Hope in HIV-positive women*

ESPERANÇA EM MULHERES PORTADORAS DA INFECÇÃO PELO HIV

ESPERANZA EN MUJERES PORTADORAS DE INFECCIÓN POR HIV

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ABSTRACT

The objective of this study was to assess the hope in the lives of HIV-positive women, using the Herth Hope Scale (HHS). Participants were 111 HIV-positive women who attended a referral outpatient clinic in Fortaleza-CE. From January to May 2009, interviews were held to collect biopsychosocial variables, and the HHS was applied. Data were analyzed using SPSS-8.0 and revealed an average hope index of 34.86, indicating that these women have little hope in life in view of their diagnosis of HIV. The scale item with the highest score was faith. This probably derives from the fact that Aids is incurable, transmissible and generates negative stigma, in addition to its relation with the idea of imminent death. In conclusion, measuring hope among HIV patients through the use of an instrument permits intervention assessment and planning, promoting assistance and motivation to live better and maintain a hopeful attitude.

DESCRIPTORS

HIV
Acquired Immunodeficiency Syndrome
Life expectancy
Public health nursing

RESUMO

Objetivou-se avaliar a esperança na vida de mulheres infectadas pelo HIV mediante uso da Escala de Esperança de Herth (EEH). Participaram 111 mulheres portadoras de HIV atendidas em ambulatório de referência em Fortaleza-CE. De janeiro a maio de 2009, foram conduzidas entrevistas que captaram variáveis biopsicossociais e aplicou-se a EEH. Os dados analisados pelo programa SPSS-8.0 revelaram índice médio de esperança de 34,86, apontando que as mulheres possuem moderada esperança na vida diante da vigência do HIV, cujo item da escala com maior pontuação relacionou-se à fé (3,57). O que provavelmente decorre do fato de a AIDS não ter cura, ser transmissível e produzir estigma, estando ainda relacionada à ideia de morte iminente. Segundo concluiu-se, a medida da esperança entre portadores de HIV mediante o uso de um instrumento possibilita avaliar e planejar intervenções, promovendo ajuda e motivação para viverem melhor e manterem a esperança na vida.

DESCRITORES

HIV
Síndrome da Imunodeficiência Adquirida
Esperança de vida
Enfermagem em saúde pública

RESUMEN

Se objetivó evaluar la esperanza en la vida de mujeres infectadas por HIV mediante uso de Escala de Esperanza de Herth (EEH). Participaron 11 mujeres portadoras de HIV atendidas en ambulatorio referencial en Fortaleza-CE. De enero a mayo de 2009, se condujeron entrevistas que captaron variables bio-psicosociales y se aplicó EEH. Los datos, analizados con el programa SPSS-8.0 apuntaron índice medio de esperanza de 34,86, determinando que las mujeres poseen moderada esperanza en la vida ante la presencia del HIV, cuyo ítem de escala con mayor puntuación se relacionó con la fe (3,57). Probablemente, eso deriva de que el SIDA sea incurable, transmisible y productor de estigma, estando aún relacionado a la idea de muerte inminente. Según se concluyó, la medida de esperanza entre portadores de HIV mediante uso de un instrumento posibilitó evaluar y planear intervenciones, promoviendo ayuda y motivación para vivir mejor y mantener esperanza en la vida.

DESCRIPTORES

VIH
Síndrome de Inmunodeficiencia Adquirida
Esperanza de vida
Enfermería en salud pública

*Extracted from the study *Avaliação de diferentes aspectos entre portadores de HIV/aids: qualidade de vida, esperança e coinfecção por tuberculose em Fortaleza, Ceará*, Universidade Federal do Ceará, 2009.

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Received: 04/22/2010
Approved: 04/29/2011

INTRODUCTION

Hope is considered a constitutive element of the human existence in time, since it supports the opening to the future of can/be that we are, and feeds our ability to dream and walk. Living without hope would make life "a useless passion". Among the different definitions of hope, in a final analysis, it is what livens and impels our peregrine soul, and constantly makes us move forward, impelling our being to walk for the simple joy of walking and breaking horizons. All clinical work is supported and driven by hope. Therefore, the therapeutic consequences are catastrophic when one has to deal with hopelessness[1].

