Quality of Life and the Concept of "Living Well" With HIV/AIDS in Sub-Saharan Africa

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Purpose: To increase understanding of the meaning of quality of life for people living with HIV/AIDS in four countries in sub-Saharan Africa: Botswana, Lesotho, South Africa, and Swaziland.

Methods: Using a cross-sectional design and convenience sample, we administered a survey and collected data on demographic characteristics, measures of severity of illness, and perceptions of quality of life. The purposefully selected sample (N=743) consisted of community-based people living with HIV/AIDS in 2002. Based on the Wilson and Cleary framework for organizing variables related to quality of life, a hierarchical multiple regression was conducted with quality of life as the dependent variable.

Results: The sample of 743 persons was 61.2% female with a mean age of 34 years. Approximately 62% of the sample reported having received an AIDS diagnosis. Ten predictor variables explained 53.2% of the variance in life satisfaction. Those participants with higher life satisfaction scores were less educated, had worries about disclosure and finances, did not have an AIDS diagnosis or other comorbid conditions, had lower symptom intensity, had greater functioning, and had fewer health worries. None of these participants was taking antiretroviral medications at the time of this study.

Conclusions: Several dimensions of the Wilson and Cleary model of quality of life were significantly related to life satisfaction for people living with HIV/AIDS in sub-Saharan Africa. Quality of life for this sample was primarily defined as overall functional ability and control over symptom intensity. These findings are similar to studies in developed countries that have shown the significant relationships among functional abilities, symptom control, and perceived quality of life. As antiretroviral medications become more available in these areas, community members and care providers can help clients realize the possibility of living well with HIV/AIDS, and can work with clients to improve functional ability and control symptom intensity to make living well a reality.

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Accepted for publication January 11, 2005.

ub-Saharan Africa is home to 29.4 million people infected with HIV/AIDS; no other region of the world has a higher prevalence of the disease. In four sub-Saharan African countries, national adult HIV prevalence has risen higher than was once thought possible, exceeding 30% in Botswana (38.8%), Lesotho (31%), Swaziland (33.4%) and Zimbabwe (33.7%; UNAIDS, 2002). By 2010, the number of AIDS-related deaths is predicted to be twice as large as that from all other causes of death combined (Bradshaw, Schneider, Dorrington, Bourne, & Saubscher, 2002). Although testimonies of the devastating effects of HIV/AIDS are abundant, few studies have shown the effects of living with HIV/AIDS on a person's quality of life in sub-Saharan Africa.

The quality of life of people with HIV/AIDS is a complex constellation of disease, poverty, stigma, discrimination, and lack of treatment combined with family life, work, and social activities. HIV/AIDS affects not only the infected person, but also his or her family, community, and country. Without treatment, people experience accelerated losses. At the household level, people have loss of companionship and income. At the community and national levels, they experience loss of productivity because of absenteeism and death. Many young women and men are too ill to participate in their schooling or work, few people are available to care for the very young and very old, and parents are burying their children. Many people do not have enough money to buy medicines. And with fewer people to care for the land, the small-farm economies are being destroyed. In short, HIV/AIDS is devastating at all levels. As a result of the magnitude of the pandemic, however, the plight of individuals—particularly their quality of life—might be overlooked. With the promise of antiretroviral medications, this grim picture has the potential to improve.

Few people with HIV/AIDS in sub-Saharan Africa currently have access to antiretroviral therapy. Consequently, community members and health care workers have little recognition that a person can have a productive life and live well with HIV/AIDS. Although HIV-testing programs exist in sub-Saharan Africa, many people still do not get tested, and they get health care only when they are already severely compromised, often with active tuberculosis or pneumonia. Some women are tested for HIV during pregnancy and, if found to be HIV-positive, they receive medications to reduce maternal-child transmission. Little effort is made, however, to continue treating the mothers after delivery. These women often disappear, leaving the health care system and hiding their HIV/AIDS status until they lose significant weight, develop infections, and develop what is commonly referred to as "slims" disease. These trends strengthen the association of HIV/AIDS with death.

