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Explore the Self-Care and Lifestyle Modification of People Living with HIV Infection - Descriptive Analysis

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Abstract

Background: Human Immunodeficiency Virus (HIV) infection remains a global health challenge, affecting millions of individuals across diverse communities. As medical advancements continue to improve the prognosis for those living with HIV, the significance of self-careand lifestyle modification in managing the condition has become increasingly apparent. This qualitative study seeks to delve into the intricacies of the self-care practices and lifestyle modifications adopted by people living with HIV infection, aiming to contribute valuable insights to the existing body of knowledge.

Methods: Data collected using a non-probability purposive sampling technique, the researcher adopted a qualitative research design from 10 patients attending ART Center, RGGH, Chennai-03.The tools include the background variables, self care practices of patients with HIV also analyzed here. The data were entered into SPSS (version – 20.0) for windows and descriptive statistics were performed.

Results: Majority of them were males, married and completed some technical education , not insured for health , diagnosed for HIV within 1 to 5 years ago and not on ART. Half of them belonged to the age group of 35-44 years, unemployed and not aware of any support groups or counselling groups related to HIV. Self-care practices were identified subsumed under four (3) main themes.

Conclusion: Self-care practices undermine efforts to effectively abate the spread and burden of HIV and reduce AIDS-related mortality. Therefore, there is need for sensitization campaigns on the benefits of ART and the risks associated with widespread self-prescription of antibiotics and use of scientifically unproven herbal remedies.

Key words: Self Care Practices, Life Style Modifications, HIV Patients

Background

HIV continues to be a serious global public health concern, having taken 40.4 million lives to date (32.9 51.3 million), and it is still spreading throughout all nations. Some have even reported rising rates of new infections after years of decline. By the end of 2022, there were an anticipated 39.0 million [33.1 45.7 million] HIV-positive individuals worldwide, of which two thirds (25.6 million) resided in the WHO African Region. In 2022, 1.3 million [1.0 1.7 million] people contacted HIV, and 630 000 [480 000 880 000] people died from HIV-related causes. The global health sector is guided in implementing strategically focused responses to achieve the goals of ending AIDS, viral hepatitis B and C, and sexually transmitted infections by 2030 by means of global health sector strategies on HIV, viral hepatitis, and sexually transmitted infections for the period 2022–2030 (GHSSs).The GHSS recommends national initiatives that are coordinated and disease-specific, backed by initiatives from WHO and partners. They take into account the changes in the context, technology, and epidemiology from prior years, encourage learning throughout the spectrum of diseases, and provide chances to use new and innovative insights to combat the diseases. For each disease that targets disparities, they demand a specific focus in order to reach the most impacted and vulnerable individuals. They help to realize the objectives of the 2030 Agenda for Sustainable Development by fostering synergies within the scope of primary healthcare and universal health coverage. Antiretroviral therapy is a treatment and prevention strategy for HIV (ART). HIV can develop into AIDS if left untreated, frequently years later. According to WHO guidelines, Advanced HIV Disease (AHD) is defined as CD4 cell count fewer than 200 cells/mm3 or adult and adolescent WHO stages 3 or 4. All HIV-positive children under the age of five are regarded as having advanced HIV illness. A healthy lifestyle is linked to almost 40% of deaths worldwide. Changing this factor involves not only creating an atmosphere that encourages healthy behaviour but also improving knowledge, attitudes, and practices. In order to quantify these factors for the educational diagnosis of populations, the Knowledge, Attitudes, and Practices Survey (KAP) was developed. This tool is versatile and can be used to organize health promotion initiatives and assess individual or community interventions.

Objectives

The objective of the study is to Explore the Self-Care and Lifestyle Modification of People Living with HIV Infection.

Methods and Materials

The study approach was a qualitative research approach. The information was gathered from 10 adults attending ART Center, RGGH, Chennai-03 by non probability sampling technique. The purpose of the study was explained to all the patients. The tools includes the background variables, self care practices of patients with HIV also analyzed here. The self care was assessed by recording the experiences shared by the participants. Confidentiality was maintained throughout the study. The data were entered into SPSS (version – 20.0) for windows and descriptive and inferential statistics were performed.

