were gained from all participants before proceeding with the interview.

2.5. Data Collection

Data were collected between September 2015 and February 2016 through in-depth interviews with participants and descriptive diary writing. Because of the sensitive issues and the need to establish a rapport with the participants it was necessary to conduct follow up interviews with some

of the participants, this was to clarify some points that had emerged during transcription or data analysis.

2.6. Interview

In-depth one to one interviews were digitally recorded then transcribed verbatim. All interviews were conducted in a private place at various locations including a room in the hospital, in a quiet space in a public park, and universities. Interviews included a set of broad open-ended questions that did not explicitly use the terms spirituality and dignity but focused more on purpose in life. Three experts reviewed the interview guide to ensure content validity. The guide included broad open-ended questions. The necessary probing questions were used to explore an issue in more depth. Questions focused on meaning and purpose in life, which is an essential component of spirituality and human dignity. For example: How do you live with HIV? How do you feel about living with HIV? What are your experiences in managing and living with HIV? For participants who reported that, their life had changed the following probing questions were used: You said that HIV had changed your life, could you please explain how it changed your life? How do you overcome your changing situation? How do you maintain your health status? And What helps you to be able to live with HIV?

The length of interview ranged from 40 to 60 minutes. The numbers of interviews conducted with participants ranged from 1–3 with the average being 2. This was to explore issues that needed clarifying from the first interview, primarily about establishing a rapport, and connection with each participant.

2.7. Descriptive Diaries

A descriptive diary was used in-conjunction with in-depth interviews to enhance the credibility of the data. This was optional and not all participants undertook this activity. Descriptive diaries can provide important data presenting the perspective and the attitudes about those events that are important to the person (Jacelon and Imperio 2005). Participants kept a daily narrative about themselves including their activities at home, school, and workplace. The diaries helped capture participants' life experiences of living with HIV by reflecting more on the questions mentioned above, in particular, three questions: How do you overcome your changing situation? How do you maintain your health status? What helps you to be able to live with HIV?

Participants recalled events and drew pictures in their diaries and these were reviewed during follow-up interviews this enriched the data adding to its trustworthiness and encouraged participants to share their experiences. These were analyzed to identify duties, daily activities, and special events that may describe the spirituality and dignity of the participants.

2.8. Trustworthiness and Credibility

Trustworthiness and credibility were increased by recruiting and interviewing participants who were able to describe their experience of living with HIV and were able to engage throughout the duration of the study. Prolonged engagement entailed interviewing on more than one occasion if necessary to obtain a rich understanding and to explore and uncover the experience that the participants gave to their ideas, feelings, experiences and perceptions. Participants were forwarded a copy of their interview(s) transcripts to read and validate.

2.9. Data Analysis

We analyzed interview transcripts and diaries using an adapted version of Colaizzi's (Colaizzi 1978) phenomenological method to draw out the phenomenon of spirituality and dignity and how these may be used by Thai adolescents living with HIV. Thematic analysis using the following steps revealed how Thai adolescents living with HIV achieved meaning and purpose in life, and how attributes of spirituality and dignity contributed to this process.

(1). First, all interviews were transcribed verbatim.

- (2). Each participant's transcript and diaries were read thoroughly and analyzed line-by-line.
- (3). Keywords and sentences were highlighted and coded, each code was given a name to represent it and similar names were grouped.
- (4). All codes were reviewed and extracted statements were described based on interpretation of the transcript and diaries.
- (5). Next, the researcher(s) clustered the codes and identified themes that enabled the integration into a rich description of the phenomenon observed.
- (6). Finally, the researcher(s) shared the themes with the participants to verify accuracy of the content and interpretation.

3. Findings

Interestingly, Thai adolescents did not use the words spirituality and dignity explicitly during the course of the interviews. However, attributes of these phenomenon, do feature implicitly in the strategies and decisions participants used to enhance their well-being and find meaning and purpose in life for example find meaning and purpose, relationships with others and moral responsibility. The main category developed was titled "Living life responsibly" this comprised of six themes: (1) Understanding the disease and accepting the truth in life, (b) Maintaining hope for cure, (c) Focusing on life's purposes, (d) Making choices for life, (e) Caring for oneself, and (f) Responsibility towards others. These themes all include or involve a degree of 'responsibility' either in terms of self, others or wider society with the outcome of enhancing life and conserving human dignity.

