Needs assessment and coping strategies of persons infected with HIV in Egypt

I.A. Kabbash,¹ M. El-Gueneidy,² A.Y. Sharaf,² N.M. Hassan¹ and A.N. Al-Nawawy³ المتطلّبات التقييمية واستراتيجيات التأقلم للمتعايشين مع فيروس العوز المناعي البشري في جمهورية مصر العربية

إبراهيم علي كباش، ميرفت مصطفى الجنيدي، أميرة يوسف شرف، نديرة منصور حسن، علي نعمان النواوي الخلاصة: استهدفت هذه الدراسة تحديد المتطلبات النفسية الاجتماعية والرعاية الصحية للمتعايشين مع فيروس العوز المناعي البشري ومرض الإيدز، علاوة على تحديد استراتيجيات التأقلم. وقد أجريت الدراسة في ثلاث محافظات في مصر على 153 شخصاً متعايشاً مع الفيروس. وقد جمعت المعطيات من خلال الاستبيان التفصيلي واللقاءات المتعمقة، وبيَّنت أن غالبيتهم قد أرغموا على تغيير أنماط سلوكياتهم الجنسية. كما تكرر التعبير عن الخوف من الوصمة والشعور بالقلق واليأس والإحباط، مما أثر بصورة سلبية عليهم من الناحية النفسية والاجتماعية. ويرى الباحثون أن من شأن حفض مستويات الوصمة وتوفير الدعم النفسي الاجتماعي، أن يساعد المتعايشين مع الفيروس والإيدز على استخدام الأساليب الفعالة للتأقلم مع العقابيل السلبية للعدوى.

ABSTRACT The aims of this study were to identify the psychosocial and health care needs of persons living with HIV/AIDS and to determine their coping strategies. The study was conducted in 3 governorates of Egypt on 153 people infected with HIV. The data were collected using a structured questionnaire and in-depth interviews. The majority of the people had been forced to change the pattern of their sexual behaviour. Fear of stigmatization and feelings of anxiety, hopelessness and depression were frequently reported, resulting in a negative psychosocial impact on the infected person. Decreasing stigma and providing psycho-social support would help people living with HIV/AIDS to utilize effective ways of coping with the negative sequelae of the infection.

Évaluation des besoins des personnes infectées par le VIH en Égypte et stratégies adaptatives de ces personnes

RÉSUMÉ Cette étude avait pour objectifs de recenser les besoins sur le plan psychosocial et en termes de soins de santé des personnes vivant avec le VIH/sida, et de déterminer leurs stratégies adaptatives. L'étude a été menée dans trois gouvernorats d'Égypte auprès de 153 personnes infectées par le VIH. Les données ont été recueillies par le biais d'un questionnaire structuré et d'entretiens approfondis. Il a été constaté que la majorité de ces personnes avaient été contraintes de modifier leur comportement sexuel. La peur de la stigmatisation et les sentiments d'angoisse, de désespoir et de dépression étaient fréquemment évoqués et avaient des répercussions psychosociales négatives sur la personne infectée. La diminution des préjugés et l'apport d'un soutien psychosocial aideraient les personnes vivant avec le VIH/sida à mettre en œuvre des moyens efficaces pour faire face aux suites défavorables de l'infection.

¹Department of Public Health, Social and Preventive Medicine, Faculty of Medicine, University of Tanta, Tanta, Egypt (Correspondence to I. Kabbash: Kabbash-ia@maktoob.com).

²Department of Psychiatric Nursing and Mental Health, Faculty of Nursing, University of Alexandria, Alexandria, Egypt.

³Department of Public Health and Community Medicine, Faculty of Medicine, Al-Azhar University, Cairo, Egypt. Received: 15/04/07; accepted: 19/09/07

Introduction

The AIDS pandemic continues to be an escalating health problem throughout the world [1]. It has drawn attention to global inequalities in access to appropriate health care and the lack of basic human rights [2,3]. While the prevalence has been falling in some countries and advances have been made in treatment and care, the global AIDS epidemic is still an issue of concern [4]. In Egypt, according to the latest data obtained by the end of 2006, the total number of reported people living with HIV/AIDS (PL-HIV) was 934 [5].

