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ORIGINAL RESEARCH

Palliative Needs of People Living with HIV in Illness Trajectory

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Purpose: HIV infection is one of the most important health, social, and economic issues of humanity today and one of the greatest concerns and dilemmas in many countries around the world. It is a multifaceted issue with biological, social, and psychological consequences that affect the individual and social lives of those infected. The aim of this study was to investigate the palliative needs of people living with HIV in Illness trajectory in Iran.

Patients and Methods: This study was of qualitative type. Purposeful sampling was used to select the participants from the People living with HIV, their caregivers, and professionals in this field. 27 participants were interviewed. The main data collection instrument was semi-structured interview with open questions. Additionally, the collected data were analyzed via inductive content analysis method.

Results: Data analysis resulted in 4 main categories, including providing essential information, social facilities, psychological rehabilitation, and healthcare services.

Conclusion: People living with HIV and their caregivers face diverse needs on the path of living with this disease. Therefore, controlling HIV infection is impossible without understanding the needs of patients and their caregivers and planning to meet these needs. Study findings provide an opportunity for HIV planners and policymakers.

Keywords: PLHIV, palliative care, qualitative research, Iran

Introduction

Human immunodeficiency virus (HIV) remains a significant global public health problem.[1] While prevalence has declined in some countries, and there have been advances in treatment and care, the global acquired immunodeficiency syndrome (AIDS) epidemic remains a serious concern.[2] Since the beginning of the epidemic, 88.4 million (71.3–112.8 million) people have been infected with HIV, and approximately 42.3 million (35.7–51.1 million) people have died from AIDS.[3] HIV prevalence in the *Eastern Mediterranean* Region is 0.1% (low epidemic). 70% (252 000) PLHIV live in 3 countries Pakistan, Islamic Republic of Iran and Sudan.[4] The number of infected individuals in Iran has been reported to be 46,000 (35,000–64,000), of which 2300 (1600–3600) have died.[5] Stigma is rife in the Region and presents a major obstacle to uptake of HIV services. Political developments in the past decade in the Region have also not been conducive to de-criminalization and de-stigmatization.[4]

There is currently no cure for HIV infection. However, with access to effective HIV prevention, diagnosis, treatment, and care, including for opportunistic infections, HIV infection has turned into a manageable chronic health condition, allowing individuals with HIV to live long and healthy lives.[1]

HIV is stigmatized and associated with shame all around the world, making access to testing, care, treatment, or counseling difficult due to fear of judgment.[6] Research conducted in Iran also demonstrates that patients experience a kind of forced segregation from society, suffer from serious stigma in society,[7,8] and face problems like humiliation, discrimination, weaker family functioning, and loss of income.[9,10]

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Palliative care needs defined as individual-level problems, symptoms, distress and concerns in the physical, psychological, social and spiritual domains of life which have the capacity to benefit from a palliative care intervention.[11] For effective planning and implementation of palliative care for people living with HIV/AIDS (PLWHA), identification of their needs is important.[12]

Caring for patients with life limiting conditions require a thorough understanding of not only the disease but also the personal circumstances of individual patients and their families, finding out appropriate needs for patients and family remain an important first step in providing quality palliative care.[13]

As a vulnerable population, individuals with HIV experience HIV infection-related problems, including the pain of illness, social discrimination from the community, and a lack of resources for care and the threat of their disease. Moreover, these individuals are compelled to strive to cope with psychological problems, such as loneliness, social isolation, etc. All of these psychosocial and physical restrictions can increase the need of individuals with HIV for comprehensive care, including attention to their personal environment and receiving support from family and friends. It is hypothesized that providing greater support and care to individuals with HIV could culminate in preventing or at least mitigating these negative psychological consequences.[14] In the context of HIV, needs encompass prevention, diagnosis, treatment, long-term home care, and psychosocial support. High-risk groups and asymptomatic individuals are dispersed throughout the country, making access to them difficult. Due to social, cultural, and economic barriers, high-risk groups have difficulty establishing connections with healthcare centers. Healthcare workers should be directly involved and have close contact with high-risk groups to provide health services. At the same time, they should also be aware of the general public. Additionally, the cost of HIV prevention, with a focus on high-risk groups, is much lower than the treatment costs of HIV infection.[15]