In this context, hope is perceived as a feeling that makes human beings believe in positive outcomes regarding their life events and circumstances. There are traces of perseverance in hope, since we often believe something is possible even when there are indications of the contrary.

Having hope means to look at the limitations of the situations, perceiving, at the same time, the existing opportunities[2]. Furthermore, hope is also indicated as an inner power that enriches human beings, allowing them to transcend from a bad situation to a better one[3-4].

The natural history of AIDS has suffered a substantial change after the introduction of high-potency antiretroviral therapy. It is no longer considered a fast progression terminal disease of high lethality; its mortality and the incidence of opportunistic diseases decreased; the life expectancy of people with AIDS increased and, therefore, it became a chronic disease[5].

In face of a chronic disease, other factors become preeminent, such as the compliance to the treatment and its side effects, living with the disease, quality of life, the uncertainties and insecurities triggered by the pathology and the feelings of hope resulting from the increase of survival of HIV-positive people. Thus, the attention drawn to this feeling of hope in the lives of individuals with HIV roused the interest in assessing the way hope acts or interferes in the life of HIV-positive women.

As observed, AIDS affects its carriers physically and emotionally. The biopsychosocial impact of the diagnosis brings feelings such as the fear of social rejection, the disease itself, being abandoned by the family, partner and friends, anxiety, decreased self-esteem, the feeling of losing control, the loss of social function, and the stigmatization[6].

Both the psychosocial impact and the adverse effects caused by the therapy have a negative effect on the quality of life of HIV-positive individuals. A study that analyzed the quality of life of 106 women revealed some areas were harmed, such as the level of independence that contemplates aspects related to the physical mobility, activities of the daily living, aptitude to work and dependence on medication. Another area with harmed scores was the environment, which concerns social care, leisure, physical environment and transportation[7]. In face of this situation, it is necessary to develop public health strategies aimed at minimizing this reality, thus, improving these people's hope in life. Keeping hope, even in face of adversities, is related to having something or someone to live for. Family union, good relationship with friends and faith are essential to strengthen hope in the life of these people.

In this context, the present study was proposed based on the hypothesis that hope encourages and strengthens the everyday life of HIV-positive women. This information is corroborated by a study revealing that the confrontation of the disease process is more appropriate for patients who have hope[8]. Hope is what motivates patients toward seeking treatment, despite of being wearying and expensive, to submit oneself to uncomfortable procedures, to change one's routine and to remain, despite of all difficulties, in treatment. Although it does not promote the cure, hope provides the courage to keep fighting for improvements, even though they know there is a small chance of survival[8].

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The dominant approach in nursing considers hope as a multidimensional and dynamic force, characterized by the expectation, at the same time confident and uncertain, of achieving a significant objective[2]. In the function of stimulating hope in his/her patients, the nurse is the professional who stands out due to the proximity developed from the multiple hospitalizations and outpatient clinic care[3]. The care provided by the nursing team is rich in meanings capable of transmitting hope, even through small actions.

Especially in patients with chronic diseases, such as AIDS, keeping hope provides more quality of life, despite of the difficulties imposed by the disease and its treatment. In the care practice with HIV-positive patients, it is common to observe the feeling of hope demonstrated during the health follow-up.

Different scales have been developed to measure hope under the nursing perspective, especially to assess the hope of patients with cancer. The Hert Hope Index (HHI)[4], specifically, of American origin, is an adaptation of the Herth Hope Scale, designed to assist the assessment of the states of hope among patients and the assessment of affectivity in the strategies to increase hope[9].