Psychological research with PLHIV has reflected a conceptual shift towards perceiving HIV and AIDS as a chronic disease [1,6]. Accordingly, health care providers are required to recognize and address the needs of the growing population of PLHIV [1]. Infected individuals suffer a number of concerns and fears related to future economic security, sexuality, disease transmission, infections, eventual ill health and death [7].

PLHIV need information and counselling services to change high-risk behaviours or to regain or to maintain low-risk activities [1,8]. Studies have pointed out that psychiatric distress/disorders may be reported in a high percentage of PLHIV and that several variables facilitate the onset of emotional disturbances secondary to HIV infection [6,9]. It was reported that anxiety and depression can be present as an enduring clinical syndrome that affects clients' health status and compliance to treatment protocol and can also significantly alter clients' quality of life [6,8]. Thus, the need for coping with such psychosocial morbidity represents a field of specific interest in HIV and AIDS literature [6,9]. Studies show that PLHIV who use denial as a coping strategy suffer greater pain [10], and disengagement or avoidance of the issue has been associated with greater health-related stress [11].

Successful coping for PLHIV is a priority in maintaining their quality of life [8,9]. Accordingly, assessment of clients' needs and coping strategies will allow health care providers to plan an intervention to directly address these needs in a way that accommodates their lifestyles. The aims of this study were to identify the psychosocial and health care needs of PLHIV in Egypt and to determine the coping strategies used.

Methods

Study design and setting

This was a cross-sectional study conducted during the period 1 June 2006 and 30 November 2006. The study was conducted in the 3 governorates of Egypt with the highest number of reported cases of HIV (Cairo, Alexandria and Gharbia governorates).

Subjects

The subjects of the study were 153 PLHIV out of 283 in contact with the health authorities in the above-mentioned governorates. Among those contacted, only those available during the study period and consenting to participate in the study were included. Refusals to take part represented 10%. Table 1 shows the sampling for each governorate. The total number of PLHIV participating in the interviews during the study period rep-

Table 1 Number of reported persons living with HIV/AIDS (PLHIV) in Cairo, Alexandria and Gharbia governorates at 1 June 2006 [5]

Governorate	Total PLHIV	No. interviewed	%	
Cairo	170ª	86	50.6	
Alexandria	69	44	63.8	
Gharbia	44	23	52.3	
Total	283	153	54.1	

^aTotal number was 255 but no contacts were available for 85 persons.

La Revue de Santé de la Méditerranée orientale, Vol. 14, Nº 6, 2008

resented 54.1% of all PLHIV contacted in the above-mentioned governorates.

Tools

The structured interview schedule for needs assessment was developed by the researchers to assess the needs of PLHIV based on Maslow's hierarchy of human needs and a thorough review of the literature [1,6,9,12,13]. Maslow proposed a hierarchy of 5 innate needs in a ladder of motivations, namely physiological (food, water, elimination and sex), safety and security, belonging and love, esteem needs and needs of self-actualization.

The coping scale was developed by Jalowiec and Powers in 1981 [14]. The original scale included 40 questions evaluating the different strategies of coping. One of the questions in the original scale was divided into 2 parts, so the adapted scale included 41 questions. The response to each question was rated as never, rarely, sometimes, quite frequently and always. Answers were scored from 0–4. The scores were reversed in questions that reflected maladaptive coping. The scale included 15 questions measuring problem-focused methods with a total score of 60 points, and 26 questions measuring affective-focused methods with a total score of 104 points. A high score is considered as better coping.

In-depth interviews were also conducted with 10 PLHIV to asses their needs.

In addition, a demographic datasheet was formulated to include items related to the general characteristics of PLHIV such as age, sex, marital status, education, etc.

The content validity of the coping scale and the in-depth interviews was done by 7 experts and modifications were done accordingly. A pilot study was carried out on 15 PLHIV selected randomly to ensure clarity and applicability of the structured interview schedule and coping scale. Test-retest reliability was conducted on 20 PLHIV apart from the original study subjects. The correlation coefficient was 0.73.

Ethical issues

The following ethical procedures were followed. Official approval was obtained before starting the study. The research team exerted no pressure of any kind on the study group to participate in the study. Informed consent was obtained. The interviewees were informed about the place of the interview, which was selected to ensure confidentiality and comfort, and were offered other optional places to avoid any inconvenience. All transportation expenses were refunded. Confidentiality was guaranteed by not writing names on the study tools. Completed sheets were kept securely.