HIV infection imposes significant psychosocial pressures on patients, their families, partners, and healthcare professionals. These pressures manifest as reactions, such as anger, restlessness, anxiety, presentiment, fear, depression, suicidal thoughts, physical weakness, social isolation, hypochondria, expectant behaviors, hopelessness, low self-esteem, and cognitive deficits due to the involvement of the central nervous system. All of these reactions significantly impact quality of life, life satisfaction, and self-efficacy.[16]

Psychological research on individuals with HIV has shown a conceptual shift toward understanding HIV as a chronic condition. Consequently, healthcare providers are required to identify and address the needs of the growing population of individuals with HIV.[17] Since the widespread prevalence of HIV until now, when this disease still persists as a global issue, numerous studies have been conducted regarding this disease in the fields of medicine, sociology, psychology, and so on. Due to the fact that HIV is not merely the entry of a virus into the body and, apart from its effects on health status, in most cases, it has profound impacts on other aspects of patients' lives,[18] assessing the needs of these patients enables healthcare providers to plan interventions to directly address these needs in such a way that they are compatible with their lifestyles. In this regard, the assessment of the palliative needs of Iranian people living with HIV in Illness trajectory was viewed as the present study's objective.

Materials and Methods

Study Design

The present study was a qualitative study conducted using a content analysis approach to investigate the palliative needs of people living with HIV throughout their illness. Content analysis is a research method used to objectively, systematically, and quantitatively describe the explicit content of communication messages. The main area of focus in the research was the palliative needs of HIV patients throughout their disease course. This qualitative study was conducted in Iran from June 2023 to July 2024. Data were collected through semi-structured interviews with HIV patients and their caregivers. Interviews were also conducted with several experts in the field of HIV.

Participants

The main participants of the study, who were selected through purposive sampling, were people living with HIV who referred to the Behavioral Diseases Counseling Center and Positive Club for receive services.

The main criteria for inclusion of people with HIV are age between 18 and 65 years and that the diagnosis of HIV has been confirmed by a doctor. The inclusion criteria for caregivers were also that they were the main family members of people with HIV, living with them, and caring for them.

Additionally, inclusion criteria for Experts were that they should have more than 5 years of experience in palliative care or HIV disease or have research experience in these two fields and have at least a bachelor's degree. The exclusion criteria for all participants were that they did not have sufficient mental capacity to participate in the study or that they lost the desire to continue participating in the study.

Data Collection

Data collection was conducted in the second half of 2023. Twenty-seven in-depth, semi-structured (face-to-face) interviews were conducted through open-ended questions, by A B and with the guidance of other members of the research team. The data collection was primarily performed using in-depth, semi-structured (face-to-face) interviews through open-ended questions. The field note-taking method was employed as a complementary data collection technique. All interviews were conducted in Persian and each interview lasted between 30 and 90 minutes and was audio-recorded and supplemented by written notes. Interviews commenced with a general question and progressed to more relevant inquiries. The first open question posed to HIV patients was, "Please discuss your needs regarding your HIV treatment process". Subsequent questions were selected by the interviewer to delve deeper into the topic under discussion. Probing questions (such as "Please elaborate on this issue") were also used to allow participants to fully explain their experiences and enrich the data. All interviews were audio-recorded with participants' consent, transcribed verbatim, and stored securely to ensure confidentiality.

Data Analysis

Graneheim and Lundman's approach[19] was employed to analyze the data. Initially, all participants provided their consent for audio recording. Each interview was listened to multiple times and transcribed into a Word document. Data analysis was conducted concurrently with data collection. Each interview was analyzed, and then the next interview was conducted. To this end, in the first step, the interviews were reviewed, a general understanding was reached, and the core concepts were identified. Initially, the interviews were coded line by line, and then the codes were grouped into larger categories based on similarities and relationships. Subsequently, code generation, data reduction review, and categorization of similar codes were carried out. Finally, the merging of similar categories, continuous comparison and iteration between data, category naming, and prioritization based on content importance and frequency were performed. It took one year to complete the sampling and data analysis process. The MAXQDA 2020 software was used for the coding process. Rather than imposing predetermined themes on the data, an inductive approach was used. This allowed themes to emerge naturally from participants' narratives and experiences, ensuring that they were rooted in the data and reflected participants' perspectives.