3.1. *Understanding the Disease and Accepting the Truth in Life*

Accepting some truths about life and death was the first and the most important attribute of spirituality and dignity from the experience of Thai adolescent living with HIV. Although the participants in this study were adolescents having to accept the truth of having HIV and being reminded that death is part of life was probably the most difficult task for them, several of them realized they had to accept this truth/reality in order to live in harmony with HIV. They could not change this situation. However, the thing that they could change was their perception towards HIV and death. Some participants said that it was important to believe that people living with HIV have value, are able to live life normally and are not a burden to others. HIV need not reduce life expectancy or have a negative impact upon their lives provided they took good care of themselves. Moreover, for some participants HIV was a strong motivator for change because they were acutely aware that they might have limited time and opportunity in the future. They also felt they might have a better life than some other people experiencing difficulties in life. They also are able to live in peace having no fear of death because they understand that death is part of life. As Ton, a male participant described:

The first thing that we have to do is accept it. We have to understand what HIV is and HIV is not too bad. HIV is regarded as an individual's chronic illness. When we understand and accept, we can live with happiness just the same as general people (who do not have HIV). We just only take ART on time every day, do regular exercise, eat healthy food and the most important thing is having a clam mind. We have to face HIV with a brave smile...I think, sometimes, having HIV is good because it motivate me to take more care of myself.

Having sufficient knowledge and information proves to be of significant help to participants in accepting their situation. Searching for new knowledge and information related to HIV is a specific role of adolescents living with HIV. Especially online searching about HIV has several advantages such as easy and convenient to access, can take place anytime, and help to keep HIV status secret. Having knowledge leads the participants to understand more about HIV while providing guidance about the way to take care of themselves. Tum, male participant, explained how he searched for information about HIV on the internet:

I search from this (mobile phone). No one knows what I read. I can search anytime I want. I don't need to ask anyone. When I want to know something, I can search by myself. This is the reason that I have the mobile phone so I can access the internet. I think knowing information about HIV is important. The information brings hope to me and encourages me to take good care of myself.

Another factor that encourages the participants to accept the truth, especially the truth in life, is religious doctrine including the law of Karma. Some participants pay specific attention to develop a peaceful of mind by doing merit, practicing meditation, letting go, and helping others after they understand about the religious doctrine. Nim states the following:

When I first know my HIV status, I felt very bad and confused. But after I have watched the video it makes me understand that everyone will die sooner or later. Religious doctrine helps me feel calm and gives energy for me to move on... So, I don't feel scared of dying although I have HIV. Now, I feel calm. If we die it would be good because we don't face with the problem of suffering in life. We have to learn to let go... But if we still alive we should have a good experience.

3.2. *Maintaining Hope for Cure*

One of the main reasons for participants to live as healthy a lifestyle as possible is the hope that one day medical science will discover a cure for HIV and that, when this day arrives, they will be healthy enough to receive this treatment. Another hope of participants is to live normally and raise a family of their own. Therefore, in addition to having hope to be cured, the hope to have a family encourages them to live healthy and to adhere to ART drug therapy. They believe then they will become normal people and be able to live longer and to have a family with no risk of spreading HIV to others. This hope is based in reality because they know that groups of scientists are trying to search for the drugs to cure HIV. As Chit said:

I know that the scientists are searching for the drugs to cure HIV. So, I have to take care of myself well and I have to survive until that time comes.

Having knowledge leads the participants to understand more about HIV and bring hope about living and being free from HIV. As Num, a male participant who lost his mother from AIDS, said with strong emotion that he hoped to be free from HIV, explained:

For ART drugs, it is important to take on time. Although the sizes of ART drugs are very big and I have to take six tablets, I have to take it because I know that it is very important (vital). I also never ask why I have to take ART because I have read the article and know that ART drugs are important. ART drugs will suppress the HIV that will help me to be healthy. Although ART drugs cannot cure HIV, I have hope to be cured one day because the scientists try to discover the way to treat HIV. I hope to be cured. So, I have to maintain my body to be healthy and wait for the day to have the drugs that can treat HIV. I would like to live longer with the one that I love.