Data collection

Contacts were made with PLHIV according to available data kept by officers of the Egyptian National HIV/AIDS Programme in the study governorates. The contacted persons were asked to participate in the study and attend for interview at the predetermined places. Interviews were conducted either at the office of the Directorate of Health Affairs or at the patient's home, after establishing rapport and trust which took 2–3 sessions for each patient before starting the actual study. The data were collected over a period of 6 months.

Statistical analysis

The collected data were organized and statistically analysed using the *SPSS* software, version 12. The mean and standard deviation (SD) were used. Student *t*-test was used to compare between 2 means, and analysis of variance was used to compare more than 2 means. For categorical variables, the number and percentage distribution was calculated. The level of significance was set at P < 0.05.

Results

Quantitative data

Background characteristics of sample Table 2 shows the characteristics of the sample of PLHIV. Their ages ranged from 16 to 56 years with a mean of 34.93 (SD 10.20) years. The number of years the participants had known their HIV serostatus ranged between 0.1 and 16 years, with a median duration of 3 years. The majority of the PLHIV were males (73.9%) and of urban residence (79.1%). Illiterate persons represented 22.9% of the study sample, while those with university education represented 20.9%. As regards occupation, the highest percentage of PLHIV was skilled manual workers (41.2%). Students represented 7.8%. The majority of the study sample reported having sufficient income for their needs (60.1%). Living with the family was reported by 94.1% and 44.4% were married.

Changes in basic needs

Table 3 shows the changes in basic needs of PLHIV since becoming infected. Concerning nutritional changes, 41.8% reported having increased appetite. The majority of the PLHIV (79.1%) could eat what they wanted. Nearly a third (30.1%) were forced to change their diet. Nausea and vomiting were frequently reported (26.8% and 21.6% respectively). Cough was reported by 50.3%, and 42.5% had troublesome cough. More than half the respondents (54.9%) had dyspnoea on usual effort.

The main excretory complaint was diarrhoea (57.3%), which was frequent among 37.3% and needed treatment in 47.1% of patients. The majority of PLHIV were forced to change the pattern of their sexual behaviour secondary to their HIV infection (79.7%) in terms of frequency of sexual acts or condom use. Only 53.6% had informed their sexual partners about their HIV status.

Table 2 Characteristics of the studied persons living with HIV/AIDS (PLHIV)

Characteristic	PLHIV (<i>n</i> = 153)		
	Mean	SD	
Age (years)	34.93ª	10.20	
Knowledge of serostatus			
(years)	3.26 ^b	2.65	
	No.	%	
Sex			
Male	113	73.9	
Female	40	26.1	
Residence			
Urban	121	79.1	
Rural	32	20.9	
Educational level			
Illiterate	35	22.9	
Primary	38	24.8	
Secondary	48	31.4	
University	32	20.9	
Occupation			
Unemployed	8	5.2	
Manual worker	19	12.4	
Skilled manual worker	63	41.2	
Housewife	23	15.0	
Employee	10	6.5	
White-collar employee	18	11.8	
Student	12	7.8	
Perceived level of income			
Insufficient	58	37.9	
Sufficient	92	60.1	
More than sufficient	3	2.0	
Living accommodation			
Family	144	94.1	
Friends	1	0.7	
Alone	8	5.2	
Marital status			
Married	68	44.4	
Single	53	34.6	
Divorced	11	7.2	
Widowed	21	13.7	

^aRange 16–56 years.

^bRange 0.1–16years.

n = total number of participants.

La Revue de Santé de la Méditerranée orientale, Vol. 14, Nº 6, 2008

Table 3 Changes in basic needs of persons living with HIV/AIDS since becoming infected

•	n = 153)
No.	%
12	7.8
77	50.3
64	41.8
27	17.6
121	79.1
41	26.8
33	21.6
46	30.1
45	29.4
84	54.9
67	43.8
77	50.3
65	42.5
28	18.3
88	57.5
57	37.3
72	47.1
19	12.4
122	79.7
82	53.6
	12 77 64 27 121 41 33 46 45 84 67 77 65 28 88 57 72 19

n = total number of participants.

