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HIV/AIDS

HIV nursing consultants: patients' preferences and experiences about the quality of care

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Aim and objectives. We were interested to find out how human immunodeficiency virus (HIV)-patients judge the quality of care received from their HIV nursing consultants, compared with the care delivered by HIV specialists and general practitioners. Furthermore, we were interested in how the opinions of HIV patients on the HIV nursing consultant compared with the opinions of patients with rheumatic diseases on the care they receive from their specialized nurses.

Background. The role of nurses has changed over the years. For patients with chronic diseases there seems to be an increasing role for nursing consultants in the delivery of care. In evaluating quality of care, patients' views are considered important especially for the chronically ill who can be seen as experts by experience.

Methods. Between February 1999 and June 2000, 250 patients, receiving care from both general practitioner and specialist, received a questionnaire [Quality of Care Through the Patient's Eyes (QUOTE)-HIV] to assess HIV-related quality of care, as perceived by them. Aspects were formulated as 'importance' and 'performance' statements. Items were scored on 4-point scales. A ratio score ($R_{ij} = P_{ij}/I_{ij}$) was calculated by dividing the perceived performance score (P) of an individual patient (i), on a health service (j) by his importance score (I). A comparison was made with patients with rheumatic diseases by using data from the QUOTE-Rheuma.

Results. Patients judged the quality of care from the HIV nursing consultant as predominantly good. Five aspects showed an unfavourable ratio score ($R < 1.0$) which indicates room for improvement. On the dimensions 'professional performance' and 'attitude of the professional' the HIV nursing consultant scores between the general practitioner and the HIV specialist. Patients with rheumatic diseases seemed to be more satisfied than HIV patients with the care from their nurse consultant.

Conclusions. The HIV nursing consultants have an important role in the care of patients infected with HIV. The HIV nursing consultants are judged as good and are ranked in between the general practitioner and the HIV specialist. Given the orientation towards a more integrated care for chronically ill patients, there should be more attention paid to the position of the HIV nursing consultant.

Relevance to clinical practice. In the Netherlands and in the United Kingdom there is a tendency to a greater degree of differentiation of tasks in health care. This study shows that there is room for a position like the nursing consultant and that this is highly valued by patients.

INTRODUCTION

With the introduction of HAART (highly active anti-retroviral therapy) survival for human immunodeficiency virus (HIV)-infected patients has greatly improved and, in the Western world, HIV has become a chronic disease (Rosenbrock et al. 2000). As a result, HIV-infected patients have become regular users of the healthcare system. They consult both their general practitioner (GP) and HIV specialist, which requires good communication between these two physicians.

The Netherlands has a system of shared care for most chronic diseases, including HIV infection, health care consists of a two-tiered system: office-based primary care and hospital-based speciality care. Most HIV patients use both types of care simultaneously (Van der Linden 1997). In general, patients are registered with a GP who, at a certain time after HIV has been diagnosed, will refer the patient to an HIV specialist in one of the country's regional HIV centres. Each of these HIV centres employs one or more HIV nursing consultants (HNCs) who are working in the outpatient department (Danner 1996). HNCs are specialized nurses who provide illness-related information and support patients in coping with their illness, both practically and emotionally.

Patients' views, both positive and negative, are considered increasingly important in evaluating the quality of care (Richards 1999). Negative patient evaluations are relevant because they are indicators of potential opportunities to improve the quality of care (Jung et al. 2002). Moreover, patients' views are crucial for optimizing the coordination of care, particularly when different care providers are involved. Insight into patients' views may help care providers to adapt their consultations with patients as well as the delivery system to suit their patients' needs and preferences better (Wensing & Grol 2000). This is even more true for the chronically ill, who are frequent users of healthcare services and may be considered as experts by experience (van der Waal et al. 1996, Lorig 2002, Thorsteinsson 2002).

