

# The Roles of Spirituality in People Living with HIV/AIDS: A Qualitative Meta-synthesis

Yuttachai Chaiyasit, RN, MNS<sup>1</sup>; Rattiya Thong-on, RN, MNS<sup>2</sup>; Prasert Piboonrungraj, RN, MNS<sup>3</sup>; Paiwan Kotta, RN, PhD<sup>1</sup>



Yuttachai Chaiyasit,  
RN, MNS

## Abstract

This qualitative research synthesis was conducted to explore the roles of spirituality in people living with HIV/AIDS (PLWHA) by using a systematic literature review and a meta-ethnographic method. CINAHL, PubMed, Science Direct, Clinical Key, Wiley Library Online, Thai LIS and Thai Jo databases were searched for articles published from 2000 to 2018. Eleven studies involving 310 participants were included. According to the findings, the following positive roles of spirituality for PLWHA were identified: 1) enhancing peace and happiness; 2) cultivating inner strength; 3) illness understanding and self-acceptance; 4) improving self-healthcare; 5) developing a sense of compassion; 6) finding purpose in life; 7) maintaining hope; and 8) creating relationships and a sense of connection. Nevertheless, a negative role of spirituality for PLWHA, internalized conflict, was also identified. Evidence from this study can provide in-depth understanding for healthcare providers to create spiritual care for PLWHA.

**Keywords :** spirituality, spiritual roles, HIV/AIDS, qualitative meta-synthesis

<sup>1</sup> Lecturer, Faculty of Nursing, Ubon Ratchathani Rajabhat University, Ubon Ratchathani Province, Thailand.

<sup>2</sup> Lecturer, Boromarajonani College of Nursing Nakhon Phanom, Nakhon Phanom University, Nakhon Phanom Province, Thailand.

<sup>3</sup> Lecturer, Faculty of Nursing, Princess of Naradhiwas University, Narathiwat Province, Thailand.

\*Address Correspondence to author:

Yuttachai Chaiyasit, RN, MNS

Faculty of Nursing, Ubon Ratchathani

Rajabhat University,

2 Ratchathani Rd., Muang, Ubon Ratchathani,

34000, Thailand

email: yuttachai.c@ubru.ac.th

The spread of HIV/AIDS continues to be a major problem for public health around the world. People living with HIV/AIDS (PLWHA) steadily climbed from 35.6 to 36.9 million between 2015 and 2017, with 940,000 people dying from HIV/AIDS during the aforementioned period.<sup>1</sup> Similarly, the number of PLWHA in Thailand increased from 445,000 to 450,000 with approximately 15,000 people dying from HIV/AIDS during the abovementioned period.<sup>2</sup> Due to the increasing numbers of people receiving antiretroviral therapy (ART), HIV-related deaths have dropped by 38%,<sup>1</sup> and AIDS has changed into a chronic disease drawing new challenges for health care providers.<sup>3</sup>

PLWHA are faced with stressful life events related to the illness including physical health problems resulting from declining immune status, psychological distress related to stress, anxiety and depression, social isolation due to social stigma, fear and uncertainty about death, loss of self-control, self-blame, internalized conflict, and hopelessness.<sup>3-9</sup> The aforementioned problems might lead PLWHA to become spiritually distressed and commit suicide.<sup>4,6,9</sup> Spirituality is a broad concept consisting of several key features and it is the source of human beings that can help people to accept themselves and their illness, find meaning and purpose in life, create inner strength, maintain hope, improve the sense of self-transcendence, create relationships and connect with other people as well as a higher power, divine or God.<sup>3,8,9-11</sup> Moreover, spirituality can play a vital role in supporting PLWHA. According to the studies of Ironson et al (2006),<sup>12</sup> Ironson et al (2016),<sup>13</sup> and Black and Slavice (2016)<sup>14</sup> it was found that spirituality/religiousness significantly correlated with better CD4 cell count and controlling of viral load. Consequently, spirituality has a significant effect on controlling disease symptoms and slowing the progression of disease,<sup>5,15</sup> while ensuring life-satisfaction, quality of life, well-being,<sup>5,16</sup> and long-term survival.<sup>13</sup>

