HOSPITAL SERVICES FOR PEOPLE WITH HIV INFECTION IN FLANDERS: PATIENTS' SATISFACTION

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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 organisations: 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 hospitalised in a ward specialised 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 multi-disciplinary approach, offered by the Antwerp University Hospital, was widely appreciated by patients and could be used as an example for organising patient care for other diseases.
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INTRODUCTION

Caring for hospitalised AIDS patients is particularly challenging. Apart from medical and nursing care, also psycho-social support is required for the patients themselves, their partners, family members and friends. Sometimes prolonged or recurrent hospitalisations are needed. Intravenous (IV) drug users with AIDS need special services including extra psycho-social 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) (Torres, Barr 1997, Colebunders et al. 1999, Pallela et al. 1999). The main reasons for hospitalisation now are:

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. psycho-social 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 (Fakhoury et al. 1996, Fitzpatrick 1991, Carr-Hill 1992). 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 organised among people with HIV infection in Flanders. Questionnaires were distributed by HIV treatment centres, general practitioners and HIV support organisations. 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 hospitalised persons with HIV infection, hospitalised 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 ¼ 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%) homosexual or bisexual. During the 6 months immediately prior to filling out the questionnaire, 115 (36.5%) people reported that they had been hospitalised, 85 (74%) of them were men. The last hospitalisation 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 hospitalised in a single room, 38 (33%) in a two-bedded room and 22 (19%) in rooms with three or more beds.

Seventy-four percent of the study participants preferred to be hospitalised in a specialised HIV ward if needed. Seventy-two percent 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 percent mentioned they preferred to be hospitalised in a private room. Forty-seven percent mentioned, that in case they had to be hospitalised 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 judgmental 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 percent 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 percent met another HIV infected patient during their stay in hospital. Sixty-five percent of them experienced this contact as supportive, sixty-three percent as instructive, fifty-nine percent as pleasant, however, twenty-seven percent felt this contact had a discouraging effect and thirty-six percent mentioned that it increased their fear. Discriminating comments by other patients or staff during their hospitalisation were mentioned by twelve percent of patients.

A large number of patients (66%) was 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 hospitalised patients with HIV infection**

During the study period, 112 patients with HIV infection were hospitalised, 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, 2 because they were severely ill and 5 because the duration of hospitalisation was too short (< 2 days). We omitted to give the questionnaire to 2 patients.

Thirty-four patients with HIV infection (72% of those who received the questionnaire) 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%) was 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 percent 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 percent 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 10 minutes.
Patients with HIV infection had significantly more often contact with other health care providers: 47% reported a 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% versus 42% for patients with lung disease) and 53% mentioned they preferred to be hospitalised at 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 hospitalisation and palliative care, has decreased with more than 50% because of HAART (3).

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 co-ordinated by the Institute of Tropical Medicine, patients with HIV infection followed at the Institute and hospitalised at the Antwerp University Hospital were over-represented, (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 hospitalisation 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 hospitalised in a ward specialised in HIV care. Contact with other HIV infected patients was generally considered as 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 specialised 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 hospitalised 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 hospitalised patients with pulmonary problems.

The CIRCA '93 survey was performed in the pre-HAART period and the survey at the Antwerp University at a 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 multi-disciplinary approach offered at the Antwerp University hospital was widely appreciated by patients and could be used as an example for organising patient care for other diseases.
REFERENCES


Table 1: Questionnaire survey among patients hospitalised at the Antwerp University Hospital: patients' characteristics

<table>
<thead>
<tr>
<th></th>
<th>Patients with pulmonary diseases (n=83)</th>
<th>Patients with HIV infection (n=34)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Men</strong></td>
<td>57 (69%)</td>
<td>32 (94%)</td>
<td>OR=7.3 (1.5&lt;OR&lt;47.6)</td>
</tr>
<tr>
<td><strong>Mean age (yrs)</strong></td>
<td>50</td>
<td>42</td>
<td>T-test=4.7 (p=0.93)</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>29 (35%)</td>
<td>5 (16%)</td>
<td></td>
</tr>
<tr>
<td>Secondary school</td>
<td>37 (45%)</td>
<td>20 (58%)</td>
<td></td>
</tr>
<tr>
<td>Higher education</td>
<td>17 (20%)</td>
<td>9 (22%)</td>
<td></td>
</tr>
<tr>
<td><strong>Living alone</strong></td>
<td>12 (14.5%)</td>
<td>19 (56%)</td>
<td>OR=7.5(2.8&lt;OR&lt;20.8)</td>
</tr>
<tr>
<td><strong>Belgian nationality</strong></td>
<td>82 (99%)</td>
<td>34 (100%)</td>
<td></td>
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</table>
Table 2: Questionnaire survey among patients hospitalised at the Antwerp University Hospital: frequency of contact with physicians

<table>
<thead>
<tr>
<th></th>
<th>Patients with pulmonary diseases (n = 83) Number (%)</th>
<th>Patients with HIV infection (n = 34) Number (%)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Contact with physician &gt;once daily</td>
<td>14 (17%)</td>
<td>16 (47%)</td>
<td>OR=3.9(1.5&lt;OR&lt;10.6)</td>
</tr>
<tr>
<td>2. Contact &gt; 10 min.daily with physician</td>
<td>10 (12%)</td>
<td>9 (27%)</td>
<td>OR=2.4(0.8&lt;OR&lt;7.4)</td>
</tr>
<tr>
<td>3. Daily physical exam.</td>
<td>22 (26%)</td>
<td>16 (47%)</td>
<td>OR=2.1(0.9&lt;OR&lt;5.4)</td>
</tr>
<tr>
<td>4. Daily contact with physician during weekends</td>
<td>6 (7%)</td>
<td>19 (56%)</td>
<td>OR=12.4(3.5&lt;OR&lt;45.7)</td>
</tr>
</tbody>
</table>