Ethical considerations

The Institutional Review Board and Institutional Ethics Committee examined and authorized the study . Before being included in the study, each participant received a subject information sheet that included a thorough explanation, and their written informed consent was acquired.

Validity and Reliability:

The validity of the tool was assessed using content validity. Content validity was determined by experts from Medicine and Nursing. They suggested certain modifications to the tool. After the modifications, they agreed on this tool for assessment. The reliability of the tool was assessed by using the Cronbach alpha method. These correlation coefficients were very high and it is good tools for assessing self care practices of patients living with HIV AIDS. Instrument Part A, which had socio-demographic factors was given to a panel of nine subject experts to establish the content validity The pilot study was conducted with five participants to assess the reliability in the local population being studied. They were not a part of the main study and the Cronbach's alpha value for the self care practices was 0.82 . Hence, the tool is found to be adequate and reliable in assessing the intended outcome of the study.

Data collection procedure

The study was conducted after approval of the Institutional Ethical Committee. Samples were selected by non-probability judgmental method. The purpose of the study was explained to the participant. Informed consent was obtained from the participants. Structured interview questionnaires was administered to study participants; it will take 10-15 minutes. The data was collected from 10 adults attending ART Center, RGGH, Chennai-03. The data was analyzed according to the objectives and hypothesis of the study. Data analysis was compiled after all the data was transferred to the master coding sheet. The data was analyzed, tabulated and interpreted using appropriate descriptive and inferential statistics.

Results and Discussion

The distribution of background characteristics of the patients in this study shows that majority of them were males, married and completed some technical education , not insured for health , diagnosed for HIV within 1 to 5 years ago and not on ART. Half of them belonged to the age group of 35-44 years, unemployed and not aware of any support groups or counselling groups related to HIV.

Self-care practices were identified subsumed under four (3) main themes: Therapeutic and physical health maintenance; psychological well-being; healthy lifestyle and risk reduction practices.

Therapeutic and physical health maintenance practices

Utilizing natural remedies Taking herbal treatments to treat opportunistic infections, lessen HIV symptoms, replenish nutrients, increase appetite, and "wash toxins" from the body was necessary to maintain physical health. Herbal medicines that were most frequently used were garlic, ginger, aloe vera gel, and moringa. Two PLHIV shared their stories about using natural remedies: We have a moringa tree in our backyard, and I take some of its tiny leaves. I simply add it to tea or even veggies that we cook and combine with other veggies. Occasionally, we cook moringa with groundnuts added to make a relish. Alternatively, you may mix moringa into cereal. (A woman in her 40s) "You are aware that when using herbs to cough, you obtain. Periodically, some PLHIV needed the financial assistance of family members to purchase these herbal treatments. Traditionally, certain herbal treatments, such as moringa and ginger, were mixed into meals, tea, or juice to treat or prevent ailments like the common cold, the flu, diarrhea, or just to generally "boost" the immune system and reenergize the body. Herbal therapies were claimed to not require the high levels of adherence that ART does. They were taken if and when they desired, according to PLHIV. Some people living with HIV found herbal medicines appealing since they were less restrictive than traditional HIV medication, which needed tight adherence. This was partly due to the