Social, psychological, work and financial changes and needs

The majority of PLHIV had informed 1 or more persons about their HIV seropositivity (96.7%) (Table 4). Families were informed by 47.7%. Those who informed their spouse only constituted 17.6%. Nearly a half of interviewed PLHIV feel stigmatized by others (51.6%), and 43.1% reported changes in people's view towards them. Nearly twothirds of PLHIV (66.7%) isolated themselves from their community because of fear of stigma. Concerning relatives' behaviour, 44.4% reported change in that behaviour. More than half (53.6%) PLHIV felt useless to their community.

The majority of PLHIV suffered from anxiety (88.9%), angry feelings (86.9%) and feelings of helplessness (79.1%) (Table 4). Despair and lonely feelings were reported by 71.9% and 71.2% respectively. The majority of PLHIV declared that they needed support because of fear that others may know about their HIV infection, and fears about getting ill and suffering from pain (92.2%, 76.5% and 73.9% respectively). Also, Table 4 shows that nearly two-thirds of the sample (64.7%) needed someone to share feelings with.

The majority of PLHIV had no opportunity for recreation activities (83.0%) and did not practise any hobby (80.4%) (Table 4).

Concerning working and financial changes, 43.8% could not perform their work with the same capacity (Table 4). More than half of the PLHIV (64.1%) lost their work ambitions after acquiring the infection. The majority had enough money to have proper nutrition (72.5%). However, 56.2% reported that their financial status had been adversely affected by being HIV infected.

Opinions about health care services

Nearly three-quarters of the PLHIV reported having easy access to needed health care services and drugs (74.5% and 75.2% respectively) (Table 5). Only 34.0% received antiretroviral (ARV) therapy. Among those with a regular intake of drugs, 56.2% reported that the cost was reasonable.

Coping patterns

Table 6 shows the mean coping scores of PLHIV. The mean percentage of the total score of the emotion-focused ways of coping was higher than the problem-focused ones: 60.3% (SD 9.4%) and 51.4% (SD 13.3%) respectively. Age was not found to

Table 4 Social, psychological, work and financial changes and needs of persons living with HIV/AIDS since becoming infected

Variable	Total (<i>r</i> No.	9 = 153) %
Informed others about their HIV		
status		
No	5	3.3
Yes	148	96.7
Spouse only	27	17.6
Whole family	73	47.7
A friend	8	5.2
1 or 2 family members	40	26.1
Stigma and discrimination		
Feel stigmatized	79	51.6
Sensed a change in people's		
view	66	43.1
Isolated him/herself	102	66.7
Relatives' behaviour changed	68	44.4
Feel useless to the community	82	53.6
Feelings associated with HIV		
Anxiety	136	88.9
Anger	133	86.9
Helplessness	121	79.1
Depression	118	77.1
Despair	110	71.9
Loneliness	109	71.2
Needs support because of:		
Fear of others knowing their		
HIV status	141	92.2
Fear of developing disease	117	76.5
Fear of pain	113	73.9
Fear of the future	113	73.9
Fear of death	81	52.9
Other fears	66	43.1
Needs someone to share feelings	s 99	64.7
Recreational activities		
Not practising hobbies	123	80.4
Not having chances for		
recreation and trips	127	83.0
Work and financial changes		
Changed work	41	26.8
Cannot perform work as before	67	43.8
Loss of work ambitions	98	64.1
Have enough money for		-
proper nutrition	111	72.5
Finances adversely affected	86	56.2
n = total number of participants.		

significantly affect the coping pattern. Men had higher mean percentage scores of emotion-focused coping pattern and problemfocused coping than women. However these sex differences were not statistically significant. PLHIV living in rural areas had a significantly higher mean percentage score of emotional-focused coping [64.0% (SD 9.0%)] than those in urban areas [59.3% (SD 9.3%)] (*P* = 0.012). Marital status and occupation were not found to affect significantly the coping pattern of PLHIV. Those with higher income had higher mean coping score [57.9% (SD 9.0%)] than those with insufficient income [55.6% (SD 8.4%)]. However, the difference was not statistically significant.

Results of qualitative data

Qualitative data obtained from in-depth interviews with 10 PLHIV (6 males and 4 females) revealed that they had all received counselling from a trained person on HIV and AIDS after knowing their HIV status.

