

Depression, self-concept, future expectations and hope of people with HIV

Depressão, autoestima, expectativa futura e esperança de vida de pessoas com HIV Depresión, autoestima, expectativa futura y esperanza de vida de personas con VIH

ABSTRACT

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Objective: To analyze conditions of depression, self-concept, future expectations and hope in people with HIV/AIDS. **Method:** Cross-sectional survey of 108 individuals living with HIV/AIDS, carried out in a reference hospital for the treatment of infectious diseases in Northeast Brazil. The following instruments were employed: sociodemographic data, and questionnaires for ascertaining participants' emotions, including scales for self-concept, hope, depression (HAMD-D), and future expectations. Descriptive statistics using the following tests were performed: Mann–Whitney, Kruskal–Wallis, chi-square, and t-test—considered significant when $p \le 0.05$. **Results:** 31.5% presented mild depression and 21.3% presented moderate depression; 63% reported difficulty in obtaining decent employment; 52.8% considered life a failure; 52.8% felt worthless. Fear, guilt and loneliness influenced self-concept ($p \le 0.05$). Loneliness influenced hope ($p \le 0.05$). **Conclusion:** It is is necessary to raise the attention of nursing professionals and healthcare managers to the importance of providing health services that consider the mental health of people with HIV/AIDS, contributing to treatment adherence and well-being. **Descriptors:** HIV; Emotions; Depression; Self-Concept; Hope.

RESUMO

Objetivo: Analisar depressão, autoestima, expectativa futura e esperança de vida de pessoas com HIV/aids. **Método:** Pesquisa transversal, com 108 indivíduos vivendo com HIV/aids em um hospital de referência no tratamento de doenças infectocontagiosas no Nordeste do Brasil. Utilizaram-se instrumentos: sociodemográfico, sentimentos, escalas (autoestima, esperança de vida, depressão HAM-D, expectativa de futuro). Realizaram-se estatística descritiva e testes (Mann-Whitney, Kruskal-Wallis, qui-quadrado, teste t), significativo quando p≤0,05. **Resultados:** 31,5% apresentaram depressão leve e 21,3% moderada; 63% referiram dificuldade de emprego digno; 52,8% consideram a vida um fracasso; 52,8% sentem-se inúteis. Medo, culpa e solidão influenciam a autoestima (p≤0,05). A solidão influencia a esperança de vida (p≤0,05). **Conclusão:** É preciso despertar a derção da enfermagem e dos gestores para a disponibilização de serviços de saúde que se preocupem com a saúde mental de pessoas com HIV/aids, contribuindo com a adesão ao tratamento e o bem-estar.

Descritores: HIV; Emoções; Depressão; Autoimagem; Esperança.

RESUMEN

Objetivo: Analizar la depresión, autoestima, expectativa futura y esperanza de vida de personas con VIH/sida. **Método:** Investigación transversal, con 108 individuos que viven con VIH/sida en un hospital de referencia en el tratamiento de enfermedades infectocontagiosas en el Nordeste de Brasil. Se utilizaron instrumentos: sociodemográfico, sentimientos, escalas (autoestima, esperanza de vida, depresión HAM-D, expectativa de futuro). Se realizaron estadística descriptiva y pruebas (Mann-Whitney, Kruskal-Wallis, chi-cuadrado, prueba t), significativo cuando p<0,05. **Resultados:** el 31,5 % presentó una depresión leve y el 21,3 %, moderada; el 63 % refirieron dificultad de lograr un empleo digno; el 52,8 % considera la vida un fracaso; el 52,8 % se siente inútil. El miedo, la culpa y la soledad influyen en la autoestima (p<0,05). La soledad influye en la esperanza de vida (p<0,05). **Conclusión:** es necesario despertar la atención de la enfermería y de los gestores hacia la oferta de servicios de salud que se preocupen de la salud mental de personas con VIH/sida, de modo a contribuir a la adhesión al tratamiento y al bienestar. **Descriptores:** VIH; Emociones; Depresión; Autoimagen; Esperanza.

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INTRODUCTION

HIV/AIDS infection is considered a worldwide public health problem, especially due to its continued growth and shortcomings regarding the infection's control. Medical science's many achievements and advances notwithstanding, coping with HIV remains a challenge, given factors such as clinical complexity, stigma, prejudice and opportunistic diseases⁽¹⁾.

