PHENOMENOLOGY STUDY: HIV TRANSGENDER PATIENT EXPERIENCE TO FULFILL SPIRITUAL NEED

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ABSTRACT

The prevalence of HIV cases increases significantly in the vulnerable population; it is Transgender. The high prevalence of HIV in transgenders requires treatment and treatment services. However, until now the transgender community is a group that is often not served in various health facilities. Transvestite identity intersections produce unique life experiences, such as multiple identities and spiritual identities. The purpose of the study was to explore the experience of transgender HIV patients when hospitalized in fulfilling spiritual needs. Research method with qualitative design phenomenology study approach. This study involved 12 transvestite participants who had been hospitalized because of HIV positive. Retrieving data using in-depth interviews, data analysis using Colaizzi. The results of the study found four themes namely (1) Spiritual according to HIV patients transvestites means believing in the existence of God; (2) Be grateful for the conditions they have; (3) get closer to God by doing good things.

Keywords

HIV, transvestites, transgender, spiritual needs
INTRODUCTION

The Joint United Nations Program on HIV and AIDS (UNAIDS) states that the development of HIV-AIDS has increased significantly, including also an increase in HIV prevalence in vulnerable groups, namely transgender (WHO, 2015; Codex & Commission, 2015). A vulnerable population is a group that has a risk of experiencing health problems more easily than other people (Stanhope & Lancaster, 2004). Data on HIV-AIDS cases reported by UNAIDS in 2015, there were 35.3 million people with HIV disease throughout the world, as many as 3.9 million people in Southeast Asia. 17% are estimated to be transgender. Indonesia as one of the Southeast Asian countries has become an HIV-AIDS epidemic with a 162% increase since 2001. 2015 UNAIDS data, the number of HIV cases in Indonesia ranges from 600,000 to 790,000 or with an estimated 690,000 People Living With HIV-AIDS (PLWH ) According to the 2015 Integrated Biological, and Behavior Surveillance, HIV prevalence in the transgender community in Indonesia was 25.8% or with an estimated size of 37,998 transvestites (UNAIDS, 2015; Codex & Commission, 2015). The number of individual transgender is difficult to estimated (Markwick, 2016; Baral et al., 2013). The reason is due to a lack of accurate data collection for transgender women or transgender man (Markwick, 2016; Brent, 2016). The prevalence of HIV infection in transgender women is higher compared to female sex workers and male sex workers (Evans, Pablos-méndez, Group, & Agency, 2016; Poteat et al., 2014; Baral et al., 2013).

Transgender individuals come from a variety of backgrounds, races, religions, ethnic groups, and socioeconomic status, with fully productive lives (Markwick, 2016). Transgender is a term for individuals with different gender presentations or individuals with gender identities and expressions that are different from the sex when they are born (Aleshire, 2016; Quinn et al., 2015; Codex & Commission, 2015; Baral et al., 2013). Some terms are used to refer to transvestites, the names of which vary between cultures. In Indonesia, women are known as Transvestite, from the Indonesian word which means women and men. Many among Transvestite who avoid formal employment opportunities, choose to live on the margins of society, unstable family life of poor quality (Koeswinarno, Litbang & Diklat, 2011). Transvestites as transgender worker sex (TSW) face with a combination of unique risk factors, namely biology, individuals, interpersonal, structural. Biological risk factors (e.g. prohibited use of hormones, silicone injection), individuals (needs to emphasize gender), interpersonal (e.g. high-risk male partners) and structural (e.g. discrimination, sexual violence, population problems) (Reisner et al., 2016; Poteat et al., 2014).