In Brazil, the HHI has suffered a cultural adaptation and the was validated to be used with cancer patients,

and was later called *Escala de Esperança de Herth* – EEH, Herth Hope Scale, in Portuguese[3]. However, it may be used in several contexts, such as with unsheltered families, patients with cancer or at home, in older people in the community or in institutions, to assess pain, to assess patients receiving palliative care, for chronic diseases and also to plan interventions in the nursing service, among others[3,9]. As observed, it is possible to perform assessments in all contexts involving hope.

In this aspect, considering the meaning of the AIDS diagnosis impact due to the assumption of imminent death, hope is the encouragement to achieve the cure. Furthermore, the process of confronting the disease may be more pleasant for patients who have hope, being this aspect the incentive for the development of the theme.

Therefore, this study is based on the proposition that assessing hope in the life of HIV-positive women permits a more appropriate planning of interventions in the practice, which may reduce the impact of the disease.

Taking into consideration the tendencies of the AIDS outbreak, especially the feminization, a result of the vulnerability experienced by the women both in the biological and in the sociocultural aspect, and the biopsychosocial consequences of living with a chronic, incurable and stigmatizing disease, the following question was elaborated: in what ways being HIV-positive affects women's hope in life?

In order to answer this inquietude, the authors decided to study the hope in life of HIV-positive women using a scale validated in Brazil, designed specifically for this purpose[3].

METHOD

This, cross-sectional, descriptive and exploratory study has a non-experimental design. This type of study permits to obtain information regarding the prevalence, distribution and interrelationships of variables in the scope of a certain population.

Face-to-face interviews were applied by a trained interviewer in a consecutive sample of 111 HIV-positive women who were cared for at the outpatient unit of the São José Hospital of Infectious Diseases, located in Fortaleza, capital of the state of Ceará.

The population of the study was defined according to the use of inclusion and exclusion criteria for HIV-positive women seen from January to May 2009. Therefore, 111 women were interviewed.

The inclusion criteria adopted for the participants were: female; 18 years of age or older; aware of the HIV-positive diagnosis and agreeing to participate in the study. As exclusion criteria: presence of mental disease or cognitive difficulty.

Aimed at avoiding any methodological bias and considering the possibility of some patients manifesting comprehension difficulties, reading was used for the application of the instruments, one for the sociodemographic variables and the Herth Hope Scale.

The Herth Hope Scale, validated for the Portuguese language, was used to assess hope[3]. The scale analyzes hope through the use of 12 affirmative questions. Each question of the scale has four likert-type options: *completely disagree, disagree, agree* and *completely agree*, respectively scoring 1 to 4 points. Therefore, the total score (value) of the scale may vary from 12 to 48 points, being 12 the lowest level of hope and 48 the highest. Questions 3 and 6 have inverted scores, in other words, the option *completely disagree* in these items scores four points, and *completely agree* only one.

The items of the scale comprehend the following sentences: 1. I am optimistic towards life; 2. I have short and long-term plans; 3. I feel very lonely; 4. I can see the possibilities amidst the difficulties; 5. My faith comforts me; 6. I am afraid of the future; 7. I can remember happy and pleasant times; 8. I feel very strong; 9. I feel capable of giving and receiving affection/love; 10. I know where I want to go; 11. I believe in the value of each day; and 12. I feel my life is useful and worthy.

In the results analysis, data were input and analyzed using the statistical program SPSS-8.0, considering the means of the items in the Herth Hope Scale.

As required, the study was approved by the Research Ethics Committee of São José Hospital, which approval is described under the protocol number 044/2008. All participants were clarified regarding the study and signed and Free and Informed Consent Form to assure their participation.

RESULTS

A brief presentation of the sociodemographic data is provided to understand the population participating in this study. Among the 111 HIV-positive women, their age ranged between 18 and 67 years (mean of 38 years), 43.8% were married or living common-law marriage and 46.4% had studied for less than eight years.

Regarding their religion, 55.4% were catholic. As for work, 35.7% of the women had a paid job and, among these, only 22.5% had a formal job.

To allowing the analysis, the results obtained through the application of the Herth Hope Scale were organized in Table 1, which presents the mean of the scores for each item in the scale. In the present study, the obtained mean of hope was 34.86. Among the different items of the scale, number 5 obtained the highest mean (3.57), related to the comfort produced by faith.

