

Research Paper ■

## Information Needs of Health Care Professionals in an AIDS Outpatient Clinic as Determined by Chart Review

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**Abstract** **Objective:** To examine the information needs of health care professionals in HIV-related clinical encounters, and to determine the suitability of existing information sources to address those needs.

**Setting:** HIV outpatient clinic.

**Participants:** Seven health care professionals with diverse training and patient care involvement.

**Methods:** Based on patient charts describing 120 patient encounters, participants generated 266 clinical questions. Printed and on-line information sources were used to answer questions in two phases: using commonly available sources and using all available medical library sources.

**Measurements:** The questions were divided into 16 categories by subject. The number of questions answered, their categories, the information source(s) providing answers, and the time required to answer questions were recorded for each phase.

**Results:** Each participant generated an average of 3.8 clinical questions per chart. Five categories accounted for almost 75% of all questions; the treatment protocols/regimens category was most frequent (24%). A total of 245 questions (92%) were answered, requiring an average of 15 minutes per question. Most (87%) of the questions were answered via electronic sources, even though paper sources were consulted first.

**Conclusions:** The participating professionals showed considerable information needs. A combination of on-line and paper sources was necessary to provide the answers. The study suggests that present-day information sources are not entirely satisfactory for answering clinical questions generated by examining charts of HIV-infected patients.

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Health care workers who treat AIDS patients often encounter difficulties due to the rapid evolution of knowledge about the HIV infection.<sup>1,2</sup> This study examines the information needs of workers caring for

HIV-infected patients, and the adequacy of the resources commonly available to address those needs. As such, this study has potential applications to patient management and to the organization and development of more effective information sources.

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The study of information needs is especially important for workers caring for patients with HIV infection. In little over a decade, the AIDS epidemic has spread throughout the world, and it is expected to continue to grow. As of July 1993, 315,390 cases of AIDS had been reported within the United States,<sup>3</sup> and a cumulative total of 718,894 cases had been reported to the World Health Organization (WHO).<sup>4</sup> Because underreporting of AIDS cases is common, the WHO estimates that 2.5 million AIDS cases have actually occurred worldwide.<sup>5</sup> Corresponding to the

increasing proportions of the epidemic, it has been observed that the body of literature concerning HIV infection doubles in volume every 22 months.<sup>2,6</sup> Sengupta and Kumari<sup>1</sup> examined 628 journals known to have published AIDS literature. They found that 50% of the AIDS-related articles were concentrated in 35 journals, but the remaining 50% were scattered among 593 journals, making it very difficult to locate all relevant articles. These information management problems add to the complexity of the task and to the cost of care.

Experimental computer-based systems are now being proposed as decision support tools for the diagnosis and treatment of AIDS.<sup>7-11</sup> If properly constructed, such systems would have the potential to enhance the delivery of health care to this patient population. For these systems to succeed, however, it is necessary to ensure that they provide the specific information needed by health care workers.

This study was conducted with two goals in mind: 1) to determine what types of questions might be generated when examining medical charts of HIV-infected patients; and 2) to determine how well the available information sources can answer these questions. We asked the participating health care workers to review the information contained in patients charts from an AIDS outpatient clinic, and to consider each case as though they were the primary care providers. Each participant was asked to generate specific questions regarding patient care that were raised by each encounter recorded on the charts. We then attempted

to answer the questions using available printed sources and electronic databases, to analyze the questions posed by different reviewers, and to record which information sources answered the questions.

## Methods

### Setting

The study was conducted at the Pittsburgh AIDS Center for Treatment (PACT), which is part of the University of Pittsburgh Medical Center. The PACT provides ongoing medical care to HIV-infected patients at its own clinic site. Inpatient care is coordinated so that continuity of care is maintained in both outpatients and inpatient settings. Since its opening in May 1989, the PACT has consistently grown in annual patient visits, increasing from 486 to over 2,000 per year; currently, it serves over 700 patients.