The Study Rigor

In order to enhance the research's credibility, Graneheim and Lundman's approach[19] was employed. The participants were selected in a way that ensured the greatest diversity in terms of age, marital status, education, and employment in order to obtain a broad range of perspectives. In order to ensure dependability, the research findings were presented to some of the participants for their feedback, and all of them ultimately confirmed the findings. In order to improve the confirmability, any form of prejudice was avoided. All authors were involved in the analysis and coding process and provided their feedback and through meetings, consensus was reached on thematic categories. In order to promote transferability, the research process was described in detail, and participants' direct quotes were included.

Ethical Considerations

Prior to the commencement of the study, both oral and written informed consent was obtained from all participants. Participants were assured of the confidentiality of their names and were informed that their participation was voluntary and that they could discontinue the interview at any time. They were also informed about the interview process and how

the results would be disseminated. Researchers made every effort to avoid any bias or prejudice and refrained from using any words or labels that might upset participants.

Results

The present study aimed to investigate the palliative needs of people living with HIV.

In total, 27 participants were considered as interviewees, including 17 HIV patients, 5 caregivers of HIV patients, and 5 social work and HIV specialists. The sample size was left open until saturation is reached, and finally, after interviewing 27 people, no new codes were added, and the sample size reached saturation. The characteristics of the participants are listed in Table 1.

Table 1 Characteristics of Participants in the Research

People with HIV						
Gender	**Age**	**Marital Status**	**Education**	**Occupation**	**Duration of Diagnosis (years)**	**Number of family members**
Female	48	Divorced	Elementary school	Embroidery	4	2
Female	47	Widow	Elementary school	Embroidery	10	3
Female	32	Married	Diploma	Unemployed	7	6
Female	52	Widow	Elementary school	Unemployed	5	4
Female	51	Widow	Middle school	Retired	22	3
Female	32	Married	Diploma	Unemployed	1	3
Female	49	Married	Elementary school	Unemployed	15	5
Female	42	Married	Bachelor	Social worker	15	4
Female	55	Widow	Elementary school	Unemployed	8	5
Female	49	Widow	Elementary school	Unemployed	15	2
Female	34	Married	Bachelor	Pistachio business	7	2
Female	35	Married	Diploma	Unemployed	6	3
Male	48	Married	Diploma	Driver	10	4
Male	30	Married	Diploma	Club manager	5	2
Male	36	Single	Bachelor	Employee	6	1
Male	52	Married	Diploma	Pensioner	4	2
Male	45	Single	Middle school	Waste collection	2	1
Caregiver of people with HIV						
Gender	**Age**	**Relationship with Patient**	**Education**	**Occupation**	**Family member's illness duration (years)**	
Male	45	Spouse	Diploma	Self-employed	8	
Female	21	Child	Associate degree	Employee	2	
Female	42	Spouse	Diploma	Housewife	8	

(*Continued*)

Table 1 (Continued).

Female	30	Sister	Middle school	Housewife	19
Female	47	Mother	Diploma	Housewife	21
Social work and HIV experts					
Gender	**Age**	**Expertise**	**Occupation**	**Duration of activity in the field of social work or HIV (years)**	
Female	42	Social worker	Bachelor's	12	
Female	48	Social worker	Bachelor's	11	
Male	36	Social worker	Masters	10	
Female	43	Counselor	Masters	14	
Male	45	General practitioner	General practitioner	22	

The mean and standard deviation of the age of caregivers of People living with HIV was (30 ± 9.93). Regarding people living with HIV, the mean and standard deviation of age (43.35 ± 8.10) and time since diagnosis (8.35 ± 5.38) years were calculated (12 women and 5 men).

Data analysis resulted in 1001 primary codes that were summarized in 18 subcategories and 4 main categories including provision of essential information, social facilities, psychological rehabilitation, and medical services. Table 2 shows the categories and subcategories resulting from the research.