flexibility of herbal treatment requirements..A constant issue among the study participants was their acknowledgement of the effectiveness of ART; nonetheless, the challenges of lifelong therapy, strict adherence requirements, and medication side effects drove them to turn to herbal therapies. "Even if the ARVs work, people say they are for life and have side effects," a man stated. People choose to utilize herbs instead of prescription drugs after learning this since they don't want to deal with the negative effects or take them forever. Herbs are said to have no negative side effects. (A man of 23 years old) Spiritual healing as a treatment for HIV Curative uses also included faith healing. (A 48-year-old man) "The problem is, God gives me instructions when I pray. God then appeared to me in a vision and said, "You are healed." Ever since I stopped therapy and prayed, I have never again become ill or taken medicine. The only thing that is known to be secret is to pray and have faith in God. (Man, 45; no longer receiving ART) Paradoxically, a number of HIV-positive healthcare professionals, including those employed by the ART clinic and qualified for ART, also chose to use herbal treatments and/or faith healing: Additionally, I've taken anointing water for Because the man of God prays for it, they say it cures if you have faith. (27-year old man;) Using traditional medicine, but exclusively for the treatment of infections linked to HIV Certain PLHIV did not entirely sever their connections to the official health system, since they were acutely aware of their developing health and the limitations of alternative self-care techniques. When herbal remedies were ineffective or symptoms persisted, some PLHIV sought medical attention from a formal provider; nonetheless, they were only treated for opportunistic infections with conventional drugs. The most often reported HIV-related illnesses were gastrointestinal tract, respiratory, and skin infections. Among the most commonly reported conventional pharmaceuticals utilized were antibiotics, including flagyl, amoxicillin, septrin (co-trimoxazole prophylaxis), and anti-diarrheal medication. It is claimed that several PLHIV utilized antibiotics that their wives on ART had taken. According to two PLHIV, "I simply go to the clinic, they give me amoxil, and occasionally I go to hospital.Due to their precarious livelihoods, which are characterized by a lack of stable employment opportunities and "adequate" income, many PLHIV found it difficult to support themselves. However, this issue was mitigated by modifying local food menus, such as by adding pounded groundnuts to vegetables like cabbage and pumpkin leaves, which would nourish their bodies and enhance their health.

Risk reduction practices Safe sexual activity and ending relationships Some PLHIV, particularly those who are single, reported either engaging in safe sex practices or ending all sexual connections as a means of preventing re-infections, especially through unprotected sex. Some PLHIV learned from the experiences of other PLHIV who, in part because they had supposedly avoided re-infections, had apparently continued to live "healthy" and "normal" lives without the use of antiretroviral therapy. Subsequently, a culture of "let's start using condoms" emerged throughout the household. Then, you know, I believe that occasionally God enters. We have been using condoms like that since I had been praying that he would consent to it. He was definitely not like, no what, what. He's been at ease with it. Then I think sometimes God comes in, you know. He has been comfortable with it and we have been living like that." (38-year old man;)

Psychological well-being self-care practices

I put my faith and spirituality in Jesus Christ. Some PLHIV were found to incorporate religion, especially Christianity, into their daily lives, making it a potent self-care technique. Because HIV infection is often associated with inappropriate sexual behavior and a sinful lifestyle, some PLHIV found solace and hope in the biblical promises of cure, even in the face of potential stigma in religious communities. Through

organized religion, some PLHIV were members of Christian denominations that were more receptive to PLHIV, especially those whose pastors or leaders claimed to be able to heal HIV-positive individuals. Some PLHIV apparently placed "everything in the hands of God" in their hopes for treatment. They claimed to have prayed privately and individually with their pastors, going pastors professed to offer healing for people with HIV. While hoping for healing, some PLHIV reportedly put 'everything in the hands of God'. They reported conducting private individual prayers with their pastors, going for collective intercessory prayers in which they opened up to one another and religious leaders about their HIV condition. Another PLHIV explained her prayer life: "Even if you take the medicine, if you do not look to God for healing, you cannot get cured. So everything only works if you also involve God. So I also pray to God for me to be cured. I go for prayers every morning. Prayers are held every morning, everyday.

