Doi: 10.11606/issn.2317-0190.v15i1a102908

ORIGINAL ARTICLE

The International Classification of Functioning, Disability and Health and AIDS: a core set proposal

A Classificação Internacional de Funcionalidade, Incapacidade e Saúde e a Aids: uma proposta de core set

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ABSTRACT

The advent of the highly active antiretroviral therapy (HAART) altered the natural history of AIDS, decreasing its mortality and the incidence of opportunistic diseases as well as increasing the life expectation of people living with AIDS. As a chronic disease, other issues started to be relevant and among them, treatment adherence, its adverse effects and the quality of life of people undergoing treatment. The International Classification of Functioning, Disability and Health (ICF) constitutes an adequate tool to identify the characteristics of functionality, the environment and personal conditions that interfere with quality of life. Tools for its application, called core sets, have been developed for several health conditions. Aiming at proposing a core set for AIDS, two preliminary steps of the proposed model were developed for the construction of these tools. The first phase, which consisted of a systematic review, searched in MEDLINE for articles that included the key words HAART and quality of life, published in English, from 200 to 2004. A total of 31 studies were selected that resulted in 87 concepts, 66 of which could be identified as ICF categories. These comprised the questions of the interview applied to 42 volunteers, who were patients at a Reference Center for STDs and AIDS in Sao Paulo, Brazil. Among the conditions more frequently associated with the treatment are changes in body image, the consequence of lipodystrophy, pointed out in 84% of the studies and 93% of the interviews. Alterations in digestive functions, intimate relationships and sexual function were important conditions identified in the study. The two phases defined 40 ICF categories as a preliminary core set proposal for AIDS patients.

KEYWORDS

International Classification of Functioning, Disability and Health, Acquired Immunodeficiency Syndrome, quality of life

RESUMO

O advento da terapia anti-retroviral de alta potência (HAART) alterou a história natural da aids, diminuindo sua mortalidade e a incidência de doenças oportunistas e aumentando a esperança de vida das pessoas vivendo com aids.Como uma doença crônica, outras questões passam a ser relevantes, entre elas a adesão ao tratamento, seus efeitos adversos e a qualidade de vida das pessoas nessa condição. A CIF constitui um instrumento adequado para identificar as características da funcionalidade, do ambiente e condições pessoais que interferem na qualidade de vida. Instrumentos para a sua aplicação, core sets, têm sido desenvolvidos para várias condições de saúde. Com o objetivo de propor um core set para aids, foram desenvolvidas duas etapas preliminares do modelo proposto para a construção desses instrumentos. A primeira etapa, de revisão sistemática buscou no MEDLINE artigos com descritores HAART e qualidade de vida, publicados em inglês, de 2000 a 2004. Foram selecionados 31 estudos que resultou em 87 conceitos dos quais 66 puderam ser identificados como categorias da CIF. Estas formaram as perguntas da entrevista aplicada em 42 voluntários, pacientes de um centro de referência para DST e Aids de São Paulo. Entre as condições mais freqüentemente associadas ao tratamento, estão às mudanças na imagem corporal, conseqüência da lipodistrofia, apontada em 84% dos estudos e em 93% das entrevistas. Alterações das funções digestivas, das relações íntimas, e das funções sexuais foram condições importantes identificadas no estudo. As duas etapas definiram 40 categorias da CIF como proposta preliminar de um core set para pacientes com aids.

PALAVRAS-CHAVE

Classificação Internacional de Funcionalidades, Incapacidades e Saúde, Síndrome de Imunodeficiência Adquirida, qualidade de vida

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Received on February 18, 2008; accepted on March 03, 2008.

INTRODUCTION

The natural history of the acquired immunodeficiency syndrome (AIDS) underwent a significant change after the introduction of the Highly Active Antiretroviral Therapy, or HAART, when it stopped being a terminal disease of rapid progression and elevated mortality and became a chronic disease.

