

Hospital services for people with HIV infection in Flanders: patients' satisfaction

R. COLEBUNDERS,^{1,2} E. BOTTIEAU,^{1,2} V. WILLAEYS,¹
Y. FLEERACKERS,¹ FAN YI HU,¹ E. DE DROOGH,^{1,2}
W. SCHROOTEN,^{1,2} C. DREEZEN¹ & R. KOECK²

¹Institute of Tropical Medicine & ²University Hospital, Antwerp, Belgium

Abstract *Two questionnaire surveys about satisfaction with hospital services were carried out among HIV-infected people in Flanders. In a first survey (CIRCA '93 study) between 1993 and 1995, before highly active antiretroviral treatment (HAART) was available, questionnaires were distributed by HIV treatment centres, general practitioners and HIV support organizations: 315 people with HIV infection completed the questionnaire. The level of patient satisfaction was generally higher with services at university hospitals than at general hospitals. Most patients preferred to be hospitalized in a ward specialized in HIV care. Contact with other HIV-infected patients was generally experienced as supportive. The second survey included 34 patients with HIV-infection and 83 patients with lung disease. They were admitted to the same ward at the Antwerp University Hospital, between July 1996 and July 1997. Patients with HIV infections were expecting more services than patients with lung disease. Both studies showed that HIV-infected patients wanted to be actively involved in diagnostic and treatment decisions. The multidisciplinary approach, offered by the Antwerp University Hospital, was widely appreciated by patients and could be used as an example for organizing patient care for other diseases.*

Introduction

Caring for hospitalized AIDS patients is particularly challenging. Apart from medical and nursing care, also psychosocial support is required for the patients themselves, their partners, family members and friends. Sometimes prolonged or recurrent hospitalizations are needed. Intravenous (IV) drug users with AIDS need special services including extra psychosocial support and medical care concerning drug-related problems. People belonging to ethnic minorities need assistance in translating and assistance for problems such as poverty, access to medical care, social isolation, immigration, etc.

Certainly in 2000, the need for hospital care is not as important as a few years ago, because of the use of highly active antiretroviral treatment (HAART) (Colebunders *et al.*, 1999; Pallela *et al.*, 1999; Torres & Barr, 1997). The main reasons for hospitalization now are:

Address for correspondence: R. Colebunders, Institute of Tropical Medicine, Nationalestraat 155, B-2000 Antwerp, Belgium. Tel: + 32 3 247 64 26; Fax: + 32 3 247 64 32; E-mail: bcoleb@itg.be

- (1) AIDS-related complications in patients who are not on adequate HAART treatment, either because they are not aware of their HIV status, they decline HAART or are not adherent to their treatment
- (2) complications of HAART
- (3) lymphomas and other tumours
- (4) psychosocial reasons
- (5) medical problems, unrelated to HIV infection

To evaluate the quality of health care, it is important to determine the level of patient satisfaction (Carr-Hill, 1992; Fakhoury *et al.*, 1996; Fitzpatrick, 1991). In this paper, we present the results of two questionnaire surveys among HIV-infected people in Flanders, regarding the level of satisfaction with hospital services, obtained before the introduction of HAART.

Methods

Survey among people with HIV infection in Flanders (CIRCA '93 study)

From 1993 to 1995, before HAART was available, an anonymous questionnaire survey was organized among people with HIV infection in Flanders. Questionnaires were distributed by HIV treatment centres, general practitioners and HIV support organizations. People could participate in the study if they were known to be HIV-seropositive for longer than three months and if they were able to understand and answer all the questions unaided. The questionnaire contained many items concerning care. In this paper we only discuss the response on questions regarding hospital experience. In order to obtain maximal cooperation of the major HIV treatment centres, the study participants did not have to disclose the name of the hospital, only the status of the hospital was defined.