3.3. *Focusing on Life's Purposes*

Most of the participants indicated that people living with HIV should focus on the future and focus on having a positive purpose in life rather than feeling worried about the past. Once they found a meaning and purpose, they then had a reason for living, reinforcing the significance of their life. Having a positive purpose in life guided them to approach life positively preventing them from making decisions that could compromise this such as stopping sexual intercourse and being more cautions and proactive. When the participants reflected upon their purpose in life, they often experienced a number of positive outcomes such as high prosocial reasoning, active engagement, achievement, and high self-esteem as well as achieving their life goals in a positive way. One of the goals for participants in this study was having a better life particularly for those born into the low-income families, broken homes, and with a lack of love and relationship in their families. These

individuals endeavored to have a good and secure life. As Geng, a male participant who had a strong desire for a better life said:

I don't give a priority to HIV. HIV is nothing to me. I do not think having HIV is a problem. I accepted having it and I take care of myself well. I think telling others is not necessary but the necessary thing that I have to do is focusing on the future and purpose in life. I have to learn how to live my life, how to move on with my life... I do not look back but look forward... Some of my friends said, they never thought about their future that is different from me. I have my future plans. I set a goal that I have to have a better life than I have right now. All I need is to have a better life in every aspect.

3.4. *Making Choices for Life*

Making life choices is an essential aspect of adolescents living with HIV who may have to face a long journey and path in life. Taking opportunities that may enrich or make for a better life, they felt would enable them to live 'normally' in the society with dignity and respect. Although, some of them had to change the direction of their life such as putting on hold plans for study and work, the suffering they encountered did not prevent or stop them from being positive and forward thinking. Having choice in life increased the participants' sense of self-respect, sense of being normal generating positive attitudes of living with HIV.

Three choices were identified by participants' which they felt would lead to a better life lived with dignity and respect. The first is having the choice of disclosure of HIV status. Some participants felt that disclosing their HIV status to others including their family member is not necessary; this was because they felt worried that the family members may become distressed and not accept the situation. They also recognize the need to take responsibility for themselves and never be a burden to anyone. The second choice is having sources of support. Several participants realized that they could ask for support from several sources in particular family, health professionals, or others if necessary. It makes them feel secure to live with HIV. The last is being able to organize their own life. The participants wanted autonomy to select what kind of study, job, or family they want, that they felt free or unconstrained to live with HIV having no limitations in their life. Having freedom and being able to self-transcend the situation was important for them. Some of them decided to continue study and increase qualifications, and train for a variety of skills to provide greater choices in life. Ton, a male participant, infected with HIV through sexual intercourse considered that if he does not give up and remains committed to his purpose, success would happen:

I failed when knowing of having it (HIV)... When I was studying in high school, I loved to learn the Chinese language... I knew 100 % for sure, that that only I would receive the scholarship to study in China. I would go to China to study for bachelor and this is my main goal. Everything was perfect at that time. I saw my prosperous life. But when I knew I got it (HIV), my life's goal was shut down...I felt very sad and distressed. I kept HIV as a secret. I put myself in the room and kept quiet for a while. Until, when my teacher told me that there was a scholarship available to study a short course in China. I searched the internet and found that if I go for short course training, I don't need to do blood test for HIV. It was fortunate for me. I think after the big storm always come clear skies. Therefore, my goal that had been previously shutdown returned back to me... So, my purpose of studying Chinese in China is always there. After that, I enrolled to study in the university in Thailand and I still focus on Chinese language. I hope to work as a tour guide or a translator in the future. I also hope to go to China again.

However, two participants did not finish primary school. They faced uncertainty in life and had less security especially economically. They were more vulnerable than others in many aspects such as limited access to knowledge and information, restricted access to care, and less prospects of a secure and permanent job. They found it difficult to find a permanent job to make their life secure. They have very few opportunities especially when they have HIV. As Koy, an 18-year-old female

participant who, although separated from her husband, is trying to finish her study at boarding school to improve her job opportunities explained:

I tried to finish my study (primary school). If I finish, I can apply for some jobs. When I don't have qualification, I cannot work. I have only choice of working in the local food shop and it is very hard work. If I do not study, I will have no work. I aim to study more.