According to the literature review, limited research studies have been conducted in Thailand about the role of spirituality among PLWHA. Most research studies were quantitative research studies and focused on the

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level of spiritual well-being and factors predicting spiritual well-being among PLWHA, while only three qualitative studies were found to address spiritual well-being. The first study examined spiritual healing in Buddhists with HIV.<sup>18</sup> The second study highlighted the good spirit of people living with HIV / AIDS, and the last study explored spirituality and spiritual needs based on asymptomatic HIV experiences.<sup>18</sup> The participants aged in these researches ranged from 26 to 58 years. The focus was on Thai Buddhism without studying homosexual groups and none of the studies directly addressed spiritual roles among PLWHA.

Qualitative meta-synthesis from systematic literature reviews can provide in-depth understanding about the roles of spirituality based on the viewpoints and experiences of PLWHA. The findings from this study can be applied to create appropriate spiritual care and spiritual need interventions for PLWHA. Moreover, it may increase the effectiveness of antiretroviral therapy in order to encourage life quality, longevity and spiritual well-being.

## Methods

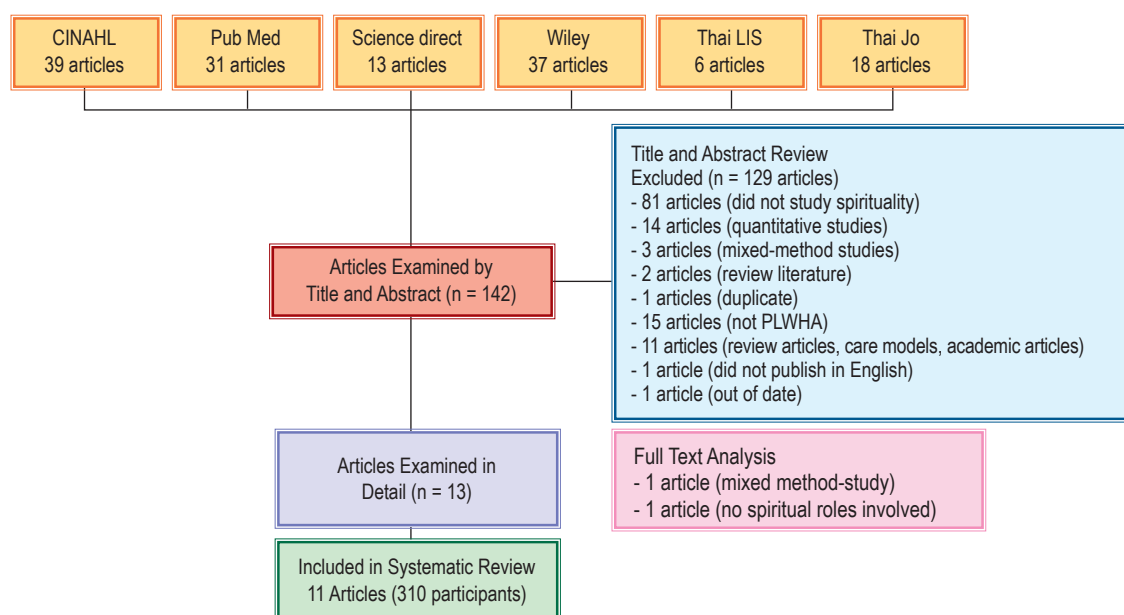
Meta-ethnography synthesis was applied in the present study, utilizing seven steps of Noblit and Hare in this meta-ethnography review.<sup>19-24</sup>

1. **Getting Started:** Determine the research question: In this step, researchers can find the question from qualitative studies. In this review, the question was: *How do the roles of spirituality affect people living with HIV/AIDS?*
2. **Determining What Information Is Important and Relevant to This Study.** In this meta-ethnography, the researchers selected the articles that studied people living with HIV/AIDS and emphasized the roles of spirituality. Moreover, owing to the restriction of meta-ethnography, this cannot be generalized to other fields.