Providing Essential Information

Providing essential information was identified as one of the primary categories. Many patients and their caregivers stated that upon receiving an HIV diagnosis, they were shrouded in uncertainty due to a lack of knowledge and information

Table 2 Research Categories and Subcategories

Categories	Subcategories
Providing Essential Information	How to Disclose
	Increasing Information about HIV
	Disease Treatment and Progress
	How to Track One's Health Condition
Social Facilities	Freedom from Stigma and Discrimination
	Having Equal Opportunities
	Raising Public Awareness
	Tackling Employment Challenges
	Financial Support
	Membership in Communities

(*Continued*)

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Table 2 (Continued).

Categories	Subcategories
Psychological Rehabilitation	Individual and Family Counseling
	Interaction with Peers
	Strengthening the spirit of life
	Empathy-Based Understanding
Healthcare Services	Controlling disease complications
	Preserving Patient Dignity
	Facilitating Access to Healthcare Services
	Constant Connection with Medical Staff

about the disease. One of their fundamental needs is to acquire more information in this area. In the following, some interviews related to this concept are presented.

How to Disclose

My son says, "Do not tell my sister. She is a child and she will tell everyone." I have not told her, but what if my daughter hears it from someone else someday? I do not know how she will react. I wish someone could teach me how to handle this. I am so scared.

Increasing Information About HIV

I was at a wedding party. I wanted to eat an orange and accidentally cut my finger with a knife. I was thinking to myself, "God, what would happen if this knife ended up in someone else's hands?" I was so stressed. I stealthily slid the knife under the table, opened my bag, and dropped it inside. Afterward, I buried it in the garden. I was so scared. Later, they told me that washing with dishwashing liquid would have been enough. They should have taught us these things.

Disease Treatment and Progress

I have no physical problems. However, every now and then, my test results are lower than normal. I do not know if it is because of stress or my diet. Just a few days ago, the doctor asked me if I was taking my medication regularly. I was surprised and said that my tests must be wrong for him to say that, but the doctor has not explained anything to me.

How to Track One's Health Condition

I told you that from 2008, when my husband passed away, until 2012 when I tested positive myself, no follow-up was done, neither by me nor by the hospital. I did not know how to do it; I should have been informed that regular testing was required. I had no idea where to go or what to do.

Social Facilities

Another important and fundamental category in the experiences of participants in this study was the need to receive social amenities. According to patients, one of their substantial needs was to have appropriate conditions in society, including freedom from stigma and discrimination, having equal opportunities, raising public awareness, tackling employment challenges, financial support, and membership in communities. The following are some of the participants' comments in this regard.

Freedom from Stigma and Discrimination

Do not other people get sick? How are they dealt with? They are asked what their problem is and do their job. However, their attitude changes when it is our turn. They are afraid. Until these behaviors are corrected, many people will avoid seeking treatment.

Having Equal Opportunities

Does not the right to citizenship mean that everyone is equal? However, as an HIV patient, I face discrimination in many places. For example, while others receive medical services, I am denied. Others are granted citizenship, but I am not. I cannot travel freely. I cannot work in a government job. I also deserve to have my rights respected.

Raising Public Awareness

The information available to the public about HIV and AIDS is outdated. People believe it is easily transmitted and incurable. Therefore, as soon as you notice you are affected, you say to yourself, "Do not tell anyone", and all your concern becomes focused on this issue, whereas if the community were better educated, others would be more supportive.

Tackling Employment Challenges

I often had to take leave, either for doctor's appointments or because I was simply too unwell to get out of bed. I had become depressed. My supervisor expressed dissatisfaction with my performance, but on days when I felt better, I tried to compensate. Some people might assume that individuals with HIV are incapable of working, but it is essential to recognize our limitations. We do not possess the physical or mental capability to overcome every obstacle.

Financial Support

My husband is now taking methadone regularly. He is using fewer drugs and is working more, although there is not much work available, and his income is low. Still, we are grateful for what we have, but we are always in need financially. Everything is so expensive, and we are always struggling. We are both sick, with two school-age children.

Membership in Communities

In my opinion, if an individual with HIV does not isolate themselves at home and instead interacts with society, I believe they can live 10–20 years longer. In my view, HIV, while there is medication for it and it can be controlled, primarily affects the mind and nervous system.