3.5. *Caring for Oneself*

The participants recognized that a fundamental aim for people living with HIV especially adolescents who want to have a normal life expectancy and perhaps one day be free from HIV can only achieve this by caring for themselves. Caring for oneself brings a health in body and mind, pride in self, self-value, self-respect, and dignity and the perception of being normal. Three duties were described caring for self. The first is taking care of themselves. They know that the main role is maintaining good health in order to preserve their immunity, avoid (prevent) physical health problems, not spread HIV to others, and be able to live integrated within society. They are focusing on adjusting to a different way of living such as taking regular exercise, eating healthily, and not consuming alcohol. As Oat, a male participant who has his mother as a good role model in maintaining health said:

Having HIV is not a problem to me. I only know that HIV can make me weak and my immunity decline. So, I fix it. I used to have skin problem. At that time, I don't know I have HIV. But after I know, I have it. I do not let myself run down (physical problems). My mom always told me what to do to be healthy. I trust her because my mom is healthy (although she lived with HIV). I do exercise. I eat fruit and good foods. I drink milk every day. I eat 4 meals a day rather than 3 meals. If someday I study late into the night and I feel tired, I go to bed and take more rest during the next day. I think, we have to observe our self how we feel, if we feel tired, we take a rest or go for exercise. If we feel hungry, we eat. Just do a very simple thing, we can be healthy. It is not a problem.

The second is taking ART drugs. All participants know that taking ART drugs is essential for them. ART drugs can maintain their hope for the future and preserve their life. Several factors encouraged the participants to adhere to taking their ART drugs: (1) Taking ART drugs is essential for life, (2) ART drugs are easy to take, (3) ART drugs do not need to be taken with food, (4) ART drugs are easy to carry, and (5) ART drugs are perceived as similar to vitamins to nourish the body. As Keng said:

A Taking antiviral drug is similar with taking dietary supplements. It is good for the body. I take ART drugs at 6 a.m. and 6 p.m. So, when I am working and it's time to take ART drugs, I told my boss that I would like to go to the toilet or I would like to get something from the kitchen. Actually, I want to take ART drugs. I have so many reasons to tell my boss to leave from work for a few minutes because taking ART drugs takes less than one minute. For example, when I go to the toilet, I swallow it and come out and then drink water. If I forgot ART drugs at home, I cannot stand it. I have to tell my boss, I forgot something at home. Then I go back and get it. I have to take it. I cannot live without it.

The last is being mindful. Several participants' perceived mindfulness as one of the best strategies that enabled them to live in harmony with HIV particularly when they are adolescents who may always feel impatient. Being mindful can prevent them from fighting with others. It encourages them to let go of a problems and teaches them to know what to do and what not to do all of which bring peace and calm to their mind. Being mindful or conscious enabled them to find ways to solve problems. As Num, a male participant explained:

Before doing things we have to know what will be happen and what the long terms consequences might be. If it is not good, we should not do it. We have to be mindful and conscious about the things we do. For example, we have to know what kind of food we can eat or we cannot eat. When my eyes seem dizzy, I have to eat tomatoes and carrot. Also, we

have to have enough sleep. We should sleep before midnight and get up around 7 a.m... Also for fighting, I never fight with anyone because I know the consequence. (If I fight) I may have to quit from my school.

3.6. Responsibility Towards Others

This study found that participants also recognize a duty and responsibility to others and society. The responsibility for society they felt would help minimize the negative image and stigmatization of people living with HIV. In addition, it reflected their sense of gratitude and compassion to others. The concern towards other and society was expressed in three ways: first the prevention of spreading HIV to others. The prevention of HIV is the main responsibility toward society because they realized that no one wants to get HIV. The methods which they used to prevent HIV are: (1) preventing the spread of HIV through sexual transmission by avoiding having a girlfriend or boyfriend, avoiding sexual intercourse, using condoms when having sexual intercourse, and not intending to have children, and (2) preventing the spread of HIV through sharing things. Some participants especially female said that they should not share their things with friends especially piercings such as earrings. As Suk, a male participant said:

I use condoms. I bring them with me all the time. When I go out with friends I bring the condoms.

If I am not ready to disclose my HIV status, I don't have a girlfriend or I don't have sexual intercourse.

The second concern is avoiding being a burden to others. The participants who are adolescents perceived that living a good life means being able to take care of themselves and their (own) family. Therefore, if they could not take care of themselves and their own family, they should not have a family because they would not be burden to anyone. In addition, in order to avoid relying on others, some of them do not intend to have children. Two female participants who perceived that children will bring high responsibility and they would feel pity if their children were infected with HIV, so one of them decided to have permanent contraception. As King, a female participant who used the permanent contraception to prevent pregnancy said:

I used tubal ligation...If I don't tubal ligation it is possible that my children will receive it (HIV) the same as me. I don't like them to be faced with the same difficulty as me.