Sexual needs and changes

Many of those infected did not inform their partners of their HIV-positive status. The main reported reasons were that they had sex with irregular partners they did not know or they were reluctant to inform others about their serostatus for fear of stigma. Most of those interviewed were forced to

Table 5 Opinions of persons living with HIV/	
AIDS about health care services	

Variable	Total (n = 153)		
	No.	%	
Health care accessible	114	74.5	
Drugs accessible	115	75.2	
Receiving antiretroviral therapy	52	34.0	
Need certain drugs regularly	105	68.6	
Cost of drugs reasonable	59	56.2	
n = total number of participants.			

n = total number of participants.

total number of participants

Variable	Problem-focused coping		Emotion-focused coping		Total	
	Mean % score	SD	Mean % score	SD	Mean % score	SD
Age (years)						
< 30	51.7	13.9	59.5	9.5	56.6	9.0
30-	52.2	12.1	60.3	9.0	57.3	8.7
40+	50.3	13.8	61.1	9.8	57.2	9.0
	F = 0.265;	P = 0.768	F = 0.383;	<i>P</i> = 0.683	F = 0.083;	<i>P</i> = 0.921
Sex						
Male	52.1	13.1	60.6	9.3	57.5	8.7
Female	49.2	13.7	59.3	10.0	55.6	9.2
	<i>t</i> = 1.166;	<i>P</i> = 0.246	t = 0.733;	<i>P</i> = 0.464	<i>t</i> = 1.138;	P = 0.257
Residence						
Urban	51.2	12.8	59.3	9.3	56.3	8.7
Rural	52.2	15.2	64.0	9.0	59.7	8.9
	t = 0.387;	<i>P</i> = 0.700	t = 2.558;	$P = 0.012^*$	<i>t</i> = 1.930;	<i>P</i> = 0.055
Marital status						
Married	52.5	13.7	61.1	10.4	57.9	9.4
Not married	50.5	13.0	59.6	8.6	56.3	8.3
	<i>t</i> = 0.918;	P = 0.360	t = 0.945;	P = 0.346	t = 1.146;	<i>P</i> = 0.254
Occupation						
Not working	49.5	13.7	58.4	9.7	55.1	8.5
Manual worker	51.1	14.0	61.4	9.3	57.62	8.9
White-collar employee	55.3	9.2	60.0	9.5	58.3	7.5
	F = 1.627;	<i>P</i> = 0.200	F = 1.409;	<i>P</i> = 0.248	F = 1.442;	<i>P</i> = 0.240
Perceived level of incom	е					
Insufficient	49.1	14.0	59.3	9.2	55.6	8.1
Sufficient/> sufficient	52.8	12.7	60.9	9.6	57.9	9.0
	t = 1.670;	<i>P</i> = 0.097	t = 1.029;	P = 0.305	<i>t</i> = 1.617;	<i>P</i> = 0.108
Total	51.4	13.3	60.3	9.4	57.0	8.8

Table 6 Mean percentage scores of coping strategies of persons living with HIV/AIDS in relation to studied variables

*Statistically significant at P < 0.05.

SD = standard deviation.

change their sexual behaviour. Among married persons, some had divorced or were separated but the majority continued their marital relations with infrequent sexual relations using condoms or complete abstinence for fear of infecting an HIV-negative wife. Some were found to have a regular sexual life without using condoms. Others complained that they were no longer capable of practising sex. Impotence was also one of the reported reasons:

The reason for not having sex is because of financial and psychological problems and the use of condoms.

There has been no sex with my wife at all for a while now.

I have no ability to have sex, and when I do it is infrequent.

Among non-married persons, some reported resorting to masturbation. Others could not have sex because their partners refused after becoming aware of their condition:

I have no desire and when I think of sex I remember my getting infected.

Now I don't have any sex and sometimes I masturbate.

I want to have a serious relationship, but I'm afraid to tell anyone about my situation.

Social needs

Stigma was high among interviewed persons. Although the majority had told someone about their HIV infection, fear that other persons may know was very high. The majority had been accepted by relatives after disclosing their HIV-positive status. The majority of wives of infected persons, after the initial shock period of knowing about the HIV infection, continued marital life and considered this condition a matter that they should cope with as other things from God:

My wife was surprised and shocked. She rejected me and went to her family.

My wife told me if I was bones in a basket, she would not leave me.

She became angry and psychologically upset but later things settled down and she understood the situation.

She understood the situation and insisted on still living with me for the sake of love and the children. She left everything up to Allah.

Some relatives and friends were hostile to PLHIV and severed relationships:

Because they were afraid of infection, they rejected me, cut off relations with me and prevented me from entering their homes and asked my sister to avoid me.

