

MINISTRY OF HEALTH OF BRAZIL



Recommendations for
Integral Care
for Adolescents
and Young Adults
Living with HIV/AIDS

Brasília — DF
2013

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Foreword

The AIDS epidemic among adolescents and young adults has remained a challenge for health professionals over the last 30 years, both in the field of preventing new cases and in the field of treatment, especially owing to the tendency of increased HIV infection prevalence in young people.

Appropriate attention to this age group comprised of adolescents and young adults, which the World Health Organization and the Ministry of Health delimits as being aged 10 to 19 and 15 to 24, respectively, must take into consideration specific sociocultural and demographic characteristics and needs.

With the aim of introducing health professionals to aspects of integral care which promote quality of life and quality service provision, this document addresses themes relating to the epidemiological aspects of HIV infection in this population group, considerations regarding adolescence, diagnosis disclosure, treatment adherence, sexual health and reproductive health, nutritional assessment and transition.

The themes selected for this document were chosen based on discussions with representatives of the National Network of Young People Living with HIV and AIDS, professionals and researchers. Its contents were prepared based on scientific evidence and experiences proposed by a Working Group comprised of professionals and researchers who work with this age group.

We hope that this document will qualify health professional activities and assist with an integral understanding of adolescents and young adults living with HIV and AIDS.

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Chapter 1

Epidemiological aspects of STDs and HIV/AIDS in adolescents and young adults

Adolescence is a stage in life characterized by big biological, psychological and social transformations. Adolescent sexual behaviour is a normal stage in development¹ and when adolescents start being sexually active they can be vulnerable to sexually transmitted diseases (STD) and AIDS.

Factors that place adolescents and young adults at greater risk of STDs include becoming sexually active at an early age, incorrect or inconsistent condom use and experimenting with alcohol and other drugs².

1.1 Brazilian Population Knowledge, Attitudes and Practices Study (KAP Study). Principal results for youth (15-24 years old)

The Brazilian Population Knowledge, Attitudes and Practices Study (KAP Study) is a household survey of a significant sample of the Brazilian population aged over 15 in all the country's regions applied every three years by the Ministry of Health³.

The objectives of the survey were to collect data to build monitoring indicators for the STD/AIDS epidemic with regard to sexually transmitted disease prevention and control measures, as well as to analyse knowledge about HIV and other STD transmission and monitor situations of vulnerability relating to HIV infection.

The KAP Study included 8,000 individuals aged 15 to 64, including 2,485 young people aged 15 to 24. The sample was stratified according to the country's five macro regions (North, North-East, South-East, South and Midwest) and urban/rural situation. A modular questionnaire was used regarding sociodemographic conditions; knowledge about HIV and other STD transmission; STD prevention and control; HIV testing; illicit drug use and sexual practices.

1.1.1 Knowledge of HIV infection transmission routes and prevention methods

Only 51.7% of the 2,485 young people demonstrated correct knowledge of HIV transmission routes, the lowest percentage among the age groups studied. Some 97% know they can get infected having sexual intercourse without using condoms.

1.1.2 Sexually transmitted disease prevention and control

Young women account for the highest percentage (17.3%) of sexually active women who have never had a gynaecological examination. 3.3% of young men have had urethral discharge. 67.2% of males and 78.8% of females who are sexually active, aged between 15 and 24 and have a prior history of STDs, sought treatment the last time they had one of these problems, principally those better educated (men), belonging to social class A/B and living in urban areas (women).

1.1.3 Sexual practices related to HIV transmission

Certain sexual practices are considered to be associated with greater risk of HIV transmission and were measured by the KAP study. Among young people, 36.9% of males and 17% of females (35% when considering both sexes) reported having started their sex lives early, i.e. before they were fifteen. 77.6% of young people reported having had sexual activity at some time in their lives.

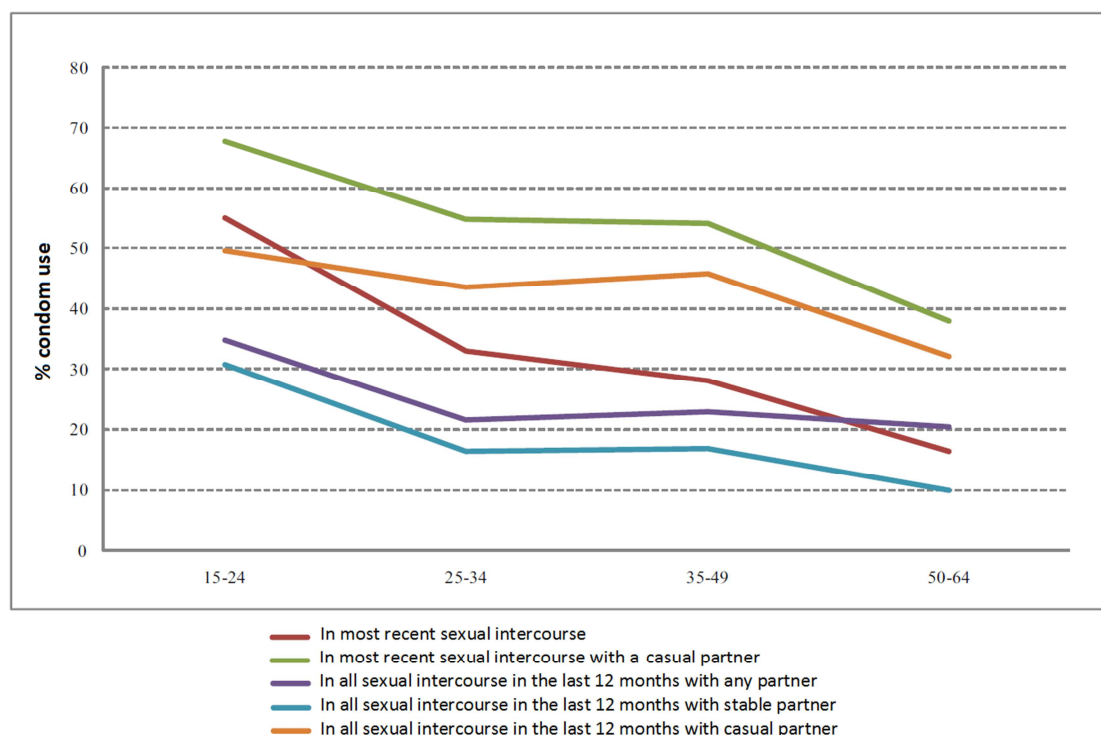
Having sex with someone of the same gender is more frequent among young people when compared to other age groups. A rate of 8.7% was reported. A higher frequency of multiple sex partners (casual sex more than five times) in the last twelve months is found among young people (14.6%). Young people also account for the highest proportion of those who have had casual sex partners in the last

twelve months (43.5%) and who have had sexual intercourse with people they met on the Internet (6.5%).

Almost 61% of the sexually active population aged 15 to 24 stated having used a condom the first time they had sex. Condom use in most recent sexual intercourse, regardless of the kind of sex partner, was 55% among young people, reaching almost 68% when the most recent partner was casual. Almost 35% of young people reported regular condom use regardless of the kind of sex partner.

Condom use frequency among young people is higher than among older age groups in all the parameters assessed (Graph 1).

Graph 1: Percentage (%) of individuals aged 16 to 64, by condom use indicators and age group. Brazil, 2008.



Source: Brazilian Population Knowledge, Attitudes and Practices Study (KAP Study), 2008.

Approximately 35% of young people with incomplete elementary education stated having used a condom the first time they had sex, compared to 65.8% with complete elementary education. Condom use among young people who stated that they did not live with a partner was consistently higher than among those in the same age group living with a partner. 50% of the latter reported using a condom the first time they had sex, compared to 65.3% who did not live with a partner.

68.2% of individuals aged 15 to 24 belonging to social class A/B stated having used a condom the first time they had sex, compared to 52.4% in class D/E.

In terms of the association between condom use and region of residence, as shown in Table 1, statistically significant differences were only observed in the indicator on condom use in individuals aged 15 to 24 having sex for the first time. The proportion was around 69% among those resident in the Southern Region, 56.1% in the Northern Region and 52.1% in the North-East Region.

Table 1: Percentage (%) of individuals aged 15 to 24, by condom use indicator and region of residence. Brazil, 2008.

Population	Condom use	N	NE	SE	S	MW	Total
Young (15-24 years) sexually active population	First sexual intercourse	56.1	52.1	64.6	69.1	64.4	60.9

Source: Brazilian Population Knowledge, Attitudes and Practices Study (KAP Study), 2008.

1.1.4 Testing to identify HIV infection

Only 30.1% of sexually active young people had tested for HIV at least once in their lives: 16.1% males and 45.7% females. Many people living with HIV are unaware of their serological status. Effective strategies for promoting increased access to HIV counselling and testing are fundamental for early diagnosis, reducing transmission and improving this population's quality of life.

1.1.5 Drug use

In recent years there has been a significant change in illicit drug consumption in Brazil. This change may have resulted in a relative reduction in AIDS cases in the exposure to injecting drugs category as can be seen in the epidemic's trends in recent years⁴. However, reported consumption of amphetamines and ecstasy among youth and vulnerable population groups continues to increase. The use of crack has increased among the poorest populations and there are signs that it is also present in the lower middle class⁵.

Studies performed in Brazil provide evidence of greater vulnerability to HIV among drug users when compared to the general population, principally owing to more frequent risk behaviours among alcohol and illicit drug users. Knowledge of transmission routes, perception of risk, attitudes and practices of individuals and groups in relation to sexual behaviour are key elements for defining individual vulnerability⁶.

Table 2 shows drug use frequency in the young population assessed in the 2008 KAP study.

Table 2: Percentage (%) of individuals aged 15 to 24 according to drug use. Brazil, 2008.

Drugs	Use	15 – 24 years (%)
Alcohol	At some time in their lives	79.5
	Current	37.5
Cigarette	At some time in their lives	42.9
	Current	18.7
Cannabis	At some time in their lives	16.2
	Current	4.3
Crack	At some time in their lives	2.5
	Current	0.7
Cocaine	At some time in their lives	8.6
	Current	1.6

Source: Brazilian Population Knowledge, Attitudes and Practices Study (KAP Study), 2008.

1.2 HIV infection in adolescents and young adults⁷

In Brazil, the HIV infection prevalence rate in the young population is tending to increase. According to studies with army conscripts aged 17 to 20, prevalence in this population increased from 0.09% in 2002 to 0.12% in 2007⁸.

Table 3 shows the number of AIDS cases in adolescents and young adults by age group and sex, per year of diagnosis.

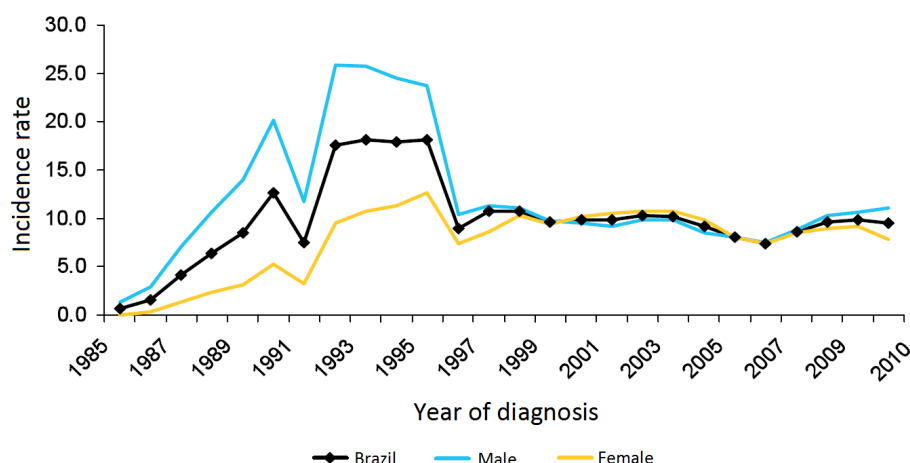
Table 3: AIDS cases (number and incidence rate per 100,000 inhab.) by age group and sex, notified on the SINAN system, reported on the SIM system and recorded on the SISCEL/SICLOM system, per year of diagnosis. Brazil, 2005-2010⁷.

Year	2005		2006		2007		2008		2009		2010	
Age group	rate	no.	rate	no.	rate	no.	rate	no.	rate	no.	rate	no.
Male												
13-19	1.3	208	1.3	225	1.8	265	2.0	296	2.0	300	1.9	296
20-24	13.1	1317	11.2	1200	11.9	1324	13.3	1531	13.6	1570	14.3	1641
Female												
13-19	2.1	333	2.2	361	2.4	358	2.7	410	2.7	410	2.1	349
20-24	11.0	1207	9.2	1049	10.1	1157	9.7	1159	10.0	1190	8.0	1009

Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

With regard to new AIDS cases among young people aged 15 to 24, it can be seen that in the year 2010 Brazil had an incidence rate of 9.5/100,000 inhabitants. At the beginning of the epidemic, the AIDS case incidence rate in young people aged 15 to 24 increased progressively, reaching a peak between 1993 and 1995. From 1996 onwards the incidence rate has remained stable (Graph 2).

Graph 2: AIDS incidence rate (per 100,000 inhabitants), in young people aged 15 to 24, by sex and year of diagnosis. Brazil, 1985-2010⁷.

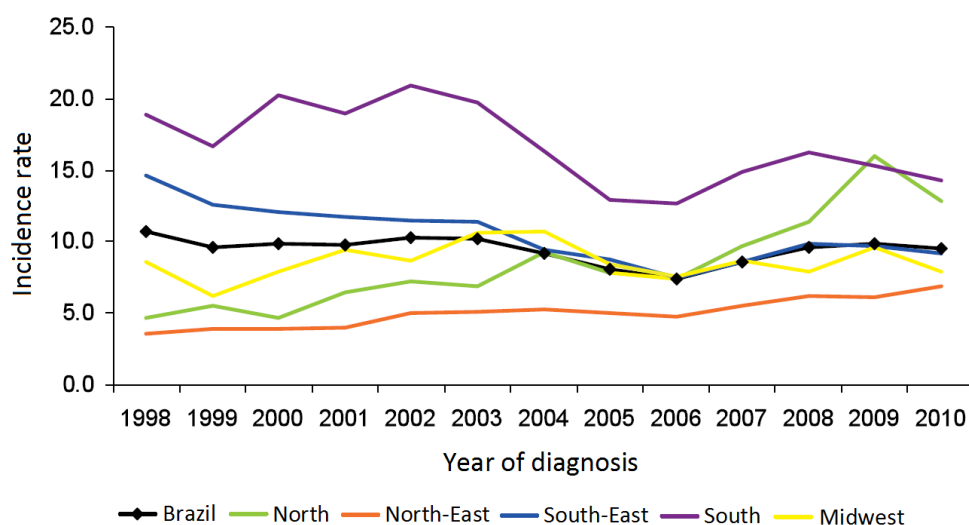


Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

When analysing the country by its regions, in the year 2010 there was an incidence rate of 14.3/100,000 inhabitants in the South, 12.8 in the North, 9.2 in the South-East, 7.9 in the Midwest and 6.9 in the North-East. Between 1998 and 2010, AIDS case incidence in young people increased in the North and North-East, decreased in the South-East and South and remained stable in the Midwest (Graph 3).

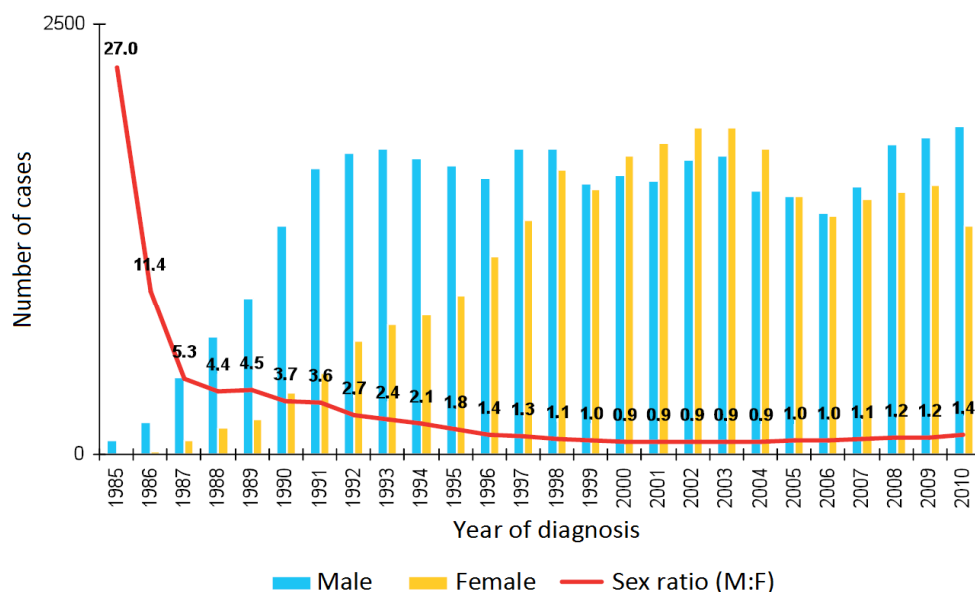
In 2010, the AIDS case incidence rate in males aged 15 to 24 was 11.1/100,000 inhabitants and 7.8 in females. With regard to the sex ratio, since the beginning of the epidemic there has been a decrease in the proportion of male and female cases in this age group. Between 1985 and 2010, the sex ratio dropped from 27 to 1.4 male AIDS cases for each female case. It is appropriate to highlight that between 2000 and 2004 the sex ratio was inverted, with 0.9 young male cases for each young female case (Graph 4).

Graph 3: AIDS incidence rate (per 100,000 inhabitants) in young people aged 15 to 24, by region of residence and year of diagnosis. Brazil, 1998-2010⁷.



Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

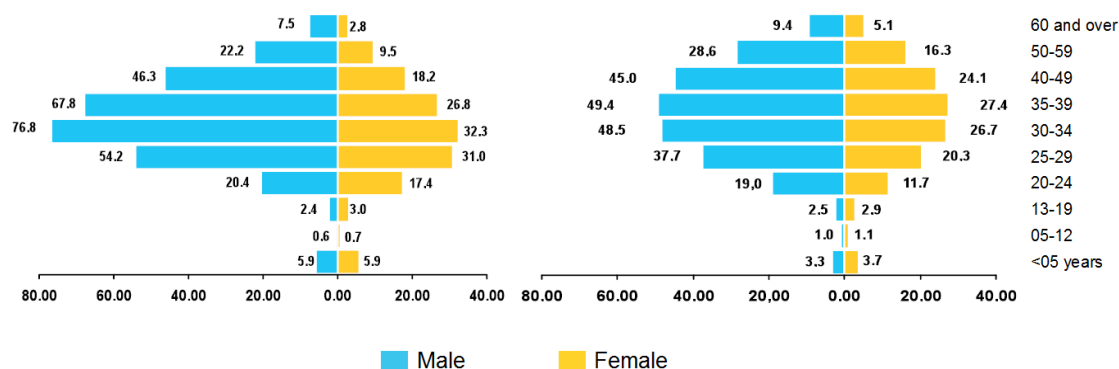
Graph 4: Number of AIDS cases in young people aged 15 to 24 and sex ration, by year of diagnosis. Brazil, 1985-2010⁷.



Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

When assessing the incidence rate by age pyramid (Graph 5), stability can be seen in the adolescent age group (13 to 19 years) and young adults (20 to 24 years), between 1998 and 2010, differently to what occurs in other age groups⁷.

Graph 5: AIDS incidence rate (per 100,000 inhab.) by age group and sex.



Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

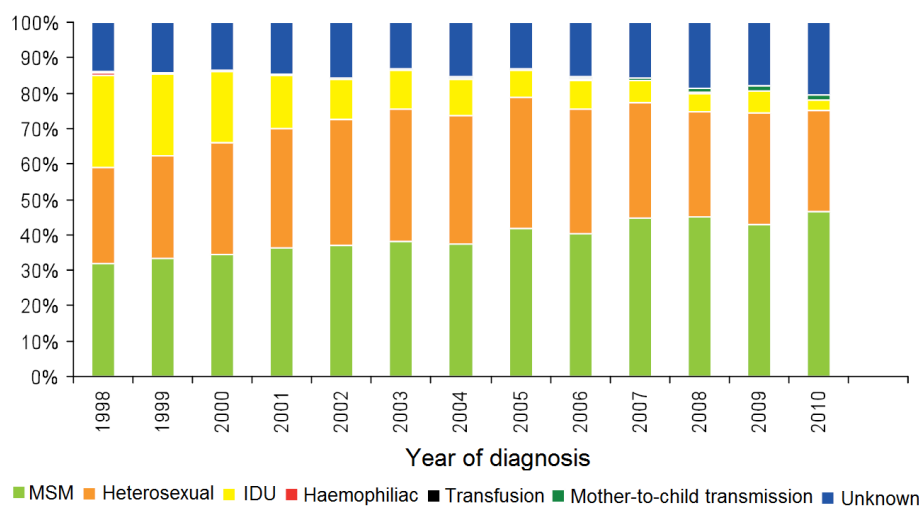
Young gay men are seen to be particularly vulnerable to HIV/AIDS. According to the tendency observed in the most recent studies with young male army conscripts aged 17 to 22, HIV infection prevalence in young MSM increased between 2002 and 2007, from 0.56% to 1.2%. It is appropriate to emphasize that the prevalence observed in MSM conscripts is higher than that observed in the total conscript population (0.09% in 2002; 0.12% in 2007)⁸.

With regard to AIDS case exposure category notified on the Health Ministry's Notifiable Disease Information System (*Sistema de Informação de Agravos de Notificação - SINAN*) among males aged 15 to 24, in the last 12 years the MSM exposure category has shown a proportional increase, from 31.8% in 1998 to 46.4% in 2010 (Graph 6).

In a study performed exclusively with homosexuals, there was 70.8% condom use the last time young MSM had sex with a casual partner. However, when assessing condom use in all sexual intercourse in the last 12 months with a casual partner this percentage dropped to 54.3%⁹.

In 2010, homosexual exposure accounted for 28.5% of young males diagnosed as having AIDS, whereas heterosexual exposure accounted for 83% of young women diagnosed in 2010.

Graph 6: Proportion of AIDS cases in males aged 15 to 24, by exposure category and year of diagnosis. Brazil, 1998-2010⁷.



Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

In Brazil, late diagnosis of mother-to-child HIV transmission cases is still a reality. In 2010, 165 (31.8%) of the 518 AIDS cases attributed to mother-to-child transmission diagnosed in the country were in adolescents aged 13 or over.

1.3 AIDS indicators in adolescents and young adults by state of residence

Table 4 shows the number of AIDS cases in young people for each state of residence, i.e. adolescents and young adults aged 15 to 24 with confirmed diagnosis (notified AIDS cases). Cases of young HIV-positive people who did not meet the criteria defining AIDS cases are not included in this table.

Table 4: AIDS cases (number and incidence rate per 100,000 inhab.) in young people aged 15 to 24 notified on the SINAN system, recorded on the SIM system and registered on the SISCEL/SICLOM system, by state and region of residence per year of diagnosis. Brazil, 2005-2011 (as at 30/06/2011)⁷.

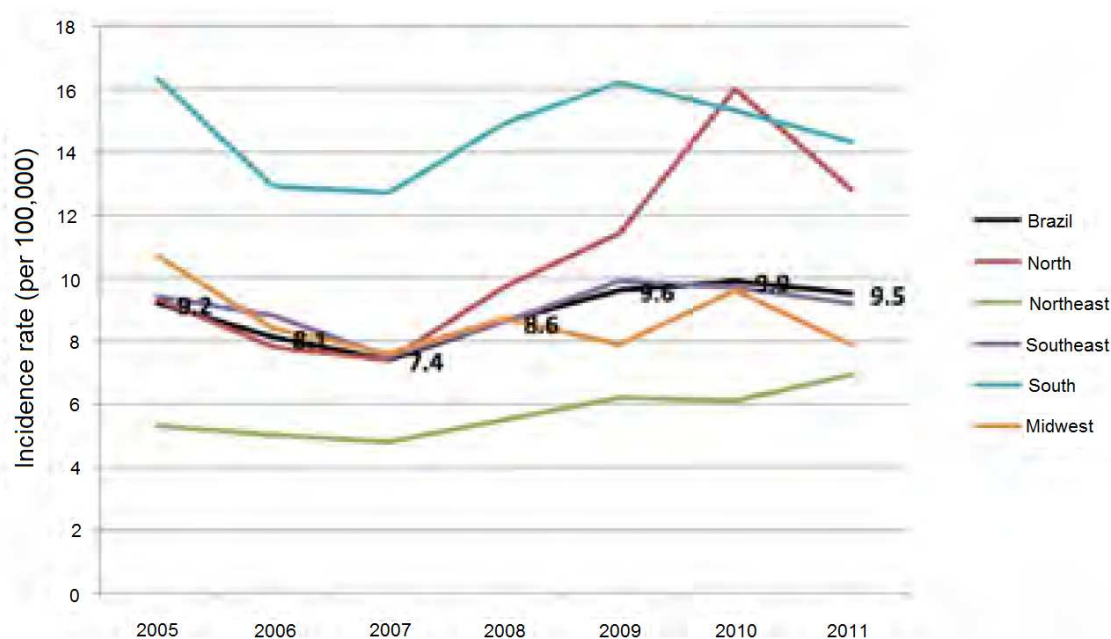
Year	2005		2006		2007		2008		2009		2010		2011	
State	rate	no.	rate	no.	rate	no.	rate	no.	rate	no.	rate	no.	rate	no.
Brazil	9.2	3006	8.1	2788	7.4	3045	8.6	3330	9.6	3409	9.9	3238	9.5	1401
North	9.3	252	7.8	243	7.4	313	9.7	356	11.4	501	16.0	410	12.8	181
Rondônia	7.6	20	6.1	26	7.8	21	6.5	19	6.3	16	5.4	26	8.5	13
Acre	3.7	7	4.7	4	2.6	9	6.2	11	7.9	3	2.2	6	4.1	2
Amazonas	14.4	103	14.3	105	14.3	108	15.2	122	17.6	188	27.0	178	25.3	86
Roraima	16.4	9	10.7	11	12.6	16	18.8	17	20.5	17	20.4	17	18.8	3
Pará	8.5	101	6.6	83	5.3	132	8.6	155	10.2	246	16.1	160	10.4	69
Amapá	10.5	5	3.8	5	3.6	17	12.5	21	16.2	12	9.2	14	9.9	3
Tocantins	3.3	7	2.5	9	3.1	10	3.5	11	4.2	19	7.3	9	3.3	5
North-East	5.3	544	5.0	529	4.8	581	5.5	654	6.2	630	6.1	699	6.9	259
Maranhão	6.7	74	5.5	87	6.3	64	4.6	86	6.3	110	8.2	100	7.5	43
Piauí	4.8	27	4.1	35	5.3	39	6.0	37	5.8	44	7.0	37	6.1	15
Ceará	6.6	87	5.3	67	4.0	90	5.3	124	7.3	120	7.1	128	7.7	49
Rio Grande do Norte	2.5	30	4.9	22	3.5	35	5.6	22	3.6	25	4.1	44	7.3	10
Paraíba	4.0	34	4.6	20	2.7	30	4.1	35	4.7	40	5.5	32	4.6	19
Pernambuco	7.5	142	8.1	129	7.3	138	8.2	131	7.8	110	6.7	150	9.2	50
Alagoas	3.8	30	4.6	34	5.2	37	6.0	48	7.8	34	5.6	36	6.0	14
Sergipe	4.2	12	2.9	19	4.4	24	5.9	28	7.1	18	4.7	18	4.5	9
Bahia	4.0	108	3.5	116	3.7	124	4.4	143	5.0	129	4.7	154	5.9	50

South-East	9.4	1336	8.8	1158	7.5	1197	8.6	1342	9.9	1304	9.7	1253	9.2	466
Minas Gerais	5.6	244	6.4	175	4.5	173	4.8	188	5.3	189	5.4	191	5.5	84
Espírito Santo	8.3	58	8.3	55	7.7	46	7.0	48	7.6	56	9.1	47	7.5	20
Rio de Janeiro	14.7	383	13.7	352	12.4	358	14.1	376	15.0	397	15.9	418	16.2	135
São Paulo	9.5	651	8.3	576	7.2	620	8.6	730	10.6	662	9.7	597	8.6	227
South	16.3	646	12.9	647	12.7	732	14.9	778	16.2	731	15.3	672	14.3	383
Paraná	11.7	175	8.9	178	9.0	211	11.1	304	16.1	257	13.6	214	11.7	119
Santa Catarina	15.9	164	14.7	144	12.7	149	13.5	130	12.0	146	13.5	130	11.7	89
Rio Grande do Sul	21.0	307	15.8	325	16.5	372	19.6	344	18.9	328	18.2	328	18.8	175
Midwest	10.7	228	8.4	210	7.6	222	8.7	200	7.9	243	9.6	204	7.9	112
Mato Grosso do Sul	11.7	23	5.1	38	8.3	34	7.7	40	9.2	38	8.8	25	5.6	15
Mato Grosso	14.0	64	1.9	38	6.4	59	10.4	59	10.4	58	10.2	56	9.8	30
Goiás	9.8	111	9.6	101	8.6	91	8.4	70	6.6	104	9.8	75	6.9	46
Distrito Federal	8.0	30	5.7	33	6.2	38	8.3	31	6.5	43	9.0	48	10.3	21

Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

The AIDS incidence rate in young people in each of the country's regions compared with the national rate is shown in Graph 7.

Graph 7: AIDS incidence rate (per 100,000 inhab.) in young people aged 15 to 24, by region of residence and year of diagnosis. Brazil, 2005-2011 (as at 30/06/2011)⁷.



Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

1.4 Pregnant adolescents and young adults

A significant percentage of HIV-infected pregnant females is found in the 15 to 19 age group. This indicates the need to address the theme of sexual and reproductive health in this population with the aim of minimizing the risk of both horizontal and vertical HIV transmission. In 2009, of the 6,289 pregnant women with HIV in Brazil, 0.8% were aged 10 to 14 and 13.7% were aged 15 to 19. In 2010, of the total of 5,666, the rates in the same age groups were 0.9% and 15%, respectively, totalling 900 pregnant adolescents with HIV⁷.

Syphilis diagnosis in pregnant adolescents is also frequent. In 2010, 160 (1.6%) of pregnant females with syphilis were aged between 10 and 14, and 2,054 (20.4%) were aged between 15 and 19⁷.

1.5 Youth AIDS mortality

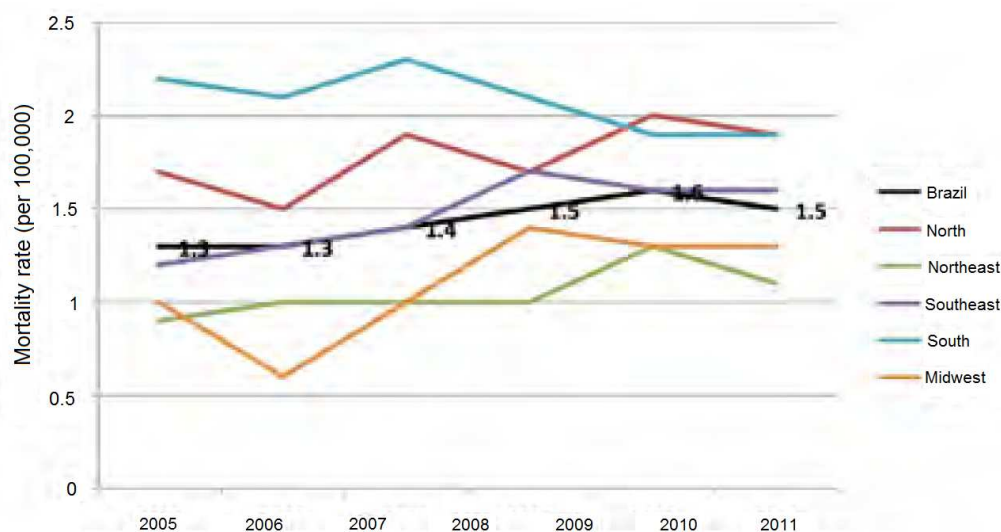
The number of deaths in young people attributed to AIDS has remained stable in recent years. Nevertheless, the Northern and Southern Regions have maintained a specific AIDS mortality rate above the national rate, in particular in the states of Amazonas, Roraima, Rio de Janeiro and Rio Grande do Sul (Table 5 and Graph 8)⁷.

Table 5: AIDS deaths (number and mortality rate per 100,000 inhab.) in young people aged 15 to 24, by state and region of residence per year of death. Brazil, 2005-2010⁷.

Year	2005		2006		2007		2008		2009		2010	
State	rate	nº	rate	nº	Rate	nº	rate	nº	rate	nº	rate	nº
Brazil	1.3	484	1.3	475	1.4	497	1.5	523	1.6	539	1.5	508
North	1.7	56	1.5	49	1.9	62	1.7	54	2.0	63	1.9	62
Rondônia	0.6	2	0.6	2	1.8	6	1.0	3	0.7	2	1.3	4
Acre	3.4	5	0.0	0	0.7	1	0	0	0.7	1	0.7	1
Amazonas	1.9	14	1.8	13	2.4	17	2.6	18	3.0	21	2.4	17
Roraima	3.6	3	3.4	3	4.7	4	4.8	4	6.0	5	2.2	2
Pará	2.0	31	2.0	31	2.0	31	1.8	28	2.2	33	2.2	34
Amapá	0.8	1	0	0	0.7	1	0	0	0	0	1.4	2
Tocantins	0.0	0	0	0	0.7	2	0.4	1	0.4	1	0.7	2
North-East	0.9	102	1.0	106	1.0	106	1.0	105	1.3	132	1.1	109
Maranhão	1.3	18	1.2	16	1.2	17	1.3	18	2.2	29	1.0	14
Piauí	0.6	4	0.5	3	0.8	5	0.5	3	0.6	4	1.2	7
Ceará	0.9	14	0.6	10	0.6	10	1.1	19	0.9	16	0.5	8
Rio Grande do Norte	0.2	1	0.2	1	0.5	3	0.3	2	1.0	6	0.7	4
Paraíba	0.8	6	0.7	5	0.3	2	0.8	6	0.5	4	0.9	6
Pernambuco	1.9	34	2.0	35	2.3	39	1.6	27	2.4	39	2.1	34
Alagoas	0.8	5	0.5	3	1.1	7	1.1	7	0.3	2	1.7	10
Sergipe	0.5	2	0.5	2	0.2	1	0.5	2	1.3	5	0.7	3
Bahia	0.6	18	1.0	31	0.8	22	0.7	21	1.0	27	0.9	23
South-East	1.2	188	1.3	194	1.4	193	1.7	228	1.6	220	1.6	217
Minas Gerais	0.6	24	1.0	39	0.7	24	0.6	21	0.8	29	1.0	35
Espírito Santo	1.1	8	1.4	10	1.2	8	2.1	13	1.3	8	1.4	9
Rio de Janeiro	2.2	62	2.1	60	3.0	76	3.1	77	3.0	75	3.2	83
São Paulo	1.2	94	1.1	85	1.2	85	1.7	117	1.6	108	1.3	90
South	2.2	111	2.1	109	2.3	111	2.1	101	1.9	91	1.9	87
Paraná	1.5	29	1.2	23	1.3	25	1.0	19	1.0	18	0.8	14
Santa Catarina	1.7	19	1.3	15	2.0	22	1.8	20	1.6	17	1.6	18
Rio Grande do Sul	3.2	63	3.6	71	3.4	64	3.4	62	3.1	56	3.1	55
Midwest	1.0	27	0.6	17	1.0	25	1.4	35	1.3	33	1.3	33
Mato Grosso do Sul	1.3	6	1.1	5	1.4	6	1.4	6	1.6	7	0.4	2
Mato Grosso	1.7	10	0.5	3	0.9	5	1.6	9	2.1	12	1.8	10
Goiás	0.8	9	0.6	7	0.9	10	1.0	11	0.8	9	1.3	14
Distrito Federal	0.4	2	0.4	2	0.9	4	1.9	9	1.0	5	1.5	7

Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

Graph 8: AIDS mortality rate (per 100,000 inhab.) in young people aged 15 to 24, by region of residence and year of death. Brazil, 2005-2010⁷.



Source: Epidemiological Bulletin: AIDS and STD, year 8, n. 1, 2011.

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Chapter 2

Living with HIV in adolescence

According to the Brazilian Statute on Children and Adolescents, adolescence covers the period from 12 to 18 years of age¹. Restricting adolescence to an age group, although it does not permit a broader understanding of the process, does make it possible to delimit a population group for which health policies can be formulated. The Ministry of Health follows the World Health Organization (WHO) definition of adolescence as being the period between 10 years and 19 years, 11 months and 29 days, and youth as being between 15 and 24 years of age. There is, therefore, an intersection between the second half of adolescence and the first years of youth².

Moreover, adolescence can be understood to be a process of 'deconstruction' and 'reconstruction' of identity, in which adolescents have to 'dismantle' their childhood world and rebuild it in their own way. Adolescents undertake a complex journey from the childhood world to the adult world, just as one day all of us undertook. As a consequence of the changes taking place in this period, family members, teachers, health professionals and others involved with adolescents may feel insecure and even resistant, thereby losing important possibilities of establishing a bond of trust with them.