Transgender has unique health needs and requires special health services (Sedlak & Boyd, 2016). Transgender behavior makes it more risky for HIV infection than other sex workers (Winter et al., 2016; Defechereux et al., 2015). High HIV prevalence in Transvestite, makes transgender need prevention, treatment and care services (Baral et al., 2013). However, to date, the transgender community is a group that is often overlooked and underserved in interventions in various health facilities (Aleshire, 2016; Reisner et al., 2016; Irwig, 2016; Boekting, Robinson, Benner, & Scheltema, 2004). The gap in health experienced by transgenders is related to socio-economic problems, stigma, and discrimination. It causes a higher risk of HIV, victims of violence, substance abuse and psychiatric disorders (Logie, Lacomb-Duncan, Lee-foon, Ryan, & Ramsay, 2016; (Reisner et al., 2016); Defechereux et al., 2015). Young transgender women are more likely to be homeless, have higher depression scores and are at risk of
Transgenders in addition to experiencing health inequalities, they have problems of spiritual needs (Rosenkrantz, Rostosky, Riggle, & Cook, 2016). Transgender is an individual whose pattern of affection, partner choice and sexual identity opposes religious norms and communities, and often causes disputes. Their efforts to integrate religion, spiritual life, and sexual needs are full of conflicts (Hampton, Halkitis, Perez-Figueroa, & Kupprat, n.d., 2009). Also, the views of several religions, transgender are still opposed (Koeswinarno, Litbang & Diklat, 2011). According to Cole 2009, the intersection of transvestite identities produces unique life experiences, such as multiple identities and spiritual identities. The spiritual experience for transvestites is a profound experience, influencing interpersonal, social and religious aspects (Safavifar, Eftekhar, Alavi, & Negaranneh, 2016; Ab, Witten, Fgsa, Kidd, & Witten, 2016). Spiritual needs often arise when individuals experience a health crisis (Rosenkrantz et al., 2016). It is increasingly difficult if the health problem is HIV infection. The reason is that HIV disease is a great stressor in life, giving great pressure to life orientation. The stigma of PLWH such as being fired from work, being expelled from home, being ostracized from the religious community because it is associated with homosexual behavior, unmarried sexual relations, drug use, which overall behavior is contrary to various religious beliefs (Cotton et al., 2006); (Waluyo, Culbert, Levy, & Norr, 2015). As a result, transgender PLWH does not have adequate spiritual resources to overcome the problem of their relationship with God (Trevino et al., 2010).

**METHOD**

**Research Design**

The experience of HIV positive transgenders is certainly very different from that of individuals in general. Therefore research studies are needed that can explore these experiences, namely with phenomenological research. Phenomenology research means an approach to understanding one's life experience by looking for "essence" from experience explored (Polit & Beck, 2012; Cresswell 2013). In this study using a phenomenological approach because: 1) Phenomenology is a research model that explains the facts of phenomena as life experiences. The experience of transgender women who have been HIV positive in their spiritual lives is a statement that is experienced directly, real and different; 2) The purpose of phenomenology, explains the essence of the phenomenon of life experience to look for the unity of the meaning of the phenomenon under study and describe it through everyday life experiences (Polit & Beck, 2012; (Exploration, 2015).

**Participant**

The principle of determining the number of samples in qualitative research is based on data saturation. Data saturation occurs when the desired information is achieved, and no new information is found, or information is repeated, so no additional participants are needed (Polit & Beck, 2012). The participants involved in this study were 12 participants. Determination of participants refers to inclusion criteria: 1) transgenders. Information about the identity of the transgender was obtained from the head of the organization that oversees transgenders at the research site and based on self-
reported as transgender; 2) having been hospitalized because of HIV positive or HIV positive was upheld with medical record data or medical diagnosis. Exclusion criteria: 1) participants are not transsexuals who have undergone sex change surgery; 2) Not Transvestite which performs cross-dressing for sexual satisfaction; 3) not intersex genetic disorders that have both sexes.

**Time and place of research**

This research was recruitment participants in December 2017 - September 2018 in one hospital in Sidoarjo Regency

**Research collecting data**

The researcher uses a key person, in this case, a facilitator from an organization that handles HIV. The process of introducing rapport is done in about 15 minutes at a place and time agreed upon beforehand. After that, the facilitator will leave the researcher for the next step. After participants understand the explanation of the researchers about the objectives and research procedures. And fill out informed consent, the researcher will begin an in-depth interview. Research instruments: 1) researchers; 2) voice recorder; 3) structured interview guide; 4) researcher notes; 5) field notes. Researchers do bracketing, which is the process of suppressing, holding back thoughts and storing assumptions about the phenomenon under study. Researchers also do intuitiveness, which is immersed by phenomena. During the interview, researchers used language that was easy to understand. The researcher sits in front of the participant so that he can observe his non-verbal expression. Retrieving data using in-depth interviews, data analysis using Colaizzi (Sanders, 2003).

**RESULT**

**Theme 1: Spiritual according to HIV patients transgenders means believing in God's existence**

Taking this theme comes from two categories, namely having confidence in God and relationships with the Creator. Categories have confidence in God, obtained from a combination of codes from participant statements in the form of expressions about the way they define that spiritual is a belief in God. Belief in God revealed 10 out of 12 participants.

"Yes, I am sure there is Allah, Mom, even though like this I am still convinced of the existence of Allah .... (P1, line 92)"

The second category in the form of relations with the Creator is obtained from the incorporation of the codes of participant statements in the form of expressions about human relations with the Creator. This expression is obtained from 5 participants namely P2, P4, P3, P6, P12. Following are the participants' expressions that support:

"Yes, if it is natural, it means that it is more to (the participant is silent for a moment) more to the creator (P2, line 40)"

**Theme 2: Be grateful for the conditions they have**

In this theme, the description that transgender women who are HIV positive feel grateful because there is an opportunity to improve life after the diagnosis of HIV. This theme illustrates that transgender patients who are sick with HIV still have gratitude in conditions of a health crisis due to HIV. Taking this theme comes from two categories, namely being grateful to feel still healthy and grateful to be able to keep working after diagnosing HIV.
Since 2005 Alhamdulillah I was fine. (participant pauses) I am truly grateful. Even though people like me, let alone 12 years, just five years, so I'm grateful (P11, line 47) "

The second category of gratitude can continue to work after the diagnosis of HIV is delivered by P2 and P12.