It is noteworthy that, between 1980 and June 2017, there were 882,810 cases of AIDS in Brazil, among which 194,217 were registered in the last ten years. Worldwide, there are 36.7 million people living with HIV/AIDS, according to data from 2017⁽²⁻³⁾.

Technological and medicinal advances have exerted a significant impact on the health of HIV-infected individuals, with antiretroviral therapy (ART) allowing for a significant increase in quality of life. However, levels of hope of people living with HIV/AIDS remain reduced in comparison to those of the general population. This is particularly true for older people and for late treatment adopters⁽⁴⁾.

HIV infection causes a number of clinical, psychological and social changes, which can lead to feelings of inferiority and devaluation. Negative stereotypes, discriminatory and prejudiced labels also contribute to these feelings. Thus, anxiety, loneliness, depression, lack of will to live, low self-concept and social isolation accompany people living with HIV/AIDS⁽⁵⁾.

Although ART provides several benefits, the infection's psychic and social impacts may pass unnoticed by the health team. These impacts require care beyond the scope of physiological and biological issues, emphasizing systematic and multiprofessional actions in order to contribute to emotional balance, favoring treatment adherence and quality of life⁽⁶⁾.

Considering that HIV/AIDS infection is a grave public health concern, and that the emotional traits of people living with HIV/AIDS are usually neglected, this study's justification lies in identifying emotional characteristics that can influence adherence to treatment, leading to strategies to prevent further worsening of HIV-bearers' clinical condition, as well as direct health promotion.

Furthermore, since nursing also has the responsibility of referring people with HIV/AIDS, this research highlights how important it is for nursing professionals to consider psychological aspects in the treatment of people with HIV/AIDS, verifying interference factors, helping patients resignify emotions, and contributing to their well-being.

Thus, the following research hypotheses were formulated: people living with HIV/AIDS will have depression, low future expectations, compromised self-concept and hope; future expectations will be influenced by self-concept; fear, guilt and loneliness will be present and correlate with depression, self-concept, future expectations, and hope.

OBJECTIVE

To analyze depression, self-concept, future expectations and hope in people with HIV/AIDS.

METHOD

Ethical aspects

The research followed the ethical principles set forth in Resolution No. 466/2012 of the National Health Council, concerning guidelines and norms for research with human beings⁽⁷⁾.

Design, location of the study and study period

This was a cross-sectional and quantitative study carried out in a reference hospital in the treatment of infectious diseases. The hospital is located in the city of João Pessoa (Paraíba, Brazil). Data were collected between September 2017 and August 2018.

Population and sample, inclusion and exclusion criteria

Patients aged 18 years or over, diagnosed with HIV/AIDS were included in this study. Participants also had to be registered and receiving follow up at the HIV/AIDS Specialized Care Service (SAE) of said hospital. HIV/AIDS patients with neoplasias, hepatitis, renal, neurological, pulmonary and cardiac diseases were excluded.

The study population consisted of 307 people registered in the SAE and living with HIV. A sample calculation was performed using a 99% confidence and a 10% sample error margin, resulting in 108 individuals, selected by means of convenience sampling. This procedure was performed in the *Statdisk* (United States) program for Windows.

Study protocol

Research objectives were explained individually to each participating volunteer, and the signature of two copies of the study's Informed Consent Form was then requested, with one of the copies remaining with the researcher.

Six instruments (sociodemographic, questionnaire regarding emotions, self-concept scale, hope scale, depression scale and future expectations scale) were used, individually applied by means of a 50-minute interview.

The sociodemographic instrument presented the following variables: sex, age, marital status, educational level, type of HIV/ AIDS exposure, monthly income, job, number of children, and diagnosis time. Emotion-related items of the questionnaire addressed fear, guilt and loneliness.

The Hamilton Depression Rating Scale (HAM-D) contains 24 items and has a maximum score of 70. There is no current standard for cut-offs, with the following being accepted in clinical practice: between 7 and 17, mildly depressed; between 18 and 24, moderately depressed; equal or above 25 points, severely depressed⁽⁸⁾.