### Study Participants

Seven health care professionals participated in the study by reviewing patient charts from the PACT. They had diverse educational and professional backgrounds and different degrees of professional involvement with HIV-infected patients. The reviewer codes and descriptions for these professionals were:

- A—information scientist trained in searching the AIDS literature
- B—nurse practitioner who did not routinely treat HIV-infected patients

Table 1 ■

Numbers of Questions Generated by Reviewing the Patient Charts, Organized by Category and Reviewer

Category	Reviewer*							Total (%)
	A	B	C	D	E	F	G	
Treatment protocols/regimens	2	12	8	4	6	27	6	65 (24.4)
Diagnosis/etiology	12	1		14	5	4	9	45 (16.9)
Disease complication	5			2	6	11	6	30 (11.3)
Description of disease	3	10	1	4	2	1	7	28 (10.5)
Adverse effects of drug therapy	10			7	1	7	3	28 (10.5)
Drug information			1	1	14	3		19 (7.1)
Efficacy of drug therapy		1		1	3	5	1	11 (4.1)
Diagnostic procedure		1		2	3	2	2	10 (3.8)
False-negative rate of diagnostic procedure	5		1	2	1	1		10 (3.8)
Efficacy of diagnostic procedure					1	4		5 (1.9)
Patient workup			2		2	1		5 (1.9)
Clinical trial protocol		1			2			3 (1.1)
Diet therapy		2					1	3 (1.1)
Patient information/education		2						2 (0.7)
Patient counseling						1		1 (0.4)
Morbidity/mortality of diagnostic procedure			1					1 (0.4)
TOTAL	37	30	14	37	46	67	35	266

\*A = information scientist; B = nurse practitioner; C = nurse practitioner; D = research physician; E = internist; F = internist; G = internist.

Table 2 ■

## Numbers of Questions Answered during Phase I and Phase II, Organized by Reviewer

Reviewer	Profession	Cares for AIDS Patients	Total Number of Questions Generated	Number of Questions Answered in		% of the Total Number of Questions Answered
				Phase I	Phase II	
A	Information scientist	No	37	28 (76%)	6 (16%)	92
B	Nurse practitioner	No	30	23 (77%)	3 (10%)	87
C	Nurse practitioner	Routinely	14	14 (100%)	0 (0%)	100
D	Research physician	No	37	30 (81%)	4 (11%)	92
E	Internist	No	46	33 (72%)	10 (22%)	93
F	Internist	Occasionally	67	44 (66%)	17 (25%)	91
G	Internist	Routinely	35	25 (71%)	8 (23%)	94
TOTAL			266	197 (74%)	48 (18%)	92

C—nurse practitioner who routinely treated HIV-infected patients

D—research physician who did not see patients

E—practicing internist who rarely, if ever, treated HIV-infected patients

F—practicing internist who occasionally treated HIV-infected patients

G—practicing internist who routinely treated HIV-infected patients

### Collection of Clinical Questions

To protect confidentiality, only charts of deceased patients were reviewed. From a drawer containing 60 complete outpatient records (multiple visits over time, collated into a single chart), ten charts were selected at random manually. The selected charts comprised a total of 311 typewritten pages and represented a total of 120 patient encounters, for an average of 12 patient encounters per chart.

Each chart was reviewed independently by each study participant. Reviewers were given the following instructions: "Identify questions (e.g., points you would like to have more information about) that you think could be answered through information sources in printed or electronic form, such as journal articles, medical textbooks, printed abstracts, treatment protocols, etc."

While reading the medical charts, each reviewer recorded his or her list of clinical questions. The questions generated by each reviewer were then collected and analyzed. Complex questions (i.e., questions that addressed more than one specific point) were divided into individual topics, and each topic was considered as a separate question. An example of a complex question was "Describe the diagnosis and treatment of pulmonary blastomycosis in HIV-positive patients." This was split into two questions, one concerning diagnosis and one concerning treatment.

Concepts from the National Library of Medicine's Medical Subject Headings (MeSH) were used to categorize the questions. For example, questions concerning drug side-effects were classified under "drug therapy, adverse effects," combining a MeSH heading and a subheading. When questions did not fall precisely under any MeSH heading, we created new categories (e.g., "patient workup"). The following are examples of questions and their corresponding categories:

1. What is the outcome of recurrent and multiple pneumothoraces secondary to PCP? (Disease Complication)
2. What is the treatment protocol for CMV esophagitis? (Treatment Protocols/Regimens)

### Answering Clinical Questions

The two authors formally trained in library and information science (NBG, JTH) sought to determine whether the questions could be answered by existing information sources. They did so by reading printed sources and by conducting searches of the literature, as described below. Work on a question ended if the two authors located the answer in a printed source, or if an electronic literature search produced at least one reference that contained the answer in its abstract. Each reference retrieved by a search was examined, and a count was kept of how many retrieved references provided the answer (often, this count was higher than one). A reference that did not contain the answer in its abstract was not considered, even though the corresponding article might in fact have contained the answer. If no available information source provided an answer, the question was recorded as unanswered.