The role of nurses has changed over the years (Kesby 2002). Nurses have become an integral part of the multidisciplinary team in planning the care of patients. They are leaders within their own specialities, which has led to an upsurge in clinical nurse specialist posts, with roles such as breast care nurses, pain control nurse and palliative care nurses (Raja-Jones 2002).

We were interested in the role of another specialized nurse, the HNC, within the care of people infected with HIV. How do patients infected with HIV judge the quality of care received from their HNC? How does this compare with the care delivered by HIV specialists and GPs? And how does the opinion of HIV patients about the HNC compare with the opinion of patients with rheumatic diseases about the care they receive from their specialized nurses?

METHODS

This is a cross-sectional study to evaluate the position of the HNC from the patients' perspective. For this study we used the baseline measurement collected from 1999 to 2000 of our longitudinal, prospective study into the quality of care for people infected with HIV. The objective of the longitudinal study is to evaluate the effects of work agreements and of a regular communication strategy between GPs, HIV specialists and HNCs on the quality of health care for people infected with HIV.

Four regional HIV centres (18 HIV specialists and 10 HNCs) in Amsterdam participated in this study and 46 GPs were recruited. The GPs were identified by a survey by the Amsterdam Municipal Health

Service. They were required to have at least five HIV-infected patients in their practice. HIV-infected patients ($n = 446$) from the participating GP practices, who saw a specialist in one of the four participating hospitals, received a letter with information about the study from their GP. Patients who agreed to participate were included in the study after they had returned a signed consent form.

Questionnaire

We developed an HIV-specific section of the QUOTE questionnaire to assess the quality of care from the patient's perspective. This questionnaire which has been described elsewhere (Hekkink et al. 2003), has been shown to possess good validity and reliability with an internal consistency of ≥ 0.80 (Cronbach's alpha). QUOTE questionnaires for several categories of frequent users of health care services like asthma and/or chronic obstructive pulmonary disease patients, patients with rheumatic diseases, patients with severe physical limitations and frail older persons have already been developed (Sixma et al. 1998).

The QUOTE-HIV discusses 27 healthcare aspects: 13 generic items and 14 HIV-specific items. Of these 27 aspects, 23 were used to assess the quality of care for the HNC. These aspects are formulated as 'importance' and 'performance' statements. Patients were asked to rate the importance they attach to the healthcare aspects (1 = not important, 2 = fairly important, 3 = important, and 4 = extremely important) for the GP, HIV specialist and HNC separately. Likewise, patients were asked to rate the perceived performance score (1 = no, 2 = mostly no, 3 = mostly yes, and 4 = yes) for all care providers separately. From these importance and performance scores a ratio score ($R_{ij} = P_{ij}/I_{ij}$) was calculated by dividing the perceived performance score (P) of an individual patient (i), on a health service (j) by his importance score (I). A ratio score of 1.0 or higher indicates a favourable score on the corresponding healthcare aspect. If, for instance, a patient rated the importance with a score 3 (important) and the performance of an aspect with 2 (mostly no), the ratio score of 0.67 (2.0/3.0) would indicate an unfavourable score on that aspect. This means that there is room for improvement.

Because the distribution of the ratio scores was unknown we used the 'bootstrap' procedure (percentile method) with 1000 replications to estimate the standard error and to calculate the confidence intervals of the ratio scores (Efron & Tibshirani 1993). The analyses were performed using STATA 7.0 (Stata Corporation, College Station, TX, USA).

The QUOTE-HIV contains three dimensions on quality: professional performance (seven aspects), attitude of the professional (seven aspects) and organization of care (nine aspects). The HNC is compared with the GP and the HIV specialist on these three dimensions of quality of care. A weighted evaluation score (WES) on a scale from 1 to 10 was calculated for each dimension of the QUOTE-HIV. In formula, $WES = \Sigma R \times I/\Sigma I$, where R is (100 – percentage of patients rating 'no' or 'mostly no')/10 and I is the mean importance score of the aspect.