The validated Future Expectation Scale⁽⁹⁾ includes 18 items distributed into three factors: conditions of society; professional and financial success; and personal achievement. Answers follow a Likert format: 1 = completely bad; 2 = partially bad; 3 = neither good nor bad; 4 = partially good; and 5 = completely good. For items 2, 13, 15, 16 and 17, scores are reversed.

The Self-Concept Scale is comprised of 10 questions, dealing with personal satisfaction, self-deprecation, perception of qualities, competence, self-pride, self-worth, respect and feelings of failure. The scale also has Likert-type response options ("strongly agree," "agree," "disagree," and "strongly disagree"), with each item receiving a score ranging from 1 to 4 points. In this study, items 3, 5, 8, 9 and 10 had their scores reversed, as recommended by the instrument's author. Participants with scores \geq 26 were classified as having high self-concept, while those with scores below 26 were classified as having low self-concept⁽¹⁰⁾.

The Hope Scale has 12 positive statements, and four possible answers to each one: "strongly disagree" (1), "disagree" (2), "agree" (3) and "strongly agree" (4). Items 3 and 6 are answered through an inverted scale, i.e. "strongly disagree" (4), "disagree" (3), "agree" (2), and "strongly agree" (1). Total score varies from 12 to 48: the higher the score, the higher the level of hope⁽¹¹⁾.

Statistics and data analysis

The data were processed using *Statistical Package for Social Sciences* (SPSS) version 19.0. Descriptive statistics considered absolute and relative frequencies, means, standard deviations of the mean, maximum and minimum. To test the association between variables, statistical tests with $p \le 0.05$ were performed.

To test the hypothesis that the future expectation score of hospitalized people living with HIV/AIDS is influenced by selfconcept classification, the Mann–Whitney test was applied.

To verify if fear, guilt and loneliness correlated to depression score, the Kruskal–Wallis test was applied. The chi-square test

was used to correlate fear, guilt and loneliness with self-concept. To correlate fear, guilt and loneliness with future expectations and hope, the t-test was applied.

RESULTS

Study subjects had a mean age of 32.64 ± 12 years (32% male and 68% female). As for schooling, 16%were illiterate, 42% had incomplete elementary school, 15% had complete elementary school, 11% had incomplete high school, 6% had complete high school, and 10%had complete higher education.

Concerning civil status, 63% were single, 12% married, 15% divorced and 10% widowed. The minimum monthly income was BRL \$800, and the maximum was BRL \$2000.

Contamination by unprotected sex was reported in 89% of cases, while 11% did not know how they were exposed to the virus. Regarding jobs, there were 36% retired workers, 15% who took care of the house, 13% self-employed, 8% cleaning ladies, 7% students, 6% construction supervisors, 5% police officers, 5% teachers, and 5% unemployed. Number of children ranged from zero to five.

The time since the HIV/AIDS diagnosis was at least one week and at most 23 years. Table 1 presents information regarding depression scores.

Table 2 presents data on future expectations.

Studied individuals' self-concept was high in 58.9% and impaired in 41.1%. Table 3 shows information concerning the selfconcept scale. Only 11.2% completely agreed that they were valuable persons, 10.2% completely agreed that they were able to do things as well as most people, 52.8% agreed that they sometimes felt worthless, and 58.4% completely agreed that they sometimes felt worthless.

Table 1 – Classification of depression in people living with HIV/AIDS, João Pessoa, Paraíba, Brazil (N = 108)

Classification of depression	n	%		
Absence of depression	51	47.2		
Mild depression	34	31.5		
Moderate depression	23	21.3		
Severe depression	0	0.0		
Total score				
Mean		8.34		
Standard deviation		5.36		
Median		5		

Table 2 - Information regarding future expectations of people living with HIV/AIDS, João Pessoa, Paraíba,Brazil (N = 108)