In Brazil, the mortality by AIDS went from 9.7 per 100,000 inhabitants in 1995 to 6.0 per 100,000 in 2005, demonstrating the success of the government's policy of free and general distribution of AIDS medications, adopted since 1996.[1] A total of 184,252 individuals are being currently treated in the country, which corresponds to 94.8% of those with indication to receive the antiretroviral therapy.[2]

In spite of this picture, the impact of the infection is still important, considering the fact that it involves physical, psychological and social aspects. Additionally, some adverse events of the therapy are very prevalent, such as nausea, anorexia, sexual dysfunction, insomnia and lipodystrophy, among others. The presence and intensity of these conditions impair the quality of life of people, in addition to interfering with treatment adherence.[3,4]

The International Classification of Functioning, Disability and Health (ICF) constitutes an adequate tool to identify the conditions of functionality and the environment, as well as the personal characteristics that interfere with quality of life. In addition to standardizing the language related to disability, helping the communication and information exchange, it allows the approach of different perspectives to adapt the attention conditions to the patients' needs.[5]

Hwang & Nochajski,[6] in a review of the American literature on the use of the ICF in AIDS, suggested that the classification can be useful to identify the nature and magnitude of the social, clinical and personal aspects, as well as to identify the health attention needs, adapt the intervention programs and establish policies for people living with HIV and AIDS. Forms, denominated Core sets, are being developed with the objective of adapting the use of the ICF in several health conditions (Core set Development Project, available at http://www.icf-research-branch.org/research/reaserchprojects.htm).

OBJECTIVE

The objective of this study is to develop a core set directed at AIDS, after the introduction of the HAART.

METHODS

Based on the model of core set construction proposed by Stucki and cols.,[7] the present study developed two preliminary phases: the systematic review of the literature and collection of empiric data through an interview with the patients.

The first part of this study, the systematic review of the literature, was based on studies published in the English language at PUBMED/MEDLINE, between January 2000 and December 2004, using the following key words for the search: quality of life and HAART.

These key words were chosen to identify studies of which focus was to associate the treatment with the determinants of the patient's life status. As pointed out by Seidl & Zannon[8], the information about quality of life has been used as an indicator to evaluate certain treatments, the physical and psychosocial impact of the disease, in addition to aspects related to the adaptation of the patient to his or her new condition.

The period between January 2000 and December 2004 is justified, so that studies carried out after the advent of HAART could be selected.

The systematic review allowed the identification of a set of conditions, mentioned in quality of life measurement tools, which formed the base for the construction of a checklist or core set adapted to AIDS patients.

The process followed the currently used methodology that searches, for each condition selected as important for quality of life of patients living with AIDS, the equivalent categories in the International Classification of Functioning, Disability and Health (ICF).

This set of categories formed the base for the interview applied to the individuals with HIV/AIDS that used the Ambulatory Service of the AIDS Reference and Training Center of the State Secretary of Health, in the city of Sao Paulo.

The second phase of the process consisted in interviewing individuals with AIDS undergoing treatment, to assess the most important conditions, under the patients' perspectives. The choice of the interview does not exclude the attainment of the focal group, as suggested in the model of construction of this tool and it can be carried out with patients as well as with health professionals.

The construction of the core sets has improved as they are developed and tested.[9] Thus, starting from the initially proposed model,[7] phases started to be introduced that addressed the point of view of the researcher, of the health professionals and the patients,[9] in order to guarantee the quality of the tool.

The patients waiting to be seen by their infectologists were approached in the waiting room, informed on the conditions of the study and invited to participate. After they accepted to participate, they signed the free and informed consent form and, after the consultation, they were referred to another room, where the interview was carried out.

The following inclusion criteria were used at this phase: to be HIV-positive, aged 18 to 45 years and receiving treatment with antiretroviral agents for at least six months. Pregnant women, individuals with CD4 ≤ 200 and history of hospitalization or surgery in the previous six months were exclusion criteria of the study.

All interviews were carried out by the same person in a private place and lasted an average of 25 minutes.