For the comparison with patients with rheumatic diseases we used the tables in the publication from Temmink et al. (2000a). This study was carried out in transmural rheumatology nurse clinics, where transmural care is defined as patient-tailored care provided on the basis of close collaboration and joint responsibility, between hospitals and home care organizations. The clinics are additional to standard care. Despite their rheumatic diseases, patients included in this study had an adequate capacity for normal activities (class 2 Steinbrocker) and duration of disease of around 11 years. In this study, the QUOTE-rheumatic patients was used, which contains a comparable generic section of the QUOTE questionnaire and a disease-specific section.

This study was approved by the medical ethics committee of the participating hospitals.

RESULTS

General characteristics

Between February 1999 and June 2000, 250 patients from 39 general practices returned the informed consent form. From these patients 226 (90%) actually filled in the QUOTE-HIV questionnaire. From these patients 153 have had contact with their HNC (68%). Patients recently diagnosed with HIV (1–3 years) or who were participating in a medical trial seem to have more contact with the HNC (Table 1).

[TABLE 1]

Quality of care

The mean importance score for the HNC ranges from 3.57 for the aspect 'has special knowledge about HIV' to 2.44 for the aspect 'bring bad news gently' (Tables 2 and 3).

[TABLES 2-3]

For the HNC, there were five health care aspects with an unfavourable ratio score ($R < 1.0$) (Tables 2 and 3). Particularly the aspects 'allows me to ask a second opinion' ($R = 0.82$; 95% CI: 0.72–0.93) and 'can easily be reached by phone' ($R = 0.91$; 95% CI: 0.86–0.95) indicate room for improvement.

For the dimensions 'professional performance', 'attitude of the professional' and 'organization of care' the WES was calculated. The scores for all dimensions are good ($WES > 7.0$) for the HNC as well as the GP and HIV specialist (Table 4). The HNC is ranked between the GP and HIV specialist concerning the dimensions 'professional performance' and 'attitude of the professional'. For the dimension 'organization of care' the HNC scores slightly lower than the HIV specialist.

[TABLE 4]

HIV vs. rheumatic disease consultant

Compared with HIV patients, patients with rheumatic disease are predominantly women, who are older, have a lower level of education and live with a partner or family.

Table 2 shows high importance and performance scores on aspects used in the QUOTE-HIV as well as in Quote-Rheuma (Temmink et al. 2000a). With an importance score of 3.6 for the HIV patients and an importance score of 3.7 for patients with a rheumatic disease the aspect 'take me seriously' is rated as most important by both groups of patients. Waiting for more than 15 minutes in the waiting room is the least important to both HIV patients and patients with rheumatic diseases, with importance scores of 2.5 and 2.4 respectively. Having the opportunity to ask a second opinion and having a specialized nurse who is aware of their situation is more important to patients with a rheumatic disease than to HIV patients.

The performance scores indicate that patients with rheumatic diseases are more satisfied than HIV patients. In particular, the three aspects 'allows me to ask a second opinion', 'being aware of my situation' and 'never let me wait in the waiting room longer than 15 minutes', show large differences between the performance scores of patients with rheumatic diseases (3.4, 3.8 and 3.8) and those of HIV patients (2.0, 2.8 and 3.0).

For the nursing consultant for rheumatic diseases all the mean ratio scores are 1.0 or higher (Table 2), which indicates that on all health care aspects, patients' perceptions are positive.

DISCUSSION

We studied the quality of care delivered by HNCs as perceived and judged by HIV patients. We developed and used for this purpose the QUOTE-HIV, a questionnaire which contains 23 healthcare aspects to assess the quality of care for the HNC from the patients' perspective and which makes a distinction between importance and performance. The overall score of the quality of care was good, and comparable with the quality of care by the HIV specialist and GP. On the dimensions 'professional performance' and 'attitude of the professional' the HNC scored in between the GP and the HIV specialist. Patients with rheumatic diseases seemed to be more satisfied with the care from their nurse consultant than HIV patients, this is reflected in higher performance scores and more optimal ratio scores.