The question-answering process was subdivided into two phases. In phase I, the two authors (NBG, JTH)

Table 3 ■

## Numbers of Questions Answered during Phase I and Phase II, Organized by Category

Category	Total Number of Questions Generated	Number of Questions Answered in		% of the Total Number of Questions Answered
		Phase I	Phase II	
Treatment protocols/regimens	65	54	9	97
Diagnosis/etiology	45	29	10	87
Disease complication	30	14	11	83
Description of disease	28	24	2	93
Adverse effects of drug therapy	28	25	3	100
Drug information	19	15	4	100
Efficacy of drug therapy	11	10	1	100
Diagnostic procedure	10	7	3	100
False-negative rate of diagnostic procedure	10	6	1	70
Efficacy of diagnostic procedure	5	3	2	100
Patient workup	5	5		100
Clinical trial protocol	3	3		100
Diet therapy	3		2	67
Patient information/education	2			0
Patient counseling	1	1		100
Morbidity/mortality of diagnostic procedure	1	1		100
TOTAL	266	197	48	92

used printed sources of information and electronic databases. The printed sources that were used in this phase are readily available to most internists. They included two general medicine textbooks, Cecil's<sup>12</sup> and Harrison's<sup>13</sup>; Mandell's *Principles and Practice of Infectious Diseases*<sup>14</sup>; the *Physicians' Desk Reference (PDR)*<sup>15</sup>; and the American Medical Association's *Drug Evaluations*.<sup>16</sup> The four electronic databases, which were all accessed through GRATEFUL MED, included AIDSLINE, AIDSDRUGS, AIDSTRIALS, and MEDLINE.

A standard search order was followed when looking for the answer to each clinical question. The printed material was always examined first, in the order indicated; if an answer was found, the search stopped. If an answer was not found in the printed material, AIDSLINE was consulted; AIDSDRUGS and AIDSTRIALS were searched next, when appropriate. Finally, if none of the previous sources had yielded an answer, MEDLINE was searched.

During phase II, all questions that had remained unanswered after phase I were subjected to an intensive library search, conducted at the local academic health sciences library. The search involved reading the AIDS-specific printed material listed in the appendix and conducting additional on-line searches. The purpose of this intensive search was to determine a practical upper limit for the coverage of questions generated during the study, using all available sources. The final result of phase II was a set of the references used to provide specific answers to the clinical ques-

tions. All answers were divided into those obtained from printed sources and those obtained from electronic sources.

## Results

Review of the medical charts by the seven study participants yielded a total of 266 clinical questions, which were divided into the 16 categories listed in Table 1. The distribution of questions in terms of the reviewers and the 16 categories is shown in Table 1.

Questions tended to cluster within a few categories. Categories I (Treatment Protocols/Regimens), II (Diagnosis/Etiology), and III (Disease Complication) accounted for 53% of all questions; the top five categories accounted for almost 75% of all questions. Questions related to treatment protocols/regimens were generated most frequently overall (24%). At the other end of the scale, the eight least common categories combined accounted for only 15% of all questions.

The following are examples of the questions generated for chart 2, patient encounter 3, for which every reviewer asked at least one question (reviewer codes are defined in Table 2):

- A—*Are there false-negative LP and CT scan cases in the literature that ultimately present with CNS infection such as toxoplasmosis that would account for mental status changes?*
- B—*What is the toxoplasmosis protocol?*

- C—What is the likelihood of CNS toxoplasmosis with negative toxo titers?
- D—Are there studies describing differences between CNS lesions due to toxoplasmosis versus lymphoma?
- E—What is the probability of CNS toxoplasmosis given AIDS and negative toxo titers? That is, are toxo titers of any value in making this diagnosis?
- F—What are the available regimens for CNS toxoplasmosis?
- G—What is the differential diagnosis of caudate nucleus CNS lesions?

Phase I of the answering process took a total of 43 hours for 266 questions, or almost 10 minutes per question (answered or unanswered). Phase II, which analyzed the 69 questions left unanswered in phase I, required an additional 25 hours (average of 22 minutes per question). Therefore, the group of 69 questions required an average of 32 minutes per question. The grand total for the two phases was 68 hours, yielding an average of more than 15 minutes per question. However, the average time does not reflect the time necessary to physically locate textbooks or to establish an on-line connection and log onto the system.

The results of the two phases are reported in Tables 2 and 3, which show the total numbers of questions, the numbers of questions answered during phase I, the numbers of questions answered during phase II, and the percentages of the total numbers of questions answered at the end of the study. The success rate

of phase I was 74%; during that phase, 197 of 266 questions were answered successfully. The success rate of phase II was similar: 70% of the questions unanswered during phase I were successfully answered during phase II.