People reject me. They ignore me, saying I have bad morals and that is why I'm infected. They treat me like the plague and are all afraid of me.

At the mosque when they found out, the lady hajja caught me and beat me and said 'You have AIDS, don't enter the mosque again'.

Reported self-stigma was much greater than stigma by others. Interviewed PLHIV preferred to isolate themselves from relatives and friends because they were afraid to infect others; afraid that other people would get to know about the sexual behaviour that led to their getting infected; or afraid that others may notice changes in their health status that may happen secondary to infection:

[Because of] feeling guilty, I feel when others look at my face that they know what I did.

I feel they know my HIV infection and are watching the progress of the infection and disease.

I isolate myself because I'm afraid if people know, my children and family will be stigmatized.

They lacked the needed family support, either through their own choice for fear of family members' reactions or because they cared about not hurting their loved ones who would suffer grief and pain if they knew: I socialize less with others. I put a distance between me and friends for fear of infecting them.

I feel that I did something wrong and people are aware of it.

I feel like I committed a crime and when others look at my face I feel that they know what I did.

I feel that I'm different from other people and I don't deserve to be with them.

I avoid my friends for fear of their knowing about my [HIV] status.

I avoid people. I'm feeling down and I think people speak behind my back and are watching the disease progress.

Fears of PLHIV

Reasons for fear were fear about the future and what will happen when they get ill; concerns about the future of their families and children; fear of lack of financial resources due to increased demands or restricted work activities; fear of getting ill and not finding suitable treatment; fear of rejection from others; fear of the possibility that they will not be able to find ARV drugs in the future or suffer irregular supply of ARV therapy; fear of the unknown.

My only hope is to feel like a normal person.

I'm afraid of getting infected or infecting others.

I'm afraid about the future, afraid that people will know about the nature of my disease and afraid that my daughter could be isolated by others because of me. I'm afraid that the curative treatment will take longer and the awareness of Egyptians continues to be low.

I'm afraid to get sick and be unable to find treatment, and afraid of the scandal.

Financial needs and work conditions

Some interviewees were forced to change their work due to their health condition, which became incompatible with their kind of work. However, the main problem with work among PLHIV was the fact that many of them were unemployed or had irregular jobs. They had financial problems and were afraid that in the future they might not be able to support themselves. Insufficient income was reported as the main problem that prevented PLHIV from having adequate nutrition and health care:

Once I knew I was HIV-positive I felt that my life and future stopped at that point.

My supervisors did not accept me. I was dismissed from work and now I'm sitting at home and the workplace sends me the salary at home.

I changed my work because of feeling tired and exhausted and also due to the appearance of manifestations [of HIV].

I can't concentrate as before. I get angry easily and I'm afraid that if I do hard work I may get sick.

I left my work at the school and stayed at home.

I prefer to rest and avoid heavy work that may affect my health.

My problem is being unemployed and having insufficient income.

Health care and ARV drugs

Interviewed PLHIV reported having good support from the National AIDS Programme staff particularly when in need of major health care services such as surgery. However, some of them suffered from the negative attitude of the physician who informed them about their HIV status. ARV drugs were obtained from the National AIDS Programme free of charge. But they had fears that, for one reason or another, they may not be able to have access to a regular supply of ARV drugs:

I did not receive the viral treatment because I did not perform the required testing at the central Lab in order to get the medications and I'm still in a good state of health.

Hopes

Finally PLHIV felt they still needed to live like others without stigma, fears or stress:

I need good treatment from others, to talk with persons living with HIV like myself and get rid of the stigma. I need work to be able to live and change my house to a place where I can feel comfortable.

I wish from Allah that when I perform the test again I find myself negative or find a curative treatment so I can regain my life as it was before my HIV situation, because every time the follow-up date comes I feel depressed and in pain for many days.

I would like if I could to live in dignity with a spouse when the curative treatment becomes available and I can get *married like any other youth and make my parents happy.*

Discussion

PLHIV are faced with a broad array of physical and psychosocial problems across the trajectory of their illness [15]. The results of this study revealed that HIV infection induces a number of biopsychosocial changes in the life of the infected person. Biological changes such as diarrhoea and dyspnoea were a source of trouble for some PLHIV. As a result, some people were forced to change their work. Along the same theme, Vosvick et al. reported that PLHIV find it challenging to attend to daily tasks of living, participate in moderate to vigorous physical activities or have sufficient energy or vitality to engage in an active social life while managing HIV and AIDS [6].