To meet the changing and complex care demands of chronic patients, knowledge of their disease is essential. In our study, for the HNC 'having special knowledge about HIV' is rated as most important to patients. A specialized nurse consultant, like the HNC, seems to fulfil this aspect (ratio score = 1.02). The problems associated with the aspects that indicate room for improvement, have more to do with organization than the ignorance of the HNC, and could be solved by setting up special phone consultation hours, or by devoting some space for the possibility that a patient might require a second opinion during the consultation.

From the 226 patients in our study, 153 (68%) had visited the HNC in the preceding year. This means that a majority of the patients actually had contact with the HNC. This assumes that there is an important role for these consultants in the care for HIV-infected patients.

We are not familiar with the reasons why 73 of the patients did not contact the HNC. These patients can bias our results. There are two possible reasons why patients do not visit the HNC: (i) patients may think that the HNC has no surplus value with respect to the care and information the HIV specialist and/or GP can give; (ii) patients may think that the performance of the HNC is not sufficient and therefore do not visit them anymore. If the first reason is applicable, the importance score of aspects could be rated lower and therefore the ratio scores higher. In the latter situation an overestimation is seen of the performance and ratio score for the HNC and there could be more aspects that need improvement. This bias is more important than the first one and we should be careful to state that the care of the HNC does not need any improvement on aspects with favourable ratio scores.

Although there is always a chance that patients will not criticize their caregivers, we believe that in this specific group of patients, who are known as well educated and critical, this will be of minor influence. This is supported by the fact that there is a wide variation in performance scores, which shows that the patients in our study are willing to criticize their caregiver.

The overall positive judgement of the quality of care by HIV patients reassures us that the HNCs are indeed capable of filling this position. This links on to the concept of transmural nurse clinics (Temmink et al. 2000b). These clinics are often implemented to meet patients' demands for education and counselling; these are care activities, which often receive insufficient attention during medical outpatient clinics. The principal tasks of the specialized nurse at the clinic are providing illness-related information and supporting patients in dealing with the illness. Temmink et al. (2000b) state that the fact that nurses perform tasks in the hospital outpatient clinic as well as in the home setting, might be of importance in improving the communication, cooperation and match between professionals. Schroeder et al. (2000) described a dual role for nurses in ambulatory settings consisting of a coordinating role for the population of chronically ill and a managing role for individuals. Futch and Phillips (2003) state that we must recognize and support nursing as a separate discipline that provides services to the patient which are not provided by any other profession. All these arguments are in favour of the intermediate role of the HNC in our study and health care setting.

Judging from the performance scores, patients with rheumatic diseases seem to be more satisfied with the care of their nursing consultant than people infected with HIV (Table 2). This might be caused by differences in patient characteristics. Prior research in cancer patients has identified a younger age and a high education level as factors positively associated with both preference for participation in treatment decision making and actual participation (Cassileth et al. 1980, Haug & Lavin 1981, Ende et al. 1989, Street et al. 1995). This can explain the differences in judgement of performance scores between HIV patients, who were younger and more educated than patients with rheumatic diseases.

Radwin (2000) held semi-structured interviews with 22 oncology patients, who were clinic patients at the time of the study. From these patients' perspectives, the nurse who delivered excellent care used her or his professional knowledge, established rapport, formed a partnership with the patient and treated the patients as individuals. The nurse was also caring, attentive and provided continuous, coordinated care. Thorsteinsson (2002) concludes that professional caring is the most important part of the quality of nursing care as perceived by individuals with chronic diseases. Although these were clinic patients and therefore not completely comparable with the patients in our study, we recognize that knowledge and attitude of the professional are important to patients.