The interview followed a model with personal identification questions such as sex, age, date of birth and time of treatment. The conditions identified at the phase of systematic review, which formed the checklist or preliminary core set, were transformed in questions. Each question also allowed obtaining the degrees of intensity of the condition, in the format used by the ICF Checklist,

a) Projeto de desenvolvimento dos Core sets, disponível em http://www.icf-research-branch.org/research/reaserchprojects.htm

proposed by the WHO.

RESULTS

The first assessment of the publications identified 193 articles. The reading of the Abstracts was the form of selection used to identify those that involved the use of quality of life tools, totaling 31 studies, shown in Chart 1.

The reading and the analysis of all the studies allowed the identification of 143 concepts, of which 87 were mentioned in more than 10% of the studies that were considered, the value used as cutoff. From that frequency on, the condition was selected and its equivalence with the ICF categories was carried out.

Of the 87 concepts selected at the systematic review of the literature, 66 showed equivalence with ICF categories, constituting the first list of ICF categories to be associated with AIDS patients.

Table 1 presents this association and the frequency of each category and subcategory of the ICF identified in the studies that addressed the quality of life of the patients with AIDS undergoing treatment. It can be observed that, in addition to the conditions specified in the Table, 16 concepts do not show equivalence in the ICF categories and 5 consist of conditions that are not sufficiently specified.

At the interview phase, 42 patients were invited and accepted the invitation to participate in the study, of whom 28 were males and

CHART 1

Studies selected in the systematic review, according to the name of authors, year of publication, country, type of study, size of the sample and quality of life data collection tools used in the study.

AUTHOR	YEAR	Country	Type	SAMPLE	INSTRUMENTO
1.Badia et al 10	2004	Spain	Cohort	118	MOS-HIV
2. Blanch et al 11	2004	Spain	Transversal	150	PLC
3. Brechtl et al 12	2001	USA	Case-Control	70	KPRS, BPI, EFAT,
4. Burgoyne et al 13	2004	Canada	Cohort	41	MOS SF 36+ SSS
5. Burgoyne et al 14	2004	Canada	Cohort	41	MOS SF-36
6. Carbalo et al 15	2004	Spain	Transversal	235	MQoL-HIV
7. Casado et al 16	2004	Spain	Transversal	63	MOS-HIV
8. Carrieri et al 17	2003	France	Cohort	399	MOS SF 36
9. Cook et al 18	2002	USA	Cohort	1668	CES-D
10. Coplan et al 19	2004	USA	Cohort	1156	ACTG QoL 601-602
11. Corless et al 20	2004	USA	Transversal	40	MOS-HIV + Body Image Scale
12. Dorz et al 21	2003	Italy	Transversal	109	COPE +MOS-HIV
13. Gill et al 22	2002	USA	Transversal	643	MOS –HIV Parse
14. Hughes et al 23	2004	S. Africa	Case-Control	123	EURO QoL
15. Jia et al 24	2004	USA	Cohort	226	HIV Cost & Service + Coping with
16. Johnson et al 25	2002	USA	Transversal	109	HIV
17. Krentz & Gill 26	2003	Canada	Case-Control	50	MOS SF36
18. Miners et al 27	2001	UK	Transversal	128	MOS-HIV
19. Mirmirani et al 28	2002	EUA	Cohort	76	EUROQoL+MOS-HIV
20. Moyle et al 29	2004	UK	Case-Control	555	Skindex
21. Murri et al 30	2003	Italy	Cohort	809	BACRI
22. Nieuwkerk et al 31	2001	Holland	Cohort	159	MOS-HIV
23. Penedo et al 32	2003	USA	Transversal	116	MOS-HIV
24. Preau et al 33	2004	France	Cohort	360	MOS SF 12 +
25. Rabkin et al 34	2000	EUA	Cohort	173	MOS-SF 36
26. Safren et al 35	2002	EUA	Cohort	84	Endicott Enjoy+ Satisfaction
27. Saunders et al 36	2002	Canada	Cohort	56	QoL Inventory
28. Tramarin et al 37	2004	Italy	Case-Control	90	MOS SF36
29. Tramarin et al 38	2004	Italy	Case-Control	74	MOS-HIV
30. Tozzi et al 39	2004	Italy	Transversal	70	Nottingham Health Profile
31 Yen et al 40	2004	Thailand	Transversal	41	MOS-HIV
					WHOQOL + SSS