Percentage of answerable questions was not significantly related to the clinical status of the reviewers who identified the questions from the chart (Table 2). Differences among reviewers were not statistically significant ( $p = 0.89$ ; chi-square test = 2.26).

The relation between the category of a question and the likelihood that the question would be answered is shown in Table 3. These differences were more marked than the ones shown in Table 2. While 83% of all questions in the Treatment Protocols/Regimens category were answered during phase I, only 47% of all questions in the Disease Complication category were answered during the same phase. After the intense scrutiny of phase II almost 97% of the questions in the former category were answered, while only 83% of those in the latter category were answered. Differences among categories, however, were not statistically significant ( $p = 0.79$ ; chi-square test = 10.44).

The number of questions answered during phase I using on-line information sources was also recorded. Of the 197 questions answered during phase I, 26 (13%) were answered by paper sources and the remaining 171 (87%) by on-line sources.

Table 4 ■

#### Numbers of Questions Answered during Phase II, Organized by Information Source

Information Source*	Year of Publication (Edition)	Number of Questions Answered	% of the Total Number of Questions Answered
Devita	1992 (3)	23	32.4
Cohen	1990	22	31.0
Lacey	1993	4	5.6
Levy	1989	4	5.6
Long	1992	3	4.2
Disbrey	1970	2	2.8
Friedman-Kien	1989	2	2.8
MEDLINE	1990–1993	2	2.8
Stockley	1991	2	2.8
Al-Doory	1992	1	1.4
Baron	1991 (3)	1	1.4
Cotran	1989 (4)	1	1.4
Dollery	1991	1	1.4
Haddad	1990 (2)	1	1.4
Mehta	1992 (46)	1	1.4
Spiro	1993 (4)	1	1.4
TOTAL		71	

\*The appendix contains complete reference information for these sources.

Table 5 ■

Numbers of Literature References Retrieved during Electronic Searches That Were Identified as Containing Answers to the 245 Answerable Questions, Organized by Year of Publication and Reviewer

Year of Publication	Reviewer*							Total (%)
	A	B	C	D	E	F	G	
1993	17	13	5	5	3	6	14	63 (3.6)
1992	43	38	32	70	94	203	49	529 (30.3)
1991	43	31	43	55	66	181	50	469 (26.8)
1990	36	25	20	30	40	72	27	250 (14.3)
1989	40	21	23	50	50	63	41	288 (16.5)
1988	23	16	9	3	1	6	7	65 (3.7)
1987	8	4	9			1	6	28 (1.6)
1986	4	2	4			2	6	18 (1)
1985	8	4	4			1	4	21 (1.2)
1984	8	1	2				1	12 (0.7)
1983	2	1	1					4 (0.2)
1982	1							1 (0.1)
TOTAL	233	156	152	213	254	535	205	1,748

\*A = information scientist; B = nurse practitioner; C = nurse practitioner; D = research physician; E = internist; F = internist; G = internist.

Table 4 shows the number of questions answered during Phase II for each of the information sources consulted (full references to these information sources are listed in the appendix). Two well-known textbooks about AIDS each provided more than 30% of all answers, but several other sources were needed to answer the most difficult questions handled in this phase. More than one reference was required to answer some questions; hence, the 48 questions that were answered during phase II required a total of 71 uses of a reference. As indicated by Table 4, and unlike phase I, essentially all questions in phase II were answered using printed sources. Two questions were finally answered using the MEDLINE bibliographic database, but only after intermediate information was obtained by consulting printed sources.

The electronic searches conducted during phases I and II resulted in the creation of lists of references that contained answers to the questions; 171 questions were answered electronically in phase I, and two in phase II. Table 5 shows the total numbers of references retrieved by the searches, organized by year of publication; each question was answered by an average of 10.1 references. Of the 1,748 references, one was located using AIDSTRIALS; 25 were located using MEDLINE's current file, which extends back to 1990; and the remaining 1,722 were located using AIDSLINE, which extends back to 1980. As shown in the table, most of the references were fairly recent; 75% of all references had been published since 1990, and almost 60% had been published in 1991 and 1992.

## Discussion

The study of physicians' information needs is an active area of research.<sup>17-22</sup> Information needs are typically assessed via questionnaires, interviews, or direct observation of physicians engaged in clinical activities. Unfortunately, many studies conclude that information needs are not being met,<sup>18</sup> especially for practicing physicians (as opposed to researchers).<sup>23</sup>

Cimino and Barnett<sup>24</sup> collected 38 questions posed by three physicians, each of whom examined ten medical records for his or her current patients. Rather than assessing information needs, the primary emphasis of that study was to determine whether the Meta-1 controlled vocabulary was sufficient to describe precisely the questions. No attempt was made to answer the questions or to determine what information sources could provide the answers.