**2.1 Searching Strategy:** A systematic review for examining and unifying literature was utilized. CINAHL, PubMed, Science Direct, Clinical key, Willey Library Online, Thai LIS and Thai Jo databases were searched for articles published from 2000-2018 with the keywords “spirituality”, “HIV/AIDS” and “spiritual roles”. The screening of titles and abstracts was aimed at finding articles meeting the following inclusion criteria: 1) Qualitative researches studying the roles of spirituality among PLWHA; 2) Full-text articles only; 3) Primary sources; and 4) literature reviews.

**2.2 Quality Appraisal:** The articles that did not show qualitative data were excluded. Figure 1 shows the eligibility of assessment of all articles used in this review by using consolidated criteria in reporting qualitative research (COREQ).<sup>25</sup>

The initial search yielded 142 articles that were included in this review. The abstracts of the studies were read and screened to exclude non-matching content. Thus, 129 articles were excluded from this study (81 articles did not focus on spirituality, 14 articles were quantitative studies, 3 articles were mix-method studies, 2 articles were literature reviews, 1 article was a duplicate, 15 articles were not studying PLWHA, 11 articles were review articles, models of care and academic articles, 1 article was not published in English, and 1 article was out-of-date). Next, the researchers read every full-text paper selected to identify thirteen studies and excluded two studies (one study was a mix-method study; one study did not involve the roles of spirituality). In the last step, eleven articles involved 310 PLWHA (Figure 1). Data were gathered from interviews, focus groups and observation of participants (from qualitative approach, phenomenological study, and grounded study) conducted in the USA, Cameroon, Brazil, Belgium, Canada, and Thailand. (Table 1)



**Figure 1:** Search strategy to identify publications included in the review.

**Table 1:** Selecting articles that were relevant

Author, Year	Country	Participants (n)	Age (Years)	Data collection	Methodology	Analysis
Siegel & Schrimshaw, 2002 <sup>8</sup>	USA	Male&Female (63)	50 - 68	Interview guide	Qualitative study	Thematic analysis
Seeger, 2007 <sup>26</sup>	USA	African American gay (10)	33 - 62	Interview guide	Transcendental phenomenological study	Transcendental phenomenological methods
Foster et al., 2011 <sup>13</sup>	USA	African American gay (31)	18 - 30	Semi-structured interviews	Grounded study	Thematic analysis
Tawaisab, 2011 <sup>27</sup>	Thailand	Male & Female (9)	30 - 58	In-depth interview, Participant observation	Qualitative study	Content analysis
Mbetbo, 2013 <sup>7</sup>	Cameroon	Gay (45)	21 - 40	Open-ended group discussion	Qualitative study	Content analysis
Caixeta et al., 2012 <sup>28</sup>	Brazil	Male & Female (8)	23 - 62	Semi-structured interviews	Qualitative study	Thematic analysis
Dalmida et al., 2012 <sup>29</sup>	USA	African American female (20)	38 - 61	Focus group interview	Phenomenological study	Content analysis
Balthip et al., 2013 <sup>9</sup>	Thailand	Male & Female (28)	18 - 54	In-depth interview	Grounded theory	Opened, axial and selective coding
Arrey et al., 2016 <sup>30</sup>	Belgium	Sub-Saharan African male (44)	20 - 67	Semi-structured interviews	Qualitative study	Thematic analysis
Balthip et al., 2017 <sup>11</sup>	Thailand	Adolescent Male & Female (22)	15 - 19	In-depth interview	Qualitative study	Thematic analysis
Emlet et al., 2018 <sup>31</sup>	Canada	Male & Female	50 - 73	Semi-structured interviews	Grounded study	Constructivist grounded theory technique

