Development and testing of the South African National Nutrition Guidelines for People Living with HIV/AIDS

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Malnutrition is a common consequence of HIV infection, and weight loss is used as a diagnostic criterion for HIV/AIDS. The relationship between HIV/AIDS and malnutrition and wasting is well described,[1,2] with nutritional status compromised by reduced food intake, malabsorption caused by gastrointestinal involvement,[3] increased nutritional needs as a result of fever and infection, and increased nutrient losses.[4,5] Malnutrition contributes to the frequency and severity of opportunistic infections seen in HIV/AIDS[6] and nutritional status is a major factor in survival.[7-9] Failure to maintain body cell mass leads to death at 54% of ideal body weight.[10,11] The effectiveness of nutrition intervention has been documented[12,13] and dietary nutrition counselling is considered critical in the treatment of HIV/AIDS,[14] especially in view of the fact that drug treatment is inaccessible to many people living with the virus in Africa.

In November 1999 the South African National Department of Health issued a tender for the Development of the South African National Nutrition Guidelines for People Living with HIV/AIDS (Guidelines). The final document was specifically intended for people living with HIV/AIDS as well as their caregivers. The project plan envisaged a printed English document aimed at reaching as wide a cross-section of the South African population as possible.

Methods

After a competitive application process, AFRICON (African Engineering International (Pty) Ltd) was awarded the contract for the period 1 March 2000 to 28 February 2001, with technical support provided by the United Nations International Children's Emergency Fund (Unicef). The project was planned to include a research and development phase (March - August 2000) and a test phase (September 2000 - January 2001). During the first phase, examples were sought from around the world and the scientific literature was researched extensively. The information collected was used to compile the first draft of the Guidelines. The topics to be covered were decided on by a multidisciplinary participative project co-ordinating committee representing various directorates within the Department of Health and included the relationship between HIV/AIDS and nutrition, nutritional support of the immune system, food safety with regard to HIV/AIDS, home-care management of nutrition-related problems caused by HIV/AIDS, special considerations for children with HIV/AIDS, and general advice for self-care. Extensive circulation of this and subsequent drafts ensured the inputs of a wide selection of role players and decision makers in the fields of nutrition and HIV/AIDS care. The test phase set out to investigate the comprehensibility, practicability and user-friendliness of the final draft of the Guidelines among the intended target group.

Sample selection

The AIDS Training, Information and Counselling Centres (ATICCs) attached to local government bodies were identified as feasible co-operating organisations for the execution of the test phase. The ATICC or alternative agency in each of the eight (of nine) participating provinces was requested to identify 40 respondents from among its members or clients and to include both people living with HIV/AIDS and uninfected people who care for or support them. This sample was to be as representative of the diverse South African population as possible. Racial as well as ethnic (language) group representation should reflect the national demographic spread. Forty copies of the final draft of the Guidelines were delivered to each agency with instructions to distribute them to the respondents at least 1 week before the arranged test session. This would ensure sufficient time for the respondents to familiarise themselves with the contents. Budgetary constraints of the extended test phase did not allow for financial incentives. As a sign of gratitude the respondents were promised a copy of the final printed Guidelines by post.

The questionnaire

A questionnaire was developed to gain information from the readers and respondents on the user-friendliness, practicability and comprehensibility of the Guidelines. There was no intention to test factual knowledge, values or attitudes of the respondents. The additional collection of relevant demographic data would enable a description of the sample. The questionnaire and data sheet were translated into the 11 official languages for use in the provinces.

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Administration of the questionnaire

The project nutrition consultant visited each province to administer the questionnaire. Agency staff were trained to assist respondents who visited the centres outside of the visits by the nutrition consultant. During each session the respondents received information informing them of the process and they were assisted with completion of the questionnaire. In a few cases the help of translators was required to clarify instructions. Where 40 respondents were not secured during the visit, arrangements were made with the co-operating centres in an effort to optimise the sample size. Respondents could visit the centres at their convenience after the visit to complete the questionnaire with the help of the trained staff at the centre and these were later returned by post.