An important aspect to be considered is that, although there is a psychological process underway, experiencing adolescence is also the product of the moment in history and the sociocultural environment and each individual goes through this in a singular manner. In recent decades, globalization and the emphasis on consumption has influenced changes of values, modifying people's behaviour, principally that of young people, whereby individualism and market forces are predominant. On the other hand, because they are going through a period of intense transformations, adolescents are also very critical of prevailing values and currently have great influence over youth cult in society.

Puberty, the principal biological component of adolescence, is universal. Puberty refers to the morphological and physiological changes (shape, size and function) resulting from the reactivation of the neurohormonal mechanisms of the hypothalamic-pituitary-adrenal/gonadal axis.

In girls their "look" takes on a prominent position in puberty; i.e., they signal what can be seen by others. The image of the body's transformation is related to two aspects: the quest for a socially accepted model and confirmation by their family or even their peers of the changes to their bodies. What was a child's body becomes transformed, or is transformed by what girls identify with in magazines, TV programmes, and by recognition from their families and friends: a transformation from the childhood body to the desirable body³. In boys their "voice", principally when it breaks, reveals an important process of identification. This is why boys spend a lot of time talking about their supposed conquests and romantic or sexual performance, even before having achieved them³.

The body's image is affected by the modification of its attributes (hair, breasts), by its functioning (ability to have sex, menarche, change in the voice), by the similarity with the adult body, by the importance of other people's recognition, by being able to arouse desire in others. A body which now has desires and is desirable³.

2.1 Being adolescent

Adolescence is a time of intense physical, psychological, social and cognitive transformations which progress inexorably, capable of creating many uncertainties and trepidations in adolescents and their families. It is important for health professionals to be able to facilitate the process of interlocution between adolescents and their families.

Francoise Dolto (1984 *apud* Rassial, 1999)³, considers adolescence to be the transition to adulthood, a socially accepted abnormality. According to Arminda Aberastury⁴, there are three losses adolescents have to deal with: the loss of their childhood body, the loss of their childhood parents and the loss of their childhood identity. A set of specific signs appears. They have been called the Syndrome of Normal Adolescence – and comprise:

a. Search for oneself and one's identity

Adolescents experience a certain "strangeness" of not knowing who and how they are, and go through a period of getting to recognize themselves.

b. Tendency to form groups

The peer group is a strong source of support to adolescents in building their independence from their parents and breaking away from the family nucleus in favour of their own social group. All the adolescents in the group experience the same process and feel more secure, protected and supported. To a certain extent the group represents their own identity.

c. Need to intellectualize and fantasize

The development of abstract thinking makes adolescents capable of intellectualizing, enabling reflection about themselves and about the world. Often adolescents use this mechanism or fantasies to escape from a reality that is hard to face up to.

d. Religious crises

Adolescents can oscillate between radical atheism and religious fanaticism. There is a tendency towards extremes.

e. Displacement in time

Adolescents have a particularly singular relationship with time: they can demonstrate urgency in getting organized for situations that will only take place months later, or feel that there is a lot of time in what is really just a few hours.

f. Evolution of sexuality

Experiencing sexuality in adolescence follows a path that ranges from self-eroticism in the initial stage, progressing to a stage of exploring oneself and others before finally reaching sexual intercourse itself and the integration of affection and eroticism.

g. Demanding social attitude

Adolescents view the world around them critically and want to transform it into a better place. They, who passively undergo bodily changes, want to play an active role in transforming the outside world.

h. Successive contradictions in behaviour

The quest for adult identity leads adolescents to experiment with different and often contradictory roles. Their behaviour is dominated by action and is impulsive and unpredictable, both in their outer and inner world.

i. Progressive separation from parents

Breaking away from one's parents is part of the human being's evolution towards independence and autonomy. On the other hand, this process can lead to anguish and suffering, both for parents and adolescents.

j. Constant mood swings

Adolescents live their emotions with great intensity and are capable of swinging very quickly from one extreme to another. Thus, depending on the experiences they have, there may be large mood variations in a short space of time.

Nevertheless we should remember that adolescence is a process accompanied by certain losses, such as those mentioned by Arminda Aberastury⁴, whilst also being a period of certain gains, i.e. new experimentations.

Adolescents in search of autonomy experience things for the first time, such as: their first kiss, having sex for the first time, being allowed to go out on their own with their friends, a new way of seeing the world and their family, oscillations between feelings of self-confidence and insecurity, as well as greater freedom.

There are, however, new experiences and experimentation that put them at increased risk, such as for example: experimenting with alcohol and other substances, making them more vulnerable to getting involved in traffic accidents, fights, petty crimes and difficulty in discerning attitudes of self-care (such as using condoms, adopting harm reduction measures, correct use of medication).

2.2 Being an adolescent living with HIV/AIDS

A variety of aspects need to be considered in order to ensure the most adequate care for adolescents living with HIV/AIDS.

- Not knowing their HIV status or a tacit agreement between adolescents and their parents not to talk about the subject can prolong dependence even more, delaying autonomy and self-care. This situation reveals the importance of dialogue between family members and the role of health teams in facilitating this process. (See chapter 3)
- There must be constant attempts to achieve a balance between encouraging adolescents to be independent and the need for care, especially in situations of illness, given that the body's fragility can result in carers, family members and even health teams being overprotective based on their own experiences, in addition to delaying the process of adolescents reaching maturity.
- The fantasy of not being vulnerable, proper to adolescents, may hamper understanding and acceptance of living with HIV/AIDS, often compromising adherence to treatment. Difficulty in following a treatment regimen, keeping medical appointments, having laboratory tests, principally if there are not yet any clear symptoms of the disease, is related to their magical manner of relating to time and the notion of indestructibility and cure.
- Questioning and transgressive attitudes and the quest for independence may hamper or even impede good treatment adherence. Dependence on doctors, medication and rigorous health controls is contrary to all efforts to achieve independence and autonomy, and these must always be provided in accordance with each adolescent's abilities. Depending on the stage of adolescence, concepts such as HIV, CD4 and viral load are very abstract to be well understood; young people are more concerned about and involved with the transformations to their bodies, their losses and gains⁵.
- Identification with peer groups, which is so important in this period of a person's life, can be damaged if adolescents feel or are seen as being different; heightening the feeling of loneliness and not belonging to the social group. Health teams should encourage adolescent activism and social leadership, associated with a posture of self-care and good adherence to treatment.
- Self-esteem can be undermined by the disease, by body image or by the effects of the medication taken. In some cases lipodystrophy may be accentuated, as well as a delay in weight and height gain, thus creating a childlike image of the adolescent in question, thereby contributing to cases of depression, anxiety and isolation.
- Feelings of revolt, loneliness, symptoms of anxiety and depression, which may or may not be associated with experiences of prejudice, discrimination, moral suffering and even thinking of suicide in this phase. Drug and anabolic substance use as well as unprotected sex must not be underestimated. Health teams must be aware of these signs and symptoms and provide opportunities for dealing with these issues, individually or with groups of young people, using games, role playing and discussions of experiences.
- Encouraging adolescents to take an active part in their treatment and to believe in their ability to care for themselves are important steps for establishing a relationship of trust. Understanding what they are going through and being open to their difficulties is extremely important for more in-depth care of their health.
- Approaching adolescents and getting them to talk about their dreams and plans for their lives, encouraging them to achieve them and get involved in social projects with this aim.

2.3 Family or carer interface

The health team needs to remember that it has a role of mediator between adolescents and their families, as it is often possible to identify situations in which family members have difficulty in conversing with each other.

It is important to take into consideration that complex situations are frequently found in the families of adolescents living with HIV/AIDS frequently, such as: being orphaned, parents or brothers and sisters being ill, hardships, adoption and being institutionalized⁶.

Carers can also be seen to experience feelings of loneliness, because of not having someone with whom they can share their apprehensions, fears, opinions and notions about diagnosis and treatment. Meeting with families as a whole, individual family members or groups of family members helps the health team to get to know the family scenario of each adolescent (life history, history of HIV in the family, as well as a biopsychosocial overview). These are privileged opportunities for addressing issues common to families and in so doing enabling and strengthening ties with the health team.

Families, whether they be formed by biological parents, grandparents, aunts, adoptive parents or social carers must therefore be included in the entire process of diagnosis disclosure, treatment negotiation and adherence. Health professionals must welcome and counsel these carers regarding their insecurities, uncertainties, fears and anxieties throughout the entire treatment process.

2.4 Pubertal development and sexual maturation

The body undergoes intense changes during adolescence. As adolescents mature, they need to adapt to their new bodies and reconstruct their body schemes. This undoubtedly takes time. This situation frequently causes them anxiety. In some cases lack of knowledge about the body and its physiological changes, as well as psychological changes and changes to body image cause apprehension and can be an obstacle to approaching subjects such as self-care, sexual and reproductive health, condom use, STDs and HIV/AIDS and family planning. These issues can be dealt with through group strategies, with the aim of not only providing knowledge but also creating a new space for reflection and debate.

The process of puberty is unleashed and regulated by neuroendocrine mechanisms involving the hypothalamic-pituitary-adrenal/gonadal axis, the maturation of which culminates in gametogenesis and fertility. The body transformations characteristic of puberty comprise considerable physical growth and sexual maturation. Usually there is a very large variation in the speed with which the modifications progress and in the age at which puberty starts.

According to Marshall and Tanner^{7,8}, puberty is characterized by:

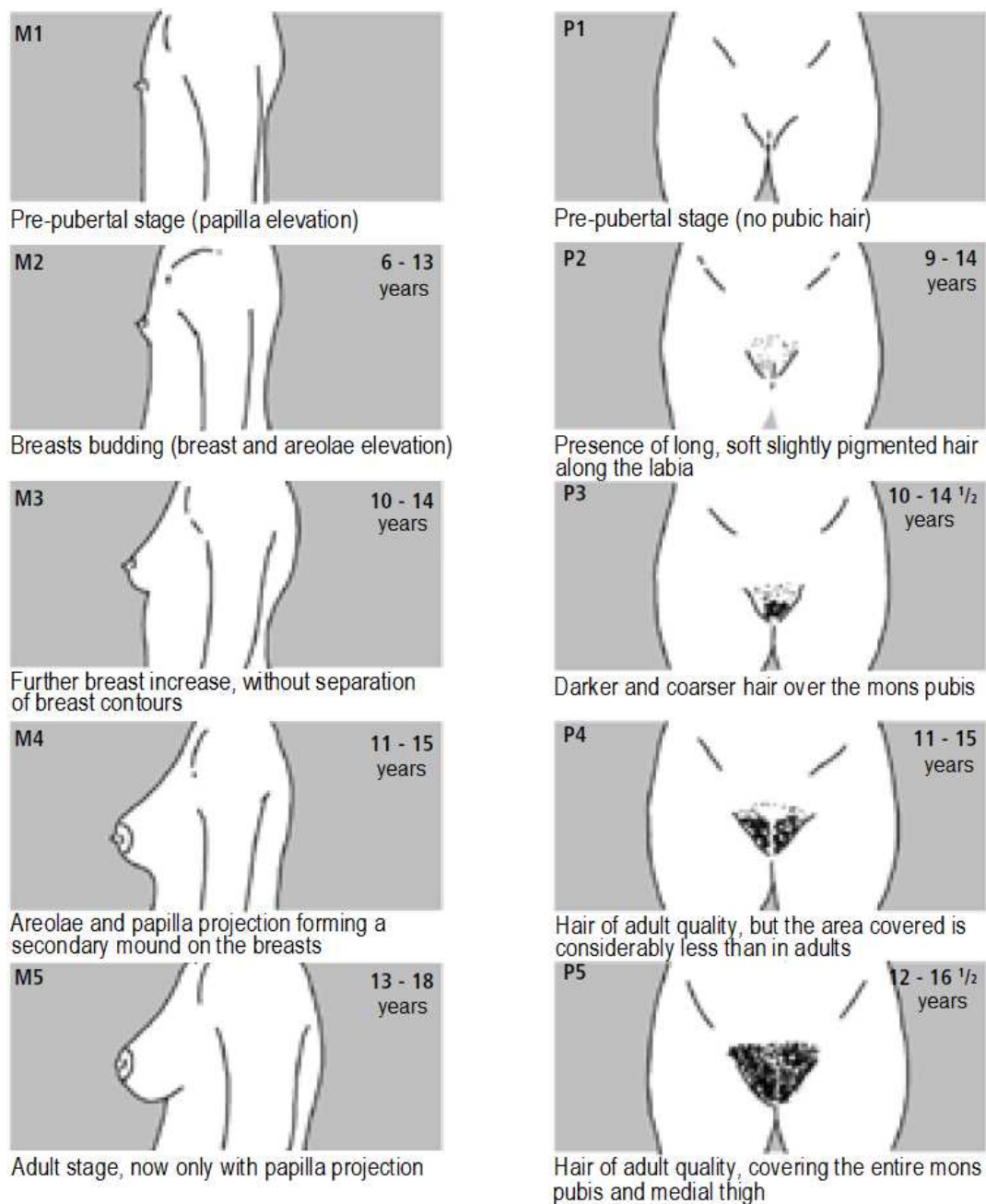
- Growth acceleration and deceleration until it finally stops;
- Modifications in the body's composition which include skeleton and muscle growth, as well as changes in the amount and distribution of fat;
- Development of the cardiovascular and respiratory system, with increased strength and resistance principally in the male sex;
- Maturation of neuroendocrine control and consequent development of the gonads and secondary sexual characteristics (sexual maturation).

The larche is the name given to the beginning of breast development; gyneacomastia is the enlargement of mammary gland in boys; pubarche is the appearance of pubic hair; menarche is the first menstruation; semenarche is the first ejaculation; sexarche is the onset of sexual intercourse.

In 1962, English doctor James Tanner proposed a scale measuring the stages of sexual maturation and this has become a reference for the majority of professionals for accompanying the evolution of puberty. He classified pubertal development in five stages, taking into account breast development in females, genital development in males and public hair in both sexes.

The figures below show the stages Tanner proposed.

Figure 1 – Tanner’s Classification – Stages of Puberty – Females⁷



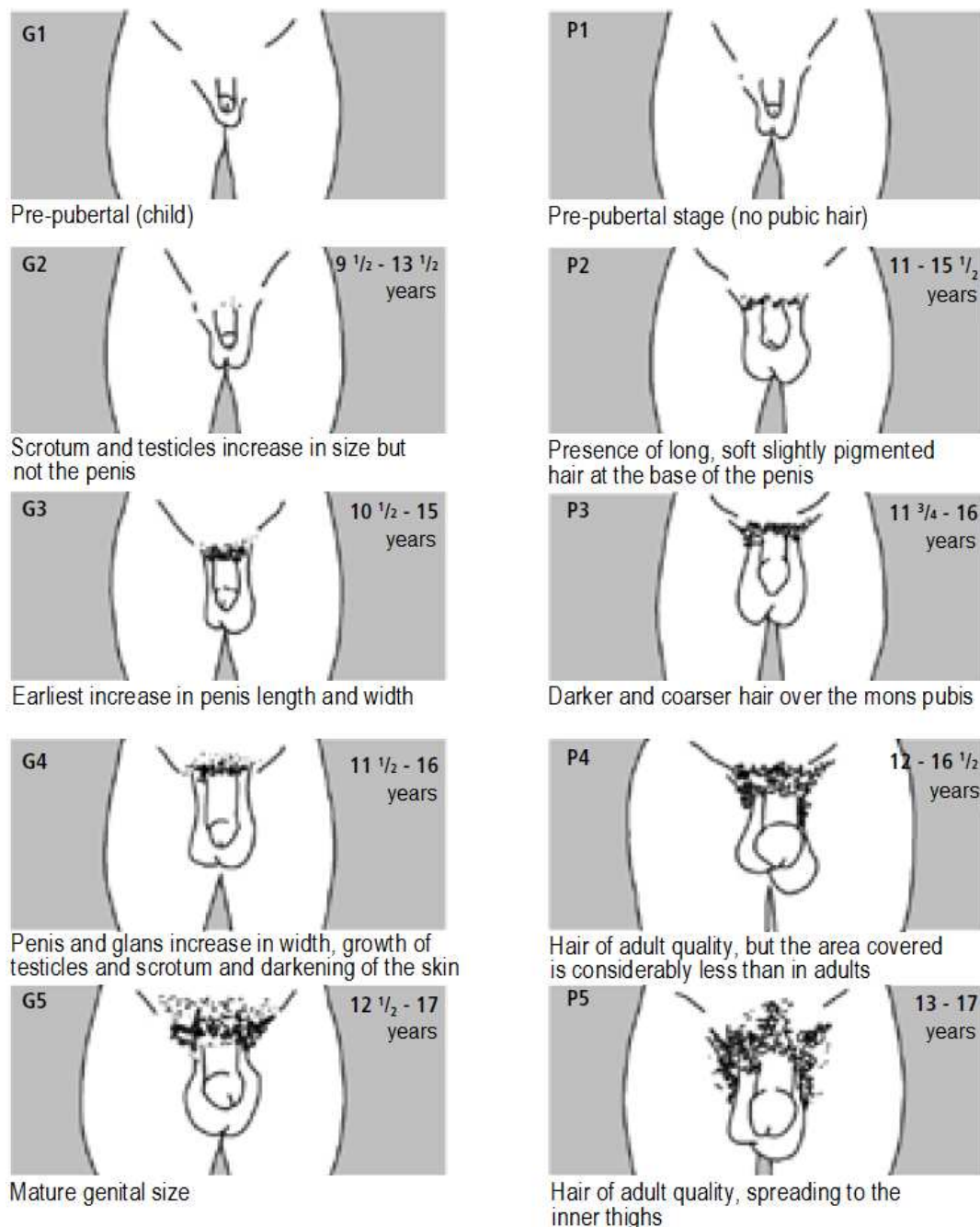
Source: Marshaw WA, Tanner M. 1969. Variations in pattern of pubertal changes in girls. Arch Dis Child, 44(235):291-31.

In boys, the spurt of growth generally starts in G3, reaching its maximum peak in G4 and decelerating in G5.

Apart from genetic aspects, socio-economic status, chronic diseases, psychosocial factors, physical exercises, geographical and climatic factors also influence puberty. Inadequate food and living conditions, lack of basic sanitation, precarious medical care, disturbances in family dynamics, use and abuse of alcohol and other drugs are some of the factors that can lead to delays in growth and pubertal maturation.