Table 1 – Presentation of the means of each item in the Herth Hope Scale (HHS) obtained among HIV-positive women - Fortaleza, 2009

Items of the Herth Hope Scale	Mean
1. I am optimistic towards life	2.85
2. I have short and long term plans	2.66
3. I feel very lonely	2.29
4. I can see the possibilities amidst the difficulties	2.81
5. My faith comforts me	3.57
6. I am afraid of the future	2.44
7. I can remember happy and pleasant times	3.13
8. I feel very strong	3.04
9. I feel capable of giving and receiving affection/love	3.18
10. I know where I want to go	2.69
11. I believe in the value of each day	3.05
12. I feel my life is useful and worthy	3.15
Total	34.86

DISCUSSION

The mean hope in life obtained through the HHS, in HIV-positive women, showed low values (34.86), indicating moderate hope. This result is lower that that observed in patients with chronic diseases such as cancer and diabetes, whose mean rates are higher than 40[3]. This result is probably due to the fact that AIDS is transmissible and stigmatized, and there is no cure for it, being still related to the idea of promiscuity and imminent death.

By analyzing each of the 12 items (statements) on the scale, by the index order obtained in the assessment of hope, from the highest to the lowest index, it was observed that the statement "My faith comforts me" obtained the highest score of hope. This result shows the importance of faith to keep up hope, since religious practices influence the way people experience traumatizing events, such as the HIV diagnosis. Faith promotes behaviors that favor resilience, learning with the experience and the self-confidence to act in face of adversities[10].

According to the literature, the religious belief constitutes an important part of the culture, principles and values used by the clients to form judgments and process information. The confirmation of beliefs and perceptive inclinations may provide order and the comprehension of painful, chaotic and unpredictable events[11].

Therefore, in the present study, the results demonstrate strengthening in the process of adaptation and confrontation of the disease as a result of the hope nurtured by women, religiosity, spirituality and personal beliefs.

Several studies corroborate the findings of this study[12-13]. An assessment study with thousands of people regarding the state of happiness and the religious practice evidenced a positive correlation between these variables[12]. Similarly, a review study observing the association among spirituality/religious involvement and mental and physical health and quality of life showed that spirituality and religious belief are associated with better health indexes, including greater longevity, handling skills and quality of life, as well as anxiety, depression and suicide[13].

A meta-analysis of 49 studies involving around 13 thousand subjects investigated the association between the religious handling and the psychological adjustment. As indicated, religiosity promotes changes in people's lives[14]. Another study investigating the relationship between religiosity/spirituality and mental health revealed that higher levels of religious participation were associated to better well-being and mental health[15].

Furthermore, as another researcher verified, in women and people with lower education levels there is a prevalence of confrontation of stressful events through emotion and the search of religious practices, whose religiosity would be related to strategies to handle problems, besides working as a reason, attributing to the divine both the cause and the solution of the problem[16].

Therefore, studies suggest that the increase of hope may be considered an important factor for better mental and physical health, better quality of life and well being, greater longevity and happiness. It is also important in HIV-positive women in the attempt to help them understand and elaborate their losses.

It becomes necessary for health professionals to recognize spirituality as an essential component of the individual's personality and health; to clarify the concepts of religiosity and spirituality; to include spirituality as a health resource in the education of new professionals; to adapt and validate scales of spirituality/religiosity to the Brazilian reality and specific training for the clinical area.

The statement *I feel capable of giving and receiving affection/love* was the second score of hope. This fact reveals that women infected by HIV are able to adapt to the new reality, after the initial impact of learning the diagnosis, which is a variable time from subject to subject. They feel capable of giving and receiving affection and love from their partners, children, family members and friends. Although affective relationships may be complicated in face of the new reality, there is a wish to keep affective bonds.

In a certain way, the progresses in the diagnosis and treatment of HIV have been making this infection more and more similar to diseases referred to as chronic, which improvements have a positive effect on the lives of patients, decreasing the fear of death, allowing to maintain social, work, leisure and effective relationships in life.