The last responsibility towards others is shown by avoiding making significant others feel sad about loss. The participants who were born from a mother infected with HIV, some of them lost their parents because of HIV. The loss of significant person brings sadness to the family members' especially elderly people such as grandparents. Therefore, the participants recognized that it was very important for them to remain healthy and live a long life. Therefore, they avoided placing themselves at risk. They did not want to make the person they love feel sad because of loss again. They are the representatives/legacy of their parent who passed away. As, Ton, a male participant who was cared for by grandparents after his mother passed away from AIDS said:

HIV makes me aware that I have to stay alive. I don't want to make the person I love feel sad again. My grandmother has lost her daughter (my mother)... I have to live to be the representative of my mom. If I am alive, it's like my mother is still alive. If I die, my family will feel sad. I don't need them to feel sad again because lost bring sadness that it is difficult to explain... I should have good behavior. I should continue my life.

4. Discussion

This paper has described how the concepts of spirituality and dignity have relevance for Thai adolescents who have been living with HIV for more than 3 years. Although participants' did not use the words spirituality and dignity explicitly, what they spoke about and discussed in relation to living life responsibly with HIV reflected key attributes of these concepts. For example, the

importance of relationships, love, connectedness, self-esteem, identity, finding meaning and purpose in life and living responsibly are all related to spirituality and human dignity.

The findings indicate that HIV is a life-altering situation that may be similar to other serious chronic illnesses that affect a sense of self and identity, resulting in uncertainty, stigma and imposing limitations on life (Di Risio et al. 2011). However, once the participants in this study began to love themselves, they viewed life more positively evidenced by living life responsibly and finding meaning and purpose in their situation. We have argued that most participants in this study had found peace and harmony in their lives perceiving themselves to have a good quality of life. This finding is consistent with those of (Berglund et al. 2006) who explored the perceptions of quality of life among 126 young people in Sweden. They identified that the quality of life referred to having well-being, happiness, love, development, respect, friendship, education, occupation, economy, and sense of security.

Understanding the disease and accepting truth in life is a unique and important attribute of spirituality and dignity of people living with HIV in the Thai context (Balthip 2010; Balthip et al. 2013). Although the participants in this study are adolescents aged 15–19 years old, they understood and accepted the truth of having HIV and the truth about life and death. They perceived that people living with HIV have value, are able to live normally and are not a burden to others. They acknowledge that HIV although life changing was not significant for them. They described how HIV could not destroy their life. On the contrary, HIV helped them to reach the goal of living a normal life (Di Risio et al. 2011) or better than a previous state because they understand more about the world and acknowledged the significance of being alive. It reflected that their spirituality was manifest after experiencing crisis and illness (Weathers et al. 2015). When they gain insight and accept the reality of the situation, participants experience calm and peace. They have the ability to deal more positively with the situation of living with HIV and are able to live in harmony with the condition (Balthip 2010). Acceptance encouraged the participants to transcend the physical issues enabling them to be able to live with happiness and harmony with all the ‘ups or downs’ associated with their physical well-being (Berglund et al. 2006).

One of the main reasons that encouraged the participants to accept their situation is having sufficient knowledge and information. Having knowledge led them to understand more about HIV, bringing hope about the future and developing coping strategies to take care of themselves. Therefore, services should improve and make knowledge and information easier to access for young people so that they may be more aware and up-to-date on what is good for their health and well-being. Another significant factor that encouraged participants to accept the truth of life was their ‘religious’ doctrine based on Buddhist beliefs especially those indicating nothing is permanent in this life. The participants begin to learn how to live their lives harmoniously and happily under their new circumstances. They understand that their life has changed with a blend of success and difficulties but they accept this and feel happy. They establish their inner peace and calm as the strongest protection (Balthip 2010).

Maintaining a hope for a cure or being free from HIV was another unique attribute of spirituality and dignity of adolescent living with HIV. Participants hoped to have drugs to cure HIV and meaning they would be finally free from the condition. They indicated that they intended to take good care of themselves and be healthy. This hope was because nowadays, the evidence shows that HIV/AIDS is no longer a major cause of death. Adolescents living with HIV have potential to live longer. The average life expectancy after HIV diagnosis increased from 10.5 to 22.5 years from 1996 to 2005 (Harrison et al. 2010). Moreover, if people living with HIV can maintain undetectable viral load through sustained adherence to ART, it can prevent transmission of the virus to sexual partner (Vernazza et al. 2008). In addition, a further reason that fostered hope for a cure is all of them had HIV since birth and were now healthy despite some having experienced opportunistic infections previously. They described HIV as a general disease that they can deal with. This finding is consistent with other studies on quality of life where young people explained that the most important factor related with quality of life based on the physical well-being (Berglund et al. 2006).