Table 1 – List of ICF categories identified by the conditions mentioned in the studies selected by the systematic review*

	BODY FUNCTIONS (b)	% (n =66)
b126	Energy and impulse functions	59
b134	Sleep functions	46
b152	Emotional functions	54
b1801	Body image	92
b265	Tactile function	21
b280	Pain sensation	18
b410	Heart functions	39
b4200	Blood pressure increase	36
b430	Hematological system functions (anemia)	28
b435	Immunological system functions	87
b455	Exercise tolerance functions	44
b4550	General physical resistance	59
b4551	Aerobic capacity	43
b4552	Fatigue	47
b515	Digestive functions	78
b5153	Food tolerance	71
b525	Defecation functions	85
b530	Weight maintenance functions	82
b535	Sensations associated to the digestive system	73
b5350	Nausea sensation	69
b540	General metabolic functions	82
b5403	Fat metabolism	78
b555	Endocrine gland functions	77
b640	Sexual functions	62
b650	Menstruation functions	48
b6500	Menstrual cycle regularity	41
b670	Sensations associated to genital and reproductive functions	39
b6700	Discomfort associated to sexual intercourse	59
b6701	Discomfort associated to the menstrual cycle	43
b840	Skin-related sensation	36
	ACTIVITIES AND PARTICIPATION (d)	%
d2401	Dealing with stress	38
d2402	Dealing with crisis	29
d530	Care related to excretion processes	14
d5301	Regularity of defecation	47
d5302	Menstrual care	44
d570	Care after one's health	16
d5701	Diet control and physical shape	53
d630	Preparing meals	18
d640	Housework tasks	12
d770	Intimate relationships	82
d7700	Romantic relationships	67
d7701	Marital relationships	45
d7702	Sexual intercourse	82
d845	Acquiring, maintaining and leaving a job	53
d8451	Keeping a job	21
d855	Non-remunerated job	16
d870	Economic independence	79
d8700	Personal economic resources	23
d8701	Public economic rights	58
d910	Community life	53
d920	Recreation and leisure	74
d9201	Practice sports	65
d930	Religion and spirituality	79
d940	Human rights	63
d950	Political life and citizenship	52
	ENVIRONMENTAL FACTORS (e)	%
e445	Individual attitudes of strangers	33
e450	Individual attitudes of health professionals	47
e455	Individual attitudes of healthcare professionals	47
e460	Social attitudes	59
e5550	Services provided by associations and organizations	43
e570	Services, systems and policies of social security	68
e5700	Services of social security	68
e575	Services, systems and policies of general social support	65
e580	Services, systems and policies of health	72
e585	Services and policies of education and training	39
e590	Services, systems and policies of work and jobs	61

*only conditions mentioned with a frequency > 10% and with ICF equivalence.

14 females; one male individual was a transsexual that identified herself with the female social sex. Twenty-five male individuals identified themselves as homosexuals.

Age varied from 29 to 52 years, with a median of 38 years. The time of medication with retrovirals varied from 1.2 to 13 years and 59% of the interviewed individuals had been using this type of therapy for 4 to 5 years.

The use of the checklist was to rescue information on the patients' perspective, more specifically on their functionality and perception of health.

The most relevant question, according to these interviewees, was the lipodystrophy syndrome and the consequent impairment of body image, pointed out by 60% of the men and 31% of the women interviewed. Additionally, the sexual functions (b640) were mentioned as being a problem by 76& of the interviewees, with sexual intercourse (b7702) being mentioned by 65% and discomfort associated with sexual intercourse (b6700) by 63%.