- 3. Reading the Studies:** Three crucial processes were conducted in this phase including: 1) Turning into the caution of the studies and try to gain more understanding 2) Information classification from each study, and 3) Identify the relevant concept related to the research question.<sup>22</sup>
- 4. Identifying Associations among the Studies:** The relationships among the different studies were considered. The researchers examined the different papers for common and recurring concepts. Subtheme and theme were established in this step.<sup>21</sup> Tables were used to show the

overall concept of study that was normal for meta-ethnography review. In the present study, the researchers extracted the results of the selected eleven studies, then identified and coded the concept of spiritual roles among PLWHA, listing in terms of initial code with definitions and frequencies in the dataset, then grouped and analyzed the same meanings of spiritual roles of PLWHA in the themes in order to determine how the studies were related (see Table 2).

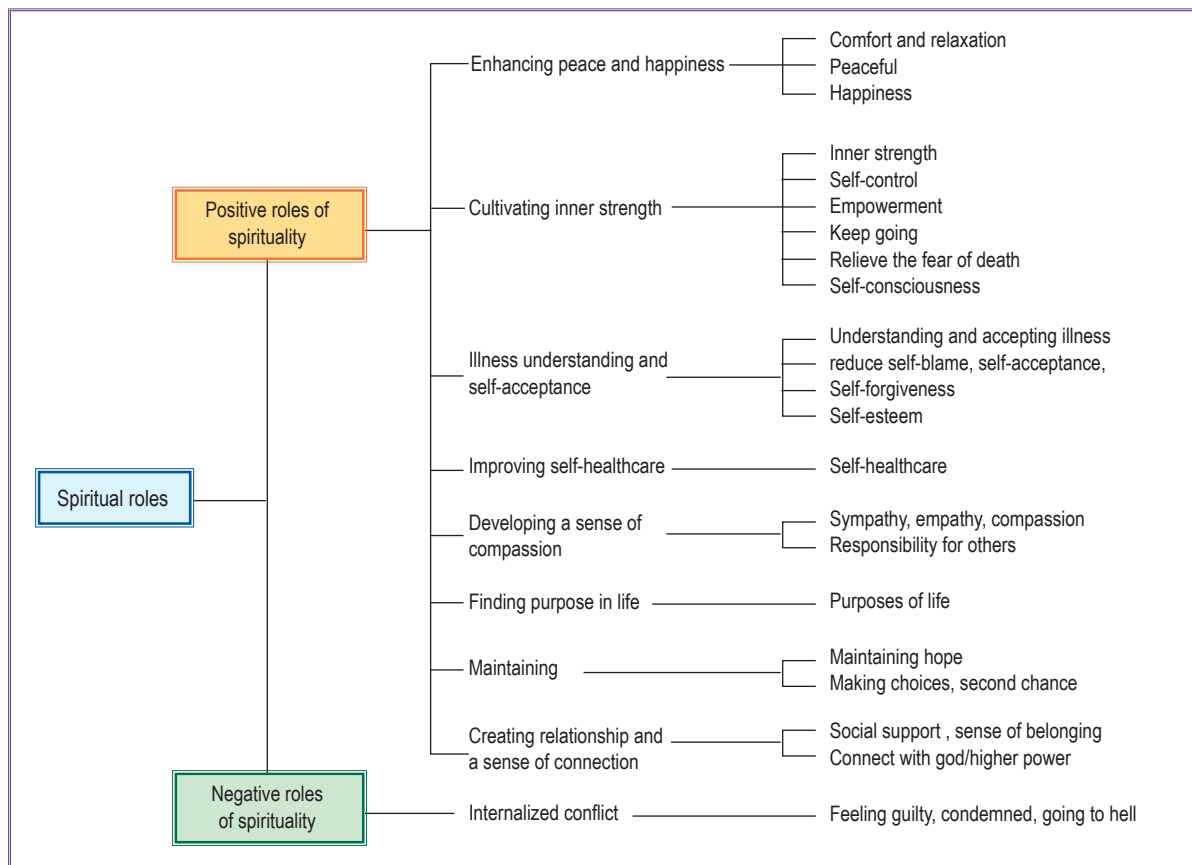
**Table 2:** Summary theme, sub-theme and coding from the data