Survey among hospitalized persons with HIV infection, hospitalized at the Antwerp University Hospital

From July 1996 to July 1997 an anonymous questionnaire was distributed to all patients with HIV infection, at the moment of discharge from the Antwerp University Hospital. For every person with HIV infection two control patients admitted for lung disease, who left the hospital the same or the next day, were chosen. If more patients with lung disease were discharged than patients with HIV infection, those patients with lung disease were chosen that most closely matched the patients with HIV infection (concerning sex, age and ethnicity).

At the Antwerp University Hospital, people with HIV infection and lung diseases are admitted to the same ward (ward B2). Only a quarter of the patients on the ward are patients with HIV infection. Patients with HIV infection are treated by physicians of the Institute of Tropical Medicine, whereas patients with lung diseases are treated by the chest physicians of the Antwerp University Hospital. Both groups of patients had to answer the same questions, but patients with HIV infection were asked to answer additional questions. Excluded from the study were: patients unable to answer the questions unaided, e.g. because of neurological problems or because they were very ill, patients who only stayed one or two days and patients unable to speak Dutch.

Results

Survey among persons with HIV infection in Flanders (CIRCA '93 study)

In the CIRCA '93 study, 315 patients with HIV infection completed the questionnaire. Two hundred and fifty-one (80%) were men, of which 203 (81%) were homosexual or bisexual. During the six months immediately prior to filling out the questionnaire, 115 (36.5%) people reported that they had been hospitalized; 85 (74%) of them were men. The last hospitalization was for 74 (64%) of the 115 patients in a university hospital and for 41 (36%) in a general hospital. Fifty-five (48%) had been hospitalized in a single room, 38 (33%) in a two-bedded room and 22 (19%) in rooms with three or more beds.

Seventy-four per cent of the study participants preferred to be hospitalized in a specialized HIV ward if needed. Seventy-two per cent mentioned they would like to be cared for at home for as long as possible and 50% chose 'home' as preferred place to die. Seventy per cent mentioned they preferred to be hospitalized in a private room. Forty-seven per cent mentioned that, in case they had to be hospitalized in a room with other patients, they would prefer them to be other HIV-positive patients.

Satisfaction with nursing care was significantly higher in university hospitals: e.g. 32% of the patients found that nurses in general hospitals had a judgemental attitude, compared to only 10% of nurses in university hospitals. Patients mentioned that nurses in general hospitals were more likely to dislike body contact and that they were less experienced with HIV, compared with nurses in university hospitals. Nurses in university hospitals were considered to be friendlier, more respectful and showed more empathy, compared with nurses in general hospitals. However, even in university hospitals, 33% of the patients considered that nurses did not have enough time for them and 39% of patients felt that nurses acted insecure because of insufficient training about HIV infection. Eleven per cent felt that nurses took excessive and useless precautions during nursing care in university hospitals compared with 30% of the nurses in general hospitals, e.g. using gloves while arranging the bed of the patient.

The degree of satisfaction with medical care, confidentiality issues and possibilities to discuss their health problems was significantly higher among patients treated at university hospitals. However, even in these hospitals, 20% of the patients mentioned that they felt they had not participated enough in the decision-making process about the diagnostic work-up and treatment.

Forty-four per cent met another HIV-infected patient during their stay in hospital. Sixty-five per cent of them experienced this contact as supportive and 63% as instructive, 59% as pleasant; however, 27% felt this contact had a discouraging effect and 36% mentioned that it increased their fear. Discriminating comments by other patients or staff during their hospitalization were mentioned by 12% of patients.

A large number of patients (66%) were not satisfied with the quality of the meals, the waiting time prior to examinations (60%) and the noise level in the ward (40%).

Survey among hospitalized patients with HIV infection

During the study period, 112 patients with HIV infection were hospitalized, but the questionnaires were only distributed to 47 (42%) of them. To 44 patients the questionnaire was not distributed, because they did not understand Dutch, 12 because of a neuropsychiatric disorder, two because they were severely ill and five because the duration of hospitalization was too short (< two days). We omitted to give the questionnaire to two patients.

