Original Article

Exploring the Experiences and Coping Strategies of People Living with HIV: A Qualitative Study from the Health Blog Post

Gulcan BAKAN[1], Pınar SERCEKUS AK[2]

ABSTRACT

Objective

HIV infection is considered a chronic disease and provision of appropriate care for people living with HIV is prioritized globally. The aim of this study is to describe experiences and coping strategies of people living with HIV in Turkey based on their blog posts.

Materials and Methods

The study has a qualitative design. Two hundred and fifty-three posts in a blog were examined. Data were collected by using document analysis.

Results

Findings were categorized into four themes: being diagnosed, difficulties experienced, coping and gains. They had some negative feelings after being diagnosed. While some participants reported to get sufficient support from their families, partners, friends and health professionals, others said that their friends did not want to meet up with them and that their families rejected them. Religious, beliefs, positive thinking and blog using by PLWH were found to be coping strategies. The blog users had a fear about transmitting the disease to other people and about possibility of their friends and relatives' being diagnosed as HIV. They had some gains such as positive effects on their opinions about the value of life.

Conclusions

This qualitative study was the first to explore experience of PLWH in Turkish culture. It is of importance to determine what PLWH from different cultures experience to offer appropriate nursing care. Nurses need to be aware of the effect of blogs on patients.

Keywords

HIV; blog posts; patient's experiences; qualitative study.

INTRODUCTION

The number of people living with HIV (PLWH) continue to increase in the world. According to data from the WHO, there were 38.0 million PLWH in the world in 2019 but an estimated 39.9 million people were living with HIV at the end of 2023 [1]. Turkish Ministry of Health issued in 2017 that the incidence of AIDS was 0.10 every 100,000 in Turkey [2].

HIV infection is considered as a chronic disease [3,4]. This has caused prioritization of evaluation of the quality of life and provision of appropriate care for PLWH. Individual and social prejudices about HIV have appeared and these prejudices cause PLWH to experience fear, violence, stigmatization and discrimination [4–7]. It has been shown that PLWH hide their disease due to prejudices of the society, fear of losing their friends and partners and being rejected and stigmatized, do not want to take their drugs in front of others and need emotional and social support [8–10]. Research has revealed that PLWH'

1. Gulcan BAKAN, PhD, Associated Professor, Internal Medicine Nursing Department, Faculty of Health Sciences, Pamukkale University, Kinikli Campus, Denizli, TURKEY
2. Pınar SERCEKUS AK, PhD, Professor, Obstetric and Gynecological Nursing Department, Faculty of Health Sciences, Pamukkale University, Kinikli Campus, Denizli, TURKEY.

Correspondence

Gulcan BAKAN,Internal Medicine Nursing Department, faculty of Health Sciences, Pamukkale University, Kinikli Campus, Universite Street. Number: 11 Pamukkale / Denizli 20160 TURKEY, E-mail: gbakan@pau.edu.tr

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attending support group meetings [11,12] and PLWH's receiving peer support are effective in their adaptation to disease and coping with stress [13,14]. Perceived social support is directly related to positive coping strategies [11,15,16]. Social networks and associations, online support groups and use of web based electronic health knowledge technology provide social and psychological support and enhance the quality of care and satisfaction with it [17]. With the widespread use of the Internet, blogs have become a major platform for users to share their knowledge. According to blog statistics, In 2010, 77% of internet users would have given us 370 million blog readers, while in 2019, they reached 3.1 billion [18]. PLWH are a special group of people who might wish to receive information and support from the Internet community. All this evidence from the literature underlines the fact that PLWHs are aware of the difficult process they experience and need support.

The present study is important for two reasons. First, websites have become major platforms where their users share information. Blogs are social support systems via the Internet and PLHW are a special group likely to get knowledge and seek support from the Internet. Now, it is clear that health professionals should be aware of effects of what they share on the Internet on the patients. Secondly, in spite of presence of studies about this issue in different cultures, there have not been any qualitative studies about it in Turkish culture. The aim of this study is to describe experiences and coping strategies of people living with HIV in Turkey based on their blog posts. It is of importance to determine what PLWH from different cultures experience to offer appropriate nursing care.