Psychological Rehabilitation

Psychological rehabilitation is another category identified in this study. Many patients and their caregivers expressed a need for psychological rehabilitation throughout the disease, including individual and family counseling, empathic interaction with peers, promoting a positive outlook on life, and empathy-based understanding. Some examples of the participants' statements are provided in the following.

Individual and Family Counseling

I wish the counselor at the center not only provided information about the disease but also acted as a psychological counselor to address an individual's personal life issues. I had to seek counseling elsewhere. When I mentioned my marital problems, I noticed that all the advice I received was related to the disease, but the counselor did not seem to have much experience or knowledge in that area.

Interaction with Peers

At first, you get sick and you do not know what has happened to you; you are confused. Someone who is sick themselves can be a great guide. Initially, I would come to the center and see many people coming and going, but I was too shy to talk to them. I thought "they might not be sick and I would be embarrassed", but when I attended the meeting and talked to them, I saw that we were all the same, and my heart felt more at ease.

Strengthening the Spirit of Life

I am truly delighted that this illness has a treatment. It brings me immense joy. Even if the medications have side effects and cause other problems, such as osteoporosis, I would still be grateful for the treatment. I am glad; I am hopeful for life. The hope that this treatment provides is what keeps me going.

Empathy-Based Understanding

We are a very affectionate family; I had a strong bond with my siblings. My elder brother came to the hospital and took me to the hospital yard. He kissed and hugged me and started crying. He said, "Look, sweetheart, much coin, much care. I do not know how much patience you have that God is testing you like this, but you should know that we are with you in every way. We will be by your side wherever we can". I really needed to hear those words.

Healthcare Services

The need for healthcare services is another category identified in this research. In the following, the required healthcare services for both the patient and the caregiver are discussed, and some of the points mentioned by the participants are presented.

Controlling Disease Complications

For a while, as my illness progressed, I was constantly on my way to the hospital. I began to experience fever, chills, and a severe cough. I was hospitalized for 18 days. As soon as I would come home and change my clothes, I would feel ill again and return to the hospital. I had become nothing but skin and bones. My only wish was for this pain to end.

Preserving Patient Dignity

I suffered greatly. No one can believe it. After my cesarean section, the hospital staff treated me awfully. The hospital housekeeping staff saw that I was in a terrible condition but stood at the door and said, "Madam, you yourself gather your bed sheets, put them in this plastic bag, and give them to me; I will give them back to you and you yourself throw away". I have become so reluctant to go to the hospital that I think to myself, "I will not go to the hospital until I am on the brink of death".

Facilitating Access to Healthcare Services

They do a lot of things for us right here at the center, but it would be great if there was a place that was specific for patients like us, a well-equipped clinic with all kinds of doctors, so that we do not have to explain our problem as soon as we walk in. It is hard to talk about it.

Constant Connection with Medical Staff

Something that I think would be very helpful is to have a dedicated phone number that I, as someone living with a lifelong illness, could call whenever I needed to, and I could talk to a doctor or knowledgeable medical staff who would listen to me, give me guidance, and follow up my condition from all aspects, checking in on me at least once a month to see how I am feeling physically and mentally.

Discussion

The current research aimed to investigate the palliative care needs of HIV patients. According to the findings, the needs of these patients were categorized into four areas: Providing essential information, including training on how to disclose, increasing information about HIV, disease treatment and progress, and how to track one's own health condition, social facilities including freedom from stigma and discrimination, having equal opportunities, raising public awareness, tackling employment challenges, financial support, and membership in communities, psychological rehabilitation including individual and family counseling, empathic interaction with peers, promoting a positive outlook on life, and empathy-based understanding, and healthcare services including disease complications management, compassionate and respectful treatment by medical staff, facilitating access to healthcare services, and constant connection with medical staff. In order to provide quality palliative care, it is important to pay attention to these identified needs.

In line with the findings of this study in the field of providing essential information, Lau et al[20] suggested that one of the needs of HIV patients was providing HIV-related information. Similarly, Moradi et al[21] highlighted public and accessible education and counseling for HIV patients as one of these group's fundamental needs. Shahabi et al[22] also mentioned that by acquiring knowledge about the disease, individuals with HIV gradually develop and practically apply strategies for disclosure or non-disclosure based on their circumstances and conditions.