An important change in biological function was related to sexual behaviour. The majority of PLHIV in the present study were forced to make changes in their sexual behaviour. In this respect, O'Brien reported that some individuals experience a loss of sexual desire and behaviour especially in the early course of HIV [16]. Doubtless, changes in physical health can negatively influence the quality of life of PLHIV. It has been suggested that the impact of HIV is devastating in all measured dimensions of health and its related quality of life [17].

In relation to psychosocial changes, our study revealed that most PLHIV reported experiencing or fearing stigma. Studies continue to show that AIDS is still considered a shameful disease and people look down on those who have it [17,18]. For example, only 1% of Egyptian women have positive attitudes towards PLHIV [19]. In a study among industry and tourist workers in Egypt, the majority did not think PLHIV should be allowed to continue work [20]. Another study among Egyptian secondaryschool students showed that the majority thought PLHIV should not be allowed to continue studying as usual [21]. In a study of public reactions to AIDS, 55.1% agreed that most people with AIDS are responsible for their illness [22].

In Egypt, AIDS has been associated with illegal behaviour and socially unacceptable sexual relations in the minds of many people. Thus, it seems plausible to find the majority of PLHIV in the present study were afraid to admit having a disease linked with prohibited sexual behaviour or illegal acts and preferred to isolate themselves from others. It is interesting to find that fear of stigma rather than actual experienced stigma was remarkably prevalent among the studied PLHIV. Other reasons for selfinduced isolation were fear of infecting others, fear that others will find out about his/her sexual behaviour that led to infection and fear that others may know about HIV infection or notice changes in his/her health status secondary to infection. Consequently, infected persons lacked the needed support from others. As a correlate of this, feelings of loneliness, isolation and need for support were high. Durham documented that feelings of stigmatization among PLHIV resulted in kept secrets, difficulty in reaching out for help from family and friends, social isolation and a sense of being alone, fear of abandonment and a sense of shame and of having done wrong [17].

The predominant psychological stress for PLHIV is "the knowledge and awareness of living with a fatal disease with the potential for rapid, declining course to death" [15]. Accordingly, participants in our study reported many fears related to fear of the disease itself, fear of the future and what will happen when they get ill. In addition, depressed mood and feelings of hopelessness, helplessness and despair were frequently reported by our participants. In this regard, Farber et al. reported that depressed mood was found in 73% of PLHIV [23]. This reflects the considerable emotional burden that is associated with the simultaneous challenges of living with HIV and managing the psychosocial stress associated with it.

In general, individuals develop strategies to manage stress and improve their overall quality of life. Unfortunately, some short-term coping strategies may have longer-term costs in terms of poorer quality of life and are therefore less adaptive [6]. The findings of our study indicated a high level of psychological stress among PLHIV reflected in feelings of stigmatization, isolation, loneliness, depression and despair. Definitely, these feelings make PLHIV unable to engage in problem-focused coping, which includes gathering information and resources, planning, making decisions and taking action to solve or manage the source of stress. Alternatively, they engage in emotion-focused coping, which includes avoidance, escaping, distancing, blaming oneself and others and experiencing feelings of anger, sadness, hopelessness and helplessness. Other studies have reported that emotional distress symptoms, such as depressed mood, inability to express anger, poor support and lack of interpersonal ties, interconnect to play a role in determining the way in which PLHIV respond cognitively and behaviourally to their disease [6,23]. Grassi et al. indicated that active coping strategies were related to lower mood disturbance in PLHIV, whereas avoidant coping was associated with higher emotional stress [9]. In contrast to the results of the present study, Leserman et al. reported that a sample of homosexual HIV-positive men coped with the threat of AIDS by "adopting a fighting spirit, reframing stress to maximize personal growth, planning a course of

action and seeking social support". Further, they found that satisfaction with social support networks was related to more healthy coping strategies, as social support buffers some of the difficulties associated with the threat of AIDS and helps subjects maintain a positive and empowering approach to this disease [7].