MATERIALS AND METHODS

Design

This study is directed towards describing difficulties experienced and coping strategies utilized by PLWH using a blog. Posts were that shared between 2014 and 2018 on a blog of an association whose members are PLWH in Turkey were analyzed. This study has a qualitative design. This design allows better understanding of lives, emotions and opinions of individuals [19].

Sample

There were 253 posts shared between 2014 and 2018. The posts which are not about experiences and emotions of PLWH (posts involving information about HIV and its treatment or news etc.) were excluded from the sample. A total of 165 posts about experiences and emotions of the patients were found and all of them were included in the sample.

Data collection

Posts on a blog of an association whose members are PLWH in Turkey were examined. Blog posts are accessible to anyone who visits the site. PLWH and their relatives use this blog to receive and offer information and to share their experiences and emotions. A qualitative data collection method, document analysis was used in the present study [19]. This analysis was selected since it allows accessing a larger sample [20] and does not permit a physical, behavioral or emotional interaction between researchers and participants [19].

Data analysis

Inductive content analysis was adopted to evaluate data. Closer examination of obtained data allowed detection of concepts and themes whichrepresented the data.To improve reliability of the data, the documents were examined and categories and themes about perceptions of PLWH were determined by two researchers separately. Obtained findings were discussed in light of findings from relevant studies in the literature [20].

Ethical clearence

The study was approved by University Medical Ethics Committee (60116787-020/31919). Written informed consent was obtained from the blog owners, and the users were informed about the study through the blog.

RESULTS

The results were classified into four themes; being diagnosed, difficulties experienced, coping and gains.

Being Diagnosed

Most of the participants commented that they had some negative feelings like getting shocked, panicked and anxious and becoming introverted. In addition, the participants reported that they did not know what to do, did not believe accuracy of the test for HIV.

"When I was told to have HIV, my life became gloomy and I became weary of life and even couldn't find my way out of a paper sack." (Blog Post (BP) 3)

Difficulties experienced

They told about how difficult it was to accept the diagnosis and negative feelings after the diagnosis including loneliness, weakness, helplessness, hopelessness, sadness, disappointment, fear of death, anger with the person transmitting the disease and feeling of guilt due to having an unsafe sexual relationship.

"I'm alone... There is noone to hug and cry on his/her shoulders. I feel as if my heart were torn out ..." (BP 154)

The PLWH reported to be isolated and stigmatized by the society. In addition, some participants complained about negative attitudes of health professionals, which affected them. The participants explained that health professionals did not have sufficient knowledge about HIV, did not protect their privacy and did not provide them with knowledge and care and that their behavior was affected by their prejudices.

"I may die only from prejudices, not from a virus." (BP 39)

"The nurse with brown hair wore her gloves and stretched them up to her wrists and said she would never touch anyone without gloves." (BP 147)

Most of the participants commented that they kept their disease secret for fear that they lost their friends and partners and were stigmatized.

"If a person is infected with HIV, he/she is considered as a potential threat. Such people are afraid that their diagnosis might be revealed as if they committed a crime."(BP 84)

"I didn't hide the fact that I had HIV from my real friends. Actually, I don't want to hide it from anyone, but they aren't ready to hear it."(BP 93)

Some participants commented that when they were told to have HIV, they were anxious about transmitting the disease to others and felt as if they had been aliens.

"I used to try not to touch anyone in crowds of people and I used to get angry with myself whensomebody touched me." (BP 24)

"When I get on the tram, I feel as if I was a suicide bomber. Anything I touch makes me feel distressed." (BP 14)

Coping

The participants emphasized social support. However, they can tell very few people about their disease due to prejudices of the society. This prevents them from receiving social support from their family and friends.

"I can never forget one of the nights I spent in hospital. I was having a crisis and was helpless in my bed. My mom's accompaniment gave me a sense of security and made me happy." (BP 160)

The participants mentioned that the blog posts, the association, of which they were the members, and other members were important sources of support for them. They added that PLWH understood each other very well and that support for each other was of great importance.

"At that time, I became a member of the blog and started to write to other HIV positive members...You can't imagine how good it was for me. I used to think I was alone in the world and no one could understand me. Now I have had new friends and met people I share my problems and secrets with." (BP 79)

The participants emphasized that their beliefs and religious beliefs in overcoming the disease are significant in terms of their coping.