In cases of chronic diseases such as AIDS, surrounded by prejudice and still considered by many as a death sen-

tence, the losses may reach greater proportions, affecting the several domains in women's lives, compromising their personal, affective, social, spiritual and professional life[17].

The increase of survival of HIV-positive people promotes new sources of uncertainties caused by the renegotiation to be made regarding the feelings of hope and orientation towards the future, social roles and identities, affective interpersonal relationships and quality of life[18].

The statement *I feel my life is useful and worthy* obtained the third highest score of hope. After the turbulence that takes place right after the diagnosis, there is the need to confront the feelings associated to the initial impact of considering oneself as HIV-positive, as the subject realizes it is necessary to keep living. Then, a series of changes start to take place in her daily routine[19].

Theses changes occur not only in the everyday life of the patient, but also of her family, and concern several questions, such as those related to changes of habits and routines, concepts regarding health and her own life[19].

The maintenance or the interruption of a behavior may be linked to positive or negative consequences that it brings to people's lives[20].

This is observed in the studied group, because, in many cases, the HIV-positive woman went through positive changes in her daily life after being aware of the diagnosis. As observed, this subject learns to value each day, each person, including things that were previously unnoticed, which may be related to the experience of proximity to death. Therefore, the physical and psychological suffering of acquiring the disease leads the woman to rethink attitudes in face of the facts and present changes in her behavior[20].

The statement *I can remember happy and pleasant times* took the fourth position of hope score. The high index obtained in this statement may be attributed to the fact that the patients remember times in their lives when they did not face the reality of having an incurable, serious and stigmatizing diseases, and also to the fact even if they carry a chronic disease that is marked by prejudice such as HIV/ AIDS they can still experience happy and pleasant moments. In the daily practice, we have frequently evidenced that despite of the difficulties in living with the pathology, the patients try to lead normal healthy lives, enjoying the good moments of distraction and pleasure in the company of family and friends.

Next, the statement *I believe in the value of each day*, in the fifth position, suggests that HIV-positive women tend to value each day, each person and the simple things in the daily life. This may be related to their experience of proximity to death.

At first, becoming aware of the diagnosis triggers a variety of difficult behaviors and feelings in the patients and their caregivers; but as time goes by this difficulty gives place to other feelings, such as the appreciation of life and the changes in the daily routine aimed at a better quality of life[19].

The scale item *I feel very strong* took the sixth position by order of hope score. In this statement, the patients could express that in face of the HIV reality they do not always feel strong and, therefore, they need support from their partner, family members, friends and social support networks to overcome this moment of suffering.

I am optimistic towards life is the seventh highest score of hope. In this matter, as the patients demonstrated, especially those who were in the initial stages after the diagnosis, they were not so optimistic towards life, since many women did not feel vulnerable to the infection and now faced this problem.

The literature indicates that as antiretrovirals were introduced 1996, concomitantly there were effective possibilities of treatment for HIV, as well as the expressive decrease of mortality related to the infection of HIV/AIDS [21]. Thus, a change was possible in the perspective and prognostic of AIDS, generating a wave of optimism in people with HIV/ AIDS.

It is suggested that the continuity of the social life and the appropriate compliance to the treatment may result in an improvement in quality of life and in the response to the treatment, optimizing the life of HIV-positive women.

By observing the item *I can see the possibilities amidst the difficulties*, it is perceived that it obtained a low score. This result may indicate that the women found difficulties to deal with their daily life problems, besides the fact that they had a disease marked by feelings such as fear, suffering, loneliness and prejudice.

This result also reflects the situation of deprivation in which they are inserted. As some of them mentioned at the moment of the interview, they used to give up hope when they faced great difficulties, especially the lack of resources to buy food and other goods. This situation is reaffirmed in face of what is observed in the item *I know where I want to go* and reflects the reality in which most of the women in this study are inserted: a situation of poverty, without perspectives of improvement in the future, without access to education and employment. For them, it is hard to know where to go in face of the limited choice options.