With the availability of antiretroviral therapy promised by the world's donors, HIV/AIDS will no longer be a death sentence or the beginning of a series of losses of employment or family life. Nurses and other care providers will be challenged to help their communities develop this new concept of living well with HIV/AIDS. This study was an initial exploration of quality of life for people living with HIV/AIDS without the benefits of antiretroviral medications. We identified factors perceived to be important to quality of life for people living with HIV/AIDS. Nurses and program managers can use this information to consider the positive effects of antiretroviral medications, as well as the possible negative effects, such as new HIV-related symptoms and increasing out-of-pocket expenses for the medications.

For this study, Wilson and Cleary's (1995) framework, with several dimensions of quality of life, was used to formulate hypothesized relationships of patient variables to quality of life in a sample of people with HIV/AIDS in sub-Saharan Africa. This model includes five groups of patient outcome variables—biological and physiological factors, symptoms, functioning, general health perceptions, and overall quality of life—and a linear, directional relationship among the variables (see **Figure**). In addition, the potential effects of
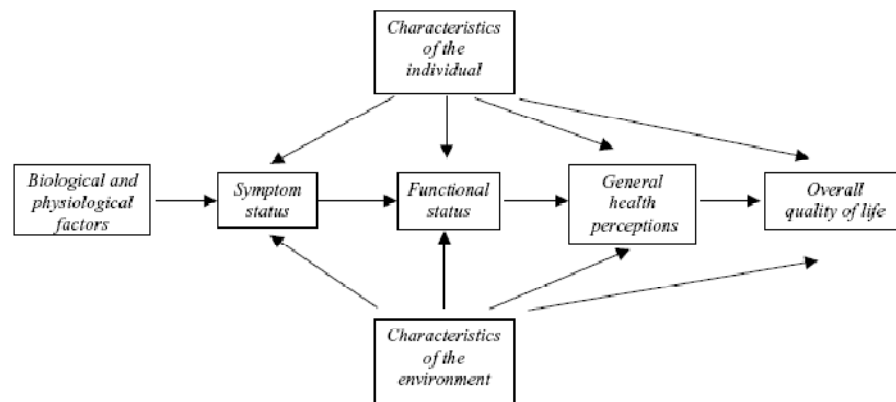

Figure. Wilson and Cleary's model of the correlates of quality of life.

individual and environmental characteristics on the dimensions of the model are briefly discussed. Aimed toward explaining the variance in quality of life, the model was developed in the West and its applicability to the concepts of quality of life in sub-Saharan Africa has not been tested previously.

Background

The progression of HIV disease most often results in a decreasing quality of life. Although quality of life is a multidimensional construct that does not have a universally agreed-upon definition, researchers have agreed on many concepts concerning health-related quality of life. The World Health Organization Quality of Life Group (1995) defined quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." Health-related quality of life refers to how well people can perform daily activities and how good they feel about their lives (Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001). After reviewing the literature, de Boer et al. (1995) reported that 11 health-related, quality-of-life instruments had been used to study HIV-infected patients, yet consensus was lacking about how quality of life should be assessed. Researchers have used the Medical Outcomes Study-Based Quality of Life measure more extensively than any other instrument in HIV-related studies (Tsasis, 2000).

Sousa et al. (1999) tested a health-related, quality-of-life model and provided support for three key dimensions of health-related quality of life among people with HIV/AIDS: symptom control, functional status, and general health perceptions. Sowell et al. (1997) regarded quality of life as a constellation of three variables: daily functioning, low levels of general anxiety, and few HIV-associated symptoms. None of this work appears to have been replicated in sub-Saharan Africa.

Studies on samples in developed countries have indicated that certain demographic factors (e.g., age, sex, ethnicity, education, and marital status) as well as physiological and psychological factors might be related to quality of life (Crystal et al., 2003; Nokes et al., 2000; Sousa, Holzemer, Henry, & Slaughter, 1999; Sowell et al., 1997). Income was reported to have a strong association with health status and functional status (Ettner & Weissman, 1994). Married women appeared to be more vulnerable than were men to disruptions in quality of life over time (Sarna, van Servellen, Padilla, & Brecht, 1999). Stage of illness had a statistically significant correlation with perceived quality of life in people with HIV infection (Sowell et al., 1997). The presence, number, and severity of constitutional symptoms in HIV disease were strongly associated with health-related quality of life in symptomatic HIV-infected people (Cunningham et al., 1998). None of these studies included people living in sub-Saharan Africa.