Focusing on life's purposes is another important attribute of spirituality and dignity of Thai adolescent living with HIV. Having a purpose in life, goal setting and achieving the goal have been identified as an essential attributes of spirituality for people worldwide (Davis et al. 2003; Weathers et al. 2015). By fostering hope for a better life, this may produce more effort toward positive expectations for the future, and promote prosocial moral behavior (Machell et al. 2015). The purpose in life for some participants emerged from a perceived need to make a better life for themselves and significant others. These adolescents recognized that they themselves could be the catalyst to make a difference for them and their family and they knew this was important for the people they love. Therefore, having a positive sense of purpose may influences how the four notions of dignity (Nordenfelt and Edgar 2005) are lived. However, some of the participants had a guardian, three lived with their parents, and six of them lived with other relatives because their parent had died of AIDS or facing difficulties in life. Only two participants reported that they had infrequent contact with the family members. This situation revealed that this lack of support and connection might mean adolescents living with HIV are more vulnerable. Therefore, this group of adolescents still requires guidance and support and cannot be taken for granted that they have access to this support to promote purpose in life.

Making life choices is one of the most important attribute of spirituality and dignity of Thai adolescent living with HIV that increases their sense of self-respect, sense of being normal providing a sense of liberation or freedom from HIV. The participants believe that people have to take chances/risks in life and have courage to accept a challenge when it comes. Since this may encourage personal growth and lead to positive self-esteem (Berglund et al. 2006). One of the important choices that bring a better life is living with dignity and central to this is having the choice to disclose ones HIV status. Some participants perceived that disclosing their HIV status to others including their family member is not necessary because they are aware of their capabilities. This autonomy and choice built a greater sense of self-worth promoting independence and self-reliance. They were aware that they can seek out new opportunities at any time because the door is always open for them. The Thai saying, "the clear sky after the big storm" and its Western equivalent "light at the end of the tunnel", convey the Thai value (and universal) of having hope, purpose, and optimism for the future.

Another noteworthy choice is being able to organize their own life giving them a greater sense of achievement in life and pride in themselves. They had a sense of freedom or self-transcendence over HIV. Some of them decided to continue study and improve their qualifications, and train for a variety of skills giving them great choices in life. Education, occupation, and economy are associated with the quality of life of young adults. Education and work status, aspect of dignity of merit may classify people in society according to rank, wealth and achievement. In a Thai context, education and employment are important often, determining future opportunities, conferring a social status. Therefore, having good education and employment were important for participants meanings they can live the same lives as other without HIV in the society. When they obtained the qualification and have job security, it created a new merit and new life. Adequate education would provide them with a reasonable standard of living. A meaningful occupation brings happiness, interests and challenges. Financial security signified being independent from others. Independence is also associated with a sense of autonomy yet a realization that if necessary someone was always there and ready to listen to them be this family, health professional.

All the above choices and attributes combined contributed (augmented) to a sense of inner peace and confidence, having freedom to make their own choice such as about career and relationship (Berglund et al. 2006). This all contributed to their dignity of merit. While the dignity of merit means "a person who has a rank or holds an office that entails a set of rights has a special dignity" (Nordenfelt and Edgar 2005, p. 18). Some adolescent living with HIV in this study perceived that they may not possess dignity or were unworthy of dignity because they had been born with HIV perceiving dignity of merit as being absent from their life or never been present.

Although Thailand has a very good education system, some participants in this study did not finish their primary education. They were face with uncertainty in life and described how they had

less security in life especially in terms of financial and economic making them more vulnerable than others in many aspects. They had limited opportunities especially when they are also living with HIV. These limitations in life made them feel more stigmatized and marginalized with restricted access to useful resources. National health information systems can miss these adolescents and priority interventions including services may not reach them. They can become a neglected group despite being one those in most need (WHO 2014). Therefore, key stakeholders such as authority leaders or the health care service should pay attention to provide the opportunity for these people to preserve and protect their dignity, human right respecting confidentiality.