Theme	Subtheme	Coding
1. Positive roles of spirituality	1. Enhancing peace and happiness	- comfort and relaxation <sup>8,28</sup> ; peaceful <sup>7,9,27</sup> ; happiness <sup>27</sup>
	2. Cultivating inner strength	- inner strength <sup>8,27,29</sup> ; self-control <sup>8</sup> ; empowerment <sup>3,8</sup> ; keep going <sup>28,29</sup> ; relieve the fear of death <sup>8</sup> ; self-consciousness <sup>27</sup>
	3. Illness understanding and self-acceptance	- understanding and accepting illness <sup>8-9,11,30</sup> ; reduce self-blame, self-acceptance, self-forgiveness <sup>8,26,28</sup> ; self-esteem <sup>26</sup>
	4. Self-healthcare	- self-healthcare <sup>8,11,30</sup>
	5. Developing a sense of compassion	- sympathy, empathy, compassion <sup>3,27</sup> ; responses for others <sup>11</sup>
	6. Finding purposes of life,	- purposes of life <sup>11</sup>
	7. Maintaining hope	- maintaining hope <sup>11</sup> , making choice, second chance <sup>11,28</sup>
	8. Creating relationship and sense of connection	- social support, sense of belonging <sup>7-8,26</sup> ; connect with god or higher power <sup>7,8,28-31</sup>
2. Negative roles of spirituality	1. Internalized conflict	- feeling guilty <sup>7</sup> , condemned <sup>7</sup> , going to hell <sup>3</sup>

5. **Interpreting and Comparing the Studies.** In this phase, the researchers interpreted the concepts and correlations in one study for comparison with the concepts and correlations in other studies. Fundamentally, there are three ways for comparing the concept with other concepts including: 1) Reciprocal interpretations; 2) Controversy interpretation; and 3) Line of argument presentation.
6. **Synthesizing Interpretations:** This phase is aimed at creating a new whole of the parts.<sup>22</sup> Figure 2 shows the

synthesis of this review towards the roles of spirituality of PLWHA.

7. **Expressing the Synthesis:** This synthesis shows the information about the roles of spirituality from the perspective of PLWHA. Researchers or healthcare providers can use the information to create the intervention for enhancing spiritual well-being among PLWHA.



**Figure 2:** Synthesis of translation: The roles of spirituality of people living with HIV/AIDS

## Results

Participants perceived the benefits from spirituality including enhancing peace and happiness, cultivating inner strength, illness understanding and self-acceptance, self-healthcare, developing a sense of compassion, finding purposes of life, maintaining hope, creating relationship and a sense of connection. Some participants reported the negative of spirituality, which was an internalized conflict.

### 1. Positive roles of spirituality

**1.1 Enhancing Peace and Happiness:** Religious practices and spiritual beliefs helped patients to enhance their peace and happiness. Participants indicated a feeling of comfort, relaxation, peacefulness and happiness.

*'I listen to a lot of church music that comes on TV or on the radio. A lot of gospel. My mother, when she was alive, would always put that on every day. And it gives me comfort. I usually hum along with the songs. I like to hear the music, and it is very relaxing and gives me a peaceful feeling. So, it has made me feel a lot better, just something to lift my day a bit.'*<sup>8</sup>

**1.2 Cultivating Inner Strength:** The participants perceived the benefits of spirituality in the form of cultivating inner strength, including self-control, self-empowerment, self-consciousness and relieving the fear of death.

*"I wouldn't be able to do this today, without, spirituality, without a relationship with my heavenly father, because I'm daily renewed, I'm daily cleansed, I'm daily strengthened."*<sup>29</sup>  
*'...consciousness reminds us to be careful... before doing something we should think first to protect mistake'*<sup>27</sup>

### 1.3 Illness Understanding and Self-acceptance:

Participants perceived that spirituality helped them to redefine the meaning of illness, understand and accept illness, reduce self-blame, increase self-acceptance, and self-esteem.