Question	СВ		PB		NBNG		PG		CG	
Question	n	%	n	%	n	%	n	%	n	%
Society will be more just and safer.	46	42.6	6	5.6	-	-	28	25.9	28	25.9
People will become even more selfish than they are nowadays.	63	58.3	29	26.9	-	-	11	10.2	5	4.6
People will be happier.	45	41.7	6	5.5	6	5.5	11	10.2	40	37.1
People will be more likely to accomplish their dreams.	40	37.0	-	-	-	-	28	26.0	40	37.0
There will be fewer injustices in the world.	60	55.5	8	7.4	-	-	-	-	40	37.1
The world will be much better.	47	43.5	9	8.4	-	-	5	4.6	47	43.5
I will reach financial independence.	17	15.8	-	-	-	-	6	5.5	85	78.7
I will be professionally fulfilled.	23	21.3	-	-	11	10.2	6	5.5	68	63.0
My family and friends will be proud of me due to my professional success.	23	21.3	-	-	11	10.2	17	15.7	57	52.8
I will be proud of myself for having struggled through life and becoming a winner.	6	5.5	6	5.5	-	-	17	15.7	79	73.3
I will be respected by all for the professional choices I made.	17	15.7	6	5.5	11	10.2	23	21.3	51	47.3
I will have a good job.	34	31.5	-	-	6	5.5	11	10.2	57	52.8
In general things will be worse for me than they are now.	40	37.0	17	15.7	6	5.5	6	5.5	39	36.3
I will have very good health.	28	26.0	-	-	6	5.5	17	15.7	57	52.8
My life will surely be a failure.	57	52.8	11	10.2	-	-	-	-	40	37.0
I will prove that, in the world we live in, putting in much of an effort is of no use.	34	31.5	11	10.2	11	10.2	6	5.5	46	42.6
I will have trouble getting a decent job.	69	63.9	11	10.2	11	10.2	6	5.5	11	10.2
I will have a home of my own.	6	5.5	-	-	-	-	-	-	102	94.5

Note: CB = completely bad; PB= partially bad; NBNG = neither bad nor good; PG = partially good; CG = completely good.

Table 4 shows [hope] results, in which 37% disagree that they have short- and long-term plans, 47.3% confessed not feeling very strong, 42.6% completely agree that they perceive possibilities in the midst of difficulties. In addition, 37% stated that they

felt very lonely, demonstrating the prevalence of loneliness in individuals living with HIV/AIDS.

When testing the association between variables, the following mutual influences were found (Table 5).

ltem	Strongly disagree		Disagree		Agree		Strongly agree	
	n	%	n	%	n	%	n	%
I feel that I have at least as much value as other people.	39	36.1	17	15.7	40	37.0	12	11.2
I think I have several good qualities.	-	-	6	5.5	62	57.5	40	37.0
All things considered, I think I'm a failure.	11	10.2	17	15.7	17	15.7	63	58.4
I think I can do things as optimally as most people.	-	-	57	52.8	40	37.0	11	10.2
I do not think I have much to be proud of.	51	47.3	34	31.5	17	15.7	6	5.5
I have a positive attitude towards myself.	-	-	57	52.8	34	31.5	17	15.7
All in all, I'm pleased with myself.	6	5.5	85	78.8	11	10.2	6	5.5
I wish I had more respect for myself.	17	15.7	6	5.5	57	52.8	28	26.0
Sometimes I feel useless.	17	15.7	34	31.5	57	52.8	-	-
Sometimes I think I'm not good at anything.	11	10.2	17	15.7	17	15.7	63	58.4

Table 4 – [Hope] scores of people living with HIV/AIDS, João Pessoa, Paraíba, Brazil (N = 108)

14	SD		D		А		SA	
ltems	n	%	n	%	n	%	n	%
1. I am optimistic about life.	-	-	17	15.7	46	42.6	45	41.7
2. I have short and long-term plans.	38	35.2	40	37.0	23	21.3	7	6.5
3. I feel very lonely.	11	10.3	17	15.7	40	37.0	40	37.0
4. I can see possibilities in the midst of difficulties.	-	-	17	15.7	45	41.7	46	42.6
5. I have a faith that comforts me.	-	-	-	-	34	31.5	74	68.5
6. I'm fearful for my future.	57	52.8	34	31.5	17	15.7	-	-
7. I have memories of happy and pleasant times.	-	-	11	10.2	68	63.0	29	26.8
8. I feel very strong.	-	-	51	47.3	46	42.5	11	10.2
9. I feel capable of giving and receiving affection and love.	-	-	23	21.2	51	47.3	34	31.5
10. l know where l want to go.	-	-	28	26.0	46	42.5	34	31.5
11. I believe in the value of each day.	-	-	10	9.3	68	63.0	30	27.7
12. I feel that my life has value and usefulness.	11	10.2	11	10.2	57	52.8	29	26.8

Note: SD = strongly disagree; D = disagree; A = agree; SA = strongly agree.