As with other chronic diseases, HIV-1 infection in the perinatal period interferes with sexual maturation owing to direct action by the virus, the presence of secondary infections, nutritional alterations as well as the action of cytokines. It is interesting to note that delayed sexual maturation in these groups of patients appears to be more accentuated in the later stages of puberty^{9,10}.

Figure 2 - Tanner's Classification – Stages of Puberty – Males⁸



Source: Marshaw WA, Tanner M. 1970. Variations in pattern of pubertal changes in boys. Arch Dis Child, 45(239):13-23.

2.5 Weight and height gain

In general adolescents grow 8 to 10 centimetres a year during the period of growth spurt and gain some 30 cm in stature, accounting for around 20% of final height. Weight also increases significantly during puberty when adolescents acquire some 50% of their adult weight. Their tissues and organs also grow, with the exception of the lymphoid tissues which undergo involution. Plasma volume increases, as does cardiac output and peripheral vascular resistance, thus increasing arterial pressure¹¹.

Weight and height gain is frequently comprised by HIV infection. This phenomenon is well documented in studies accompanying patients infected in childhood, either by mother-to-child transmission or blood product transfusion, principally in those with delayed puberty^{12,13,14}. Low growth is probably explained by nutritional and hormonal deficiencies.

2.6 Bone metabolism during adolescence

Puberty is a very important period for adequate bone mass gain. Factors affecting normal bone mineralization are calcium intake, vitamin D levels, physical activity, hormones, genetic factors and nutritional condition¹⁴. The period of growth “spurt” is a phase of significant bone mass accumulation. High incidence of bone fractures in adolescents in the general population may be related to relative bone fragility resulting from the dissociation between bone growth and mineralization¹⁵. The peak in bone mineralization corresponds to the accumulation of calcium in this tissue. Bone density decreases prior to the growth spurt and then increases during the next four years. On average, skeletal calcium deposition peaks at 12.5 in girls and 14 in boys¹⁶. Reduced bone density is recognized as a metabolic complication during the course of HIV-1 infection in adults and children. Reduction in bone density in people with HIV involves many factors and can be related to HIV-1 itself, its treatment, comorbidities and other factors unrelated to HIV infection. Bone densitometry is indicated for HIV-infected adolescents, principally those with a low body mass index, history of weight loss, prior use of steroids, and presence of lipodystrophy or Tenofovir use. Those whose weight is low for their age should be advised to do high impact exercises and to take calcium and vitamin D supplements¹⁷.

2.7 Other metabolic alterations

HIV Lipodystrophy Syndrome is of special concern in adolescence, since body fat distribution alteration, with loss of fat in the arms, legs and face and fat gain on the back of the neck and torso, may have profound repercussions at this stage in life when people acquire their adult bodies. These alterations to the body may result in consequences such as low self-esteem, social isolation and depression, interfering with psychological well-being as well as other spheres of life (emotional, sexual, social, or professional). Health teams need to be aware in order to intervene as early as possible and prevent harm, including with regard to adherence to treatment.

Patient’s complaints should never be underestimated. It is important to remember that diagnosis of bodily changes is subjective and depends on joint perception and analysis by the health professional and the patient. Various interventions exist, including changing the antiretroviral drug regime, indicating physical, aerobic and resistance exercises, food re-education, individual or group psychology sessions and facial filling with polymethyl methacrylate (PMMA)¹⁸.

In addition to alterations to the body, antiretroviral therapy is also associated with increased cholesterol and triglyceride levels and insulin resistance, making dietary counselling and encouraging physical exercise indispensable in the medical follow-up of these patients (See Chapter 6).

2.8 Brain and cognitive development

Neuroimaging studies have contributed to knowledge on brain development during childhood and adolescence¹⁹. Maximum brain volume is reached at 10.5 years in girls and 14.5 years in boys. A process of reduction in grey matter takes place in adolescence, accompanied by an increase in white matter volume. The smaller volume of grey matter reflects a reduction in the number of synapses. This stage of development is also known as “synaptic pruning”. The increase in white substance reflects improved axonal myelination, with increased transmission speed between neurons and increased anisotropy, i.e. impulses cease to propagate randomly and brain connectivity quality improves.

There is evidence that these structural and functional modifications, seen in different regions of the brain, are related to greater rational and emotional planning capacity (prefrontal cortex), greater memory capacity (temporal lobe), language ability (frontal lobe), greater intelligence quotient (frontal and occipital lobes) and greater reading ability (temporal and parietal lobes).

Synapse loss has been related to sleep pattern alterations observed during adolescence²⁰. Sleep-wake timing tends to shift during puberty so that sleep is compromised by conflicts with school times and other commitments. This may result in the high frequency of sleep deprivation observed in this age group accompanied by sleepiness during the day. This in turn may pose problems for keeping medical appointments and taking medication at the prescribed times. It is important for health teams to

be understanding and to be seen to be capable and obliging in seeking and negotiating new strategies with adolescents to facilitate adherence.

Research is also being made into the relationship between reduced sleep at night and changes in the brain reward system, which is fundamental in decision-making processes. Several behaviours observed during adolescence are associated with greater exposure to risks and may be related to physiological changes that appear to lead to reduced reactivity, thus requiring more stimuli in order to obtain the sensation of reward²⁰.

On the other hand, alterations caused by HIV-1 in certain areas of the brain in adults are well documented, principally in subcortical structures, such as loss of nerve function in the entire frontal cortex, cerebral atrophy and white matter demyelination, basically in the periventricular zone, corpus callosum, internal capsule, anterior commissure and optic tract. The most compromised cognitive domains in patients with HIV-1 infection are motor skills, expressive language, episodic memory (encoding and retrieval) executive function (processing speed, attention and working memory). The latter appears to contribute noticeably to learning, especially during childhood^{21,22,23}. Prospective memory is also affected and is related to the act of “remembering to remember”, being closely linked with taking medication at the right time and, consequently, adherence to medication. As such, brain and cognitive development in adolescents living with HIV may be compromised in different ways and may result in lower intelligence and academic performance, deficiencies of executive function (abstraction, problem-solving, cognitive flexibility, cognitive deficiencies in social skills and planning), limited memory ability, language deficiencies (in cases of encephalopathy), reduction in information processing speed, attention deficits and compromised motor coordination^{24,25}.

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Chapter 3

Diagnosis disclosure

3.1 Diagnosis disclosure. Mother-to-child HIV/AIDS transmission diagnosis in adolescence

According to the document entitled “*Recomendações para Terapia Antirretroviral em Crianças e Adolescentes Infectados pelo HIV*”¹ (Recommendations for Antiretroviral Therapy in HIV-Infected Children and Adolescents), disclosure of diagnosis to this population must be done in an individual and procedural manner together with the participation of parents and/or those responsible for them.

Similarly, the relevance of this theme has also been highlighted in the findings of the Enhancing Care Initiative/Brazil², a project integrating researchers from Brazilian institutions in cooperation with international bodies in order to enhance the care of people living with HIV/AIDS. Diagnosis disclosure was referred to as being one of the key points when aiming to achieve comprehensive and quality care for young people living with HIV/AIDS. The considerations raised include:

*[...] that the task of disclosing diagnosis be seen as a process to be undertaken by carers and professionals, taking into account each adolescent, the particularities of their social and domestic contexts, their sex and age group*².

It must be emphasized that these recommendations do not apply only to HIV-positive children or adolescents having follow-up in specialized services from a very early age and who, for the most part, were infected through mother-to-child transmission (MTCT). Special care must also be given to adolescents diagnosed later, whether as a result of sexual intercourse, drug use, blood transfusion, sexual abuse or even late diagnosis of HIV/AIDS resulting from MTCT.

- Diagnosis disclosure must be considered as a process.
- An individual approach must be used, taking into consideration the particularities of each child and adolescent, as well as their social and family context.

3.1.1 Current panorama

Despite the global recommendations on the importance of diagnosis disclosure in paediatric AIDS clinical practice, it is known that communicating and receiving diagnosis of a serious and incurable disease produces countless concerns, especially in the case of an illness that is so feared and associated with death, prejudice and discrimination. Therefore, as it is a disease pervaded with stigmatizing significations, family members and carers, including health professionals, are reluctant to disclose to children and adolescents their condition of being HIV-infected³. A scenario of concern in specialized services is the high prevalence of patients who contracted HIV through MTCT and who reach adolescence without having complete information on their serological status⁴.

3.1.2 The harm of secrecy

Even today, putting off facing the truth is seen as a way of protecting children and adolescents and banning communication appears to be the only possibility found, by most families, to deal with this situation.

Adults keeping secrets or lying can take on startling and emblematic proportions in a child's psyche⁵ and there are descriptions in the literature that link prolonged silence about HIV/AIDS to emotional disorders and suffering, feelings of anger and compromised psychosocial development⁶.

In the case of adolescents who are not aware of their HIV status, the absence of an honest and open dialogue and the exclusion of processes involving important events in their lives generate states of depression, withdrawal and mistrust which can take on a pathogenic role in the construction of their adult identity.

Generally speaking, these patients suffer psychologically, ask for help, develop symptoms and, above all, isolate themselves in an imaginary world and are left with a deep feeling of loneliness. In this context, secrecy can follow different directions and be determined by a set of factors linked to the particularities of the child or adolescent as well as by features of their social and family setting. Be that as it may, lack of dialogue or lack of access to knowledge about the truth regarding their lives can make these patients suffer, feel strange and experience anguish which, although it is part of the human condition, would be less stressful and harmful if they were understood and acted on by adults.

- Differently to what carers suppose, silence, lies or changing the subject with regard to diagnosis have disruptive outcomes and can interfere negatively with a child's or adolescent's development process.
- Barring this knowledge exposes HIV-positive patients to emotional inhibitions, psychological suffering and states of intense loneliness.

3.1.3 Consequences of silence for treatment adherence

In the case of adolescents and young adults living with HIV/AIDS, apart from having to face the changes and conflicts usually expected in this phase of life, such as the blooming of sexuality, the quest for identity and independence, they are also obliged to live with a chronic disease that demands complex treatment the side effects of which cannot be neglected. This host of stressful factors which affect an HIV-positive adolescent's life will be intensified in the event of lack of communication about the disease and will inevitably have repercussions on adequate treatment adherence in all its dimensions^{6,7}.

Many strategies for improving adherence depend on the assumption that the person's participation during medical consultations is fundamental. In this context, "adherence to treatment" should be seen as a joint activity in which the patient not only follows the health professional's advice, but also understands, acknowledges and agrees with the prescription⁸. Undoubtedly, adolescents, young adults or even children cannot be expected to collaborate with the interventions to which they are routinely submitted, to recognize their responsibility in this process or to commit themselves to something unknown (see chapter 4).

These considerations emphasize the importance of sharing necessary information about the disease, the benefits of medication and the risks associated with its incorrect use, so that addressing the issue of diagnosis disclosure in this population group becomes a priority.

On the other hand, telling adolescents they are infected in an abrupt or even careless manner will compromise their possibilities of coping with the health/illness process and may result in feelings of revolt, mistrust, rejection of medication and the disease itself or even abandoning treatment.

- Diagnosis disclosure is a decisive factor for adequate adherence to antiretroviral treatment.
- Knowledge about the disease enables greater awareness about taking care of one's health in general.

3.1.4 Principal barriers to diagnosis disclosure

a. Family member difficulties:

Generally speaking, the factors that define the decision not to disclose infection highlight concerns about the patient's psychological state or can be associated with the carers' own worries, demonstrating a high degree of anguish about prejudice and stigma arising from their children's inability to keep a secret⁹. Because of this parents or carers frequently avoid revealing to their children that they are infected as they fear they will be rejected and subject to prejudice and social isolation¹⁰. They fear, above all, that when their children find out about the disease, they will blame them and feel revolt and intolerance towards them¹¹.

Moreover, many family members do not want to expose personal issues and are afraid of condemnation and rejection, these being attitudes that could increase feelings of guilt for having transmitted the disease⁴. Some parents and carers feel unprepared to begin a conversation about infection¹⁰ whilst others imagine they will not be able to answer possible questions relating to

expectations about life and future plans. There are also those who judge themselves to be too weak to cope with their own emotions when sharing painful information¹².

In many situations when parents face the problem of disclosing their children's diagnosis, they can be seen to relive past experiences going back to when they were diagnosed as having HIV, perhaps in an inadequate manner and without being prepared. Assuming that history will repeat itself, they tend to imagine that children or adolescents will suffer the same emotional impact and, therefore, will not be able to bear the pain and suffering resulting from finding out they have this disease⁵.

b. Breaking down resistance:

Being alert about possible family member opposition and helping them to identify this range of feelings are interventions that contribute to raising awareness and acceptance of the benefits derived from clear and frank communication about infection with HIV-positive children and adolescents. In-depth reflection on the negative and positive aspects involved in disclosing HIV diagnosis can serve as support to consolidate parents' and carers' willingness to submit patients to the process of knowing they are HIV-positive.

Health services should assess the family support network and carers' psychological structure, given the importance of being open to the patient's anguish and other needs after diagnosis has been revealed. It is therefore essential that parents and carers also verbalize their personal dramas or traumatic experiences in relation to HIV, such as isolation, discrimination and loneliness as a result of living with HIV/AIDS. This means that carers also need accompaniment regarding their fears, concerns and worries, not least because as their children reach adolescence this may make them remember their own adolescence which may have been the origin of much that torments them or even their own infection with HIV.

- Understanding the reasons why carers are reluctant to disclose diagnosis to adolescents and legitimizing their concerns are procedures that promote a good relationship between family members and health teams.
- Family members should take an active part in planning and building strategies for disclosing diagnosis to their children.

c. The best time

Another reason making the process of diagnosis disclosure difficult relates to the best time to begin this conversation with the patient. Generally speaking, many authors recommend that the patient's age should not be the only consideration as to their readiness to understand information relating to the disease. Nevertheless, there is consensus that diagnosis disclosure should be begun before the onset of adolescence¹³.

If on the one hand withholding knowledge of infection compromises the emotional development process as a whole, on the other the abrupt breaking of silence without a more in-depth understanding of the child or adolescent may result in emotional harm that is sometimes hard to overcome.

For a variety of reasons there are times in the life of any adolescent when they are more vulnerable and less capable of facing new situations. In such circumstances information about the disease and treatment can cause an emotional overload and intensify already existing conflicts. It is advisable to keep a lookout for situations like this occurring and help them in working through the difficulties before putting them through the process of diagnosis disclosure. On the other hand, if these components are related to HIV being kept a secret, the conversation about their HIV status cannot be put off, as the atmosphere of something being hidden, together with ambiguous and distorted remarks about the disease, tend to confuse them and create conflicts that are hard to get over.

Be that as it may, the decision about the best time for disclosure must be shared with family members and be based on the health professionals' knowledge of child and adolescent development. This means that it is fundamental to take into consideration their cognitive capacity to understand abstract concepts, their emotional ability to deal with adverse situations and the family context in which these young patients are situated.

Many uncertainties may overlap at this time of revealing HIV diagnosis, however in more complex cases psychological assessment has proven to be a valuable resource in that it enables more

detailed knowledge of the dynamics and structure of an individual's personality¹⁴. This can help to achieve a better definition of the way in which health professionals should proceed.

Ensure that the patient is not suffering from significant psychopathological disturbances and, in case of doubt, refer them for psychological or psychiatric assessment with the aim of identifying more precisely their emotional condition and the means they have available for coping with their difficulties and conflicts.

3.1.5 Particularities of diagnosis disclosure

a. Children:

When children first manifest curiosity in relation to doctors' appointments, sample collections for tests, medication that has to be taken constantly, frequent hospital visits, among other procedures, they should receive explanations that take into consideration their ability to understand and what they have expressed concern about. Each question should be answered in a simple and objective manner. It is fundamental for adults to converse with children and put them into the context not just of the disease and treatment, but also about things that are happening in their lives in an attempt to observe and learn the ways they communicate and their favourite forms of expression. Observing the particular directions of a child's movements and valuing their perceptions and thoughts are indispensable attitudes to take, given that the majority of them are not able to verbalize explicitly their doubts and naturally tend to show their feelings through playing games and drawings.

- Types of disclosure:

Complete Diagnosis Disclosure: Complete diagnosis disclosure means communicating accurate and true information about infection as well as naming HIV/AIDS. The focus of this strategy should help a child to understand how the virus operates and cover discussions about transmission routes and any questions about stigma, prejudice and death. These considerations clearly need to be in keeping with the patient's ability to understand, their needs and particularities.

Partial Diagnosis Disclosure: This form of intervention contemplates almost all the aspects referred to above, except when some children are immature with regard to the criterion of being able to keep secrets about certain situations. Information about the illness, collecting samples for tests and treatment is also provided, but specific mention is not made of HIV/AIDS. In this sense partial explanations are also helpful, especially for children, as long as adults give explanations that are not distorted and are close to reality.

b. Adolescents:

Adolescents diagnosed in early childhood have a long history of frequenting health services, sometimes involving serious aspects such as stays in hospital and complex treatment with medication.

Some of these young people find out on their own, i.e., they know their HIV status even though this has not been explained by an adult. In some situations, adolescents really do not know the name of the illness for which they have follow-up and are treated. In other situations, they may be refusing to recognize a traumatizing and unsupportable reality. Denial mechanisms are commonly found in adolescents who have been deprived of knowing the truth about their stories and may take on pathological dimensions in response to the fantasy that what cannot be seen does not exist. In such cases, the diagnosis disclosure process is conducted so as to focus on approaching the issue gradually, addressing themes related to the illness. The context of these sessions needs to achieve high levels of trust, security in the relationship with the health professional and the patient becoming emotionally stronger.

Offering emotional support with the aim of helping patients to deconstruct fantasies and give new meanings to the disease and its treatment is an essential strategy when disclosing HIV/AIDS

diagnosis during adolescence. On the other hand, psychological or psychiatric follow-up cannot be dispensed with in situations requiring more in-depth interpretative interventions.

c. Children and adolescents living with HIV-positive families:

Keeping the disease a secret can have a harmful effect on the psychological development of children and adolescents who, even though they do not have the virus, live in families in which one or more members is HIV-infected. Usually these children and youths receive few explanations about why their parents or brothers and sisters are taken into hospital, have frequent doctor's appointments or why they are taking treatment. Despite being concerned about their family members' health, many feel alone and do not understand why they are being excluded from privileges and care and need to be prepared to understand how to deal with AIDS in all its dimensions.

Similarly, interventions relating to diagnosis disclosure should be extended to the generation of children who are uninfected but were exposed to the virus because they were born to HIV-positive mothers and have annual follow-up in specialized health care units until they become adolescents. The interest in this relatively little known population should not be limited only to possible clinical repercussions because of their having been exposed to HIV or antiretroviral drugs. It is necessary to understand how they live, how their psycho-affective development took place and whether the information about their first years of life was kept secret. In these cases it must be taken into consideration that accessing personal memories regarding earlier stages of development will integrate current contents with the past and, when well guided, this may structure and organize personality.