*'Yeah, in the beginning when I was first diagnosed and everything, I was angry at myself. I felt like, this was happening because I let it happen and I was getting like I couldn't stand myself for it. But it took a lot of time, and through the spiritual part of my life I've gotten to be understanding that I have to forgive myself and I have to forgive him [man that infected her] and God forgives both of us.'*<sup>8</sup>

*'After living with this disease and facing the dying experience, I understood that being born, getting old, being sick and dying is a normal cycle of human beings and natural experiences. In the past, I hardly thought about dying. But now I could see the reality of life. Nothing is permanent. We should learn to let go, then we can obtain inner peace.'*<sup>9</sup>

**1.4 Improve Self-health Care:** The participants perceived that spirituality led them to accept the illness and promote healthy lifestyles.

*'...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.'*<sup>11</sup>

**1.5 Developing a Sense of Compassion:** Participants perceived that spirituality led them to create a sense of compassion including feeling sympathy, empathy and responsibility to others.

*'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.'*<sup>1</sup>

**1.6 Finding Meaning of Life:** Participants perceived that spirituality helped them to find the meaning of life.

*'Probably more affirmed than anything. I feel more that I have a purpose and I'm going to fulfill it before I pass away. And that's the only reason I'm alive is that I have something to do. I may not know what it is, it may not be something that has big proportions. It may be just something like talking to you. But I think there's something I have to do before I pass away. There must be a reason.'*<sup>8</sup>

*'...I have my future plan. 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.'*<sup>11</sup>

**1.7 Maintaining Hope:** Participants perceived that spirituality encouraged them to maintain hope, make choices and enjoy their second chances.

*'To me it's just like I get a second chance. Grace, to me, means I get another chance! ...and I thank Him (God), for giving me another chance.'*<sup>29</sup>

*'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.'*<sup>11</sup>

### 1.8 Creating Relationships and a Sense of Connection:

Participants perceived that spirituality created interpersonal relationships, feelings of support and a sense of belonging as well as a sense of connection with a higher power, divine or God.

*'When I think of spirituality—I think of my spirit, I think of God and I think about what I believe in-my belief in God. To me spirituality is the ability to step out of yourself and just become one with God.'*<sup>29</sup>

*'...I have survived because of them. My parents, my brother, my sister, my wife and my children are very valuable to me. They have given me constant support. I feel happy when I am with them and my inner strength increases each day.'*<sup>10</sup>

## 2. Negative Roles of Spirituality

Some of the participants, including both gay and heterosexual men and women, described a negative feeling from spirituality in the form of internalized conflict, including the feeling of guilt, condemned, and going to hell.

*'I feel guilty continuing to do what I do. ... I just cannot bear it any longer. ... Why can't I just stop this evil? I do not have enough will. How can I hear God's message for that long and still do what I am doing? There might be something wrong with me!'*<sup>7</sup>

## Discussion

According to the findings, spirituality is expressed through religious practice and faith in a higher power, divinity or God. In the Western context, PLWHA indicated that the illness had drawn them to use religious and spiritual practices more than in the past. Most of the participants described that the sources of spiritual support resulted from believing in God.<sup>3,7-8,26,28-31</sup> On the other hand, PLWHA in Thailand indicated that the source of spirituality came from religious practice, family support and adherence to the Lord Buddha's teachings.<sup>9-11,27</sup> The above factors provided the PLWHA with the power to manage stressful life events and illness. The participants described the positive roles of spirituality in life.

