Outpatient HIV care in the Netherlands

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Patients’ perspectives on outpatient HIV care in the Netherlands

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Submitted for publication
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Abstract

Background
Responding to patients’ needs and preferences is important in the delivery of outpatient care. Recent and systematically collected data reflecting human immunodeficiency virus (HIV)-infected patients’ opinions on how their outpatient care should be delivered, are lacking. Our aim was to identify aspects of care that are of importance to HIV-infected patients in outpatient care in the Netherlands, and to evaluate to which extent the received care meets their expectations.

Methods
We measured patient preferences and experiences in a nationwide sample of HIV-infected patients using a modified, previously validated questionnaire (QUOTE-HIV).

Results
The aspects of care that were considered most important were: specific expertise of the care provider in HIV medicine, the care provider taking the patient seriously and receiving adequate information about treatment options. In addition, confidentiality of HIV status at the outpatient clinic was a major concern. Patient experiences were positive, with the majority of the respondents indicating that they always or usually received care in accordance with their preferences.

Conclusion
HIV-infected patients greatly value having care providers with HIV-specific expertise. Safeguarding the privacy of HIV status, and the provision of information about treatment options are matters that deserve continuous attention in the delivery of outpatient HIV care.
Introduction

The importance of responding to patients’ needs and preferences (i.e. ‘patient-centred care’) when delivering health care has been widely recognized.\(^1\)\(^3\) In addition to being a goal in itself, evidence suggests that patient-centred care leads to better compliance with medical recommendations and to an improved health status.\(^4\) In HIV-infected patients, patient-centred care has been linked to better adherence to combination antiretroviral therapy (cART) and higher rates of viral suppression.\(^5\)\(^7\) However, recent and systematically collected data reflecting HIV-infected patients’ opinions on how their outpatient care should be delivered, are lacking. Gaining insight in patients’ preferences and experience is important, especially given the fact that the number of HIV-infected patients using outpatient care services is growing, due to their improved survival.

The purpose of this study was to identify aspects of care that are of importance to HIV-infected patients in outpatient care in the Netherlands, and to evaluate to which extent the received care meets their expectations. To this end, we measured patient preferences and experiences in a national sample of HIV-infected patients using a standardized questionnaire.\(^8\)

Methods

Setting and design

In the Netherlands, the care for HIV-infected patients is centralized within designated HIV treatment centres (n=26 at the time of this study), in which outpatient HIV care is provided by HIV specialists (predominantly infectious disease specialists with experience in HIV medicine) and specialised nurses (“nurse consultants”). All treatment centres collaborate with the collection of data for the ATHENA observational cohort and thus all HIV-infected patients in care (with exception of those who opt out, 2%) are registered and monitored in the cohort database.\(^9\)

We conducted a cross-sectional study between July 2013 and December 2014, evaluating patients’ preferences and experiences in a sample of HIV-infected patients in outpatient care in the Netherlands.

Study population and procedures

A nationwide sample of potential participants was selected from the ATHENA database. All HIV-1-infected patients in outpatient care on 25 February 2013, aged 18 or older at time of diagnosis, and using cART for at least 6 months were eligible for participation. We randomly selected samples from each HIV treatment centre in the Netherlands, 1000 patients in total, ensuring a minimum of 20 patients per centre and accounting for the total number of patients in care in each centre (larger samples in larger treatment centres). For the selection, we used the anonymized study ID number assigned to each HIV patient in care in the cohort.
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Selected patients were approached for participation by the nurse consultants during their next outpatient visit, where patients were provided with an information letter and a password for accessing an online questionnaire in Dutch or English. A paper version was also available. The study was exempted from written informed consent by the Medical Ethics Review Committee of the Academic Medical Center of the University of Amsterdam and we considered informed consent implicit when a questionnaire was completed online or a hard copy returned to us.

Patient characteristics

We used the ATHENA cohort database to extract data regarding age, sex, region of origin, socioeconomic status (SES), route of HIV transmission, time since cART initiation and time since diagnosis.