Out of the 12 statements in the scale, there are still three: *I have short and long-term plans*, *I am afraid of the future* and *I feel very lonely*, all of them with the lowest scores of hope in the scale. As the HIV-positive women revealed, they prefer not to make plans, because due to the diagnosis they feel they live close to death. That is the reason why they fear what the future may reserve and live lonely due to fear and the need to hide the diagnosis even from their family.

The presence of HIV in someone's life produces several changes in their routine, represented by the uncertainty towards the future, the fear of the proximity to death, discrimination, changes in the appearance caused either by the disease or the medication; in the emotional life, it brings difficulty to establish new bonds; in the family life, discrimination and hostility are also faced, leading to changes in the project of life[19].

Undeniably, social support may be an attenuating factor of the negative impact of HIV in the lives of the people infected, as this external personal resource is capable of facilitating the adaptation to the disease process. In a general way, the support network may be a useful strategy for the compliance to the treatment and the increase of quality of life. The importance of social support may be highlighted as a positive influence in the encouragement and motivation to self-care. Therefore, patients with greater social and emotional support may present higher rates of compliance to the treatment and better quality of life[22].

The Herth Hope Scale aims to facilitate the assessment of hope in several clinical contexts in which the variables of hope levels are identified. It may be used in various contexts, such as the first reincidence of cancer, older people in the community or in institutions, assessment of pain and hope in patients with cancer, assessment of patients in palliative care, to plan interventions in the nursing service, among others[3]. Thus, by employing the HHS in HIV-positive women, a new alternative is corroborated to study ways to improve the routine of women, as the daily care practice indicates that many of them live an intense peregrination in health services seeking different alternatives to live longer and reach the ever dreamed cure for AIDS.

According to the literature, the confrontation of the disease process is more appropriate for patients who have hope. It motivates the patient to seek treatment, despite being wearisome and expensive, to submit herself to uncomfortable procedures, to change her routine and to remain, despite of all difficulties, in treatment. Although hope does not promote the cure to the disease, it provides courage for her to keep fighting for improvement, even in face of a small chance of survival[8].

A study indicated that positive psychosocial factors, such as optimism, presence of affection and spirituality were positive situations of confrontation, evidencing slower progression of AIDS [22]. On the other hand, negative psychological factors, such as stress, deteriorated the prognostic of infection by HIV[16].

In this perspective, nurses stand out in the function to stimulate hope in the patients due to the proximity developed through the care resulting from multiple hospitalizations and outpatient care[3]. The care provided by the nursing team is rich in meanings that may, even through small actions, transmit hope.

The maintenance of hope, especially in patients with chronic diseases such as AIDS, allows them to have better quality of life, even in face of the difficulties imposed by the disease and its treatment.

CONCLUSION

The assessment of hope, using the HHS, showed that HIV-positive women, either sick or not, had lower hope indexes than people suffering from chronic diseases. The low index of hope revealed in the study is related to the fact that AIDS is an incurable, transmissible and stigmatized disease that is still rather linked to the idea of immediate death.

Keeping hope, particularly in the case of subjects who live with a chronic disease such as HIV/AIDS, favors them to live more intensely and maybe better, even in face of the difficulties imposed throughout the disease and its treatment.

The present study allows inferring the power of hope. Assessing it may promote the planning of more appropriate interventions to instigate it and try, somehow, to ease the impact of the disease in the routine of these women.

In face of the exposed facts, the authors propose the use of the HHS in HIV-positive subjects, as this use may contribute to early interventions aimed at reaching better quality of life and the maintenance of their health.

As for its possibilities, the HHS must continue to be tested in different sociocultural and regional contexts. It is important to stress that health professionals, especially nurses due to their proximity and long experience with the patient, often permeated by bonds of trust, may be powerful allies. It is their duty to stimulate the feeling of hope in HIV-positive patients through emotional support, increasing their hope and the wish to live.

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