Another finding of the study is social facilities. Aligned with the research findings, Kusman et al[23] and Kabbash[24] suggest freedom from stigma and discrimination and social support as fundamental needs of HIV patients and propose emergency financial assistance, legal services, insurance premiums, and nutritional interventions as gaps between needed and received services. Furthermore, Lau[20] emphasizes the need for receiving financial support, while Moradi states that providing job opportunities and sufficient social support for individuals with HIV can motivate them to avoid risky behaviors and consequently reduce HIV transmission among the population. The World Health Organization (WHO) has also declared that psychosocial support for individuals with HIV can help them cope with the disease more easily, seek treatment, and consequently prevent the transmission of the disease.[25]

Psychological rehabilitation, is another identified category in the present research. Consistent with the findings of Love,[16] this category highlights the need for receiving psychological counseling among individuals with HIV. The results of this section align with Camellia's[26] study, demonstrating that HIV-positive individuals are at a higher risk of mental health problems compared to the general population. Kusman et al[23] also state that promoting a positive outlook on life is a fundamental need for HIV patients, and Morrow[17] points to the need for the development of psychosocial groups for HIV patients.

In this study, one of the main needs was identified as healthcare services. These findings are consistent with Senyurek's[27] research, which referred to interactions with the healthcare system and identified shortcomings, such as withholding information from patients, negative attitudes of some physicians toward the disease, lack of confidentiality, and discrimination. In line with the research findings, Moradi et al also pointed to incomplete and inadequate coverage of healthcare services, patient dissatisfaction with some services provided by counseling centers/clinics, non-adherence to confidentiality by medical staff, and lack of access to specialized services needed by patients.[21] Additionally, they expressed the complete retroviral treatment, continuous treatment and care, provision of care and treatment for patients with hepatitis, and provision of dental services as the needs for HIV patients. Kusman[23] also views accessible and affordable healthcare services as patients' needs. Additionally, Love et al[20] proposed medical treatment as the primary needs of patients.

The most crucial limitations of this research included its small sample size and the potential for the sample not to be generalizable to the community. Although the role of researchers' observations, their objectives, and biases in research outcomes cannot be denied, we have strived to minimize their impact on our findings. To this aim, in the interview and data analysis process, the researcher carefully avoided imposing prior assumptions or biases on the data analysis. Instead, an attempt was made to report the events as they were mentioned by the participants, without any interference of personal interpretation.

Another limitation of this study involved participants' concerns about the identification and disclosure of their personal information due to the stigma associated with the disease, which, in several instances, culminated in the absence of some participants at the scheduled time for the interview. To address this issue, participants were reassured about confidentiality before the start of the interview, and identity information, such as their full name, was not recorded.

Conclusion

This study identified the palliative needs of people living with HIV throughout their illness. The findings of the present study indicate thatpeople living with HIV and their caregivers face diverse needs at various stages of living with HIV, including diagnosis, disease progression, end of life, and post-patient death including the provision of essential information, social facilities, psychological rehabilitation, and medical services. Therefore, controlling HIV infection is impossible without recognizing the needs of patients and their caregivers and planning to meet these needs. Based on the findings of the present study, it is essential to first assess their needs in order to provide palliative care to HIV patients.

HIV planners and policymakers should also design methods or mechanisms that are appropriate to help patients and their families by understanding the needs of this group of people.

Data Sharing Statement

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethics Approval and Consent to Participate

All procedures performed in studies involving human participants were under the ethical standards of the Institutional and National Research Committees and with the 1964 Declaration of Helsinki and its subsequent amendments or similar ethical standards. The present research is a part of a doctoral thesis with the code of ethics IR.USWR.REC.1399.210 approved by the University of Social Welfare and Rehabilitation Sciences. Participation in the study was voluntary and all participants provided written informed consent. Participants also consented to publication of anonymized responses. In this study, to protect the information and privacy of the participants, a numerical code was given to each of the participants and their names were not published anywhere.

Consent for Publication

Participants informed consent included publication of anonymized responses/direct quotes.

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Disclosure

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