Region of origin was based on the country of birth and grouped into the Netherlands, sub-Saharan Africa (SSA) and other. For the SES we used a classification system previously described by the Netherlands Institute for Social Research. Here, the five classes, based on area codes were recoded as high, middle or low. Route of transmission was categorized as men who have sex with men (MSM), heterosexual contact, or other/unknown.

Outcomes

The Netherlands Institute for Health Services Research (NIVEL) developed a series of questionnaires that measure “Quality of Care through the Patient’s Eyes” (QUOTE) in different patient populations (e.g. asthma, rheumatic disease and frail elderly). In QUOTE questionnaires, both patient preferences and experiences are assessed. To measure preferences, patients give weight to various care aspects, by rating whether statements are “not important”, “quite important”, “important” or “of greatest importance” (e.g. “The specialist should always explain the advantages and disadvantages of any treatment”). Subsequently, experiences are measured by letting respondents indicate whether they “always”, “usually”, “sometimes” or “never” receive care as stated (e.g. “My specialist explains the advantages and disadvantages of any treatment”).

The HIV-specific version of this questionnaire (QUOTE-HIV) was developed in 1999 using focus groups (patients), tested for its psychometric properties, and subsequently tested in a pilot study in the USA. Our aim was to keep adjustments of the instrument to a minimum, but we modified the original QUOTE-HIV questionnaire by removing six statements that we considered no longer applicable (e.g. regarding inpatient care and euthanasia) or difficult to interpret. We also added five statements (concerning the attitude of the care provider, flexibility in care and referral to other disciplines) based on literature review and suggestions of the Dutch Association for people living with HIV. Our final version consisted of 25 statements regarding care provision by the HIV specialist, 21 statements regarding care provision by the nurse consultant, 5 statements regarding general aspects of care and 5 scores (0–100) on specific aspects of care.
Analyses
We used t-tests, Mann-Whitney U tests and Chi² tests, as appropriate, to test for differences in characteristics between respondents and non-respondents. For each statement, we calculated the proportion of respondents who considered it “important” or “of greatest importance”, hereafter jointly referred to as “highly preferred”. We then, among the patients who rated the items as “highly preferred”, calculated the proportions of patients reporting “always”, “usually”, “sometimes” or “never” receiving such care.

Results
Of the 1000 selected patients, 958 patients were eligible for participation (i.e. had not recently died, migrated or switched to another treatment centre). A total of 331 patients from all HIV treatment centres in the Netherlands completed the questionnaire (response rate: 35%). Response rates differed across treatment centres, ranging from 15% to 55%. The proportions of males (85%), patients originating from the Netherlands (77%), and men who have sex with men (MSM) (71%), were significantly higher among respondents than in non-respondents (73%, 50%, 48% respectively). Respondents were significantly older than non-respondents (median of 51 vs. 47 years) and had a significantly higher socioeconomic status (SES), but did not differ with regard to duration of HIV infection or time since cART initiation. The characteristics of the respondents are presented in Table 1.

Table 1. Characteristics of respondents (n=331)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years, median (IQR)</td>
<td>51 (44–58)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>281 (85%)</td>
</tr>
<tr>
<td>Region of origin</td>
<td></td>
</tr>
<tr>
<td>the Netherlands</td>
<td>255 (77%)</td>
</tr>
<tr>
<td>sub-Saharan Africa</td>
<td>28 (8%)</td>
</tr>
<tr>
<td>Other</td>
<td>48 (15%)</td>
</tr>
<tr>
<td>Socio economic status</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>91 (27%)</td>
</tr>
<tr>
<td>Middle</td>
<td>113 (35%)</td>
</tr>
<tr>
<td>Low</td>
<td>119 (36%)</td>
</tr>
<tr>
<td>Transmission risk group</td>
<td></td>
</tr>
<tr>
<td>Men who have sex with men</td>
<td>235 (71%)</td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>77 (23%)</td>
</tr>
<tr>
<td>Other/unknown</td>
<td>19 (6%)</td>
</tr>
<tr>
<td>HIV RNA at participation, &lt;100 copies/ml</td>
<td>319 (96%)</td>
</tr>
<tr>
<td>Time since diagnosis, years, median (IQR)</td>
<td>11 (6–15)</td>
</tr>
<tr>
<td>Time since cART initiation, years, median (IQR)</td>
<td>9 (5–13)</td>
</tr>
</tbody>
</table>
Care providers: high preference issues and experiences