Table 5 – Correlation between studied variables among people living with HIV/AIDS, João Pessoa, Paraíba, Brazil (N = 108)

Variables	Test	Р	Hypothesis
Future expectations vs. Self-concept	Mann-Whitney	0.412	Future expectation scores are not influenced by self-concept classification
Fear vs. Depression	Kruskal-Wallis	0.530	Fear has no correlation with the classification of depression.
Guilt vs. Depression	Kruskal-Wallis	0.271	Guilt does not correlate with the classification of depression.
Loneliness vs. Depression	Kruskal-Wallis	0.121	Loneliness does not correlate with the classification of depression.
Fear vs. Self-concept	Chi-square	0.001*	Fear influences self-concept.
Guilt vs. Self-concept	Chi-square	0.001*	Guilt influences self-concept.
Loneliness vs. Self-concept	Chi-square	0.001*	Loneliness influences self-concept.
Fear vs. Future expectations	T-test	0.146	Fear does not influence future expectations.
Guilt vs. Future expectations	T-test	0.011*	Guilt influences future expectations.
Loneliness vs. Future expectations	T-test	0.123	Loneliness does not influence future expectation.
Fear x Hope	T-test	0.224	Fear does not influence hope.
Guilt x Hope	T-test	0.161	Guilt does not influence hope.
Loneliness x Hope	T-test	0.001*	Loneliness influences hope.

Note:*Indicates statistical significance.

DISCUSSION

The socio-demographic variables age, sex and income show that the age group of young adults is the one with the highest prevalence of HIV/AIDS⁽¹²⁾, and also that men are among the most affected: in 2017, for every 22 cases of AIDS affecting men there were 10 affecting women⁽²⁾.

Regarding schooling, the data corroborate a study in Bahia which suggested a relationship between social impoverishment and infection, also stating that individuals with a high level of schooling may have greater access to information regarding HIV/AIDS infection⁽¹³⁾.

Here, low-income individuals predominated, agreeing with a 2016 Maranhão survey showing that socioeconomic factors influenced the quality of life of individuals with HIV/AIDS—given the fact that the drug treatment requires good nutrition, not to mention the costs of routine medical appointments and extra medications when necessary⁽¹⁴⁾.

The high prevalence of unprotected sex—confirming the inconsistent use of condoms, as well as the common occurrence of casual sex with multiple partners⁽¹⁵⁾—also stands out in our study, making it necessary to strengthen the importance of condom use in all cases, in order to prevent sexually transmitted infections.

Regarding diagnosis time (minimum of one week and maximum of 23 years), feelings of conformation and resilience are emphasized, with recent cases more likely to involve prejudice and guilt⁽¹⁶⁾.

Mild depression (Table 1) was present in 31.5% of the patients, while moderate depression was present in 21.3%. This agrees with a study with HIV/AIDS patients carried out in the city of Khartoum, Sudan, between 2015 and 2016, which also identified depression as a common occurrence, confirming that HIV/AIDS can have an enormous impact on the individual psyche. In addition, the study emphasized that depression can make treatment more difficult, increasing the infection's rate of progression⁽¹⁷⁾.

It is estimated that by the year 2030, depression will be among the top three diseases worldwide, along with HIV/AIDS and ischemic heart disease. Studies conducted in different countries, with different economic realities, show an association between HIV/ AIDS and depression, one of the main causes of suicide among people with HIV⁽¹⁸⁾.

Regarding future expectations (Table 2), a 2015 study carried out in Rio de Janeiro showed a negative representation of this variable in individuals living with HIV/AIDS, especially at the time of diagnosis, which is marked by a confrontation between past and future brought on by the awareness of having an incurable disease⁽¹⁹⁾.

Self-concept (Table 3) was impaired in 41.1% of this study's subjects. A 2013 study carried out in a city in the interior of São Paulo also identified low self-concept, associated with marital status, type of exposure and multimorbidity⁽²⁰⁾.