"I can say God doesn't give us a problem which cannot be solved and I think I'm lucky because I have a disease which can be treated very easily." (BP 151)

"... I've survived thanks to my self-confidence and beliefs in my strengths...Therefore, I thoughtthis virus couldn't beat me." (BP 142)

Gains

Some participants mentioned that there had been positive changes in their lives and that having the diagnosis of HIV had had positive effects on their health status and on their opinions about the value of life and had helped them gain strength, improve their abilities and skills and get rid of their prejudices despite difficulties in living with HIV.

"I get rid of everything in my life which are not worthy of keeping. There are only pleasant things or things which give me strength in life. Therefore, I'm strong. Believe me thinking and living this way work well." (BP 123)

"It has helped me improve myself, grow up and become mature..." (BP 82)

DISCUSSION

In this present study, the patients reported to have negative feelings like loneliness, weakness, helplessness, hopelessness, sadness, disappointment, fear of death, anger and feeling of guilt in addition to difficulty in accepting their disease. This shows that they obviously need counseling services and psychological support. Depression is the most common psychological disorder in PLWH. The rate of depression has been reported to be higher in women contracting the disease from their spouses [15]. PLWH experience symptoms of depression due uncertainty, trauma, stigmatization and fear of death and inability to take care of their children. They experience anxiety due to being rejected, left and stigmatized by their families, neighbors and friends when they share their diagnosis [21]. PLWH feel less anxious about revealing their diagnosis now. When they talk about their diagnosis with their partners, they can have a safer sexual relationship [22]. Sharing their diagnosis with their partners and supporters leads to a decrease in psychological pressure and depression and an increase in social support [23].

In the present study, since the PLWH were marginalized, they were stigmatized. They commented that they kept or had to keep their disease secret due to prejudices of the society, fear of losing their friends and partners and fear of stigmatization. Fear of being rejected and stigmatized affects their decisions about management of their disease. In a study in Tanzania, the patients were found to be unwilling to go to health centers and to take their medications due to stigmatization [8]. Patients exposed to discrimination avoid receiving counseling and support and presenting to health centers for treatment. Discrimination also increases depression while it decreases self-confidence in PLWH. This increases disease transmission from PLWH and reduces their compliance with treatment. It is clear that stigmatization and discrimination are the main barriers to struggle against HIV [9,24]. It has been noted in the literature that social support and positive relationships play an important role in coping with stigmatization and discrimination causing depression in PLWH. Social support and self-confidence are positive outcomes and stigmatization and rejection are negative outcomes of telling diagnosis of HIV to family members and friends [14,25,26]. The patients are exposed to social isolation, stigmatization and discrimination in their family environment, among their friends and in health care centers due to prejudices in the society [25]. Discrimination is an unjust and unfair treatment of PLWH. It means putting stigmatization into practice. Meetings at which both individuals with HIV and those without HIV come together [27] and programs directed towards decreasing stigmatization in the societycan increase willingness of individuals with HIV to receive support [15].

In the present study, while some participants reported to get sufficient support from their families, partners, friends and health professionals, others said that their friends did not want to meet up with them, that their families rejected them and that health professionals had negative attitudes. The participants emphasized the role of social support in coping with the problems they experienced and they had individual coping behaviors. Communication between family members and friends and their sharing information reduce stigmatization by strengthening their relationships and enhance acceptance of the disease and social support provided for them [11,13,15,26]. However, prejudices of the society, insufficient support from family and friends and fear of being stigmatized decrease the patients' demands for receiving care from health centers and the patients isolate themselves and prefer hiding and isolating strategies for coping [28,29]. The patients' participation in meetings arranged for social support improve the quality of life and self-care [10–12]. Peer support, education offered by social workers are effective in adaptation to disease and coping with stress [13,14,29]. It has been reported in the literature that relationships and communication between the patients and health professionals enhance compliance with treatment for HIV [12]. The participants in the current study explained that health professionals did not have sufficient knowledge about HIV, did not want to offer care to them, acted in accordance with their prejudices and did not protect their privacy. Consistent with this finding, studies about attitudes of health professionals to PLWH revealed that health professional had insufficient knowledge of the disease and high levels of prejudices [5,9,10,30]. In a study from China, health professionals did not accept that they stigmatized PLWH; however, they used such expressions as moral deficiencies, moral disease and punishment concerning PLWH. They had sympathy for children contracting the disease from their mothers, but they did not believe that drug addicts cannot benefit from treatment of the disease and they avoided contact with homosexual patients. Opinions of the society about homosexuality had increased negative attitudes towards PLWH [31]. In one study, the patients said that health professionals treated them as if they had been dirty while explaining verbal and nonverbal judgmental behavior of health professionals. In this case, the patients' energy and motivation to increase their survival and to carry out their self-care can decrease [32]. To eliminate prejudices, health professionals' knowledge of the disease should be increased and their education about it should be updated and continued [5,6,10,31].