Across the entire instrument, the proportion of respondents rating items as “highly preferred” (i.e. “important” or “of greatest importance”) ranged from 37% to 98%. Figure 1 presents a selection of the items that were most often rated as “highly preferred”, i.e. by 90% or more of the respondents. The items are grouped by type of care provider and in order of priority. The bars show whether the respondents reported their experience as “always”, “usually”, “sometimes” or “never” receiving care as stated.

The aspects of care that were most often considered “highly preferred”, were having a caregiver who is an expert in the field of HIV, and safeguarding privacy of HIV status. Other themes that stood out concerned how the care provider treats the patient (taking the patient seriously, and a sympathetic/involved attitude) and adequate provision of information regarding treatment (advantages and disadvantages, how to take the medication, and possible side effects).

Least often viewed as “highly preferred” were aspects regarding waiting times (37% and 59% for the medical specialist and nurse consultant respectively), being aware of the patient’s situation at home or at work (45% and 62%), discussing the possibility of requesting a second opinion (56% and 62%), and not being disturbed during a consultation with the medical specialist (55%).

A number of themes were considered important specifically for the nurse consultant. These themes were: being accessible by phone (94%), working in close cooperation with other caregivers (93%) and taking sufficient time to talk to the patient (92%).

Overall, most patients who rated items as “highly preferred”, also reported “usually” or “always” getting such care (85–100%). This applies to all the items in the questionnaire. The rates of reporting “sometimes” or “never” receiving care as stated were somewhat higher in statements regarding the provision of information. Specifically, experiences regarding providing information on advantages and disadvantages of treatments and side effects were somewhat less positive. The median scores that respondents gave to their medical specialists and nurse consultants were 93 and 94, respectively (on a scale of 0–100).

General aspects of outpatient care

With regard to priorities in general aspects of care, three themes were covered. The referral to other professionals by HIV care providers was rated as “highly preferred” by 85% of respondents, who gave a median score of 85 for this item. Being able to schedule an outpatient visit at a suitable time was rated “highly preferred” by 73%, and 92% of these patients reported usually or always being able to make an appointment at a suitable time. Extensive opening hours of the department for blood draws was considered a “highly preferred” item by 57% of respondents, and it’s median score was 82. Respondents gave the waiting times at the department for blood draws a median score of 76.
Figure 1. Care provider aspects of care: experiences of top rated statements

Note: Above statements were rated as “highly preferred” (“important” or “of greatest importance”) by ≥ 90% of respondents, and are in order of importance. Bars represent whether these respondents reported their experience as “always”, “usually”, “sometimes” or “never” receiving such care.
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Discussion

This report provides insight into HIV-infected patients’ preferences and experiences in outpatient care in the Netherlands. First, our results show that being treated by care providers with specific expertise in HIV medicine, receiving adequate information about treatment options, and the attitude of the care provider (taking the patient seriously, and a sympathetic/involved attitude) are issues that are considered of greatest importance to HIV-infected patients. Indeed, the three areas ‘provider training and competence’, ‘information and patient education’, and provider attitude have consistently been identified as crucial aspects of care delivery in the general\textsuperscript{1,2} and HIV-specific\textsuperscript{7,12,14} literature on patient-centred care. Statements concerning accessibility (flexibility in care and waiting times) were considered important, but evidently of lower priority in our study population than the earlier mentioned items. Results from previous studies suggest that priorities may vary per patient population. For instance, in a study in patients with five different conditions, de Boer et al. found that the top 10 priorities in patients with diabetes were evenly distributed among provider attitude and information, while rheumatoid arthritis patients prioritized items regarding accessibility of care (rapid referral, availability of provider when discomfort increases).\textsuperscript{15}

Second, our results highlight the fact that confidentiality of HIV status at the outpatient clinic is a major concern for patients. We have no data to verify whether this issue is specific for HIV. However, given the fact that stigma surrounding HIV continues to be a widespread problem,\textsuperscript{16} it is highly probable that HIV-positive patients are particularly concerned about how their care providers handle information regarding their HIV status.