People living with HIV/AIDS may have their self-concept impaired because of the infection's social impact, in addition to being identified with the disease's stigma. Self-concept contributes to determining whether the individual has a positive or negative outlook on life. It also bears on the issues imposed by the disease, such as the loss of social bonds, discrimination, weakened life projects and changes in habits⁽²⁰⁾. Hope (Table 4) directly affects quality of life in the face of difficulties involving the disease and its treatment. It is common for people living with HIV to show a sense of hopelessness in regards to the possibility of cure⁽²¹⁾. In fact, most respondents disagreed about being able to make plans in the short and long term, also stating they did not feel very strong and that they could not see possibilities amid difficulties.

A study carried out in Ceará indicated that the acceptance of having to live with HIV/AIDS is a long process, and showed that at the beginning there are negative feelings sometimes accompanied by suffering and difficulty in adhering to antiretrovirals. This makes the support and counseling of health professionals during treatment an irrevocable necessity, so that patients can overcome this initial phase and cope with HIV⁽²²⁾.

Regarding the studied variables (Table 5), it is noteworthy that the feeling of guilt has a direct influence on self-concept and future expectations, and that self-concept is influenced by fear and loneliness. In addition, hope is related to loneliness. A study carried out in Minas Gerais showed fear as one of the main emotions reported by individuals with HIV. It had an impact upon several facets of life with the virus, including starting relationships, death, and revealing the diagnosis to relatives and friends⁽¹²⁾.

Moreover, a study carried out with women with HIV in the state of Bahia showed that the feeling of guilt harmed respondents' social relations and mental health⁽²³⁾. Guilt is especially prevalent in people with HIV/AIDS when the disease was acquired due to lack of prevention, such as unprotected sex and intercourse with sex workers. Another study with people with HIV also pointed to feelings of guilt, shame, self-discrimination and inferiority⁽²⁴⁾.

The self-concept of people with HIV/AIDS is impaired and involves emotional factors such as fear, guilt and loneliness. These factors can and should be dealt with, since they are linked to suicide attempts⁽²⁵⁾.

The nursing team presents itself as an important element in contributing to the quality of life of hospitalized individuals living with HIV/AIDS, helping them find meaning for existence despite the disease's consequences. These professionals have the role of contributing to the development of responsibility and autonomy among assisted patients⁽²⁶⁾.

Limitations of this study

The limitations of this study are related to its design, comprised of a transversal approach that limits the comprehensiveness of the results to the universe of the participants, with its sample composed of only two health institutions. A broadening of research fields and participants may allow for a more appropriate scope, deepening the issues addressed here, and contemplating the possibility of stratification and elaboration of nursing care plans involving emotions of guilt, fear, loneliness, self-concept, future expectations and hope.

Contributions to the area of nursing, health or public policy

The research focused on the better understanding of depression, self-concept, future expectations and hope in people living with HIV/AIDS. Its goal was to collaborate with the structuring of care models directed to comprehensive and interdisciplinary care, aiming at new psychosocial demands that may arise in this segment of the population. As such, the understanding and identification of emotional aspects can help nurses and other health professionals to intervene in the control of stressors related to the disease, favoring adaptation to the therapeutic regimen.

This study also provided useful information on the psychosocial characteristics of people with HIV/AIDS, including their emotional responses. This contribution is relevant when considering that people with HIV/AIDS are still subject to a very prejudiced outlook of large parts of the general population.

Regarding public health, the importance of professionals trained to work with people diagnosed with HIV/AIDS—and able to identify changes related to physical, mental and biological health—is clear.

FINAL CONSIDERATIONS

As we have shown, the subjects of this research presented depression, low self-concept, frail future expectations and compromised hope. Self-concept has a statistically significant correlation with fear, guilt and loneliness. Future expectations are associated with fear and guilt. In addition, loneliness influences hope.

Identifying the characteristics and feelings experienced by individuals living with HIV/AIDS is an important step in developing adequate therapeutic interventions and psychosocial support. In addition, this study can be relevant to nursing care as a means of supporting its systematization, aiming to ensure comprehensive and high-quality care.

It is our hope that this study will raise the attention of health managers to the importance of considering the feelings experienced by people with HIV in the construction of public policies and clinical protocols. This behavior may contribute to the minimization of issues such as social isolation, low self-concept, loneliness, depression and lack of hope.

We emphasize that universities should include this theme in their compulsory curriculum, and also in transversal thematic discussions, in order to achieve, in addition to the prevention and drug treatment of HIV/AIDS, an integral training that considers humans as multifaceted beings.

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