In the present study, the participants mentioned that they had a fear about transmitting the disease to other people and about possibility of their friends and relatives' being diagnosed as HIV. Nurses' offering information to the patients about prevention of HIV transmissionis an important part of attempts to prevent the disease [8]. In a study on changes in lives of women contracting HIV from their spouses in Cambodia, some participants had a fear about transmitting the disease to their children, got nervous and wanted to get divorced and commit suicide. However, some participants said that their family roles changed and that their relationships got better. They added that their spouses started to value their opinions and got support from their grandparents for care of their children. [31,33]. This finding shows that perceptions and views about the disease can vary with culture and socio-economic conditions.

In the present study, things the PLWH shared in their blogs, the association that they were affiliated with and their interactions with other members of the association supported them and helped them to understand each other better. Sharing feelings, disappointments and struggles with others with similar problems help avoid loneliness and feel relaxed. The patients need to receive information, trust others and be empathized. Social networks and associations provide the patients with the support they need and an opportunity to establish communication with their peers having similar experiences and find answers to their questions [34]. In a study by Leyva-Moral et al., the participants found Internet chats very useful because they made them aware that they were not alone [25]. It has been noted in the literature that individuals unable to access health professionals utilized websites as sources of information and communicated with their peers and HIV-related associations. Joining online support groups and using web-based electronic health knowledge technology offer social and psychological support and enhance the quality of care and satisfaction with it. Internet and online groups created in an attempt to increase social support for PLWH have potential benefits and difficulties. Although they offer emotional and social support, they may cause anxiety related to digital access and literacy and reliability [26]. Holding meetings followed by forming online groups can create trust between individuals [17]. Therefore, digital literacy should be enhanced and web-based communication network should be created and strengthened in PLWH.

In the present study, the participants emphasized that religious beliefs, positive thinking and their belief that they can cope with the disease were very important in their coping. Communicating with God was the emotional coping strategy most frequently used by the participants in Turkey. Several studies have revealed that spiritual power achievedby praying, worshipping, reading the holy book, meditation and similar methods has positive effects on coping, adaptation and the quality of life [13,23,35,36]. Diagnosis of HIV has been perceived as a turning point by the patients and the disease has been found to have slower progression [11,14,37]. Nurses should be aware that religion and spirituality are important to and effective in coping behavior.

Limitations

This study had some limitations. We determined findings only based on blog posts shared by PLHW. We may have missed experiences of PLHW without access to the Internet or other forms of technology. Therefore, the findings of the study may not apply to all PLHW.

Conclusion

In this qualitative study, four main themes were identified as a result of the patients' experiences and coping strategies of people living with HIV via their blog posts: being diagnosed, difficulties experienced, coping and gains. The PLWH experienced such negative conditions as stigmatization and discrimination in addition to physical and psychological problems. They used problems- and emotions-based coping strategies such as technology, blog posts, education and counseling meetings, social support, strengthening spirituality and fulfilling religious duties. Learning about life experiences of the participants from their viewpoints will allow offering care appropriate for their needs. Further studies are needed to understand patients' use of web pages and its effects. It can be suggested that the results of the present study will be useful in terms of follow-up of patients and enhancement of social support. With technological developments and easy access to health knowledge on online platforms, health knowledge technologies can be used to increase the quality of care and life of PLWH.

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AUTHORS'S CONTRIBUTION

Data gathering and idea owner of this study: Gulcan BAKAN

Study design: Gulcan BAKAN, Pınar SERCEKUS AK

Data gathering: Gulcan BAKAN, Pınar SERCEKUS AK

Writing and submitting manuscript: Gulcan BAKAN, Pınar SERCEKUS AK

Editing and approval of final draft: Gulcan BAKAN

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