**Enhancing Peace and Happiness:** Religious practice and spiritual beliefs helped the participants to enhance peace and happiness. In the Western context, the dynamic existence, evolutionary relationship with God or a universal spirit is essential to creating theories of faith and spirituality.<sup>26</sup> O'Brien<sup>32</sup> explained that spirituality is the core of human beings. Thus, spirituality can help chronic illness patients cope with stressful life events and illness, which is a crucial factor that affects spiritual well-being. There was a significant positive relationship between spirituality and psychological change (e.g. depressive, mood states, mastery and self-esteem).<sup>33</sup> In Thailand, Buddhist teachings play a crucial role in supporting participants comprehend and reconcile that nothing is permanent. According to Buddhist doctrine, the Four Noble Truths are as follows: 1) Characteristics of suffering (Dukkha), 2) The origin of suffering (Samudaya), 3) Suffering's



cessation (Nirodha), and 4) The fact or process of ending of suffering (Maka) called the Noble Eightfold Path. The above factors are important for Thais and Buddhist PLWHA to enhance peace and harmony of life.<sup>9</sup>

**Cultivating Inner Strength:** The participants perceived the benefits of spirituality in terms of cultivating inner strength. Thus, the participants expressed strength by using religious and spiritual coping to provide a feeling of inner strength, self-control, empowerment, a will to survive or have a second chance, relief from fear of death and self-consciousness. Most of PLWHA believed everything was provided by God who always supported and helped people through every moment of life.<sup>3,8,29,30</sup> Furthermore, the participants believed God provided the heaven for the afterlife. Hence, PLWHA were able to face death and die bravely without fear of death.<sup>8</sup> However, Thai people perceive that there is nothing permanent and they live life with satisfaction, which is important in reaching peace and harmony in life.<sup>9</sup> The above factors can cultivate inner strength for PLWHA who are Buddhists.<sup>9-11</sup>

**Illness Understanding and Self-acceptance:** The participants perceived that a higher power or God had a purpose to inflicting this illness on them. He aimed at teaching the participants, changing lifestyles, creating relationships and forming connections.<sup>8-9,11,27,29,31</sup> Spiritual roles helped the participants reduce self-blame, forgive self and others, and create self-esteem.<sup>27</sup> Being diagnosed with HIV triggered the patients to participate in spiritual reflections in an attempt to find meaning in life and might have brought the participants closer to God, increase church attendance or enhance spirituality.<sup>30</sup> The above factors were able to adjust the perspectives of PLWHA into positive views leading to understanding of the illness, acceptance of illness and self. In Buddhism, the participants believed that 'Nothing is permanent' (Lord Buddha's teaching), which helped the participants accept the illness and life because this concept taught PLWHA understanding about the disease and acceptance of trust of life.<sup>9</sup> Thus, the participants were able to manage with life-struggle and illness with peace and harmony.<sup>9</sup> Moreover, when PLWHA accepted both illness and self, they were able to improve self-esteem and well-being similar to other people.<sup>9-11</sup>

**Improve Self-health Care:** The participants perceived that spirituality improved self-health care because spirituality assisted them to find the meaning of illness, understanding the illness, and accepting their illness.<sup>8,11,31</sup> It encouraged them to focus on healthy lifestyles in order to increase longevity by taking medication, performing regular exercise, eating healthy foods, getting plenty of rest, sleeping well and preventing health risks.<sup>9</sup> Ironson et al.,<sup>12</sup> and Dalmida et al.,<sup>29</sup> found that the spiritual well-being of PLWHA was correlated with medication adherence (antiretroviral therapy), increased CD4 helper T-cell counts, decreased HIV viral load, controlled symptoms of the disease and decelerated disease progression. Moreover, spiritual well-being predicted longevity for more than 17 years after diagnosis with HIV.

**Developing a Sense of Compassion:** In the present study, spirituality developed a sense of compassion for PLWHA. The participants believed that God wanted them to help others and respond to the needs of others. The participants avoided risky sexual behaviors to reduce stigmatization by using a condom every time during sexual intercourse, or tubal ligation in order to prevent spreading HIV to children.<sup>11</sup> Moreover, the participants practiced self-care in order to reduce the feeling of being a family burden, increased their capacity to support families and sought to prevent family members from feeling sad when they passed away.<sup>11,28</sup> The abovementioned factors are beneficial not only for PLWHA, but also for society as a whole to reduce stigmatization and prevent HIV transmission.

