

This is a **Sample** version of the  
**HIV Overview of Problems - Evaluation  
System (HOPES)**

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# Assessing the needs and quality of life of patients with HIV infection: development of the HIV Overview of Problems-Evaluation System (HOPES)

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**Objective:** To develop and evaluate the psychometric properties (reliability, validity etc.) of a comprehensive Quality of Life (QOL) tool, for patients infected with the human immunodeficiency virus (HIV), that was adapted from a previously validated cancer tool. **Design:** Cross-sectional, patient completed written surveys and interviews. **Setting:** The Medical Centers serving HIV infected patients in the Los Angeles community including UCLA, community physicians, Veterans Affairs Medical Centers, and a County hospital: and additional data contributed from Johns Hopkins University Medical Center CMV Retinitis Clinic. **Patients:** Patients ( $n = 318$ ) with HIV infection including asymptomatic (37%), ARC (20%), AIDS (25%) and AIDS with Cancer (18%) receiving health services at one of the above sites. **Measurements:** The patients self-administered the newly developed instrument, the HOPES (HIV Overview of Problems-Evaluation System), other QOL related tools including the Medical Outcomes Study instrument adapted for HIV (MOS-HIV) the Profile of Mood States (POMS), the Perceived Adjustment to Chronic Illness Scale (PACIS), and the Physical Activity Scale (PAS). **Brief interview to assess the Karnofsky Performance Status Score (KPS).** **Measured sociodemographic characteristics** included age, sex, race, HIV risk factor, education etc. **Assessed medical history, current medications, HIV clinical classification.** **Main results:** The sociodemographic and medical characteristics of the sample resemble those of the general

population with HIV infection in this geographic area: 96% male, 28% nonwhite, 84% homosexual contact as risk factor, 75% receiving antiretroviral therapy. The adaptation of the cancer QOL instrument to HIV appears to have face and content validity according to patients and health professionals who care for HIV infected patients. Analyses of the psychometric properties found that the HOPES has a similar structure to its parent instrument following factor analyses which results in five summary scales representing the Physical, Psychosocial, Medical Interaction, Sexual and Significant Other/Partners domains in addition to a Global Score. Internal consistency of 35 subscales is high with a mean alpha coefficient of 0.82. Correlations of the HOPES summary scales with other QOL instruments are in the predicted directions. Comparing patients within the HIV clinical diagnostic categories on the HOPES Global, Physical, and Psychosocial Summary Scales indicates that Asymptomatic Patients have better QOL than symptomatic patients. This finding is also found in the other QOL instruments which provides evidence of construct validity. **Conclusions:** The HOPES is an excellent tool for identifying the problems and needs of patients with HIV infection and for assessing their quality of life. It is reliable, valid and acceptable to patients. The tool may be especially useful in developing a normative data base.

*Key words:* Assessment of needs, HIV infection, quality of life.

This paper is dedicated to the memory of Jimmy Stophel who died of AIDS and whose sense of humour improved the quality of many people's lives.

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## Introduction

Acquired immunodeficiency syndrome (AIDS) caused by infection with the human immunodeficiency virus (HIV), is a lethal disease. HIV infection has become the dreaded illness of the 1980s and 1990s, and in many ways has replaced

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# HIV Overview of Problems - Evaluation System (HOPES)

## Scoring & administration

The HOPES is a detailed self-report of everyday problems experienced by people with HIV. Although the HOPES consists of a total of 165 items, 58 of the items that may not apply to all patients (e.g., work-related questions, partner relationships, medication side effects) and consequently may be omitted. Each HOPES item is phrased as a problem statement (e.g., "I have difficulty bending or lifting") and rated using a Likert-type scale (0, not at all; 1, a little; 2, not very much; 3, much; 4, very much) to enable providers to identify areas for intervention. The HOPES can be summarized with five higher order summary scales include physical, psychosocial, medical interaction, marital and sexual domains. Each of these summary scales are further divided into more discrete categories including ambulation, activities of daily living, pain, psychological distress, difficulties communicating with the medical team, sexual interest, communication with partner, etc.