Health teams should scale up care for children and/or adolescents who are not HIV-infected but who are affected by living with HIV-positive parents and brothers and sisters.

3.1.6 The process of taking in diagnosis – The importance of post-diagnosis disclosure follow-up of adolescents living with HIV/AIDS

Understanding the practice of diagnosis disclosure as a process means that it does not come to an end when a child or adolescent is informed of their HIV diagnosis. In addition to accompanying how the patient is assimilating and learning the information they received, it is essential to analyse the outcomes provoked by the emotional impact of finding out they have a disease that is surrounded by negative and prejudiced social values. In this context, "accompany" means "keeping company" and following with attention and in the same direction the thoughts and feelings awakened by finding out about the disease. In the same way as adults, these young people need spaces to be able to express their concerns and time to accept and take in this new reality.

It has to be emphasized that interventions must not be oriented only in terms of the disease, especially because HIV/AIDS diagnosis disclosure is also the beginning of other significant discoveries for children and youth. Keeping diagnosis a secret has different dimensions and serves to conceal other secrets such as, for example, adoption, sexual and reproductive life, death of parents owing to AIDS or other family secrets involving HIV which are not transferrable and may last for several generations. As such, many young people know how they became infected whilst not necessarily having access to the origin of their parents' infection.

When explaining about HIV transmission routes to younger children, it is necessary to know whether they have notions of sexuality and whether those responsible for them allow these subjects to be approached. With regard to patients who are adopted but are unaware of this, their parents need to understand that the atmosphere of secrecy surrounding adoption also has complex repercussions and may influence a child's healthy development. Because of issues like these, prior discussions with family members are recommended, given that knowing about infection has to do with origin and parentage.

As such all health team members must be duly trained in promoting health and open dialogues, including themes involving questions about death, origin, parentage, prejudice, uncertain future, as well as the desire to live one's sexuality healthily as part of a desire to live and plan for the future. Similarly, objective and concrete aspects regarding the illness, such as treatment, prevention and risks of transmission are issues that must be addressed and integrated into all areas of caring for adolescents and young adults living with HIV/AIDS.

On the other hand, health services need to be structured to serve this population, encouraging the creation of group spaces that favour the process of identification among peers as well as enabling other painful experiences to be shared. Personal stories shared in an atmosphere of respect contribute to reshaping meanings implicit to being an adolescent within a context of a chronic disease. It is also appropriate to bear in mind that regardless of training or professional activity, i.e. being a psychologist, a nurse, a doctor, an auxiliary and so on, some professionals feel uncomfortable in dealing with the moment of telling a child or an adolescent that they have been diagnosed as having HIV. It is important to respect each team member's individual characteristics and to identify people who have more affinity with handling the disclosure process.

In principle, all professionals caring for children and youth living with HIV/AIDS should be capable of conducting the diagnosis disclosure process. Nevertheless, this new reality delineates situations that are very specific and the inclusion of this theme in discussions about clinical cases, together with the exchange of experiences between professionals from different services, has shown itself to be an efficient and productive means for this work to take place in a humanized and less stressful manner.

- Adolescents need to be able to talk about the unspoken, about secrets that involve other secrets that remain unrevealed in the first generations.
- Professionals must be trained to help adolescents in the process of taking in the illness.

3.2 Diagnosis disclosure – diagnosis of HIV/AIDS caused by sexual transmission or injecting drug use

Adolescents who have contracted HIV through horizontal transmission have particularities that need to be recognized by health professionals and be contemplated in the approach taken when disclosing diagnosis. They are frequently young people who have weak links with health services and high social vulnerability such as, for example, injecting drug use, problems at school and on the job market, situations of extreme poverty and lack of perspectives¹.

The question of adolescence in Brazil cannot be considered nor can proposals be discussed without certain conditions being taken into account, such as early teenage pregnancy. This is one of the fundamental aspects to be considered when providing care for this population in health services. Feelings and effects produced by pregnancy in adolescent girls often shatter the relationship they have established with their bodies, their plans for the future and their social identity. If adolescent girls are unable to find ways of resignifying the meaning of pregnancy and its "benefits", they may have difficulties in preventing HIV transmission.

Other relevant questions that health professionals should carefully assess and be especially open to are cases when adolescents begin their sex life and discover they are homosexual, this being a time when they are not yet sufficiently financially or emotionally independent from their families. It is within this context that adolescents in this situation seeking health services need to find support and understanding so that their sexuality is not judged and so that their sexuality develops in a healthy manner. Not being judgemental and taking care when addressing the sexuality of these adolescents will ensure that they take on responsibility for caring for their own bodies and are able to cope with their desires in an adequate and secure manner, free from the guilt and fears that often hinder their ability to perceive risk.

Another priority issue is reducing late HIV/AIDS diagnosis by means of scaling up HIV testing, especially by using rapid tests, including among adolescents. However, great care must be taken when approaching this issue with very young adolescents, especially in the event of a positive test result. Families are not always aware of their sexuality and related aspects and for this reason sometimes adolescents may go to a health facility just to get tested, as is their right¹⁵.

Although the Statute on Children and Adolescents considers adolescents to be holders of rights¹⁵, disclosing a positive HIV test result is nevertheless a complex matter, principally when the adolescent in question is alone in this process, without a social support network comprised of adults. In this case there is increased risk of their having no ties with health services. Furthermore, access to HIV testing must include pre and post-test counselling in accordance with Health Ministry recommendations.

As such, the principal recommendations for adolescents must take into consideration:

- The counselling process, both pre and post-test, for adolescents and young adults wishing to test for HIV must be performed carefully and aim to build ties with the multiprofessional team providing this care.
- If an adolescent decides on their own to test for HIV, the health professional must assess whether they are capable of understanding what they are doing, why they want to test and whether they will be able to cope on their own after receiving the test result¹⁶. Adolescents in this situation should be encouraged share what is happening with those responsible for them or with an adult or adults they trust and who can provide them with support. It is important to take into consideration that many adolescents face a variety of situations and cannot count on the support of those who should be legally responsible for them.
- When counselling adolescents, professionals should include themes such as knowledge of the body, sexual orientation, gender identity, sexual practices and associated risks, guidance on prevention and risk management.
- Team professionals must avoid making value judgements or imposing their own values on adolescents.
- If possible the social network of young people living with HIV and AIDS should be involved, as it can be an important ally in the process of understanding diagnosis and adherence to treatment.

It is relevant to point out that for adolescents and young adults infected through sexual intercourse or drug use there may also be “harm” in relation to the secret of their HIV status. As such, professionals must check whether infected adolescents and young adults have told someone they trust about their HIV status, since they may not share this information with anyone, for fear of prejudice, discrimination or lack of support, or even because of denial of the problem. This situation can lead to psychological suffering, isolation, difficulty in adhering to treatment or even abandoning it.

3.3 Diagnosis disclosure to other people

The main concern of young HIV-positive people is being able to discern who they can trust or who they can tell about their HIV status, this being a decision involving fear of being discriminated and rejected, especially by their peers. The majority of these adolescents state that they live in silence about their HIV status and the intensity of the experience of being alone awakens feelings of inferiority and exclusion. This may interfere negatively with their possibilities of social integration. Many feel obliged to keep this secret from close friends, sex partners or other family members. Sometimes they avoid getting emotionally involved out of fear that getting closer may inevitably lead to disclosure. There are, however, no clear or defined parameters to guide the decision on whether or not to reveal one's HIV status. The alternative between being open about being HIV-positive is, usually, surrounded by ambivalences and experiences that can be negative or positive.

Yet again, professionals must be alert in relation to feelings of isolation and loneliness resulting from keeping HIV-status secret and help these young adults and adolescents to face their fears and insecurities arising from this situation. In addition to the work of the multiprofessional team, the importance of psychological follow-up must be stressed because it will enable the careful assessment of the meanings and functions keeping this secret has for each subject and to what extent continuing to keep the secret or revealing it may result in greater or lesser anguish and suffering. Ample discussion and reflection must take place with these young people, in all respects, in order to understand what disclosing HIV infection can mean, including the reason for disclosure, what to disclose and to whom, as well as the aspects relating to the right to confidentiality on the one hand and responsibility in terms of exposing other people to infection on the other.

3.4 Final considerations

Diagnosis disclosure is a moment of special importance when caring for adolescents and young adults infected with HIV/AIDS and requires preparation on the part of family members and the availability of the professionals involved. From this perspective, all children, adolescents and young adults, regardless of how they became infected, must have ensured access to knowing their diagnosis as well as access to their true stories, with all their nuances and singularities, as these are essential elements for them to become subjects in their own right and overcome their painful experiences. This means that understanding the patient, within a comprehensive view of health care, is increasingly indispensable for improving treatment in all its dimensions.

The practice of diagnosis disclosure requires not only up to date knowledge, but also the commitment and availability of all carers involved, including interventions planned to contemplate the complexity of the factors involved in telling adolescents and young adults that they are HIV-positive. This is an arduous undertaking, involving setbacks and progress and requires in-depth consideration when planning humanized care.

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Chapter 4

Adherence

Combined antiretroviral therapy (ART) is effective in suppressing Human Immunodeficiency Virus (HIV) replication, in preventing opportunistic diseases, in reducing mortality and improving the well-being of HIV-infected children and adults. Nevertheless, high adherence levels are necessary in order to obtain virologic and/or immunologic response and delay the disease's progression in the long term. Without adequate adherence, antiretroviral (ARV) drugs are not maintained in quantities sufficient to suppress HIV replication in infected cells or to reduce plasma viraemia. In addition to being associated with shortened immunologic response, poor adherence to ARV medication favours the development of drug resistance. Although the ideal level of ART adherence has not been completely defined, levels below 95% have been associated with poor virologic and immunologic response¹.

Low adherence is common, although difficult to predict. Studies do not demonstrate that socio-economic characteristics such as sex, race, age, exposure category and education level are predictors of adherence². Adherence varies not only between individuals but also in the same individual with the passage of time.

Adherence in cases of chronic diseases in adolescence is a challenge for health teams, family members and patients themselves. Studies have demonstrated that approximately 50% of adolescents with chronic conditions do not adhere to medical recommendations³. A longitudinal cohort study of adolescents infected by HIV through sexual intercourse or injecting drugs found 41% full adherence and showed only 46% of patients taking more than 80% of prescribed medication⁴. It is interesting to note that this rate is in keeping with adherence estimates for other chronic diseases and supports the idea that poor adherence is a common behaviour, even in the case of a serious disease such as HIV infection.

4.1 Adherence in adolescence

The characteristics of adolescence make treatment adherence a difficult aim to achieve. The fantasy of invulnerability and imagining there are magic solutions work against raising awareness about this still incurable disease; the particular way in which adolescents relate to time (displacement in time), the quest for independence and autonomy, impulsiveness, defiant attitudes, the desire to experiment new things and challenge danger hinder the performance of frequent clinical and laboratory controls, taking medication daily – often accompanied by side effects – as well as the planning of actions to prevent future events; peer group pressure, the wish to feel the same as other adolescents and be accepted can work against health care needs⁵ (see chapter 2).

Rao *et al.*⁶ held a focus group with young people aged 17 to 25, exploring their attitudes and experiences in relation to adherence to medication, revealing the challenges to coping with stigma and patients' efforts to conceal their HIV status from friends, family members, doctors and even themselves. The results suggest that HIV-related stigma impacts young people's treatment on several levels, ranging from the precision of their communication with the medical team, adherence and the resulting effects on their health.

The study of the perceptions of adolescents living with HIV/AIDS and their experiences with antiretroviral treatment indicated shortcomings in their knowledge about treatment, the sensation of lack of choice and unpreparedness regarding decisions about treatment, difficulties in taking medication because of this interfering with their social routine, feeling different and side effects. Unstable adherence and treatment interruptions were frequent among the adolescents in this study and confirm that adolescents' perception of their own health is a stronger predictor of adherence than are biological markers⁷.

Forgetfulness is also a reason frequently given by patients for not adhering. Medication is one of the disease's strongest representations. Forgetting about medication may mean the patient wants to forget they have the disease, as can be seen in some of the words of young people living with HIV/AIDS presented as follows:

"Taking medication reminds me of the disease."

“Not taking medication after diagnosis disclosure is associated with difficulty in facing the problem, the desire to forget, to deny the disease’s existence.”

“The feeling of taking medication is remembering every day that you are ill. This is concrete. That’s why adherence is lacking. Abandoning it means forgetting it. Forgetting you’ve got the disease”.

The literature has documented direct association between poor adherence and the complexity of the treatment dosage regime⁸. The amount of different drugs in the same regime, the never-ending tablets that have to be taken every day, diet restrictions, interference with the patient’s routine and the potential adverse effects that many patients experience are associated with ARV treatment failure. Another important aspect of adherence is adolescents’ perception of the direct benefits of the treatment they are taking. Side effects lead to treatment interruption and bad feelings in relation to treatment.

4.2 Psychosocial aspects relating to adolescent adherence

Adolescents must take part in any decision about changes to their medication, regardless of the reason for the change. Educational materials explaining about HIV, medication, viral resistance and keeping a treatment diary are useful tools for adolescent adherence⁴.

Psychosocial factors and not believing in the importance of medication play an important role in failure to adhere to antiretroviral drugs. Many young people believe they have few choices in relation to medication. The perception of treatment choice and control is particularly important in this age group, since developing autonomy is an essential factor for psychosocial development in adolescence. Without the sensation of having a choice, many young people rebel against medication. Health professionals who provide care directly to adolescents need to pay special attention to what they know about the disease, HIV and its treatment.

In addition to the peculiarities of adolescence and the data mentioned in the literature⁸, adherence suffers the influence of other individual factors relating to each person’s life story, their experiences with the disease itself, how they became infected, family dynamics, experiences of revealing their HIV status to others and social prejudice, ties of affection, bonds formed with the health team and health service, among others.

Other statements made by young people living with HIV/AIDS illustrate their experiences with medication:

“Lack of autonomy and self-esteem interfere with adherence.”

“Adolescents generally stop taking medication on their own account when the first adverse effects begin to happen.”

“Care needs to be taken when changing treatment, because of the judgement made by professionals relating to treatment failure and lack of discussion about the treatment regime, and this can interfere with adherence. Generally adolescents stop taking medication after they’ve spoken with the doctors.”

“The doctors and the team don’t know how to deal with harm reduction – they make judgements and are prejudiced.”

The different HIV transmission routes can also interfere in clinical procedure and in the indication of antiretroviral drugs. This can have consequences for treatment adherence.

In the words of this young man:

“It’s important to give meaning to subjective aspects and plans for the future in treatment adherence. The way to adherence is very different between MTCT (vertical transmission) and HT (horizontal transmission). Medication has a different meaning”.

4.3 Family or meaningful social network participation

Families or meaningful social networks play a fundamental role in the adherence of people living with HIV/AIDS, particularly in adolescence. The tendency of carers to be overprotective, frequent in vertical transmission, and the fragile nature of family references, often present in life stories of adolescents who became infected through injecting drug use or sexual intercourse, should be replaced by adolescents themselves participating as subjects of their own health through a process in which they gradually become responsible and their family unit is a source of security and support for them. The guidelines provided in the 2009 edition of the treatment guide entitled *Recomendações para a Terapia Antirretroviral em Crianças e Adolescentes Infectados pelo HIV*⁹ (Recommendations for Antiretroviral Therapy in HIV-Infected Children and Adolescents) – are clear:

“(...) the involvement of children and adolescents in their own treatment, even at an early age, is fundamental for effective participation in adherence. Actively including adolescents in their treatment and trusting in their ability to care for themselves is the first step in establishing a relationship of trust. Understanding what they are going through and helping them with their difficulties is extremely important for more comprehensive health care” (p. 61)⁹.

During adolescence, which is the crossover period from the family unit to society, ties of affection as well as love/sexual ties are important, principally in the context of a disease surrounded by stigma and discrimination. A support network needs to be built around young people living with HIV/AIDS, so that they have available all possible resources in an individualized manner. A multiprofessional team is needed to provide integral health care to adolescents living with HIV/AIDS, thus enabling contributions from several different areas of knowledge when dealing with each case and jointly building the best strategy for each individual. A strategy that recognizes their specificities and includes each individual in its construction.

4.4 The importance of adolescent and young adult ties with health teams in promoting adherence

The health team / patient relationship is the key point for establishing all actions. If there are no ties between adolescents and professionals caring for them, the space necessary for adolescents to talk about their uncertainties, fears and even about not taking medication will not be created. Nor will there be the trust necessary for the health pacts that are key to treatment success.

Strategies developed to improve adolescents’ and young adults’ adherence to antiretroviral therapy vary according to available local resources and the interests of the adolescents themselves. The team’s creativity and sensitivity to perceive potential resources, both in the community and in the team itself are fundamental.

Having appointments with each adolescent at a specific time is a practice that requires, as a general rule, nothing more than health team member availability and service organization. It facilitates the application of strategies to improve adolescents’ adherence both to the service and to treatment in general.

4.5 Strategies for promoting adolescent and young adult adherence

Practices already in use, as well as new practices, can be developed with the aim of aggregating, enabling ties to be formed between young people and health professionals and services, creating spaces for discussions on subjects of interest to adolescents living with HIV/AIDS and their carers as well as promoting interdisciplinary discussions between health professionals from different areas about clinical cases having follow-up at the health unit. Some useful actions include:

1. **Groups** – group activities are a differentiated approach to reaching out to adolescents, especially since they have a natural tendency to form groups in this stage of life. There are several ways of

organizing group activities. The methodology will depend on the objectives to be achieved, resources available and the adolescents involved in the activity. The most commonly used forms of groups in health-related activities are focus groups, socio-educational groups, psycho-educational groups, operative groups, group therapy and workshops. These groups can have a variety of names that refer more to their function than to their structure. They are complementary to individual consultations and allow adolescents jointly with their peers to gather important information and resignify it in accordance with their own reality, work on their issues regarding living with HIV/AIDS, in addition to being an opportunity to socialize and form ties with the health facility. It is an opportunity for HIV-positive adolescents to talk openly with each other about their experiences without fear of discrimination.