(48-year old man) 'I avoid thinking about it too much': positive attitudes towards HIV infection Some PLHIV acknowledged the relationship between psychological well-being and their immune system. Therefore, developing and maintaining positive attitude towards their HIV condition was viewed as another pre-condition for improved physical well-being. This meant reconstructing their lives to attain a sense of normalcy. PLHIV avoided 'thinking too much' about HIV and treated HIV as any other infection: "I just try by all means to ignore it; I just pretend as if it does not exist. I tend to live a normal life", said a 23-year old man, "I do exercises; and I keep my mind very free. I avoid thinking about it too much," said another 24-year old man. This enabled them to treat HIV not as a fatal condition; rather as something that they could live with and manage while acknowledging episodic periods of good and poor health. The self-care practices were modulated by kin and non-kin social network relationships. PLHIV treatment seeking behaviour was influenced by relationships with friends/family members and some formal health care providers. The social support received could be delineated into two: illness specific support such as provision of financial resources to access herbal remedies and over-the-counter conventional medication to mitigate HIV-related symptoms and obtain nutritional supplements. In addition, PLHIV also provided informational support to each other on illness management including which herbal remedies to use for what symptoms or ailments. They also shared information about sources of herbal remedies. PLHIV perceptions and experiences of self-care practices Some PLHIV reported a rebound in their CD4 cell count or improved physical health due to the use of herbal remedies or after going through prayer sessions and therefore believed that it was possible to live a normal and healthy life if one used herbal medication and/or 'surrendered' his life to God for care. Not withstanding the perceived effectiveness of these self-care strategies, some PLHIV reported noticeable decline in their health and all PLHIV contemplated starting ART if all other efforts failed. For others, a decline in health status was attributed to either lifestyle behaviour deemed incompatible with their condition or due to psychosocial distress. These included beer drinking, smoking, challenges of maintaining a nutritious diet, pregnancy and psychological distress due to strained family relationships. HIV treatment was viewed as not a guarantor of good health and their lives. To them, the death of PLHIV despite being on ART was emblematic of the shortcomings of ART: "It happens in life. Sometimes you can have good days and sometimes you can have bad days. So, if my health is not good today, it does not mean that it will be like that forever. Things change; starting treatment does not guarantee that you will become healthy forever. What about those people who have died despite taking ARVs?" (24-year old man).The findings of the study are supported by Dirar A.et.al.(2022) undertook a self-care practices that PLHIV used as alternatives to ART care. They found that PLHIV used - often concurrently - herbal remedies, over-the-

counter conventional medicine and faith healing, augmented by adoption of healthy lifestyle practices to promote physical and psychosocial well-being. If PLHIV opting for self care alternatives subsequently accessed health services, they never mentioned to non-ART prescribing health workers that they had opted to discontinue accessing ART or that they had opted not to start treatment. Neither did health workers inquire about the health and treatment history of these PLHIV. Thus, health workers missed the opportunity to bring these PLHIV back into ART care and treat them for the underlying cause of their ill-health. These self-care practices were modulated by availability of social level of Religious.

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Table 1 : Frequency and Percentage Distribution of Adults with HIV N=10

S.No	Demographic data	f	%
1.	**Gender**		
	Male	7	70
	Female	3	30
2.	**Age (in years)**		
	18- 24	2	20
	25-34	3	30
	35-44	5	50
	45-54	0	0
	55-64	0	0
	>65	0	0

3.	**Marital Status**		
	Single	3	30
	Married	7	70
	Divorced	0	0
	Widowed	0	0
4.	**Education Level**		
	High School or below	2	20
	Some college\technical	7	70
	Bachelors degree	1	30
	Masters degree	0	0
	Doctoral \Professional degree	0	0
5.	**Employment Status**		
	Employed full time	2	20
	Employed part-time	3	30
	Unemployed	5	50
	Student	0	0
	Retired	0	0
6.	**Annual Income (in Rupees)**		
	Less than 25,000	0	0
	25000-49999	2	20
	50000-74999	3	30
	75000-99999	5	50
	1,00,000-or more	0	0
7.	**Health Insurance Status**		
	Insured	2	20
	Uninsured	7	70
	Medicaid	1	10
	Medicare	0	0
8.	**Length of HIV Diagnosis**		
	Less than 1 year	2	20
	1-5 years	7	70
	6-10 years	1	10
	11-15 years	0	0
	More than 16 years	0	0
9.	**Current HIV Treatment Status**		
	On ART	3	30
	Not on ART	7	70
	Prefer not to say	0	0
10.	**Access to Support Groups or Counseling Services**		
	Yes, regularly attend	0	0
	Yes, occasionally attend	3	30
	No, but interested	1	10

	No, not interested	1	10
	No, not aware of any	5	50