The emotional factors were mentioned by 61% and the decrease in the general physical strength by 56%, the same proportion that identified problems in body weight maintenance.

In addition to the questions regarding the conditions included in the interview, identified by the systematic review of the literature, the opportunity of voluntary, non-stimulated manifestation was employed. That allowed the participants to point out problems of their daily living, associated to the disease or its treatment, as well as the identification of positive conditions for the improvement of their quality of life, which had not been foreseen in the interview. All these conditions were categorized, measured and identified in the ICF categories. When this equivalence was possible, the conditions started to compose the core set for AIDS; the ones that were not identified in the classification must be evaluated and incorporated.

Among the situations positively associated to the life of individuals undergoing treatment, the outcome of maintaining a positive attitude, the fact that the life-threatening condition changed the behavior of many of the interviewees, the importance of the support received, either from Church or from non-governmental organizations, were remembered.

The conditions identified at the two phases were grouped, constituting what was denominated preliminary core set. This set, containing the 40 most relevant conditions for AIDS, is shown in Table 2.

In addition to body image, very often mentioned at the two phases of the study, in 8$% of the articles and 93% of the interviews, the list allows the comparison of the relevance of each one of them. Thus, questions regarding health conditions, such as digestive functions (b515), general metabolism (b540) and weight maintenance functions (b530), appear more often in the studies. As for the questions associated to life situations, they were the most relevant ones in the interviews, such as body image (b1801), sexual functions (d770) and intimated relationships (d7702).

These 40 conditions can be altered, once the other phases of the core set construction have been developed, as focal group, interviews with health professionals, inquiries, etc.[7,9]

Table 2
Conditions selected to compose the core set for AIDS patients undergoing treatment, according to the frequency (%) that appeared at the study phases and categories and subcategories of the ICF*.

ICF Category and subcategory	Conditions	1st phase* % N=31	2nd phase* % N=42
b134	Sleep functions	71	57
b152	Emotional functions	54	61
b1801	Body image	84	93
b410	Heart functions	41	35
b420	Blood pressure functions	32	48
b430	General physical resistance	59	56
b435	Immunological system functions	43	42
b4552	Fatigue	47	19
b515	Digestive functions	87	44
b5153	Food tolerance	71	18
b525	Defecation functions	52	29
b530	Weight maintenance functions	82	58
b535	Sensations associated to the digestive function	73	46
b5350	Sensation of nausea	69	35
b540	General metabolic functions	82	43
b5403	Fat metabolism	78	40
b555	Endocrine gland functions	77	48
b640	Sexual functions	62	76
b650	Menstrual period functions	48	31
b6500	Regularity of the menstrual cycle	41	12
b670	Sensations associated to genital and reproductive functions	39	27
b6700	Discomfort associated to sexual intercourse	59	63
b840	Skin-related sensation	56	39
d5701	Diet control and physical shape	53	52
d770	Intimate relationships	82	59
d7702	Sexual intercourse	82	65
d845	Acquiring, maintaining and leaving a job	53	12
d870	Economical independence	79	44
d920	Recreation and leisure	74	16
d9201	Practicing sports	65	51
d930	Religion and spirituality	79	54
d950	Political life and citizenship	52	31
d999	Community, social and civic life, non-specialized	52	27
e445	Individual attitudes of strangers	33	22
e460	Social attitudes	59	34
e5550	Services provided by associations and organizations	43	26
e570	Services, systems and policies of social security	68	43
e575	Services, systems and policies of general social support	65	32
e580	Services, systems and policies of health	72	22
e590	Services, systems and policies of work	61	38

* The first phase of the study was the systematic review of the literature and the second refers to the interviews with the patients.

DISCUSSION

Among the 31 selected studies, the majority, a total of 12, was carried out in the United States, 7 in Italy, 4 in Canada and 4 in Spain. Most of them, or 14 studies, consist of cohort studies, eleven are transversal and 6 are case-control studies.