Conclusion

HIV infection had a negative psychosocial impact on the infected people in our study. This led them to cope with the stress by using more emotion-focused methods. Perceived or actual stigma and discrimination added to the impact. Decreased stigma and

- Morrow K, Costello T, Boland R. Understanding the psychosocial needs of HIVpositive women. *Psychosomatics*, 2001, 42:497–503.
- Global health sector strategy for HIV/ AIDS 2003–2007. Providing a framework for partnership and action. Geneva, World Health Organization, 2003.
- Coverage of selected health services for HIV/AIDS prevention and care in less developed countries in 2001. Geneva, World Health Organization, 2002 (WHO/ HIV/2002).
- Leading the health sector response to HIV/AIDS. Geneva, World Health Organization, 2003 (WHO/HIV/2002).
- National HIV/AIDS program statistics, 2006. Cairo, Ministry of Health and Population, 2006.
- 6. Vosvick M et al. Relationship of functional quality of life to strategies for coping with the stress of living with HIV/AIDS. *Psychosomatics*, 2003, 44(1):51–8.

provision of different forms of psychosocial support would help PLHIV cope with the negative sequelae of their infection. Current services in Egypt must be adapted to offer counselling and psychological support to PLHIV to help them develop problemsolving skills to deal with the stress of living with HIV.

Acknowledgements

Special thanks are due to Dr Nasr El-Sayed, Assistant Minister of Health, Ministry of Health and Population, Cairo, Egypt and Ms Maha Aon, UNAIDS Country Officer in Egypt for their great efforts to support this work.

References

- Lesserman J, Perkins DO, Evans DL. Coping with the threat of AIDS: the role of social support. *American journal of psychiatry*, 1992, 11(11):1514–20.
- Servellen GV. Persons with AIDS. In: Fortinash KM, Holoday-Worret PA, eds. *Psychiatric mental health nursing*. London, Mosby, 1996:655–65.
- Grassi L et al. Coping styles and psychosocial related variables in HIVinfected patients. *Psychosomatics*, 1998, 39(4):350–9.
- 10. Hart S et al. D. The relationship between pain and coping styles among HIV-positive men and women. *Psychology and health*, 2000, 15:869–79.
- Schmitz MF, Crystal S. Social relations, coping and psychological distress among persons with HIV/AIDS. *Journal of applied social psychology*, 2000, 30:665–83.
- Maslow I. Hierarchy of human needs. In: Schultz D, Schultze S, eds. *Theories of personality: humanistic theory*, 5th ed.

California, Brooks Cole Publishing Company, 1994:275–99.

- Burnard P. The psychosocial needs of people with HIV and AIDS: a view from nurse educators and counselors. *Journal of advanced nursing*, 1993, 18(11):1779–86.
- Jalowiec A, Powers MJ. Stress and coping in hypertensive and emergency room patients. *Nursing research*, 1981, 30(1):10–5.
- Kataoka-Yahiro M et al. Physical and social correlates of perceived psychological support among hospitalized AIDS patients. *Journal of advanced nursing*, 1996, 24(1):167–73.
- O'Brien ME. Physical and psychosocial nursing care for patients with HIV infection. *Nursing clinics of North America*, 1993, 28(2):303–15.
- Durham JD. The changing HIV/AIDS epidemic. *Nursing clinics of North America*, 1994, 29(1):9–18.
- 18. Campbell C et al. Understanding and challenging HIV/AIDS stigma. Durban,

South Africa, University of Kwa-Zulu Natal, Centre for HIV/AIDS Networking (HIVAN), 2006 (http://www.hivan.org.za/ admin/documents/stigma.pdf, accessed 26 May 2008).

- El-Zanaty F, Way AA. Demographic and health survey. Cairo, Ministry of Health and Population and National Population Council, 2005.
- El Sayed N, Kabbash I, Al Gueniedy M. Knowledge, attitudes and practices of Egyptian industrial and tourist workers towards HIV/AIDS. *Eastern Mediterranean health journal*, 2008, 14(5):1126–1135.
- Shokr F. Prevention of HIV/AIDS programme for secondary level students. [PhD thesis]. Cairo, Faculty of Nursing, Ain Shams University, 2002.
- 22. Herek GM, Capitanio JP. AIDS stigma and sexual prejudices. *American behavioral scientist*, 1999, 42:1126–43.
- Farber EW et al. Meaning of illness and psychological adjustment to HIV/AIDS. *Psychosomatics*, 2003, 44(6):485–91.