2. **Family member groups** – working in groups can also be undertaken with those who care for adolescents, regardless of whether these adolescents frequent the specific group for adolescents. They provide an important space for carers to exchange experiences, mutual support and the opportunity for health teams to provide clarification.
3. **Waiting room activities** – these are undertaken whilst waiting for individual appointments and can involve the participation of peer leaders already engaged in other activities at the health facility. There is a variety of possibilities: games, videos, distribution of magazines and books of interest to adolescents, among others. It can be a time for health education. If the adolescents' appointments do not occur at a specific time at the health facility and/or people with other complaints have appointments at the same time, a reserved area should be planned to enable the adolescents to feel more at ease about doing the activities proposed.
4. **Individual consultation or appointment focussing on adherence** – “an action aimed at specific treatment-related difficulties and doubts of people living with HIV/AIDS. This activity focuses on the individual, putting into context the social and emotional aspects of living with HIV/AIDS”¹⁰.
5. **Joint consultation** – this is when two or more health professionals see a patient with regard to their treatment. It enables integrated health care.
6. **Adherence devices and techniques** – several kinds of devices are used to facilitate adherence: pillboxes, diaries, alarms, dosage charts and maps, educational material such as leaflets and videos, lists of advantages and disadvantages, self-recording of adherence, reminders to take medication sent by mobile telephone or electronic mail, among others.
7. **Directly Observed Therapy** – (DOT) refers to health professionals or other people watching patients take their medication, at home or at the health facility. DOT for antiretroviral therapy needs to be analysed in more depth, defining populations that can be benefitted by this strategy as well as criteria for starting and interrupting it. A retrospective study described its use in five adolescents who were unresponsive to ART. Four of them responded but this response was not sustained after DOT was interrupted¹¹.
8. **Conversation circles** – These have a fairly open format which can facilitate adolescents' participation in this and other activities.

“Using the conversation circle method, participants receive encouragement and information to discuss issues of interest based on their own experiences”¹⁰.

9. **Alternatives aimed at the team** – clinical meetings of health professionals involved in providing care to adolescents living with HIV/AIDS are an opportunity to share impressions, experiences and information. They can be an important space for building the team's capacity and a time for reflection and handling cases having follow-up at the health facility in an interdisciplinary and integrated manner.

Supporting adherence is a continuous and dynamic process which occurs throughout follow-up of patients living with HIV/AIDS. Every time they have contact with the health team this should be seen as an opportunity to assess and encourage adherence.

Working to ensure adherence should be seen as a partnership between the interdisciplinary team and the service user, their family and support network, from a perspective of joint responsibility, seeking strategies to overcome difficulties and improve quality of life.

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Chapter 5

Sexual Health and Reproductive Health

5.1 Sex and sexuality

Discussion about sex and sexuality is fundamental in health services, schools, families, groups of friends, social groups and the media. As subjects associated with life and also with countless taboos, they generate doubts, controversies, debates, discussions and questioning which need to be dealt with in a frank, simple and unembarrassed manner.

Talking about sexuality is to talk about one's own story, emotions, relationships with other people, customs and desires. As a result it is often a theme that mobilizes. It would appear to be easy, but many people, including health professionals, still find it difficult to accept adolescents and young adults exercising their sexuality as a natural fact and this ends up being one of the principal obstacles to implanting policies and programmes for this audience. An example of these could be an adolescent asking a health professional a question, who in turn does not value the question nor even answer it, but rather changes the subject. Another example could be a teenage girl asking for condoms at the health centre and being told she is too young to be thinking about (and having) sex.

Today, thanks to the progress of science and the efforts of social movements, a lot of things have changed, although unfortunately many others continue to be complicated. This includes believing that one should not talk about sex as this could "encourage" adolescents and young adults to begin their sex lives "prematurely". The understanding needs to be reached that sexuality is not restricted just to the sex act, *since it involves feelings and motivates us to seek physical contact and affection, the intimacy of a relationship, whether or not reproduction occurs. In this sense, our sexuality is a process that began when we were born and will continue until we die*¹.

As such in this chapter we have sought to address some aspects relating to adolescents and young adults living with HIV/AIDS exercising their sexuality, with the aim of assisting professionals who provide care to them.

5.2 Gender identity and sexual orientation

Several aspects of sexuality are social and cultural constructs, as is the case of male and female behaviour. With the exception of biological aspects, standards and behaviours relating not only to sexuality but also to the places men and women occupy in society are learnt. For this reason it is not possible to talk about sexuality and sexual rights without addressing the concept of gender.

Gender is the set of norms, values, customs and practices through which the difference between men and women is given meaning and hierarchized culturally. It involves all forms of social construction of the differences between masculinity and femininity².

The term **sexual orientation** is related to each person's capacity for emotional, affectional and sexual attraction to individuals of a different gender, the same gender or more than one gender. It means the direction taken by a person's desire, i.e. with whom they have pleasure: whether this is a person of the same sex (homosexual), the opposite sex (heterosexual) or people of both sexes (bisexual). Affectional and sexual desire are independent of personal will and for this reason it is inappropriate to use the term "sexual option"².

Gender identity refers to each person's internal and individual experience of gender, which may or may not correspond with the sex assigned at birth or with sexual orientation. It includes the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms. In some cases, people born genetically and phenotypically with the characteristics that define a given sex, may in truth feel like an individual of the opposite sex. For example, a transsexual person is understood to be an individual who was born male but who is psychologically convinced that they belong to the female sex, or a person who is born female but clearly perceives themselves as being of the male sex.

The tenth and current version of the International Classification of Diseases (ICD 10) does not include homo or bisexuality as illnesses. They therefore cannot be treated or cured³.

Health professionals should exercise their profession without prejudice, discrimination or stigmatization and should make the most of the time spent with adolescent or young adult patients to get to know them better, since it is only in this way that they will be able to help them integrally. It is important for these patients to feel at ease and to be able to talk with the team members who provide care to them about the various aspects that determine their well-being. Experiences with sexuality and affection are, among other experiences, important points to be addressed.

As such, professionals who maintain follow-up with these patients can, in a timely and private manner, provide openings for them to manifest their doubts, concerns and experiences. Addressing issues regarding relationships of affection, such as dating or “hooking up”, may be a starting point. At this time it is important for professionals to be willing not only to listen but also to dialogue, without demonstrating prejudice they may have in relation to the subject. Once they are comfortable about talking about their relationships, adolescents may feel more at ease to talk about their sexuality and experiences they have had or plan to have.

5.3 Sexual Health and Reproductive Health

The International Conference on Population and Development (CAIRO, 1994)⁴ was a global landmark for the promotion of actions relating to equality between men and women, reproductive planning and STD, HIV and AIDS prevention, among others. The Conference report contains a large number of recommendations for the countries that signed the document with the purpose of ensuring adolescents’ and young adults’ right to education, information and assistance with reproductive health. Efforts were also made to ensure significant reduction in the number of adolescent pregnancies, through programmes involving and qualifying all people, institutions, communities, schools etc. responsible for guiding adolescents and young adults with regard to the sexual and reproductive behaviour.

Another important aspect was the creation of the concepts of sexual health and reproductive health.

Sexual health is the integration of the somatic, emotional, intellectual and social aspects of the sexual being, so as to enrich positively and improve personality, ability to communicate with and love other people. The purpose of sexual health care should be to improve life and interpersonal relationships, and not merely to provide guidance and care relating to procreation and sexually transmitted diseases.

Reproductive health is defined as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so⁴.

From then on the Brazilian Government has recognized that the sexual health and reproductive health of adolescents and young adults are rights that should be ensured so that the exercising of their sexuality be free and protected. In 1999 at the Cairo + 5 review and evaluation meeting, further progress was made with the rights of adolescents and young adults, including the right of young parents in all references to adolescents, guaranteeing their right to privacy, confidentiality, informed consent, education – including sex education in school curricula, sexual and reproductive health information and care⁵.

5.4 Sexual Rights and Reproductive Rights

The Health Ministry's definition of Sexual Rights and Reproductive Rights is as follows^{6,7}:

Sexual Rights and Reproductive Rights relate to many aspects of life: power over one's own body, health, freedom to live one's sexuality, motherhood and fatherhood.

Reproductive rights comprise the basic rights of all couples and all people *to choose how many children they will have, the space of time between having children; the opportunity to have children, to have information and the means to do so, enjoying the highest standards of sexual and reproductive health.* These rights include:

- The right of women and men to be able to decide, freely and consciously, whether or not they want to have children; and if they do want them, at what time in their lives and how many children they wish to have.
- The right to make decisions about reproduction, free from discrimination, coercion or violence.
- The right of men and women to take part with equal responsibilities in bringing up their children.
- The right to have access to quality public health services at all stages of life.
- The right to adopt and to have treatment for infertility.
- The right to have access to scientifically tested and accepted reproductive means, information and technologies.

In turn, **sexual rights** seek to ensure all people's right to:

- Live their sexuality without fear, shame, guilt, mistaken beliefs and other impediments to the free expression of desire;
- Live their sexuality, regardless of marital status, age or physical condition;
- Choose their sex partner without discrimination and with freedom and autonomy to express their sexual orientation;
- Live their sexuality free from violence, discrimination and coercion and with full respect for the integrity of the bodies of other people;
- Practice their sexuality, regardless of whether penetration occurs;
- Insist on practicing safe sex to prevent unwanted pregnancy and sexually transmitted diseases, including HIV/AIDS.

Do you think these "rights" are only for adults? No they're not.

The Sexual Rights and Reproductive Rights of young people living with HIV/AIDS are the same as those of any other young person. They include: the preservation of autonomy, confidentiality and privacy and access to services, regardless of the agreement or presence of their parents or guardians^{6,7,8}.

In this respect, in 2005 the Health Ministry's Technical Area on Adolescent and Youth Health published the document entitled *Marco Legal: Saúde, um Direito de Adolescente*⁷ (Legal Framework: Health, an Adolescent's Right), which includes national and international legislation and agreements supporting adolescents' right to receive information, guidance and care in relation to contraception and other areas of sexual and reproductive health.

Article 74 of Resolution No. 1931/2009 provides that under the Code of Medical Ethics doctors are forbidden to break professional confidentiality relating to patients under the legal age limit, including providing such information to their parents or legal guardians, as long as the minor in question is capable of discerning, save when failure to disclose may cause harm to the patient⁹.

The Brazilian Statute on Children and Adolescents

Article 3 – Children and adolescents shall enjoy all fundamental rights inherent to the human being, without prejudice to the integral protection covered by this Law, and they shall be ensured, by law or by other means, all opportunities and facilities in order to enable their physical, mental, moral, spiritual and social development, in conditions of freedom and dignity¹⁰.

N.B.: The principles set forth in the Statute are the integral protection, the absolute priority and the interest of children and adolescents. As such, the presence or agreement of parents and guardians regarding the exercising of a fundamental right, such as the right to life, freedom, health, physical and moral integrity is not an indispensable condition for accessing these rights, but rather merely desirable, considering the legal responsibilities attributed to the family¹⁰.

It is important to emphasize that the Brazilian Penal Code provides that “rape of a vulnerable person” is having sexual intercourse or practicing other libidinous acts with those aged under 14 (fourteen)¹¹.

Health promotion is not just about ensuring access to quality health services. It involves individual and collective well-being and also depends on other rights being guaranteed, in addition to the right to health. Moreover, in order to promote the health of adolescents and young adults and reduce STD and HIV incidence among them, we need to know the different contexts of risk and vulnerability and assess their ability to protect themselves^{6,7,8,12}.

5.5 Sexuality and living with HIV

In addition to facing the challenges common to this stage of life, adolescents and young adults living with HIV/AIDS also have to deal with prejudice. Discrimination can happen at school, in the street, in families, groups of friends or even in health services. As a result, the majority hide the fact of living with HIV¹².

Universal access to treatment and to prevention strategies has provided people living with HIV/AIDS with improved quality of life, reduced morbidity and mortality, as well as reduced mother-to-child transmission. This has given the epidemic the connotation of being a chronic disease and has brought the perspective of a future for which personal plans can be made. To this end, good treatment adherence and concrete possibilities of social inclusion are fundamental.

With regard to sexuality, it can be seen that just like any other person in this age group, adolescents and young adults need to be accepted by their friends and to feel they can date. However, the fact of living with HIV heightens the fear of being rejected by their peers and girlfriends or boyfriends, especially when they perceive the prejudiced world in which they live, where “having AIDS” is still a stigma.

A big challenge arises when they begin to fall in love, to date and to be interested in the sexual and emotional side of life: how to tell their partner, girlfriend or boyfriend that they are living with HIV?

This is a good opportunity for health professionals who accompany these adolescents and young adults to discuss the subject, helping them to stand up to these new challenges. Care must also be taken to see whether fear of the possible reactions of others is not reinforcing behaviours of isolation and “self-discrimination”. Chapter 3 deals with diagnosis disclosure, including disclosure to other people, and looks in more detail at the care to be taken when addressing this issue.

The *Saber Viver Jovem* Magazine (No. 1 and 2)^{13,14} provides good illustrations of situations like these:

I prepared myself as much as I could to tell them, but when it came to it I froze.
Diana, aged 14 - Rio de Janeiro (RJ)

I'm not going to tell my girlfriend. Not for fear of her ending our relationship, but for fear of her gossiping.
Moacir, aged 16 - Salvador (BA)

It's better to do some probing beforehand to see what the reaction will be. I asked my boyfriend some questions like: 'Would you date a girl who has HIV?' When I finally told him I'm HIV-positive, he wasn't bothered.

Renata, aged 16 - Rio de Janeiro (RJ)

Apart from this, health professionals need to be alert as to whether adolescents or young adults living with HIV/AIDS are only having relationships with other adolescents or young adults who are also living with HIV/AIDS, because they think it's easier or because they do not have to worry about revealing this. The care that needs to be taken in this case, because both of them are HIV-positive, is that prevention may be neglected or be put in second place.

The concept of HIV reinfection needs to be well defined. HIV-infected sex partners having unprotected sex can exchange different types and amounts of viruses. This can imply increase in viral load and transmission of resistant viruses, let alone other STDs.

When a patient requests or gives their consent, health professionals can also answer uncertainties raised by boyfriends, girlfriends or partners, always based on the principles of ethics and common sense, so as to contribute to the harmony of the relationship based on up-to-date information.

5.6 Talking about prevention

All adolescents and young adults living with HIV/AIDS should be reminded that, in addition to HIV infection, there are other diseases that can be caught when having sex. The importance of condom use is therefore justified not only because it prevents HIV transmission from our patients to other people, but also – and of equal relevance – because it prevents STD transmission and HIV reinfection.

They must be counselled to be alert in relation to signs or symptoms suggesting that they may have caught an STD as a result of having unprotected sex, such as sores, discharges (urethral or vaginal), blisters or warts in the anal and/or genital region and, in this case, to seek medical assessment as quickly as possible¹⁵.

It is known that some curable diseases, such as syphilis for example, can progress unfavourably in people living with HIV/AIDS compared to those who do not have this disease. Cases of neurosyphilis can occur earlier and more frequently¹⁵. Other viruses, such as HPV, can also present exacerbated symptoms in cases of immunodeficiency¹⁴. Hepatitis B or C and HIV coinfection deserves special attention, in particular because of being associated with increased death incidence from hepatic causes¹⁶. This is also a reason for making particularly sure that vaccination against hepatitis B is up to date.

It is important for professionals to approach the subject of condom use in a natural and open manner, avoiding moral judgements. This should be the case with all adolescents and young adults, regardless of their HIV status. Adolescents need to feel that they can trust and feel secure with the team that cares for them in order to clear up their doubts and expose their worries. If this is in place, it is easier for young people who trust the members of the health team to seek help when a condom bursts or when it has not been used, so that timely potential prophylactic, diagnostic and therapeutic measures can be taken.

If a professional identifies that an adolescent or young adult has been the victim of sexual violence, in addition to attending to them, referring them to a specialized service for victims of sexual violence and assessing whether to indicate the use of post sexual exposure prophylaxis and emergency contraception^{17,18} (generally up to 72 hours after sexual exposure), according to article 13 of the Statute on Children and Adolescents, they must also inform their parents or legal guardian and the Council of Guardianship (*Conselho Tutelar*) even though in this case it is necessary to break professional confidentiality. This is done with the aim of protecting the adolescent.

5.7 Antiretroviral use as a strategy for preventing HIV transmission

Condom use continues to be indicated as the most effective prevention strategy, since it protects against HIV, other STDs and unplanned pregnancy. Nevertheless, professionals need to be alert

with regard to adherence to treatment and to make the most of this to talk about using antiretroviral drugs as a strategy to reduce HIV transmission, especially in the case of serodiscordant partners¹⁹.

In situations in which a condom comes off, bursts or is not used, post sexual exposure prophylaxis (sexual PEP), which has been indicated for some time now in cases of sexual violence, can also be an HIV prevention alternative for serodiscordant partners. It should be recommended following risk assessment and begun within 72 hours after exposure and is considered to be an alternative for exceptional situations of sexual exposure to HIV²⁰.

In this case, if the health professional considers that the participation of the adolescent's parents or guardians is necessary, it is recommended that the matter be discussed initially with the adolescent, so that they understand the importance of their participation, encouraging them to invite their parents or guardians to take part. In this way the bond of trust is at less risk of being broken^{7,21}.

5.8 Reproductive planning

As we have already seen, from the point of view of health care and the law, adolescents and young adults need to receive adequate care and information about everything relating to this subject. This is a stage at which sexuality is usually very present, together with everything that pervades this experience. Adolescents and young adults still frequently express the opinion that health professionals do not talk about "this subject", denying their sexuality or talking with them in an evasive and superficial manner. The accounts of some adolescents living with HIV illustrate this reality:

"There is no discussion about sexuality, or guidance as to menstruation and the prevention of other STDs."

"The paediatricians do not even talk about condom use."

"The professionals do not consider sexuality and the possibility of adolescent pregnancy."

"When I got pregnant (aged 16), I felt discriminated at the health centre, I had to change doctors".

Health professionals need to be proactive, addressing not only STD/AIDS prevention but also how to practice sexuality in a safe and healthy manner, as well as verifying the existence of the desire to reproduce. Female adolescents need to receive adequate guidance about the most appropriate contraceptive method for each reality and age group, together with condom use (double protection), in addition to assessing pubertal development, menstrual cycles, breast and cervical cancer prevention. It is also important to remember to be alert in relation to possible drug interactions between antiretroviral medication and contraceptives.

Male adolescents also need to be assessed as to their pubertal development and the relationship between this and the speed at which they are growing. It is also important to provide opportunities to clear up uncertainties about changes to the body in this phase. As such, fleeting and non-pathological gynaecomastia may have no significant physical importance, but if adequate information is lacking it may be a cause of great psychosocial discomfort to a teenager. This can be an ideal moment for starting a conversation with them about sexual and reproductive maturation and reproductive planning.