The HNCs have an important role in the care for patients infected with HIV. Although there is room for improvement for some aspects, these improvements have mainly an organizational character. In the Netherlands and in the UK there is a tendency to a greater degree of differentiation of tasks in health care. For chronic diseases, the positions of practice nurses and nurse practitioners, who have an intermediate role from a medical point of view, are steadily increasing. This study shows that there is room for a position like the nursing consultant and that this is highly valued by patients. The HNCs seem to have an intermediate position between the GP and the HIV specialist. In that position they show their true worth considering the high judgement of the quality of care from HIV patients. Given the orientation towards a more integrated care for chronically ill patients in the Western industrialized countries, more attention should be paid to the position of the HNC.

CONTRIBUTIONS

Study design: CFH, LW, CJY, PJEB; data analysis: CFH, LW, CJY, PJEB; manuscript preparation: CFH, LW, CJY, PJEB.

TABLES

	HIV patients	Rheumatic patients	
	No contact with AIDS nursing consultant (n = 73)	Contact with AIDS nursing consultant (n = 153)	(n = 128)
Sex			
Male	65 (89.0)	137 (89.5)	34 (27)
Female	8 (11.0)	16 (10.5)	94 (73)
Mean age in years (SD)	44.9 (8.1)	43.6 (7.4)	61.2 (14.9)
Risk group			
Bi/homosexual	63 (86.3)	127 (83.0)	n.a.
Heterosexual	6 (8.2)	11 (7.2)	
Homosexual/ex-IVDU	—	5 (3.3)	
Heterosexual/ex-IVDU	1 (1.4)	8 (5.2)	
Missing	3 (4.1)	2 (1.3)	
Mean time since diagnosis of HIV infection in years (SD)	9.5 (4.6)	8.7 (4.4)	n.a.
1–3	3 (4.1)	18 (11.8)	
4–9	36 (49.3)	69 (45.1)	
≥10	31 (42.5)	63 (41.2)	
Missing	3 (4.1)	3 (2.0)	
Highest education			
Primary	5 (6.8)	15 (9.8)	89 (70)
Secondary	38 (52.1)	70 (45.8)	22 (17)
Higher	26 (35.6)	67 (43.8)	16 (13)
Missing	4 (5.5)	1 (0.7)	—
Living situation			
Alone	45 (62)	95 (62)	24 (19)
With partner/family	25 (37)	58 (38)	103 (81)
Missing	1 (1)	—	—
Member of HIV association			
Yes	20 (27.4)	55 (35.9)	n.a.
No	50 (68.5)	96 (62.7)	
Missing	3 (4.1)	2 (1.3)	
Participant of a medical trial			
Yes	7 (9.6)	27 (17.6)	n.a.
No	55 (75.3)	101 (66.0)	
Not applicable	10 (13.7)	22 (14.4)	
Missing	1 (1.4)	3 (2.0)	

Values as presented as n (%) unless indicated. n.a. = not applicable.

Table 1 Patient characteristics

Dimensions on quality (aspect no.)	HNC	GP	HIV specialist
Professional performance (2, 6, 9, 10, 11, 13, 15)	7.5	7.1	8.2
Attitude of the professional (1, 7, 14, 16, 19, 20, 23)	8.3	8.8	8.2
Organization of care (3, 4, 5, 8, 12, 17, 18, 21, 22)	7.7	8.5	7.9

Table 2 Patients' views on quality of care: importance scores, performance scores and ratio scores concerning specialized nurses for HIV and rheumatic patients