Sowell et al. (1997) conducted a longitudinal study with a sample of 263 HIV-infected women from eight public-health HIV/AIDS clinics serving both rural and urban areas in the state of Georgia in the United States. Social factors (disclosure and material resources) and psychological factors (fatalism, stigma, emotional distress, and intrusion) were found to be important determinants of quality of life. Limited daily functioning was correlated with stigma, fatalism, employment status, and stage of disease.

Sarna et al. (1999) studied quality of life in women with symptomatic HIV/AIDS over a 4-month period. They used the HOPES (HIV-Overview of Problem Situations-Evaluation System) to measure quality of life, with data at baseline, 2 months, and 4 months. Age was related to changes in physical summary scale, with older age associated with greater declines in physical quality of life. The most prevalent disruptions were psychosocial: financial problems, worry about the family, distress about losing others to HIV, and worry about disease progression. The study results were limited by the small sample size for each of the three time periods ($n=44$, 37, and 35, respectively). Using a national sample, Nokes et al. (2000) found that people 50 years old or older reported significantly more medical conditions such as diabetes or hypertension ($p=.000$), more limitations on physical functioning ($p=.006$), and self-disclosure of HIV infection to fewer people ($p=.000$). In this study we provide a good description of the diverse correlates of quality of life for people with HIV/AIDS.

Vidrine et al. (2003) studied quality of life and functional status outcomes in 385 multi-ethnic, HIV-positive patients in the Houston area. Men reported higher functioning than did women. Ethnic minorities and those with a lower educational level reported poorer work-role functioning. Neither clinical stage, as measured by the presence or absence of AIDS, nor the most recent CD4 cell count was associated with quality-of-life scores.

Quality of life and poverty have been shown to be inversely linked (Alleyne, 2001). The AIDS pandemic has exacerbated this problem because it profoundly reduces economic growth and income, thus increasing poverty. Good health requires an adequate income. Ill health can be a result of poverty and it also can exacerbate it, creating tremendous physiological and psychological stress and hardship for resource-poor people. Malnourishment, a common consequence of poverty, exacerbates HIV infection and hastens the progression of AIDS. Poverty precludes purchase of medications and thus it leads to increased rates of opportunistic infection. Lack of medications, in turn, significantly increases the pain and suffering related to AIDS. The cascading consequences of poverty in the context of the AIDS pandemic are staggering.

In addition to poverty, inadequate public health funding has a substantial negative effect on the lives of people living with HIV/AIDS. Several governments in sub-Saharan Africa spend less than $20 per citizen per year on all health care and a mere fraction of that amount on HIV/AIDS programs (Pharmaceutical Research and Manufacturers of America, 2003). Health services care administrators and professionals must simultaneously cope with an increasing

demand for care and the deaths of trained health personnel from AIDS (Gilks, Katabira, & DeCock, 1997; UNAIDS, 2002). UNAIDS personnel (2002) reported that Malawi and Zambia have had a five- to six-fold increase in illness and death among health workers in the previous 5 years, thus reducing the number of personnel and increasing the stress levels and workloads of remaining employees. By 2005, South Africa and Zimbabwe are projected to lose 11% and nearly 20% respectively of their workforces to AIDS (U.S. Department of State, 2002).

The patient load, insufficient personnel, lack of supplies, and lack of appropriate training for the changing HIV epidemic and new medicines overwhelm public health personnel. They see little hope of the situation improving. The shortcomings in public health worsen quality of life for people living with HIV/AIDS. Yet, with the arrival of antiretroviral medication in sub-Saharan Africa, this environment of death and despair can be altered to include the concept of living well with HIV disease. Recent research in developed countries has been focused on the improvement of quality of life since the availability of highly active antiretroviral therapy (Carrieri et al., 2003; Krentz & Gill, 2003; Safren, Radomsky, Otto, & Salomon, 2002). Reduction in AIDS-related deaths has already been reported in Botswana after the distribution of antiretroviral therapy (Kaiser Daily HIV/AIDS Report, 2004). Relatively few studies have been done, however, to explore the quality of life of people with HIV/AIDS in sub-Saharan Africa. No reports from sub-Saharan Africa are known to include the concept of living well with HIV/AIDS with the advent of antiretroviral medications.