The cohort studies pointed out the metabolic and cardiovascular disorders, contributing to establish a natural history of the treatment of the disease, whereas the transversal ones were useful in the identification of domains and categories that were relevant for the quality of life in this group.

At the evaluation of the benefits of the immunological restoration in opposition to the adverse events of the therapy, the high frequency of the emergence of the subcategory b1801, body image (92%), is noteworthy. As the main condition associated to the lipodystrophy syndrome, the negative body image constitutes an important barrier to treatment adherence.

The alterations in body fat redistribution usually appear between 10 to 18 months after the start of the treatment, manifesting as loss of adipose tissue in the face, gluteus muscles and upper limbs, together with the increase of fat in the abdominal region, nape of the neck and breasts. This situation was pointed out with a high frequency in these studies and was perceived first by the patients, later being demonstrated laboratorially and anthropometrically.

In opposition to these adverse events, however, the literature calls the attention to the positive aspects of the therapy, such as self-motivation in the presence of a longer survival and the medical and specialized community support groups.

One of the investigations on quality of life after the introduction of the antiretroviral therapy, developed by Jelsma and cols.41 in South Africa, showed a significant improvement, mainly regarding self-care, in daily activities, in pain and discomfort decrease, as well as in anxiety and depression, after one year of treatment.

Some limitations must be mentioned for the adequate assessment of the results obtained. At the first phase of work, the study selection was restricted to the MEDLINE database. Additionally, only articles published in the English language were selected, preventing conditions that were characteristic of other cultures from being considered.

The methodology of construction of the core sets has been broadly used; however, some of its phases have been modified to adequately fit the type of condition studied.[9] For the study of the conditions related to the life of AIDS patients, we chose to sue interviews to get to know the group's perspective.

At the second phase, one must consider the voluntary participation and the fact that the interviewees were patients at a reference service. The studied group does not represent the totality of individuals treated at this service, and to an even lower extension, the population living with AIDS in the city of Sao Paulo. Therefore, to this group of conditions, others can be added, the result of the development of other phases to create the core sets, as mentioned before. Additionally, the use of this set of ICF categories must be

tested in other populations.

For this reason, the conditions presented as part of a core set for AIDS must e seen carefully, as they include situations pointed out by a special group of people.

The analysis aimed at identifying the most relevant questions related to the quality of life of AIDS patients undergoing treatment, such as the importance of body image. However, several situations were mentioned by the interviewees for which no equivalence was found at the ICF, or their level of detailing showed to be inadequate.

It is also important to consider that, even the body image category (b1801), included as an item of category b180, personal experience and time functions, does not reflect the group of functional alterations of the lipodystrophy syndrome.

The fear that the body image, compromised by the treatment, will stigmatize the person as sick individual and the outcome of this situation, are difficult to identify as a classification category.

Reactions of exclusion, shame, prejudice and fear are frequent conditions in the life of individuals with HIV or AIDS and they usually present as a group, which is difficult to be transformed into an ICF unit.

However, it is worth mentioning that the more frequently used quality of life tools were not, until very recently, apt to deal with the era of antiretrovirals.

Additionally, the main conditions pointed out in this analysis and not identified as ICF categories, are mainly derived from the impact of this treatment on the patients' body image, such as the shame over one's body, the loss of self-esteem, inhibition and fear of disclosing the body, among others.

CONCLUSION

The preliminary phases developed in this study showed that a core set for patients with AIDS can be useful to follow the functional changes caused by the introduction of the antiretroviral therapy, to identify the main problems experienced by this group, to direct the actions for prevention of complications and consequently, to improve the quality of life.

A core set to be applied to AIDS patients must include the most important questions for the individuals living with the disease, constituting a minimum set of ICF categories that address the amplest aspects. Furthermore, in order to be adequate, it must contemplate different social and cultural groups.

As it refers to a dynamic epidemic, it must be broadly tested and periodically reviewed.

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