Thirty-four patients with HIV infection (72% of those who received the questionnaire)

Table 1. Questionnaire survey among patients hospitalized at the Antwerp University Hospital: patient characteristics

	Patients with pulmonary diseases (<i>n</i> = 83) Number (%)	Patients with HIV infection (<i>n</i> = 34) Number (%)	Statistics
Men	57 (69%)	32 (94%)	OR = 7,3 (1,5 < OR < 47,6)
Mean age (years)	50	42	t-test = 4,7 (p = 0,93)
Level of education			
Primary school	29 (35%)	5 (16%)	
Secondary school	37 (45%)	20 (58%)	
Higher education	17 (20%)	9 (22%)	
Living alone	12 (14,5%)	19 (56%)	OR = 7,5(2,8 < OR < 20,8)
Belgian nationality	82 (99%)	34 (100%)	

filled in and returned the questionnaire. During the same period also, 83 patients with lung disease filled in the questionnaire. Of the latter patients, 45% presented with chronic obstructive pulmonary disease, 39% lung cancer, 8% pneumonia and 8% another pulmonary disease.

Patients with HIV infection included more men (94%) (Table 1), and were slightly younger than patients with lung disease. More than half of the patients with HIV infection (56%) were homosexual. In general, they had a higher level of education than patients with lung disease. They complained more often about anxiety, 28% versus 16%, and depression, 28% versus 9%. They had slightly more nursing needs: 94% mentioned they required a nurse to help with their personal hygiene versus 76%, 79% needed help to walk in the room or to eat versus 60% of patients with lung disease. Twenty-three per cent mentioned they had serious financial problems, compared with only 5% of the patients with lung disease.

Patients with HIV infection reported more frequent and longer contacts with physicians (Table 2). On the other hand, patients' satisfaction with medical care was similar in both groups. Patients with HIV infection were expecting more services: 38% mentioned they would like to see a physician daily during the weekends, compared to only 15% of patients with lung disease. Slightly more patients with HIV infection mentioned they were actively involved in treatment decisions: 81% versus 62% of patients with lung disease. Patients' satisfaction concerning information given by physicians was similar in both groups. Ninety-seven per cent of patients with HIV infection mentioned they wanted complete and honest information about their health status, compared to 89% of patients with lung disease.

Satisfaction with nursing care (technical competence, psychological support, listening time, respect of privacy) was very high in both groups. Waiting time for the nurse after a call for assistance was short in both groups: 46% of patients with HIV infection and 44% of patients with lung diseases found they had to wait less than two minutes in general; only 8% of HIV-infected patients and 13% of lung disease patients mentioned they had to wait more than ten minutes.

Patients with HIV infection had significantly more often contact with other health care providers: 47% reported contact with a psychologist, 18% with a psychiatrist, 35% with a dietician, 59% with a social worker and 29% with a volunteer. Patients with lung disease had slightly more often contact with a physiotherapist (13% versus 6%). Satisfaction with these other health care providers was very good in both groups.

Patients with HIV infection more often showed a preference for a single room (59%

Table 2. Questionnaire survey among patients hospitalized at the Antwerp University Hospital: frequency of contact with physicians

	Patients with pulmonary diseases (<i>n</i> = 83) Number (%)	Patients with HIV infection (<i>n</i> = 34) Number (%)	Statistics
1. Contact with physician > once daily	14 (17%)	16 (47%)	OR = 3.9(1.5 < OR < 10.6)
2. Contact > 10 minutes daily with physician	10 (12%)	9 (27%)	OR = 2.4(0.8 < OR < 7.4)
3. Daily physical examination	22 (26%)	16 (47%)	OR = 2.1(0.9 < OR < 5.4)
4. Daily contact with physician during weekends	6 (7%)	19 (56%)	OR = 12.4(3.5 < OR < 45.7)

versus 42% for patients with lung disease), and 53% mentioned they preferred to be hospitalized in a ward with only HIV-infected patients.