"... I got my job inviting my friends, but on board, so we read the prayers, yes they came with a veil (P2, Line 507-508)"

Theme 3: get closer to God by doing good things
The third theme comes from the category realizing mistakes and expectations of forgiveness, certain times of worship, and efforts to do good deeds. The category of realizing mistakes is obtained from the incorporation of participant statement codes in the form of expressions of awareness that participants feel guilty of their existence, and expect God's forgiveness in the conditions that exist today. The expression is obtained from 10 participants, namely P1, P2, P3, P4, P5, P7, P10, P11, and P12. Transgenders realized that he sinned by choosing to become a transgenders. Transgenders realized that their existence was opposed by religion and scripture. But transvestites believe that what happened to him at this time is God's destiny.

"Every transvestite also realizes that transvestites are sinful, just because they feel comfortable, so they do other good things, so transvestites feel like God will give a chance (P2, L180-182)

Certain time categories of worship are derived from expressions about the time or condition that motivates transvestites to worship. This category describes the obligation to worship that has been abandoned since participants chose to live as transvestites. This expression is obtained from 10 participants.

"... since I went into transvestites I never prayed e mom; I just prayed because my age is now getting older, but yeah that's still a lot of holes (P12, Line 108)". The third category is all efforts made by transvestites to do good things such as charitable expressions, good deeds to parents or family. Some attempts were made by participants to get God's forgiveness for their sins. This expression is obtained from 7 participants

"Yes, I am just giving alms a lot, to change worship, giving alms to the family. If there is a mom, if you don't have it, you can't give it (P4, 182-185)"

DISCUSSION

Theme 1: Spiritual according to HIV patients transgenders means believing in God's existence
In this theme, we get the perspective of HIV transgender patients regarding their understanding of the belief or existence of God. This theme illustrates that transgenders are also spiritual beings. Spiritual is important to consider in nursing practice. Spirituality should be understood by nurses that the spiritual and religious patients cannot be separated from other dimensions of these patients because of the holistic nature of humans. Every nursing assessment cannot rule out other basic needs and only focus on certain needs. The approach to understanding spiritual with a structural-behaviorist approach is the behavior and practice related to religion is a sense of association with God. Another approach is complex relationships with values that give meaning and purpose to life (Westera, 2017).
The experience of patients with Godhead is very complex and individual. Many patients with spiritual support are assisted by nurses; patients achieve a feeling of spiritual well-being and face death calmly. Spiritual support helps clients to feel balance and relationships with greater strength (Bulechek et al. 2013). Spiritual in HIV patients is important. Pargament et al. (2004) state that religion and spirituality can bring pain and suffering due to stigma (Cotton et al., 2006). The Chaudoir et all (2012) study found that spiritual peace is a factor in countering depression related to HIV stigma. Spiritual must be understood as part of a holistic vision of one's health because spirituality is inherent in everyone so that everyone is a spiritual being. For nurses, understanding the patient's spiritual importance is important for dealing with spiritual problems. Nurses need to understand various spiritual descriptions, but the spiritual concepts that are believed by patients are important things that need to be understood by nurses (Westera, 2017). This is as stated by Kozier (2010) that fulfilling spiritual needs is personal for nurses or patients, so nurses need to communicate with sensitivity and empathy and must understand spiritual values.

**Theme 2: Be grateful for the conditions that transgender people have**

Taking this theme from the grateful category still feels healthy and grateful to be able to keep working after diagnosing HIV. They have spiritual strategies to find meaning in their lives and face death (Trevino et al., 2010). Previous quantitative studies showed that spiritual is important for PLWH. They are combining their spiritual with coping mechanisms (Cotton et al., 2006); (Ironson, Stuetzle, & Fletcher, 2006). Spiritual needs that are fulfilled give rise to a sense of spiritual well-being manifested by gratitude (Kozier, 2010). One of the characteristics of gratitude expressed by P6 and P12 has long lived as an ODHA for more than 12 years. Koenig (2004) explains that, when compared to non-religious people, religious people experience a faster recovery from illness, experience disability, and cognitive decline more slowly as they grow older, and generally live longer. Identify several mediating factors related to spirituality during illness, that spiritual impacts on the immune system, endocrine, cardiovascular, nervous system and coping mechanisms (Koenig, George, & P, 2004). Nurses need to be aware of or understand various spiritual descriptions, but the spiritual concepts believed by patients are important things that need to be understood by nurses, including spiritual concepts expressed with gratitude. Gratitude shows a stronger relationship with mental health, individual well-being and individual personality factors (Aghababaei & Tabik, 2013). Thank you and gratitude expressed expressly several times by P2, P3.