Third, our results suggest that overall, delivery of outpatient HIV care in the Netherlands meets patients’ expectations. There is some room for improvement with respect to waiting times at the department for blood draws and provision of information regarding treatment (in particular: advantages and disadvantages, how to take the medication, and possible side effects).

Strengths and limitations

The strength of this study lies in the fact that we have data from a national sample of HIV-infected patients, in which each of the designated HIV treatment centres in the country is represented. In addition, we used an HIV-specific instrument that was developed together with patients and that measures preferences as well as experiences. Furthermore, to reduce sampling bias that can occur when collecting patient reported data online,\textsuperscript{17} we offered the option of filling out a paper version of the questionnaire.

There are however also important limitations to take into account. Despite efforts to recruit a nationally representative sample of individuals with HIV, patients from the Netherlands, MSM and patients with a higher SES were overrepresented in the respondents. Moreover, the response rate in this study was relatively low (35%),\textsuperscript{11,18} with rates differing considerably across the centres.
There is a possibility that patients’ experiences impacted their willingness to respond. Indeed, previous studies have found an association between more favourable patient perceptions and higher participation rates in health survey studies. However, evidence also suggests that the overall impact of non-response bias may be small, and that increasing participation may not change conclusions of patient perception surveys.

In the absence of a validated instrument applicable to the current era of HIV care, we used an instrument that was developed more than a decade ago and has not been used extensively. Furthermore, since the development of this instrument a lot of progress has been made in the science of measuring the important aspects of the patient care experience. However, in view of the fact that our instrument was developed systematically and jointly with patients, and covers HIV-specific themes that are still relevant, we believe our results have yielded useful information.

**Implications**

Our results underline the importance of providing information that meets the needs and expectations of patients. Receiving adequate information has emerged as a particular area of concern in many previous studies. Our results therefore confirm that those involved with the delivery of care should continuously be engaged with which information patients wish to receive, how this information should be provided and whether the provision indeed meets patients’ needs.

In addition, our data show that confidentiality of patients’ HIV status is of great importance in clinical practice. Practices should consider assessing patients’ specific concerns so that measures to minimize confidentiality breaches can be identified. Examples of such issues include the physical environment (e.g. separating reception area from waiting area), staff-to-staff contact and the manner of ‘calling the patient into consultation’.

Respondents reported positive experiences across all aspects of care covered by the questionnaire. Given that the HIV care system in the Netherlands has a long history of being assigned to providers and facilities with HIV-related experience, these positive results may reflect an overall good quality of HIV care. However, considering that the questionnaire was developed in the beginning of the cART era, the questionnaire may have failed to capture a number of themes that are important to the current HIV-infected population. Acknowledged areas of particular interest may include psychosocial support, patients’ involvement in medical decisions (i.e. ‘shared decision making’) and peer support. In the absence of a gold standard, the HIV care field would benefit from a novel and validated instrument to assess HIV-infected patients’ preferences and experiences. Crucial for the development of such an instrument, is that patients are involved throughout the process. In addition, the development process should be guided by an established framework. One of the ‘patient-centred care’ frameworks that has been used extensively in research is the Institute of Medicine’s six dimensions of patient-centred care.
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The dimensions consist of: (i) respect for patients’ values, preferences and expressed needs; (ii) information, communication and education; (iii) coordination and integration of care; (iv) emotional support – relieving fear and anxiety; (v) physical comfort; and (vi) involvement of family and friends.28

Conclusion
The data in this study reflect HIV-infected patients’ opinions on outpatient care. Care provider expertise and attitude, information, and confidentiality of HIV status stand out as the important aspects of care. Experiences were generally positive with regard to the themes that were addressed, but there is need to develop a new validated instrument that is applicable to the current era of HIV care.
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