Professionals are frequently questioned by adolescents or young adults living with HIV, regardless of their sex, about the possibility of having children. Placing value on this concern is associated with quality of life and a view of the future and the desire to have children is usually related to the desire to fulfil dreams and have a family. It is fundamental to make clear that harm reduction strategies exist when planning reproduction. Nowadays it is known that if an HIV-positive woman has adequate follow-up in the antenatal period and during childbirth and does not breastfeed, the risk of mother-to-child transmission may be reduced to less than 1%²⁰. The newborn child will also need to be monitored by a doctor and take antiretroviral drugs in the first six weeks of life.

Care must be taken with regard to reducing the risk of horizontal or sexual HIV transmission. Above all this includes planning pregnancy with the infectious diseases doctor in order to choose the best clinical time for someone who is HIV-positive. Conditions such as taking antiretroviral drugs, having

good treatment adherence, undetectable viral load, being free from diseases in the genital tract and having no active opportunistic diseases can significantly reduce the risk of HIV being sexually transmitted, especially to a serodiscordant partner. Detailed guidance on planning pregnancy in a variety of different scenarios, such as seroconcordant and serodiscordant couples, have been published in Supplement III of the 2010 edition of the *Recomendações para Terapia Antirretroviral em Adultos Infectados pelo HIV*²⁰ (Recommendations for Antiretroviral Therapy in HIV-Infected Adults).

It is important to remember that adolescent pregnancy is a phenomenon involving many factors and must not be interpreted as being a public health problem. Pregnant adolescents should receive care from the multiprofessional team during the antenatal period, childbirth and the puerperium, including assessment of situations of sexual and domestic violence and appropriate follow-through with parents, legal guardians, Council of Guardianship (*Conselho Tutelar*), and so on, according to the case in question.

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Chapter 6

Nutritional Assessment of Adolescents living with HIV/AIDS

The aim of nutritional care for HIV-infected adolescents and young adults is to keep body mass at normal weight levels whilst maintaining the speed of growth; to correct nutritional deficiencies and excess weight/obesity; to minimize side effects associated with taking medication and to work on valuing body image.

6.1 Anthropometric assessment

Anthropometric nutritional assessment of adolescents living with HIV/AIDS should be performed at regular intervals and should include the following indicators:

1. Routine weight and height measurement according to standardized methods and comparison with reference values¹.
2. Body Mass Index (BMI) appropriate for age.
3. Skin fold measurements, especially the triceps and below the shoulder blades.

6.1.1 Weight and Height Measurements

Alterations in weight and height over time enable early identification of nutritional deficiencies, weight loss and compromised growth and should be used when monitoring adolescents living with HIV/AIDS, whether or not they are on antiretroviral therapy (ART).

a. Weight

Changes in body weight correspond to calorie intake alterations. Weight is a commonly used anthropometric measure having two main purposes: to determine whether it is in keeping with height, and whether there have been significant changes in a given period.

Body weight and height are closely related. Other factors needing to be taken into consideration when comparing these variables to reference tables are age, sex and body frame (skeleton size).

One evaluation method is to compare the patient's current or usual weight with their ideal weight, according to their age and sex. There are several methods for calculating ideal weight, but the most commonly used are body frame and BMI.

b. Height

Height can enable the assessment of chronic malnutrition and should be measured as accurately as possible. Whenever possible, an individual's weight and build should be appropriate to their height.

c. Weight/Height Ratio

Generally speaking, the parameter for assessing adolescents is BMI appropriate to their age.

6.1.2 Body Mass Index for adolescents (BMI)

BMI, or the Quetelet index, is defined as weight divided by height squared and has a high correlation with body fat. It is considered to be an anthropometric indicator for nutritional evaluation and has been adapted over the years so as to take into account different physiological situations. It is easy to apply and is important because of the information it can provide regarding morbidity.

It enables possible situations of malnutrition to be detected quickly and, in particular, overweight/obesity, thus making possible individual and collective interventions.

$$\text{Calculation: BMI} = \text{Weight (kg)} / \text{Height}^2 \text{ (m)}$$

Brazilian Food and Nutritional Surveillance² has adopted the BMI recommended by the World Health Organization, namely a distribution curve with sex and age percentiles (Table 1)³.

Table 1. BMI distribution in percentiles, by age (10-19 years) and sex

Percentiles	5	15	50	85	95
Age (years)	Underweight	Risk of being underweight	Healthy weight	Risk of being overweight	Overweight
Male					
10	14,42	15,15	16,72	19,60	22,60
11	14,83	15,59	17,28	20,35	23,73
12	15,24	16,06	17,87	21,12	24,89
13	15,73	16,62	18,53	21,93	25,93
14	16,18	17,20	19,22	22,77	26,93
15	16,59	17,76	19,92	23,63	27,76
16	17,01	18,32	20,63	24,45	28,53
17	17,31	18,68	21,12	25,28	29,32
18	17,54	18,89	21,45	25,92	30,02
19	17,80	19,20	21,86	26,36	30,66
Female					
10	14,23	15,09	17,00	20,19	23,20
11	14,60	15,53	17,67	21,18	24,59
12	14,98	15,98	17,35	22,17	25,95
13	15,36	16,43	18,95	23,08	27,07
14	15,67	16,79	19,32	23,88	27,97
15	16,01	17,16	19,69	24,29	28,51
16	16,37	17,54	20,09	24,74	29,10
17	16,59	17,81	20,36	25,23	29,72
18	16,71	17,99	20,57	25,56	30,22
19	16,87	18,20	20,80	25,85	30,72

Source: WHO. Physical status: the use and interpretation of anthropometry. Geneva, 1995³.

6.2 Dietary Assessment

Nutritional dietary assessment should preferably be performed by a nutritionist who should be part of the specialized HIV/AIDS care service. Its purpose is to monitor food and nutrient intake and check whether the amount habitually consumed is meeting the intake needs stipulated for the individual in question. Assessment can be made by using food diaries or 24 hour food charts.

Adolescents at risk of nutritional deficiency can be identified by observing whether they have one or more of the following problems:

- BMI below the 25 percentile²⁵;
- Up to 16 years of age: no weight gain for 3 consecutive months;
- Weight loss >10% in a period of 4 to 6 months – sharp weight loss;
- Weight loss >5% in a 4 week period or associated with dental problems, mouth sores, difficulty in swallowing, nausea and vomiting, opportunistic infections;
- Loss of appetite, reduced food and liquid intake;
- Faeces alteration (colour, consistency, frequency, smell);
- Diarrhoea and/or vomiting for 3 consecutive days;
- Persistent nausea;
- Difficulty in chewing or swallowing, complaints of mouth hurting, presence of mouth sores;
- Presence of chronic disease (e.g.: diabetes);
- Increased serum lipid levels.

Antiretroviral therapy brings the risk of alterations to lipid metabolism and peripheral insulin resistance which, together with nutritional, genetic and lifestyle factors, can cause overweight and obesity. Alterations in glucose, cholesterol e triglyceride serum levels can require, in addition to diet changes and physical exercise, the use of medication.

6.3 Recommendations for energy, protein, mineral and vitamin intake

There are few studies on the energy and protein needs of adolescents living with HIV/AIDS. Based on information published by the Institute of Medicine of the National Academies⁴ and by the World Health Organization⁵, recommended energy intake by children and adolescents with HIV/AIDS should be based initially on the estimated amount for healthy individuals (Table 2). Depending on the stage the disease is at (asymptomatic, symptomatic) or weight loss, additional energy intake is added to the initial estimate (Charts 1 and 2).

Table 2: Energy Recommendation for Girls and Boys aged 9 to 18 (IDR/2002)

Age	Weight	Height	Kcal/day			
	(Kg)	(m)	Sedentary	Not very active	Active	Very active
Girls						
9	29,0	1,33	1.415	1.660	1.890	2.273
10	32,9	1,38	1.470	1.729	1.972	2.376
11	37,2	1,44	1.538	1.813	2.071	2.500
12	41,6	1,51	1.617	1.909	2.183	2.640
13	45,8	1,57	1.684	1.992	2.281	2.762
14	49,4	1,6	1.718	2.036	2.334	2.831
15	52,0	1,62	1.731	2.057	2.362	2.870
16	53,9	1,63	1.729	2.059	2.368	2.883
17	55,1	1,63	1.710	2.042	2.353	2.871
18	56,2	1,63	1.690	2.024	2.336	2.858
Boys						
9	28,6	1,34	1.530	1.787	2.043	2.359
10	31,9	1,39	1.601	1.875	2.149	2.486
11	35,9	1,44	1.691	1.985	2.279	2.640
12	40,5	1,49	1.798	2.113	2.428	2.817
13	45,6	1,56	1.935	2.276	2.618	3.038
14	51,0	1,64	2.090	2.459	2.829	3.283
15	56,3	1,7	2.223	2.618	3.013	3.499
16	60,9	1,74	2.320	2.736	3.152	3.663
17	64,6	1,75	2.366	2.796	3.226	3.754
18	67,2	1,76	2.383	2.823	3.263	3.804

Source: Institute of Medicine, 2002 (adapted)⁴.

Chart 1: Energy Recommendation – HIV/AIDS

Asymptomatic stage = Energy recommendation + 10%
Symptomatic stage = Energy recommendation + 20-30%
Weight loss = Energy recommendation + 50-100%

Source: Institute of Medicine, 2002 (adapted)⁴.

Chart 2: Acceptable Macronutrient Distribution Ranges for Adolescents (IDR/2002)

	Adolescents aged 9-18
Carbohydrates	45%-65%
Proteins	10%-30%
Lipids	25%-35%

Source: Institute of Medicine, 2002 (adapted)⁴.

There is little evidence justifying increased protein intake by individuals with HIV/AIDS⁴. In order to calculate the amount of protein intake for adolescents, multiply the individual's weight by the recommended quantity of proteins expressed in g/kg/day (Chart 3).

Chart 3: Recommended protein intake for adolescents of both sexes

Age (years)	Protein intake (g/Kg/day)
9 – 13	0.95
14 – 18	0.85

Source: Institute of Medicine, 2002⁴.

6.3.1 Mineral and vitamin intake

Food for individuals with HIV/AIDS must provide at least 100% of the recommended amounts of mineral and vitamin intake⁴. Consensus does not exist in the literature regarding the use of nutritional supplements. However, there is evidence that the disease progresses more rapidly and there is greater risk of mortality in people living with HIV who have reduced serum levels of minerals and vitamins with immunomodulatory properties (vitamin C, vitamin B complex, vitamin A, selenium, zinc, magnesium etc.). Health professionals who decide to recommend the use of nutritional supplements must not exceed maximum tolerable intake levels.

6.4 Principal aspects of nutritional assessment and diagnosis

Adolescence should be seen as an important stage for learning about adequate nutrition as a fundamental process for preserving and maintaining one's health. Health teams should assist adolescents in promoting healthy eating habits and lifestyles, whilst not imposing or insisting.

Nutritional assessment, when it is done well, provides elements for preparing nutritional diagnosis, which can be more or less accurate depending on available resources.

Knowing a person's nutritional state enables health professionals to understand some of the body's physical conditions in terms of withstanding the disease as well as enabling a more appropriate nutritional intervention aimed at recovering and maintaining health. The multiprofessional team must have availability, flexibility and sensitivity in order to fully meet adolescents' needs.

6.5 Factors determining eating habits⁶

6.5.1 Social factors

- **FAMILY** – in childhood the family is the first reference providing knowledge about food and about values and taboos associated with food. Changes in interests characteristic of this stage in life can result in breaking away from family eating standards.
- **SCHOOL** – plays an important role in transmitting knowledge relating to nutrition. School meals also create and/or encourage healthy eating habits.
- **WORK** – establishes new meal times, principally for those who are still at school but also working. This may result in missing meals or the possibility of not eating at home.
- **GROUP** – this is the strongest factor at the adolescent stage, since it is linked to personality formation, socialization, identification with other people and new eating habits.
- **MEDIA** – has a great ability to persuade, influencing what food products are bought, introducing food fads and overvaluing body image with idealized standards of good looks. More often than not this causes an inadequate perception of the body and may be associated with eating disturbances.
- **LEISURE/SPORT** – involvement in these activities can alter adolescents' eating habits, increasing nutritional needs and altering eating habits. It is common for main meals, such as lunch and dinner to be replaced by quick snacks and this may compromise nutritional needs at this stage of life.

6.5.2 Individual factors

- **PHYSIOLOGICAL CHARACTERISTICS AND NEEDS** – adequate supply of energy and nutrients is required, principally during the spurt of growth phase in puberty (rapid growth). Given that the time when this spurt takes place varies, it is recommended that average needs should be based more on weight rather than age, as long as weight is within an acceptable range in relation to height.
- **BODY IMAGE** – conflict may occur between the loss of childhood identity and acceptance of bodily changes. Conflicts relating to sexuality may be transferred to food.
- **PERSONAL VALUES AND BELIEFS** – personal experiences can influence food preferences, choices, dislikes and fads.

Various factors are directly or indirectly related to the nutritional status of adolescents living with HIV and AIDS. As such, care should preferably be provided through an interdisciplinary approach. Anaemia, malnutrition, diarrhoea, altered emotional states, vitamin deficiencies, social isolation, as well as personal, family, economic and psychosocial aspects can modify clinical progression of HIV/AIDS.

6.6 Nutritional Counselling

When providing nutritional counselling it is important for professionals to be familiar with the adolescent's or young adult's subjectivities in order to be able to set targets jointly, whether they be short or long term, starting with a planned and well focussed interview. It is fundamental that professionals establish an empathetic relationship, free from judgements or imposition of preconceived ideas. Observing, asking, listening to adolescents' concerns, proposing questions that facilitate reflection and the overcoming of difficulties, providing emotional support and helping with the taking of decisions to adopt measures in the quest for better quality of life are all fundamental aspects of this dialogue.

Including the family or other carers during the nutritional counselling process is also fundamental, since this will be an important facilitator of adherence to treatment, given that adolescents are rarely responsible for preparing their own food.

Food, apart from being an important factor in the recovery of physical well-being, is above all a source of pleasure and this is essential for maintaining quality of life. Educational materials and demonstrations with examples of habitual adolescent practices should be used whenever possible, such as posters, photos, pictures, including food groups and their nutrient composition, to illustrate and facilitate understanding, whilst adapting this to each person's individual needs.

It should be noted that adverse effects may arise from ART use, such as morphological changes (body mass depletion, lipodystrophy, obesity), which can increase anxiety or cause low self-esteem or depression, thus compromising treatment adherence even more.

6.7 Ten steps for improving quality of life

1. Encourage adolescents to regard eating as a pleasurable activity taking place in the company of family members or friends. Avoid eating alone. Ideally they should seek to avoid stress, depression, loneliness and isolation as much as possible. Encourage participation in social activities and support groups.
2. Encourage them to eat at regular intervals, several times a day, even if they're not hungry. Ideally they should have 3 main meals and 3 small snacks in between them per day. They should choose healthy, varied and tasty food.
3. Encourage daily consumption of fruit, vegetables and salad. Preference should be given to those that are in season, making the most of them in a rational manner and ensuring the best vitamin and mineral intake.
4. Ideally adolescents should seek to include on a daily basis food containing animal and vegetable proteins (e.g.: milk and milk products, meat, eggs, beans, soya etc.). Proteins are important for maintaining the health of people living with HIV/AIDS.

5. Consider fibre and wholefood consumption as they are rich in vitamin B complex and minerals. Ideally refined flour and milled rice should be replaced with wholefood products as these preserve nutrients better. Just like wholemeal rice and bread, grains such as beans, chickpea, fruit, salad and vegetables are also very good fibre sources.
6. Encourage reduction of refined sugar in food, as well as soft drinks and sweets in general.
7. Advise on reduced use of salt. Ideally herbs and seasoning should be used to heighten the taste of food.
8. Avoid animal fat. Use olive oil or vegetable oil for cooking and salad dressing.
9. Encourage adolescents to drink at least 2 litres of water a day, whilst avoiding liquid intake during main meals.
10. Encourage adolescents not to make use of alcoholic drinks, cigarettes or drugs of any kind, as they can be harmful to their health as a whole as well as hindering the action of ART.

6.8 Nutritional recommendations for relieving clinical symptoms

Taking ART can cause side effects that can often lead to abandoning treatment. Moreover, opportunistic infections in the oral cavity hamper regular eating, cause pain and difficulty in swallowing. Nutritional strategies can be used to minimize discomfort.

Anorexia/Lack of appetite

- Encourage adolescents to consume their favourite healthy foods.
- Meals should be divided into smaller portions and eaten at more frequent intervals of time (every 2-3 hours).
- Prefer food with high nutrient density.
- Whenever possible, swallow medication with fruit juice or instant drinks.
- Consume soup, broth, mashed food and fruit liquidized with milk, all thickened with energy and protein supplements.
- Avoid drinking liquids during meals.
- Eat in calm and pleasant places.
- Chew food well.

Nausea and vomiting

- Divide meals into smaller portions (eaten 7-8 times a day).
- Keep the person hydrated. Liquids should be drunk in the intervals between meals.
- Eat mostly drier and cold food. Avoid warm or hot food.
- Ice and ice lollies relieve nausea.
- Use food that is easier to digest: rice, boiled potatoes, boiled chicken, yoghurt.

Diarrhoea

- Avoid food rich in insoluble fibres (leaves, fruit with pulp and skin, wholemeal cereals, beans, lentils, peas) and food rich in lipids (fried food, fatty food, nuts, walnuts, peanuts).
- Increase consumption of food rich in soluble fibres (peeled apples, oats, apple bananas, vegetables cooked in water).
- Reduce or avoid food containing lactose (fresh or powdered milk, milk drinks, ice cream, cheese). Yoghurt, ricotta and cottage cheese are generally better tolerated.
- Prefer food cooked in water, grilled or roasted. Food should be prepared using very little vegetable oil.
- Divide meals into smaller portions (eaten 7-8 times a day).
- Keep the person hydrated. Fruit juice should be diluted.
- Avoid consuming food containing caffeine and alcohol.
- Avoid food and sweets containing sucrose (table or commercial sugar).
- If the individual is suffering from colic, avoid food that causes flatulence: carbonated drinks (e.g.: sparkling soft drinks), beans, cabbage, broccolis, cauliflower, onion, hot peppers, chewing gum containing sorbitol, turnip, radish, garlic and sweet peppers.

Difficulty or pain when swallowing

- Choose warm or cold food. Avoid very hot and very cold food.
- Divide meals into smaller portions (eaten 7-8 times a day).
- Prefer liquid or mashed food.
- Avoid highly seasoned, peppery, salty and acidic food.