**Theme 3: Ask God for forgiveness by doing good deeds**

Based on the expressions of participants, transgender realized that they sinned by choosing to become transvestites. Transgenders also realize that their existence is opposed by religion and scripture (Shah, 2016). Transgender as a creature God has the right to interpret religion. No individual wants to be born as a transgender, and if these individuals eventually become transvestites, they still have religious rights and obligations (Koeswinarno, Litbang dan Diklat, 2011). PLWH reflect spiritually after receiving an HIV diagnosis, seeing their lives and diseases from a spiritual perspective (Dvm, Akbari, Haghdoost, Mph, & Zolala, 2015). Also, They combines previous experience with spirituality to overcome problems (Wenger, Kanouse,
Collins, Gifford, & Bozzette, 2001). PLWH also use spirituality to find meaning in life and face death (Trevino et al. 2010); (Coleman, 2004). P1 and P3 participants stated that HIV diagnosis made spiritual activity increase compared to before HIV diagnosis. Spiritual in HIV patients, important for health and well-being (Pargament et al, 2004).

The expressions of certain times in performing worship are delivered by P3, P9, P11, P10, and P12, which all of these participants approach the age of 50 and even P10 is 50 years old and lives as an ODHA for ten years. P12 who have been diagnosed with HIV for 12 years. The power of spirituality to help people face the challenges of aging with HIV infection, because of the positive impact of spirituality on the biopsychosocial function in aging (Westera, 2017). Research on older age LGBT groups has special needs to be shared with religious communities, which can help LGBT groups face challenges such as family demands, health problems and challenges related to aging (Cowie, 2009). When pain occurs in someone's life, then the person's spiritual potential is experiencing "distressing". Spiritual distressing can be spiritual pain, spiritual anger, spiritual guilt and others (Westera, 2017). Recognition of guilt and guilt is felt by individuals living with HIV (Caixeta, Nascimento, Pedro, & Rocha, 2012). The expression realizes mistakes with the term feeling a lot of sins, far from forgiveness, realizing the prohibition of God and expressing fear and remorse towards parents will share the sins delivered by P1, P2, P3, P4, P5, P9. The expression of realizing God's prohibition is conveyed by P2, P3, P4, P6, P7, P11 and P12.

The third category is obtained from participants' expressions about the business done with good deeds such as praying, giving charity and making parents happy. Coleman (2004) also describes that praying or worship is used to deal with various symptoms of HIV infection. African-Americans and Hispanics are more likely to use prayer than other ethnic groups (Coleman, 2004). The third category also felt by P2 and P6, P7 who replaced the obligation to worship by praying. And P2, P7, P10, P11 are more about the desire to do good for parents. Westera (2017) found that praying, helping others, listening to religious music or compliments were the most frequently used spiritual practices of HIV women's groups (Westera, 2017). On P3 and P12 more on doing charity, and on P11 expressing his feelings according to his hobby as a singer by listening to religious music and praise. Good deeds or practices such as those carried out by P3 and P12, it is difficult to do by P4, P7, and P8 because of low economic conditions. Transvestites tend to be low-income (Reisner et al., 2016); (Quinn et al., 2015). P4, P7, and P8 with lower economic status than other participants, jobs, and income that are not settled, and do not have a place to live. Following previous studies that transgender women are more likely to become homeless (Quinn et al., 2015). Transgender groups include populations that are often not served in health services (Reisner et al., 2016; Irwig, 2016). The gap in health experienced by transgenders is related to socio-economic problems, stigma, discrimination, and rejection of human rights (Logie et al., 2016).

CONCLUSION

Nursing properties support the fulfillment of spiritual needs, in nursing practice. In this case, nursing is a profession that is capable of spiritual care. There is always room or opportunity for nurses to provide spiritual services. So nurses in terms of talking about spiritual, it's the same as when nurses talk about other things, professionally. But in reality, this has not been done by nurses. So the expectation is nurses besides conducting a biological or physical assessment of the patient, the psychosocial condition of the
patient, but also conducting spiritual studies. The results of this study show that spiritual is important for HIV positive transgender because spiritual is inherent in everyone so that everyone is a spiritual being. In fulfilling spiritual needs, transvestites believe in the existence of God. Transvestite also realizes that their existence is still opposed by religion and society. But transvestites express their feelings of gratitude for the conditions they have.

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