Statistical analysis

All completed forms were consolidated and the data were captured electronically. Analysis was performed using the EpiInfo 6 programme.[15] Means and standard deviations (SDs) were calculated for continuous variables. All other demographic variables and the responses to the questionnaire were described using frequency distributions. Associations between demographic variables (gender, age younger and older than 35 years, HIV status and understanding of English) were tested for statistical significance using the chi-square test. Planned comparisons between provinces, ethnic and language groups could not be done because of the small sample subsets. An attempt was made to categorise similar responses to the open questions regarding what the respondents had found useful and what they had implemented.

Results

Demographic description of the sample

The sample comprised a total of 80 respondents, with an age range from 18 to 71 years (mean age 35.2 years, SD 1.92). Table I shows the age distribution of the sample, which consisted of 58 females (74.4%) and 20 males (25.6%). Note that the sample size *(N)* quoted in the results indicates the number of people who responded to the question(s). Discrepancies in the sample size among variables resulted from lack of control where questionnaires were completed in the absence of the nutrition consultant and forwarded at a later date.

The ethnic breakdown of the sample is shown in Table I. Sixty-six respondents (83.5%) lived in an urban environment and 13 (16.5%) in a rural setting. The home language of the respondents included all of the 11 South African official languages as well as one foreign language (Table I). Although the Guidelines were produced in English, only 5 of 79 respondents (6.3%) gave English as their first language. Omission of North West province from the test phase caused concern that one of the major regional languages would be excluded, but cross-border movement nevertheless led to the sample comprising 16.5% Tswana-speaking people.

Table I. Demographic description of sample

Respondents	*N*	%
Age (yrs) (mean 35.20, SD 1.92)	80*	
18 - 24	9	11.3
25 - 29	18	22.5
30 - 34	18	22.5
35 - 39	14	17.5
40 - 44	7	8.8
45+	14	17.5
Sex	78*	
Female	58	74.4
Male	20	25.6
Ethnic group	79	
Black	68	85.0
Indian	1	1.3
Coloured	2	2.5
White	8	10.1
HIV status	79*	
Infected	44	56
Uninfected	35	44
Duration of infection (yrs) (mean 4.59, SD 3.50)	44*	
0 - 5	31	70.5
6 - 10	11	25.0
11 - 15	1	2.3
16+	1	2.3
Environment	79*	
Urban	66	83.5
Rural	13	16.5
Home language	79*	
Afrikaans	7	8.9
English	5	6.3
Ndebele	1	1.3
Sepedi	2	2.5
Seswati	8	10.1
Sotho (North)	21	26.6
Sotho (South)	5	8.2
Tshivenda	1	1.3
Tswana	13	16.5
Xhosa	4	5.1
Zulu	11	14.0
Foreign	1	1.3
Level of education	78*	
No formal schooling	4	5
Schooling up to Grade 12	48	61.5
Formal and informal post-school training	37	47.5
Graduate	1	1.3

*Number responding to question.

The school education level of the sample ranged from as low as grade 3 to grade 12 in 48 of 78 respondents (61.5%). Four respondents (5%) indicated that they had no formal schooling at all and 37 (47.4%) had received some post-school training

and education, ranging from informal adult education to vocational training and in 1 case a university degree.

The majority of the respondents (56%) were HIV-positive and had known their status for from less than one year to 18 years, with a mean of 4.59 years (SD 3.50). Table II gives a breakdown of the HIV-positive group by duration of infection. Of those not infected with HIV, 71.7% reported knowing someone infected. Almost half (45.9%) of these known infected people were clients and care or support group members. The others were mostly family members (29.7%), friends (18.9%) or members of the community (5.4%).

Table II. Duration of HIV infection in the 44 infected respondents

Duration (years)	*N*	%
0 - 5	31	70.5
6 - 10	11	25.0
11 - 15	1	2.3
16+	1	2.3

About 1 in 4 respondents (26.2%) lived alone and 62.2% of the respondents were responsible for their own decisions concerning food and nutrition. Those who had assistance with nutrition matters received such support mostly from their mothers, but also spouses and other family members. In a few cases the support was forthcoming from other caregivers and support group members or workers.