**Finding Meaning in Life:** The participants explained that spirituality helped them to find the meaning of life because HIV/AIDS accelerated them to recognize that their lifespan would be shortened and they tried to find what was their purpose in life for the rest of their life. Having a meaning in life supported them to set a goal and drive them to achieve their goal with fostering hope for a better life in the future.<sup>8,11</sup> For example, living with longevity to work, helping others or looking after their family. Thus, they understood why they were still alive and what they had yet to do for their future life. Fisher J<sup>34</sup> indicated that finding a purpose in life is an important domain of spiritual well-being. Carolyn et al.,<sup>35</sup> found that finding meaning in life was related to perceived control, optimism and psychological well-being.

**Maintaining Hope:** The participants explained that spirituality helped to maintain hope, to make choices or take second chances for the future because they had to confront physical problems, psychological distress and living with an incurable disease.<sup>29</sup> PLWHA put more focus on holding to the purpose God had in mind for them in expanding their lives rather than on being able to articulate a special purpose.<sup>29</sup> Based on the perceptions of PLWHA, God always provides a second chance for life and a heaven in the afterlife when PLWHA pass away. Consequently, the participants maintained life with hope and some believed a cure for HIV would be provided by new drugs in the future.<sup>11</sup> Highfield&Carson<sup>36</sup> Fisher<sup>34</sup> indicated that hope is a crucial domain of spiritual well-being.

**Creating Relationships and a Sense of Connection:** The participants perceived that spirituality created interpersonal relationships, feelings of support, and a sense of belonging in addition to a sense of having a relationship with a higher power or God. The participants perceived that good friendships came from church attendance and created a sense of belonging. Moreover, the aforementioned activities created a sense of connection with a higher power or God. Thus, the participants were empowered in coping with a difficult situation, stressful life events and a life-threatening disease.<sup>8,28,29</sup> Thai people perceive the source of spiritual support to be family, which helped them to maintain hope and inner power for dealing with illness and stressful life events.<sup>11</sup> Carson,<sup>37</sup> Hungelmann et al.,<sup>38</sup> and Fisher<sup>34</sup> indicated that

relationships with self, others, environment, a higher power, divine or God were key sources of spiritual support.

**Negative Roles of Spirituality:** Some of the participants including both gay and heterosexual men and women described a negative feeling from spirituality in the form of internalized conflict<sup>3,7,8,26,27</sup> which was expressed by inappropriate sexual behavior. PLWHA perceived that they were sinners that influenced church attendance and had negative effects on the spiritual dimension.<sup>3</sup> This issue is important for health care providers in providing appropriate spiritual care for this group with the aim of reducing internal conflict and spiritual distress.

## Conclusion

The qualitative meta-synthesis study about the roles of spirituality among the PLWHA participants in the study provided a unique insight into PLWHA perceptions. The study proposed to synthesize and explore the spiritual roles that affected PLWHA. The following eight main themes in positive roles of spirituality of PLWHA emerged from the studies: 1) enhancing peace and happiness; 2) cultivating inner strength;

3) illness understanding and self-acceptance; 4) improving self-health care; 5) developing a sense of compassion; 6) finding purpose in life; 7) maintaining hope and; 8) creating relationships and a sense of connection. However, there was a negative role of spirituality for PLWHA, namely, internalized conflict. Evidence from this study provides in-depth understanding for healthcare providers to create spiritual care for PLWHA.

## Limitations

There were some limitations to this study. We only focused on full-text qualitative studies that were published in seven databases; CINAHL, PubMed, Science Direct, Clinical Key, Wiley Library Online, Thai LIS and Thai Jo, during 2000-2018. Therefore, some studies were not included in this study. However, further research should include studies from more databases in order to obtain a deeper insight and more data relevant to the study.

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