My nursing consultant...	HIV (<i>n</i> = 153)			Rheumatic diseases* (<i>n</i> = 128)		
	Importance score (range 1-4)	Performance score (range 1-4)	Ratio score† [95% CI]	Importance score (range 1-4)	Performance score (range 1-4)	Ratio score†
1. ...takes me seriously	3.56 (0.6)	3.62 (0.6)	1.06 (0.3) [1.01-1.12]	3.7 (0.5)	4.0 (0.3)	1.1 (0.2)
2. ...explains my medication clearly	3.24 (0.8)	3.36 (0.8)	1.10 (0.4) [1.03-1.18]	3.6 (0.6)	3.5 (1.1)	1.0 (0.4)
3. ...cooperates well with other social workers	3.27 (0.7)	3.15 (0.9)	0.99 (0.3) [0.95-1.04]	3.3 (0.6)	3.9 (0.5)	1.2 (0.2)
4. ...can easily be reached by phone	3.42 (0.6)	3.00 (0.8)	0.91 (0.3) [0.86-0.95]	3.3 (0.6)	3.8 (0.5)	1.2 (0.3)
5. ...keeps his appointments	3.03 (0.7)	3.26 (0.8)	1.14 (0.4) [1.07-1.22]	3.0 (0.8)	3.9 (0.5)	1.4 (0.6)
6. ...allows me to ask a 'second opinion'	2.80 (1.0)	2.01 (1.1)	0.82 (0.6) [0.72-0.93]	3.3 (0.7)	3.4 (1.0)	1.0 (0.4)
7. ...is aware of my situation	2.69 (1.0)	2.75 (0.9)	1.13 (0.6) [1.05-1.23]	3.4 (0.6)	3.8 (0.5)	1.2 (0.3)
8. ...never lets me wait in the waiting room longer than 15 minutes	2.48 (1.0)	2.96 (0.9)	1.53 (1.0) [1.37-1.69]	2.4 (1.0)	3.8 (0.7)	1.9 (1.0)

Values as presented as mean (SD).

*Temmink *et al.* (2000a).

† $R_{ij} = P_{ij}/I_{ip}$, the ratio (R) on a health service (i) by an individual patient (j) is equal to the (perceived) performance score (P) divided by the importance score (I).

Table 3 Patients' views on quality of care: importance scores, performance scores and ratio scores for the additional aspects of the QUOTE-HIV ($n = 153$)

My HIV nursing consultant...	Importance score, mean (SD)	Performance score, mean (SD)	Ratio score*, mean [95% CI]
9. ...has special knowledge about HIV	3.57 (0.6)	3.51 (0.6)	1.02 [0.98–1.07]
10. ...informs me about the pros and cons of a treatment	3.21 (0.9)	3.18 (0.9)	1.05 [0.99–1.12]
11. ...gives information about the use of my HIV medication	3.33 (0.9)	3.41 (0.8)	1.08 [1.01–1.16]
12. ...works efficiently	3.25 (0.7)	3.25 (0.8)	1.04 [0.98–1.11]
13. ...gives information about possible side-effects of drugs	3.21 (0.9)	3.20 (0.9)	1.06 [0.99–1.14]
14. ...maintains confidentiality about my HIV status	3.50 (0.7)	3.77 (0.5)	1.17 [1.09–1.27]
15. ...keeps me in shape with preventive methods	2.82 (1.1)	2.52 (1.1)	0.99 [0.89–1.09]
16. ...takes enough time to talk to me	3.25 (0.7)	3.42 (0.7)	1.13 [1.06–1.21]
17. ...is organized in such way, I cannot hear conversations at the desk or in the consulting room	3.26 (0.8)	2.68 (1.3)	0.92 [0.82–1.03]
18. ...is always the same person	2.63 (1.0)	2.86 (0.9)	1.27 [1.16–1.39]
19. ...has an open ear for a conversation about euthanasia	3.03 (1.0)	3.12 (1.0)	1.14 [1.02–1.26]
20. ...allows me to check my personal file	3.25 (0.8)	3.16 (1.1)	1.02 [0.94–1.10]
21. ...makes sure I have an appointment within 24 hours	3.27 (0.8)	3.17 (0.9)	1.02 [0.95–1.11]
22. ...makes sure there are no interruptions during a consult	2.90 (0.8)	3.10 (0.7)	1.19 [1.11–1.29]
23. ...brings bad news gently	2.44 (1.0)	3.11 (0.9)	1.42 [1.29–1.56]

* $R_{ij} = P_{ij}/I_{ij}$, the ratio (R) on a health service (j) by an individual patient (i) is equal to the (perceived) performance score (P) divided by the importance score (I).

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