Caring for oneself is another central attribute linked to spirituality and dignity since this foster resilience and a sense of transcendence. Not surprisingly, participants felt 'caring for self' this was the number one priority for people living with HIV. Caring for oneself brings a healthy body and mind, pride in self, self-respect, and dignity preservation and the perception of being normal. This positive identity indicated that they trusted and recognized their own autonomy and capabilities increasing self-esteem and self-efficacy. This was a positive circle, the more positive they felt then the more attention they gave to taking care of themselves including adherence to ART drugs. The sense of self, self-connectedness (Balthip and Purnell 2014) and self-motivation such as having a specific goal (Kim et al. 2015) is significant in paying attention to self-care such as medical compliance. This evidence illustrated the link between spiritual dimension and physical dimension. A longitudinal evaluation of medication adherence among HIV-positive men and women on antiretroviral therapy found that spirituality and self-efficacy motivate to adherence in particular if they received the support from others (Simoni et al. 2006). The notion of self-esteem is important because it is intimately related to the notion of dignity in particular the dignity we all possess as a human being and dignity of identity related to the dignity we attach to ourselves as integrated and autonomous individuals with a history and future involving our relationships with others (Nordenfelt and Edgar 2005).

The main characteristics that represent the self-responsibility are focusing on taking care of themselves, taking ART drugs, and be mindful. Participants provided several reasons that encouraged them to adhere to taking ART drugs especially perceiving them to be essential for life and just as important as nutrition such as vitamins to nourish the body. This meant they had a positive attitude towards ART increasing medication adherence and thereby maximizing the benefit of it (Belzer et al. 1999). Low ART adherence increases the risk of viral drug-resistance, limits treatment efficacy, leads to disease progression, and reduces future therapeutic options (Kim et al. 2014). Finally, the participants become healthy, educated, and skilled that represents that they are really important both for the future and for the present. They are a key asset and resource, with great potential to contribute to their families, communities and countries (WHO 2014).

Responsibility towards other people is an important attribute of spirituality especially for people living with HIV in the Thai context where stigmatization remains. This study found that the participants not only take responsibility for themselves seriously but this is extended to others and wider society. The concerning towards other and the society can be presented in three ways; prevention of spreading HIV to others, avoiding being a burden to others, and avoiding making significant others feel sad about loss. The responsibility to the society that they present will minimize the negative image and stigmatization of people living with HIV, reflected the sense of compassion to others (Balthip et al. 2013). This responsibility is mainly represented in the dignity of moral stature that is tied to self-respect. Participants have earned merit through their deeds for example when they recognition of some achievement or contribution to society (Nordenfelt and Edgar 2005).

5. Conclusions

The findings from this investigation may not be generalizable because of the small homogenous sample of adolescents involved and because the study was conducted in one regional hospital in Southern Thailand. Therefore, the findings may not have relevance to other settings and countries. However, findings that revealed situations and strategies that enhanced spirituality and dignity leading to a positive purpose in life may have relevance internationally for wide range of individuals

living with chronic and life changing conditions. The findings may also provide a framework or resource for those involved in the delivery of health and social care and in the educational preparation of professionals working with adolescents.

The findings provide valuable insights into the protective and positive role the concepts of spirituality and dignity may have in living life responsibly with HIV. These findings offer important insights and may be used as fundamental knowledge guiding government and local authorities, policy makers to integrate spirituality and dignity more formally in the development and delivery of health services nationally in Thailand. The voice, narratives and experiences of Thai Adolescents living with HIV demonstrate that care provision must be more than just medically, pharmacologically and therapeutically focused since the findings affirm the importance of other psychosocial and spiritual practices that enable adolescents living with HIV to cope and adjust to what is a life changing situation. Although the words spirituality and dignity were not used by Thai adolescent living with HIV this does not mean the concepts are not important or relevant. Furthermore, the lack of explicit mention to the words may demonstrate that for Thai people these concepts are interwoven and integrated within the everyday life and culture.

The finding affirm the need for comprehensive and appropriate packages of care that support adolescent-specific issues as a 'whole' but in particular the interventions to improve spiritual health and well-being. Government authorities (especially those within Thailand) should review and develop new policies that incorporate a public health message about the importance of having a positive purpose in life. This message should be communicated and embedded within a holistic care system across all levels and care setting. The importance of having a positive purpose in life while relevant for adolescents living with HIV may be useful to individuals living with other chronic or life limiting conditions. Therefore, package of care should provide guidance and support around education, employment and life purpose. Local providers of care such as health centers should be encouraged to develop programs of education for staff caring for adolescents living with HIV and update patient information stressing the importance of having a positive purpose in life.

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