Responses to the questionnaire (Table III)

After receiving the Guidelines 77.5% of the sample had up to 1 week (mean 7.1 days, SD 9.25) to familiarise themselves with it. Fewer respondents (12.6%) had up to 2 weeks and 1 in 10 respondents (10%) had more than 14 days, and up to 2 months in 1 particular case. Advance delivery of the Guidelines allowed 45.3% of the respondents the opportunity to apply some of the aspects referred to in the Guidelines. No trend could be identified from the aspects that the respondents reported to have practised or applied and each one was mentioned only once. Many of these did not relate directly to nutrition, but included other lifestyle issues such as relaxation, rest, smoking and exercise. Most people (67.9%) reported that at one stage or another they had received some information regarding nutrition for people living with HIV/AIDS before reading the Guidelines.

Table III. Responses to the questionnaire

Response	Reported (%)
Good to excellent understanding of English	73.7
Easy to very easy reading of the Guidelines	81.3
Good to excellent understanding of the Guidelines	79.5
Positive contribution to nutrition knowledge	88.5
Usefulness and feasibility of the Guidelines	97.3
Decreased anxiety around nutrition issues	65.8
Contribution to simplification of personal food choices	83.1
Contribution to self-care	76.0
Contribution to caring for others	77.0

When asked to identify the most important messages that they had learned from the Guidelines, the respondents reported a huge variety of diverse topics. Most topics were mentioned only once but the selection of foods for a healthy diet was mentioned most repeatedly (21 times), the need to avoid alcohol 7 times and advice on breast-feeding in HIV-infected mothers 3 times. No other clear pattern emerged.

Responses to the individual questions across the sample revealed a strong leaning (73.7%) towards good to excellent understanding of English, which enabled the respondents to read the document easily to very easily in 81.3% of cases. The majority of respondents (79.5%) understood the Guidelines well to excellently and 88.5% reported that it contributed positively to their knowledge of nutrition for people with HIV/AIDS. The suggestions made in the Guidelines were generally (89.8%) found to be useful and feasible (97.3%).

In 83.1% of cases the Guidelines were felt to have made a contribution to making food choices simpler.

Seventy-six per cent of the respondents felt they were better able to care for themselves after reading the Guidelines and 77% found that the Guidelines could help them to care better for other people with HIV/AIDS. Many respondents (55.7%) reported being somewhat worried about their nutrition before reading the Guidelines, but 65.8% of the respondents reported that this situation improved after reading the Guidelines.

Data for the group that claimed a good understanding of English were compared with data for those who said their English was poor. The only significant differences that became apparent were the responses to the level of difficulty in reading the nutrition Guidelines ($p = 0.000$), the degree of understanding of the Guidelines ($p = 0.003$), the degree to which the Guidelines contributed to the respondents' knowledge on nutrition for people living with HIV/AIDS ($p = 0.04$) and the degree of usefulness of the suggestions made in the Guidelines ($p = 0.03$).

When comparing the HIV-positive respondents with those not infected with the virus, the HIV-positive respondents showed a significantly lower level of understanding of English. Although there was no difference between these groups in terms of school education, the uninfected group had a significantly higher ($p = 0.04$) level of post-school training. This difference did not seem to have any impact on the individual responses, where no association was found with HIV status.

No significant association was found between the younger (< 35 years) and older (> 35 years) respondents for any of the

responses. When comparing responses from male and female respondents, the only meaningful association ($p = 0.01$) to be found was between females and receiving nutrition advice before reading the Guidelines. When analysing the responses to the questionnaire it was not considered feasible to investigate possible differences between urban and rural settings because an overwhelming majority of the respondents (83.5%) resided in an urban environment. This disproportionate sample distribution was bound to skew the results.