Nurses have the capacity to promote the idea of "living well" with HIV/AIDS because of their close proximity to patients and families and their expertise and understanding that quality of life is affected by several factors amenable to interventions by nurse, self, and family. This study provides background knowledge about the correlates of quality of life as perceived by people with HIV/AIDS in sub-Saharan Africa as a context for designing nursing care interventions.

Methods

The question for study was: How do people with HIV/AIDS in sub-Saharan Africa view their quality of life? With a descriptive, cross-sectional design, adults living with HIV/AIDS in Botswana, Lesotho, South Africa, and Swaziland were the target population. A convenience, community-based, purposefully selected sample (n=743) provided data that were collected in 2002 in face-to-face interviews. A somewhat different procedure was used in each country to gain access to participants. In some areas, home care nurses asked families whether they would be interested in participating. In other areas, outpatient clinic personnel provided referrals. Institutional review boards at the following universities approved the study protocols: University of California

San Francisco, University of Botswana, National University of Lesotho, University of South Africa, and the University of Swaziland.

Instruments. Three self-report instruments were translated into seven languages (Sesotho, Setswana, Siswati, Tswana, Venda, Xhosa, and Zulu) and were pilot tested before this study. The survey was administered in the local language of the participants, and the research team translated the results into English.

Survey. A survey booklet was used to collect information on personal and environmental characteristics including age, sex, years of education, whether participants had adequate income, whether they had children, and other variables. In addition, the survey included questions about biological and physiological factors, such as whether participants had received an AIDS diagnosis or had any comorbid conditions.

The Revised Sign and Symptom Checklist for Persons with HIV Disease (Holzemer, Hudson, Kirksey, Hamilton, & Bakken, 2001) comprises 64 items to determine the frequency and intensity of HIV signs and symptoms that the participants were experiencing on that day. The items are rated on an ordinal, three-point Likert-type scale (1=mild, 2=moderate, 3=severe). Calculations included the total number of symptoms (with a range of 0–64) and the mean intensity of symptoms (with a range of 1–3). Validity and reliability of the instrument have been reported previously for a U.S. sample (Holzemer et al., 2001). Each country-level team—consisting of experts in HIV/AIDS care, nurses working directly in home-based care, and university faculty—reviewed the sign and symptom checklist for its relevance to their communities and confirmed the instrument's content validity.

HIV/AIDS-Targeted Quality of Life (HAT-QoL). The HAT-QoL is a self-report scale to measure overall functioning, life satisfaction, health worries, financial worries, and disclosure. Holmes and Shea (1997, 1999) designed the 42-item, nine-dimensional version of the HAT-QoL scale and first tested it in a sample of 201 HIV-seropositive people. We used only five of the dimensions in this study: overall function (OF), financial worries (FW), health worries (HW), disclosure worries (DW), and life satisfaction (LS). These five dimensions have shown good psychometric properties, adequate internal consistency, and evidence of construct validity (Holmes & Shea, 1997, 1999). Further evidence of validity of this instrument was that the items on quality of life were derived directly from reports by HIV-positive people. A weakness is that, to our knowledge, the instrument had not been used in sub-Saharan Africa before this study.

We computed five dimension scores for the 5-point HAT-QoL scales by summing all of the item responses in those dimensions. For negatively worded items in the instrument, the scores were reversed. A high score indicated more favorable outcomes. Cronbach's alpha coefficient was above .80 for each scale, indicating excellent internal consistency across items. Each country's team reviewed the items of the

instrument and judged them to be adequate for use in their respective communities.

Data Analysis

Responses to the questionnaires were transcribed, coded, and entered into the Statistical Package for the Social Sciences (SPSS) for Windows software. We calculated statistics (mean, standard deviation, and frequency) to describe the sample's demographic characteristics, severity of illness, and quality of life. The variables were organized based upon the Wilson and Cleary model of quality of life. Separate stepwise multiple regression analyses were conducted for each block or set of variables. Based upon these preliminary six multiple regressions, we selected variables that were significantly related to life satisfaction for the final model. A final hierarchical multiple regression was conducted using the six blocks or sets of variables as outlined in the Wilson and Cleary model against the dependent variable, quality of life as measured by overall life satisfaction.