Discussion

The CIRCA '93 study was conducted between 1993 and 1995, before the use of HAART. This explains the fact that many of the CIRCA '93 participants had a hospital experience during the previous six months. In 1998, the number of patients developing opportunistic infections and the need for hospitalization and palliative care had decreased by more than 50% because of HAART.

Participants in the CIRCA '93 survey were certainly not representative of all people with HIV infection in Flanders: e.g. patients belonging to ethnic minorities and drug users were under represented. Moreover, as the study was coordinated by the Institute of Tropical Medicine, patients with HIV infection followed at the Institute and hospitalized at the Antwerp University Hospital were overrepresented (57% of the study participants received the questionnaire at the Institute of Tropical Medicine). Therefore the comparison of patient satisfaction between university hospitals and general hospitals was mainly a comparison between the hospitalization unit of the Institute of Tropical Medicine and these general hospitals.

CIRCA '93 showed that patients' satisfaction was in general higher at university hospitals than at general hospitals. Most patients preferred to be hospitalized in a ward specialized in HIV care. Contact with other HIV-infected patients was generally considered supportive. This study suggests that care for persons with HIV infection in general hospitals should be improved and that patients with complicated problems should be referred to specialized services.

The survey at the Antwerp University Hospital confirmed that the satisfaction rate of people with HIV infection with nursing and medical care was very high. Both studies show that HIV-infected patients like to be actively involved in diagnostic and treatment decisions.

Patients at the Antwerp University Hospital with HIV infections were expecting more services than patients with lung disease. This can be explained by the fact that people with HIV infection are generally young, well informed about their disease and anxious about their

future and thus more assertive. Moreover, they have often witnessed the death of a partner or a friend.

The patient group at the Antwerp University Hospital included in the survey was not representative of all hospitalized patients with HIV infection: a relatively large number of patients, those belonging to ethnic minorities and/or non-Dutch speaking, were not included in the study. These patients may have had special needs and could have evaluated the quality of care differently. Patients with lung disease were probably also not representative of all hospitalized patients with pulmonary problems.

The CIRCA '93 survey was performed in the pre-HAART period and the survey at the Antwerp University at the moment HAART was introduced. The focus of HIV care was then the treatment of opportunistic infections, symptomatic treatment and palliative care. The situation is very different now. We believe however that the principles to provide optimal care remain the same.

Good communication between patients and health care providers is essential. Certainly with the new antiretroviral therapies this will become even more important in order to obtain good adherence to these therapies. AIDS has changed the relationship between patients and health care providers. This relationship is one of partners with a common goal to fight this disease. The multidisciplinary approach offered at the Antwerp University Hospital was widely appreciated by patients and could be used as an example for organizing patient care for other diseases.

References

- CARR-HILL, R.A. (1992). The measurement of patient satisfaction. *Journal of Public Health Medicine*, 14, 236–249.
- COLEBUNDERS, R., CLUMECK, N., FLORENCE, E., VANDERCAM, B., VAN WANZEELE, F., VAN WIJNGAERDEN, E., LACOR, P., DEMONTY, J. & DE WIT, S. (1999). Safe and effective use of combination antiretroviral treatment. *Acta Clinica Belgica*, 54, 55–60.
- FAKHOURY, W., MCCARTH, M., ADDINGTON-HALL, J. (1996). Determinants of informal caregivers' satisfaction with services for dying cancer patients. *Social Science and Medicine*, 42, 721–731.
- FITZPATRICK, R. (1991). Surveys of patient satisfaction: I—important general considerations. *British Medical Journal*, 302, 887–889.
- PALLELA, F., MOORMAN, A., CHMIEL, J., CHAN, C., DELANEY, K., HOLMBERG, S. & the HIV Outpatient Study (HOPS) Investigators (1999). Continued decline in morbidity and mortality among patients with advanced HIV infection receiving highly active antiretroviral therapy (HAART). Chicago Conference, 31 January—4 February, Abstract 689.
- TORRES, R.A. & BARR, M. (1997). Impact of combination therapy for HIV infection on in-patient census. *New England Journal of Medicine*, 21, 1531–1532.