Discussion

The test phase relied heavily on the goodwill of would-be volunteer respondents and co-operating organisations in the provinces. As a limiting factor, the process coincided with the height of an international controversy brought on by the view of political leaders that HIV infection is not the cause of AIDS. It is possible that resistance and defensiveness on the part of those living with the virus, as well as HIV/AIDS support organisations, might very well have existed at the time and certainly may have affected the willingness of people to co-operate in what was essentially a government project. Furthermore, social stigmatisation surrounding the virus, fear of incidental disclosure and concern about confidentiality could have seriously hampered the nature of the voluntary process.

It is realised that a voluntary process can only approximate demographic representation of the national population. Competing for volunteers with pharmaceutical companies running drug trials on people living with HIV/AIDS for substantial compensation could have skewed the sample, or volunteer fatigue and generalisation with organised resistance to research by multinational pharmaceutical companies could also have played a role. The abovementioned factors could have contributed to the sample size being smaller than expected.

The demographic data clearly show that a wide cross-section of the South African population was included in the test phase sample. The ethnic distribution approximates the racial demographics of the country and all age groups are represented, with the sexually active age group in the majority. People living with HIV/AIDS were found mainly in this group. In contrast to the first and second circulation of earlier drafts of the Guidelines among health professionals in the provinces, the test phase intentionally focused exclusively on lay respondents.

Because the Guidelines were produced in English only it was important that all official languages be represented. The responses indicated a high level of understanding of English and of the Guidelines across all languages and all education levels. This result is, however, belied by the wide variety of nonspecific responses to the open-ended questions, which seems to indicate that respondents had difficulty in reflecting the important message, which in turn could indicate a level of understanding lower than that reported by the respondents. Although the Guidelines supplied respondents with a large number of diverse messages, the selection of foods for a healthy diet with food-based dietary guidelines appears to have been the most commonly learned aspect.

The response showed a clear understanding of the Guidelines and their user-friendliness. The only meaningful difference pertained to the level of English comprehension. This is a rather predictable difference and was expected. Had the response not been so overwhelmingly positive with regard to understanding the Guidelines, this would have been a matter of concern. As things now stand it points towards the need for further development of material or training to reach those with a poor understanding of English rather than blanket translation of the complete Guidelines. It is also not at all clear that it is purely a language issue, because language ability is linked to general level of education.

More than half the respondents in the test phase were HIV-positive. Since the Guidelines set out to reach people living with HIV/AIDS directly, their responses are considered of utmost importance. The responses of the HIV-positive subset indicate the user-friendliness and hands-on practicability of the Guidelines for this group. These two aspects were of particular concern to people living alone. The fact that the latter group constituted around one-fourth of the sample points to the applicability of these aspects to the direct end-users. The fact that most people who did not live alone also reported independent nutrition decisions contributes further to the validity of this aspect. Those who were not infected with the virus were closely involved with the support of people living with HIV/AIDS and their responses indicate the usefulness and support that these Guidelines supply in their role as carers. Even though the HIV-positive subset had a lower post-school education level, and reported a poorer understanding of English, their responses were no different from the uninfected group which comprised mostly support group workers. This indicates that the Guidelines are, as intended, equally appropriate to both groups.

An urban-rural analysis was unfortunately not statistically feasible and no conclusion can be made regarding the relevance of the Guidelines to the deep rural situation. Although some respondents claimed to be living in rural areas they were in a small minority and no inferences are possible from their responses.

Conclusion and recommendations

The project plan envisaged a final product that would reach as large and representative a section of the population as possible, and particularly that it would not be exclusive to health professionals and that it should reach across all education

levels. The results of the test phase among a lay sample clearly show that this objective was achieved. The Guidelines were further intended as a manual not only for people living with HIV/AIDS, but also for people caring for or supporting them. The nearly 50/50 distribution of the sample size was therefore particularly appropriate in this context and together with the overwhelmingly positive responses to the user-friendliness and practicality of the Guidelines, indicates that the Guidelines are relevant to both groups.