Results

The total sample included 743 persons with HIV/AIDS. Most participants (61.2%, n=455) were women, the mean age was 34.05 years (SD=9.59), and the mean level of education was 7.70 years (SD=3.87). Fewer than half of the participants (n=301, 40.5%) reported having an adequate income, and only 7.9% (n=59) reported having health insurance. Nearly three-quarters (n=522, 70.3%) reported having children (see **Table 1**).

This sample was relatively ill. Nearly two-thirds of participants (n=458, 61.6%) had received an AIDS diagnosis and one-third (n=238, 32.0%) reported having other chronic comorbid conditions, such as diabetes or hypertension. On the day of the interview, they reported experiencing an average of 17.58 symptoms (SD=13.74). About one-quarter (n=185, 24.9%) spent more than 80% of their day in bed.

Using listwise deletion in order to enhance the stability of the correlation matrix, a hierarchical, six-step multiple regression analysis was performed with a total of 10 predictor variables, with 522 complete data sets for this analysis. The overall model explained 53.2% of the variance in quality of life as measured by life satisfaction (**Table 2**). Each block was significant. Participants with higher life satisfaction scores were less educated, had disclosure worries and financial worries, did not have an AIDS diagnosis or other comorbid conditions, had lower symptom intensity, had greater functioning, did not spend more than 80% of their day in bed, and had fewer health worries. Participants' self report of overall functioning explained the greatest variance in life satisfaction, with a unique R^2 of 30.6%. The second variable to explain a significant amount of variance in life satisfaction was related to financial worries, with a unique R^2 of 10.1%. Slightly more than 40% of the 53.2% variance explained in the model was based on functional status and financial worries.

Table 1. Study Variables Organized by Wilson and Cleary Model of Quality of Life (n=743)

Variables	Mean	SD	n	%
Characteristics of the individual				
Sex				
Female			455	61.2%
Male			287	38.6%
Age in years	34.05	9.59	741	
Had children			522	70.3%
Characteristics of the environment				
Had enough money to cover daily expenses			301	40.5%
Level of financial worries[a]	3.03	1.51	702	
Level of worries about HIV[b]	2.77	1.34	712	
Had health insurance			59	7.9%
Living environment				
Urban			225	30.3%
Peri-urban			255	34.3%
Rural			257	34.6%
Biological and physiological factors				
Had been given an AIDS diagnosis			458	61.6%
Had comorbidities			238	32.0%
Symptom status				
Number of symptoms being experienced today[b]	17.58	13.74	683	
Symptom intensity[c]	.52	.41	683	
Functional status				
Overall functioning[a]	2.54	1.20	729	
Spent more than 80% of the day in bed			185	24.9%
Received home visits			275	37.0%
General health perceptions				
Health worries[a]	2.81	1.28	727	
Overall quality of life				
Life satisfaction[a]	3.50	1.21	728	

[a]Scale: 1 = low; 5 = high
[b]Total number of symptoms = 57
[c]Symptom intensity rated as 1 = mild, 2 = moderate, 3 = severe.

Discussion

The combination of variables in the model explained more than 50% of the variance in life satisfaction. Daily functioning was the most significant predictor of life satisfaction. People with impaired ability to carry out daily activities had the least life satisfaction. Inadequate financial resources and financial worries explained the second largest proportion of the variance in life satisfaction. The only demographic variable that was negatively related to life satisfaction was level of education. People with higher levels of education had lower life satisfaction. Demographic variables such as age, sex, and having children were not related to life satisfaction in this sample. When explored at set 4, symptom intensity was significantly related to life satisfaction. People reporting higher symptom intensity also reported lower life satisfaction. At the final step, however, when functional status was entered, symptom intensity was no longer

Table 2. Hierarchical Multiple Regression of Overall Life Satisfaction in a Sample of HIV-Positive Persons Living in Sub-Saharan Africa (*n*=522)

Independent variables	Standardized beta from last step	R^2	$R^2\Delta$ for set	sr^2	p
Block 1: Individual characteristics		.053	.053		.000
Years of education	.112			.053	.000
Block 2: Environmental characteristics		.155	.101		.000
Disclosure worries	−.061			.022	.000
Financial worries	.060			.010	.112
Enough money for daily essentials	.173			.029	.000
Block 3: Physiological factors		.176	.021		.002
Have AIDS diagnosis	−.001			.002	.219
Have other comorbidities	−.074			.029	.001
Block 4: Symptom status		.186	.011		.010[a]
Symptom intensity[a]	−.028			.011	.010
Block 5: Functional status		.492	.306		.000
Overall functioning	.432			.010	.001
Spend greater than 30% time in bed	.106			.294	.000
Block 6: General health perceptions		.532	.049		.000
Health worries	−.287			.049	.000

[a]Symptom intensity not significant at final step.

significant. This finding shows the close correlation between symptom intensity and functional status.