## Scoring:

The HOPES scoring system forms a pyramid, wherein the top is the global score, the next level includes the five higher-order factors or summary scales, the next level comprises the 35 subscales that summarize more detailed areas of need and problems, and the base of the pyramid shows individual items.

HOPES subscale scores are calculated by imputing the missing values based on the mean of the non-missing items. All subscales are transformed to a scale of 0 to 100%, with higher scores indicating worse health and satisfaction.

## HOPES Scoring Tables -

Subscales	Question Numbers	Subscale Score Range
<b>PHYSICAL</b>		
Ambulation (AM)	1, 2, 3, 4,	16 = 100% $\% = \left( \frac{AM \text{ raw total}}{16} \right) \times 100$
Activities of daily living (ADL)	5, 6, 7, 8,	16 = 100% $\% = \left( \frac{ADL \text{ raw total}}{16} \right) \times 100$
Recreational activities (RA)	9, 10, 11, 12	16 = 100% $\% = \left( \frac{RA \text{ raw total}}{16} \right) \times 100$
Weight loss (WL)	13, 14, 15, 16, 17	20 = 100% $\% = \left( \frac{WL \text{ raw total}}{20} \right) \times 100$
Difficulty working (DW)	18, 19	8 = 100% $\% = \left( \frac{DW \text{ raw total}}{8} \right) \times 100$
Pain (P)	20, 21, 22	12 = 100% $\% = \left( \frac{P \text{ raw total}}{12} \right) \times 100$
Clothing (C)	23, 24, 25	12 = 100% $\% = \left( \frac{C \text{ raw total}}{12} \right) \times 100$
Symptoms (S)	95, 97, 98, 99, 100, 101, 102, 103	32 = 100% $\% = \left( \frac{S \text{ raw total}}{32} \right) \times 100$
At work concerns (WC)	104, 105, 106, 107, 108	20 = 100% $\% = \left( \frac{WC \text{ raw total}}{20} \right) \times 100$
Antiretroviral therapy problems (AT)	155, 156, 157, 158, 159, 160, 161, 162	32 = 100% $\% = \left( \frac{AT \text{ raw total}}{32} \right) \times 100$
<b>Total Physical score -</b>		184 = 100% $\% = \left( \frac{Phy \text{ raw total}}{184} \right) \times 100$

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**HOPES**  
**HIV Overview of Problems – Evaluation System**  
**For Research**

Patient ID#: \_\_\_\_\_

Date: \_\_\_\_\_

**Instructions**

Below is a list of Problem Statements that describe situations and experiences of individuals who **ave** HIV infection. Read each statement and circle the number that best describes **HOW MUCH EACH STATEMENT APPLIES TO YOU** during the **PAST MONTH, INCLUDING TODAY**. Some sections will not apply to you. Please skip these sections and proceed to the next one as directed.

**Example**

<b>How much does it apply to you?</b>	Not at all	A little	A fair amount	Much	Very Much
1. I have difficulty walking	0	①	2	3	4
2. I find that food tastes bad	0	1	2	3	④

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## HOPES

		Not at all	A little	A fair amount	Much	Very much
1.	I have difficulty bending or lifting	0	1	2	3	4
2.	I have difficulty walking and/or moving around	0	1	2	3	4
3.	I have difficulty doing physical activities such as running and playing sports	0	1	2	3	4
4.	I do not have the energy I used to	0	1	2	3	4
5.	I have difficulty driving	0	1	2	3	4
6.	I have difficulty doing household chores	0	1	2	3	4
7.	I have difficulty bathing, brushing my teeth, or grooming myself	0	1	2	3	4
8.	I have difficulty preparing meals	0	1	2	3	4
9.	I am not interested in recreational activities like I used to be	0	1	2	3	4
10.	I do not engage in the recreational activities that I used to	0	1	2	3	4

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