The clear difference in the response with regard to the understanding of English indicates the need for further work in different languages. The production of additional or complementary material and/or training in various regional languages was suggested (a tender for the development of such materials was issued in August 2001). Some respondents voiced their need for informal nutrition education in the context of HIV/AIDS and nutrition, and support group workers voiced a need for the inclusion of nutrition in the training of lay HIV/AIDS counsellors. The development of a nutrition cadre in the field of HIV/AIDS care needs investigation on a regional basis.

It was hoped that the responses to the open-ended questions would indicate the most often-learned messages from the Guidelines. The lack of any clear indication here is probably a reflection not only of the comprehensiveness of the document but also of the complexity surrounding nutrition messages in general. It is a further indication for complementary material (e.g. pamphlets or posters) to highlight the important messages in a simple and uncluttered way.

Food-based dietary advice was the most often-learned message in the Guidelines and it is strongly recommended that the National Food-Based Dietary Guidelines be integrated with these South African Nutrition Guidelines for People Living with HIV/AIDS. The graphic representation of the food-based dietary advice was not included in the brief of the tender and is currently being developed by other workers.

Respondents and representatives of the participating HIV/AIDS agencies in the provinces indicated an urgent need for a publication of this nature and a network of organisations was developed to facilitate the distribution of the Guidelines. The Guidelines will require constant updating and should at best be incorporated in the integrated national HIV/AIDS programme.

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You can obtain 3 CPD points for reading the article: "**Development and testing of the South African national guidelines on nutrition for people living with HIV/AIDS"** and answering the accompanying questions.

This article has been accredited for CPD points for dietitians. (Ref number: 03/3/006/12)

HOW TO EARN YOUR CPD POINTS

1. Check your name and HPCSA number.
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3. Indicate your answers to the questions by coloring the appropriate block(s) in the cut-out section at the end of this questionnaire.
4. You will earn 3 CPD points if you answer more than 75% of the questions correctly. If you score between 60-75% 2 points will be allocated. A score of less than 60% will not earn you any CPD points.
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6. Send the cut-out answer form **by mail**, NOT BY FAX to: SASPEN Secretariat, SAJCN CPD activity **No 18**, c/o Department of Human Nutrition, PO Box 19063, Tygerberg, 7505 to ***reach the office not later than 30 April 2003***. Answer sheets received after this date will not be processed.

PLEASE ANSWER ALL THE QUESTIONS

(There is only ONE correct answer per question.)

1. Weight loss is a diagnostic criterion for HIV/AIDS
   [a] true
   [b] false

2. The malnutrition associated with HIV/AIDS has a multifactorial pathogenesis
   [a] true
   [b] false

3. In HIV/AIDS, loss of lean body mass is not associated with mortality
   [a] true
   [b] false

4. Nutrition intervention for HIV/AIDS has been shown to be effective
   [a] true
   [b] false

5. The SA Guidelines on Nutrition for People Living with TB, HIV/AIDS and other Debilitating Diseases address the nutrition of children with HIV/AIDS, but do not include advice on infant feeding options for HIV+ mothers
   [a] true
   [b] false

6. The test phase evaluated the nutritional knowledge of the respondents
   [a] true
   [b] false

7. The test phase was implemented in all 9 provinces
   [a] true
   [b] false

8. The subjects represented all of the 11 official languages of South Africa
   [a] true
   [b] false

9. The majority of the subjects were from an urban environment
   [a] true
   [b] false

10. Some of the respondents had been living with the virus for more than 15 years
    [a] true
    [b] false

11. The most valued message reported by the subjects pertained to food selection advice according to the food-based dietary guide lines
    [a] true
    [b] false

12. There were no differences between the responses of male and female subjects
    [a] true
    [b] false

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Please color the appropriate block for each question

(e.g. if the answer to question 1 is a: 1) a ■ b

1) [a] [b]	2) [a] [b]	3) [a] [b]	4) [a] [b]
5) [a] [b]	6) [a] [b]	7) [a] [b]	8) [a] [b]
9) [a] [b]	10) [a] [b]	11) [a] [b]	12) [a] [b]