6.9 Antiretrovirals and food intake⁷**Chart 4: Type of antiretroviral drug and nutritional guidance**

Drug	Nutritional guidance
Nucleoside reverse transcriptase inhibitors (NRTI):	
Abacavir (ABC)	Can be taken with food.
AZT + 3TC	Can be taken with food.
Didanosine (ddI)	Take 1 hour before or 2 hours after meals. Consider reducing by 20-40% if combined with TDF.
Stavudine (d4T)	Cannot be combined with Zidovudine. Can be taken with food.
Lamivudine (3TC)	Can be taken with food.
Tenofovir (TDF)	Can be taken with food. Dosage needs to be adjusted in cases of kidney failure.
Zidovudine (AZT)	Cannot be combined with Stavudine. Can be taken with food.
Non-nucleoside reverse transcriptase inhibitors (NNRTI)	
Nevirapine (NVP)	Can be taken with food.
Efavirenz (EFV)	Take on an empty stomach, preferably at night. Avoid fatty foods.
Etravirine (ETR)	Take after a light meal containing fat. Can be dissolved in water. Cannot be taken together with: Tipranavir/r, Fosamprenavir/r, full dosage of Ritonavir (1.200mg per day), PI without Ritonavir, in addition to other NNRTIs. Care must be taken if combining with Lopinavir/r.
Protease Inhibitors (PI)	
Atazanavir (ATV)	Take with food. Use of Omeprazole and other proton pump inhibitors is contraindicated.
Darunavir (DRV)	Take with food or after meals.
Fosamprenavir (FPV)	Tablets: take with or without food.
Indinavir (IDV)	Can be taken with food. Take plenty of liquid to minimize risk to the kidneys.
Lopinavir/r (LPV/r)	Take with food or after meals.
Protease Inhibitors (PI)	
Ritonavir (RTV)	Take with food or after meals. Oral solutions are only valid for 6 months.
Saquinavir (SQV)	Take with food.
Tipranavir (TPV)	Can be taken with or without food, but preferably with food because of Ritonavir. The capsule must not be broken or chewed.
Fusion Inhibitors	
Enfuvirtide (T-20)	Subcutaneous injection sites: arms, outer thigh, abdomen (alternating).
Integrase Inhibitor	
Raltegravir (RAL)	Take with or without food.

Important notes:

1. Always use oral syringes in order to ensure accurate doses of liquid formulations.
2. Always check for medication interactions. See www.hiv-druginteractions.org

Formulae for calculating body surface (BS) in m²:

$$BS = \sqrt{[\text{weight (kg)} \times \text{est. (cm)}] / 3600} \quad (\sqrt{\text{square root}})$$

$$BS = \{[\text{weight (kg)} \times 4] + 7\} / [\text{weight (kg)} + 90]$$

Source: Supplement II (2011) of the 2009 edition of the treatment guide entitled *Recomendações para Terapia Antirretroviral em Crianças e Adolescentes Infectados pelo HIV⁷* (Recommendations for Antiretroviral Therapy in HIV-Infected Children and Adolescents).

6.10 The importance of healthy eating

A healthy diet adapted to individual needs improves CD4 T lymphocyte levels, improves absorption by the intestine, reduces complaints caused by diarrhoea, loss of muscle mass, lipodystrophy syndrome and all other symptoms which one way or another can be minimized or remedied through a balanced diet. Giving guidance on healthy eating helps to improve the quality of life of adolescents living with HIV/AIDS.

Ideally all food groups should be consumed daily to ensure a healthy diet (Chart 5).

Chart 5: Nutrient types, characteristics/functions and food containing them

Nutrients	Characteristics/functions	Food containing them
PROTEINS	<ul style="list-style-type: none"> • Complex molecules comprised of amino acids linked by peptide bonds; • Involved in body and organ cell and tissue formation and maintenance. 	<ul style="list-style-type: none"> • Milk, cheese, yoghurt, meat (poultry, fish, pork, beef), offal, seafood, eggs, leguminous vegetables (beans, soya, chickpeas, peas, lentils); • Nuts (Brazil nuts, hazelnuts, cashew nuts, walnuts).
FATS	<ul style="list-style-type: none"> • Group of organic chemical compounds comprising triglycerides, phospholipids and steroids; • They are alternative sources of energy; • Influence body temperature maintenance; • Transport liposoluble vitamins; • Add taste to food and give a sensation of satiation. 	<ul style="list-style-type: none"> • Olive oil, other oil, margarine (unsaturated); • Butter, lard, cream, mayonnaise, pork crackling. (saturated); • Industrialized ice cream, hydrogenated vegetable fat.
CARBOHYDRATES	<ul style="list-style-type: none"> • Group of compounds formed by carbon, hydrogen and oxygen; • One of the cheapest sources of energy; • Ensure efficient use of proteins and lipids. 	<ul style="list-style-type: none"> • Cereals (rice, sweetcorn, wheat, oats), flour, pastry, pasta, bread, tuber vegetables (potatoes, sweet potatoes, cassava, yam); • Simple sugars.
VITAMINS	<ul style="list-style-type: none"> • Organic substances needed in small quantities for growth and staying alive; • According to their solubility, they are classified as water-soluble: vitamin B complex (B1, B2, B6, B12), folic acid and vitamin C; or liposoluble: vitamins A, D, E and K ; • Although they are not energy sources, they are essential for its transformation; Intervene in metabolism regulation; • Favour immune responses, protecting the body. 	<ul style="list-style-type: none"> • Salad, vegetables and fruit (such as spinach, vinegar plant, Chinese cabbage, rocket, lettuce, pepper (<i>capeba</i>), chicory, palm (<i>guariroba</i>), tomato, beetroot, carrot, pumpkin, <i>jatobá</i>, cashew, hog-plum, apple, papaya, orange...).
MINERALS	<ul style="list-style-type: none"> • Inorganic chemical compounds needed in small quantities for human growth, conservation and reproduction. The most well known are: calcium, iron, magnesium, zinc, iodine; • Contribute to tissue formation; • Intervene in body process regulation; • Favour nerve impulse transmission and muscle contraction; • Take part in maintaining acid-base balance. 	<ul style="list-style-type: none"> • Fruit, salad, vegetables, nuts and some food of animal origin (milk, meat, seafood principally as sources of calcium, phosphorus, iron and zinc).

Adapted from: *Nutrição Clínica no Adulto*, Lilian Cuppari, 2006 (Adult Clinical Nutrition).

Source: *Manual de Rotinas para a Assistência a Adolescentes Vivendo com HIV/Aids*, 2006. (Care Routine Manual for Adolescents Living with HIV/AIDS).

Other nutrients important for a healthy diet are⁶:

Water – is the source of what keeps us alive. It is needed to regulate the body's vital functions, such as digestion, metabolite elimination, to keep the kidneys and intestines working, to control body temperature etc. Water intake should be 2 to 3 litres a day.

Dietary fibres – are generally comprised of indigestible carbohydrates and perform a regulatory function by increasing faeces volume, reducing the time food stays in the intestine and helping intestinal microflora. They are distinguished by their solubility in water, being classified as insoluble and soluble. Adequate daily fibre intake has been associated with the prevention and/or treatment of diseases such as colon cancer, diverticulitis, obesity, diabetes and dyslipidemias.

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Chapter 7

Transition

7.1 Contextualizing “Transition”

As the HIV/AIDS epidemic has progressed over time, the difficulties faced by health teams caring for HIV-positive adolescents have changed. Whereas initially care was directed towards improving diagnosis, prophylaxis and treatment, currently questions such as diagnosis disclosure, living sexuality safely and so on are coming to the surface and becoming relevant. As HIV infection has now taken on the characteristics of a chronic disease, a new discussion issue has appeared among adolescents, their families and professionals involved in caring for this group, namely: the transition of these young people, most of whom are cared for by paediatricians, to services for adults.

This moment has been accompanied by difficulties among the various people involved in the process. Having “grown up with a certain health team” makes many young people reluctant to undergo this transition, not to mention their families and the professionals involved^{1,2}.

Some young people do not explicitly refuse, but the difficulty they are having becomes evident when they do not turn up for their appointments at the service to which they have been referred, thus interrupting their follow-up or treatment.

The ties these young people have with the paediatric team take on the characteristics of family ties and changing from one health service to another can result in the threat of breaking important emotional links^{1,2}.

“It’s like a family here, I feel they like me and care about me... she’s not just a doctor... she’s a bit like a teacher... a mother, I don’t know”. (J, male, aged 19)

Owing to the disease’s characteristics, many of these adolescents have already lost family members (mother, father, brother, sister) and the health professionals who have accompanied them since childhood form the link (that they do not want to lose) with that cherished memory.

Many report not feeling prepared for this moment and manifest their concerns. As they have not yet completely developed an active role in caring for themselves, they feel overburdened by the perspective of being responsible for making their own appointments, understanding test results, medical prescriptions and dealing with complex medication.

*“...I’ll have to take on more responsibility, I’m not ready, I’m still an adolescent”.
(M, female, aged 18)*

In addition, having had little contact with the new team who will care for them at the adult service generates feelings of anxiety and fear of the unknown.

“I’m so attached to all of you... I don’t know what she (the new doctor) will be like... If I’ll be able to win her over, if I’ll be able to get on well with her...” (C., female, aged 19)

This threat can be experienced by the various people involved and can be seen not only in the words of the young people but also in the attitudes of the paediatric team which is often reluctant to “let them go”.

The same happens with the families of these young people who are used not only to taking part in paediatric appointments, but also frequently being their key players. For this reason they are afraid of being excluded from follow-up and losing control over their now grown-up children’s state of health.

Therefore, the change of follow-up from one health service to another requires considerable ability to adapt to new situations. As such, setting up a transition clinic has become one of the current challenges in caring for this group.

7.2 Understanding health service transition

Transition can be understood to be an intentional and planned process covering medical, psychosocial, vocational and educational needs of adolescents and young adults with chronic diseases or conditions, when they change from a paediatric to an adult health service³. It is important to recognize that this transition is just part of a set of broader educational, personal, family and social transitions adolescents go through.

7.2.1 Transfer or transition?

The importance of differentiating between the terms “transfer” and “transition” needs to be emphasized⁴. Transfer is removing a person from one place to another and is therefore considered as a mere event. On the other hand, transition is understood to be a process of a change in life experienced by patients, their families and health professionals, involving devising strategies to increase the possibility of success. Within the context of health, the word transition therefore has a connotation of a psychological process of adaptation to a situation of change or rupture⁵.

Badly planned transition can be associated with increased risk of failure to adhere to treatment and follow-up at health services. This fact can have disastrous consequences, such as clinical complications, disease progression and consequent increase in mortality, as well as social and educational repercussions⁶.

7.3 They have grown up... When is the time for adolescent transition?

It is extremely important for health services caring for adolescents with HIV/AIDS to have a transition programme which meets the needs of each person in an individualized manner and has a designated person in charge⁷. The time for transition differs for each family and depends on factors such as adolescents’ “readiness” or preparation, family dynamics and can be more complex in those with poorer health conditions^{8,9}. Although some services use patients’ age as the basis for transition (18-20 years) or parallel social landmarks, such as completing high school, these should not be considered to be definitive parameters^{6,10}.

Adolescents’ transition to adult health services should be a gradual process, not determined only by age but also by each adolescent’s particularities. There must be planning involving adolescents, family members and paediatric and adult health service teams.

7.4 What should be considered when assessing adolescents’ preparedness for this change?

There are certain aspects that need to be assessed in order to achieve adequate transition, especially young people’s ability to take on responsibility for their own treatment, prior involvement in managing their illness, demonstration of responsibility and independence¹¹. It is important to assess and discuss with these young people whether they are living their sexuality safely, if they plan to study more and what job they want to do in the future, if they are capable of attending appointments without being accompanied, if they have autonomy to contact the health service to make appointments for consultations and tests and if their family supports them financially⁹.

It is important to assess whether adolescents:

- Are able to identify signs or symptoms and describe them to the health team;
- Know when to go to the medical service on a routine or emergency basis;
- Are capable of making their own appointments and changing the time of them when necessary;
- Go on their own to appointments at the right time;
- Ask for prescriptions correctly before their medication runs out;
- Understand what their tests mean for their follow-up;
- Understand the importance of good adherence in all its dimensions;
- Make prior contact with the team that will be seeing them.

7.5 How should transition take place?

There is no single model for setting up a transition programme. Furthermore this issue has been the subject of considerable discussion by various specialties caring for chronic diseases^{12,13}. Whilst respecting the characteristics of each service, the transition programme should be structured according to certain basic recommendations:

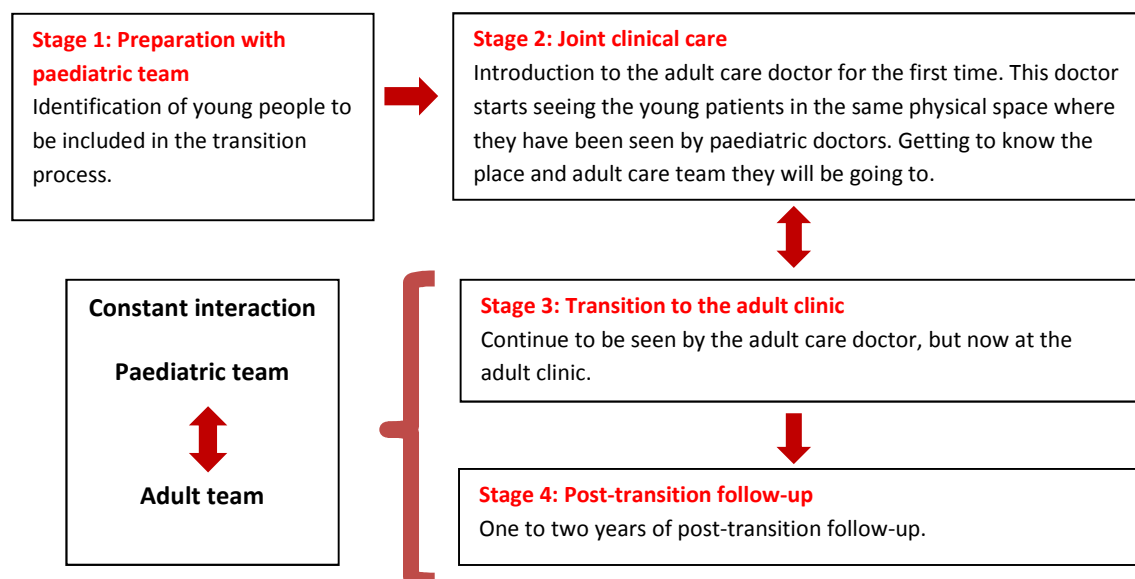
- Services must be flexible and be focussed on young people's needs;
- The teams involved need to discuss specific transition policies, including systematic evaluation of procedures and flexibility to change;
- Young people should not change from one service to another unless they are ready to attend adult services and have already gone through the stage of growth and puberty;
- A professional from the paediatric team together with a professional from the adult care team should be responsible for managing transition;
- Good communication and integration between the two services is needed;
- It is recommendable for the paediatric service to have a transition readiness assessment form for each adolescent, taking into consideration aspects such as: how they live their sexuality, school situation, employment situation, self-care ability, adherence to treatment and follow-up, family support, inclusion in social support networks like the National Network of Young People Living with HIV/AIDS. This form should be forwarded to the adult care service along with a summary of their clinical and laboratory data right from the beginning of follow-up;
- It is important to emphasize that planning transition needs to be seen as a key component for the quality of health services during adolescence.

7.5.1 Transition process stages

The following suggested model can be adapted to the conditions of each place and the teams and services involved in the transition process of these young people^{2,12}. The strategy used by the model is that of gradually introducing adolescents to the idea that they will be cared for by a new team in a new environment and that during this period an assessment will be made of their maturity to take on responsibilities and perceive the importance of a new role in caring for themselves.

The model has 4 stages, with flexibility between each of them. This means that if any difficulty is detected at a given stage, nothing prevents unresolved issues from a previous stage being returned to (Figure 1).

Figure 1: Flowchart of the transition process of adolescents with HIV/AIDS from a paediatric clinic to an adult clinic (adapted from Machado *et al.*, 2010)².



There is no set age for going through each of these stages. Nevertheless, taking into account individual variations, certain ages can be considered solely for the purpose of establishing routines in the services. For example, the age of 16 can be used as an approximate time for starting discussions about future transition with adolescents and their families (Stage 1), whilst also taking into consideration institutional variations. As such, a transition programme begins with the identification of young people aged around 16 and with initially addressing this subject with them and their family during paediatric consultations (Stage 1). As a suggestion, with effect from this period, the transition form can start to be part of the patients' records.

Stage 2 corresponds to a period of joint clinical care, i.e., adolescents get to know the adult care doctor who will be caring for them and this doctor will see them in the same physical space they are used to frequenting, as part of an interaction between the paediatric and adult care teams. During this stage it is recommended that a member of the paediatric team accompanies the young people on a visit to the new service they will soon be attending so that they can also be introduced to the other members of the adult care team. The duration of this joint clinical care stage should be considered on an individual basis, although the accounts of some services suggest that this stage can vary between 6 and 36 months.

Once the teams involved consider that each adolescent is ready to take on responsibility for their own care, they can then be attended to at the adult care service (Stage 3). Before this change takes place, it is important that there be few pending issues in relation to treatment adherence, understanding the parameters used for follow-up (CD4 levels, HIV viral load etc.), living sexuality safely, transport to the health service and other important aspects of their lives referred to above (transition form).

The post-transition period (Stage 4) needs to be considered as an important part of this process, since it is the period of most vulnerability and risk of loss of follow-up if special care is not taken. Maintaining interaction between health teams is of great importance and, as far as possible, these young people should be asked to keep in touch with those responsible for transition at the paediatric service as a means of following up on success or possible difficulties in this new stage of their lives (visits or telephone contact every 4-6 months during the first 24 months after transition). This care can be less necessary if there is regular contact between the teams and discussions between them during the post-transition period of each case in follow-up, ensuring personalized interventions with patients having difficulties with this process.

7.6 Possible barriers in the transition process

- Certain situations have been identified as possible obstacles to successful transition¹:
- Abrupt transferral with little or no preparation;
- Lack of transition planning;
- Resistance by adolescents, family members or the paediatric team itself;
- Longer waiting time for appointments in adult care services after changing from the paediatric service;
- Adult services with little preparation for handling young people with chronic conditions that began in childhood;
- Different approaches to care between paediatric services (which generally offer more support and include families in the care provided) and adult services (greater expectations of individual independence);
- Lack of communication between paediatric and adult services;
- Lack of institutional support.

7.7 Final comments

Adolescent transition from paediatric care to adult services is a process requiring flexibility and interaction between services. It is important for both teams to do prior planning, jointly with adolescents and their families. Transition should not be determined only by age, but also by their preparation and maturity. This should be assessed by the team using the parameters described above.

This time must therefore be dealt with carefully, with the aim of adolescents adapting to the new stage in their care, promoting their adherence to treatment and quality of life.

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