Although the model is an overall helpful structure in organizing the predictor variables, the findings for this sub-Saharan African sample have both consistencies and inconsistencies with findings from some U.S. studies. In U.S. multiple regression studies of quality of life of people with HIV/AIDS, level of education has not typically been related to quality of life (Sarna et al., 1999) but level of income has (Swindells et al., 1999).

This study had several limitations. First, because we collected cross-sectional data, we cannot infer a causal relationship between selected predictor variables and life satisfaction. Although our sample size was adequate, we cannot be sure that it was representative of the population of people living with HIV in these countries. This sample included people known to have HIV/AIDS and often in care settings supported by home care nurses.

This study was the first use of these instruments for measuring symptoms and quality of life in an African sample. Although local care providers paid attention to translation to local languages and content review, we cannot assume that the concepts were directly transferable to these other cultures. Further work is needed for continued exploration of these concepts in the sub-Saharan context.

In resource-rich environments where antiretroviral medications are available, health care providers and many people living with HIV/AIDS conceptualize HIV/AIDS as a chronic disease. Where treatments are not available and a person has been diagnosed with HIV/AIDS, however, he or she may perceive HIV/AIDS as a death sentence and the end to any quality of life. As a result, few people in sub-Saharan Africa have a concept of "living well" with HIV/AIDS. As antiretroviral medications become available across sub-Saharan Africa,

disability will decrease and functional status will improve among people living with HIV/AIDS and they will experience an increase in life satisfaction or quality of life (Chou, Holzemer, Portillo, & Slaugher, 2004). Then the concept of "living well" with HIV/AIDS might be developed and sustained.

The finding that high symptom intensity was related to low satisfaction with life has implications for family and community care models, specifically in the area of home-based care. For instance, in developing countries, the overemphasis on the extended family as caregivers is problematic given the rapid changes brought about by development and urbanization such as depletion of human resources at the household level and rural-to-urban migration. Few family members remain to care for their loved ones. These changes have led to different configurations of the family in its definition and composition. Reliance on traditional family structures to deliver home-based care might no longer be realistic.

How to interpret the finding that people with lower education levels reported higher scores on life satisfaction is unclear. Perhaps the participants with higher levels of education had higher goals or aspirations for themselves and their families and those hopes have been destroyed by HIV/AIDS.

Conclusions

Participants in this study were people with HIV/AIDS who were not taking antiretroviral medications. Those with higher life satisfaction scores had lower levels of education, had disclosure and financial worries, did not have AIDS diagnoses or comorbidities, had lower symptom intensity, had higher levels of functioning, and had fewer health worries.

These findings indicate the need for greater understanding of the factors associated with the quality of life of people living with HIV/AIDS in sub-Saharan Africa. Further, they illustrate several critical factors that must be addressed to improve their quality of life. Not surprisingly, poverty was directly related to lower quality of life. Poorer functional status was significantly related to lower life satisfaction. If antiretroviral medications improve functional ability, as demonstrated in other areas of the world, many people in sub-Saharan Africa can anticipate a substantial increase in life satisfaction.

Nurses are in direct contact with people with HIV/AIDS infection and have unique opportunities to influence their quality of life. Nurses can adopt positive attitudes and educate their patients toward "living well" with HIV/AIDS. Nurses can teach and support strategies to reduce functional disability, such as exercise and nutrition. Nurses can provide patient education materials on how to assess, manage, and control HIV-related symptoms. Nurses can provide support for self- and family-care interventions designed to enhance the quality of life for people with HIV/AIDS in sub-Saharan Africa through understanding and supporting the concept of "living well" with HIV/AIDS.

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