A few published studies address AIDS-related information needs. Henry et al.<sup>25</sup> describe the information needs arising in a specific area of patient management, i.e., telephone triages in a community-based AIDS clinic. Another specialized study<sup>26</sup> reports psychiatric nurses' needs for information about AIDS.

The management of AIDS patients has been the focus of a few experimental computer systems. An example is T-HELPER,<sup>27</sup> which allows physicians to record patient problems, medications, test results, and progress notes and which identifies patients potentially eligible for enrollment in clinical trials. Herrmann and Safran<sup>28</sup> describe how ClinQuery, a program for searching on-line medical records, could be used

to explore AIDS-related research questions about the patient population of a general hospital. Safran et al.<sup>29</sup> describe how the program could generate alerts when certain abnormal conditions were detected.

The present study analyzed the questions generated when health care professionals reviewed the medical charts of ten HIV-infected patients. Regardless of their backgrounds or clinical responsibilities, the professionals revealed significant information needs; each asked an average of 38 questions (3.8 per patient chart), for a total of 266 questions. Many questions required substantial effort to answer, even when AIDS-specific sources were used. Answering the most difficult questions was labor intensive and required familiarity with existing information sources.

The study also examined whether different types of health care professionals ask qualitatively different types of questions. This issue is important because the growth of the AIDS epidemic requires more and more nonphysician personnel to be involved.<sup>29-31</sup> The study showed that the percentages of questions that could be answered did not vary significantly, and no group of professionals asked questions that were intrinsically easier or harder to answer. Reviewers often asked questions related to their own primary patient care responsibilities; questions posed by the two nurses, for example, were concerned most frequently with treatment protocols and regimens. Given the small number of participants, however, one should not assume that these results would necessarily generalize to other health care workers.

Electronic and paper-based information sources showed considerable differences in their abilities to answer questions. On-line sources provided the majority (86.8%) of the answers to the more easily answerable questions in the study. However, the most difficult questions were answered only in phase II, after a laborious search of printed sources. On-line databases, including AIDS-specific ones, were of little use in answering such questions. Even after the laborious manual search of phase II, 21 questions (8% of the total) remained unanswered. This result suggests that, in spite of the large amount of literature about AIDS, a nontrivial number of questions may not be answered efficiently by present-day information sources.

Many questions belonged to four categories: Treatment Protocols, Diagnosis/Etiology, Disease Complication and Description of Disease, and Adverse Drug Reactions. However, a considerable number of questions ranged from patient workup to diet therapy and patient counseling. New information sources that combine information from different sources and cover

different aspects of patient management would facilitate care of HIV-infected patients. Further research is needed to determine precisely how such information sources can be constructed effectively.

Caution is necessary when considering the results in the perspective of clinical care. First, the questions were posed while patient charts were being reviewed; one should not assume that the findings would necessarily extend to actual clinical practice. Second, the N-of-1 study design does not allow conclusions to be drawn about the information needs of different groups of health care workers. Third, study participants generated questions while reviewing entire patient charts describing multiple encounters. The results are an average over time and over degree of severity, and give no indication of the information needs raised by a specific patient at a specific disease stage. Fourth, different stopping criteria would be used in actual practice: the person asking a question would be given the answer and would judge whether the answer was satisfactory. Also, our stopping criteria were restrictive by only considering titles and abstracts of electronic references; clearly, more questions could be answered by looking at full texts. Fifth, the study was conducted in a university AIDS outpatient clinic, and this may limit the generalizability of the results to other clinical settings. Finally, the study did not consider the information needs of the patients themselves. Such needs are great and extremely varied, as shown by the number of information sources (including "underground" publications) developed by and for HIV-infected patients.

Clearly, the combination of current information sources and access procedures is not entirely satisfactory. It is unlikely that health care workers will routinely conduct searches that are as time consuming as the ones conducted in this study (15 minutes per question for a trained information professional, not counting the time to locate textbooks or to establish an on-line connection). The study points to the need for better-integrated sources spanning different levels of detail and different types of patient management information.<sup>32</sup> Creating such sources will be an important challenge for the fields of medicine and medical informatics. Because of the need for up-to-date information about AIDS patient care, computerized information services are especially attractive. This strategy has proved very successful in systems such as PDQ,<sup>33,34</sup> a computerized database developed by the National Cancer Institute.

Considerable research will be needed to determine what information needs arise in day-to-day clinical activities. The information needs of health care workers are invariably more complex and less formalized

than commonly assumed. For example, Forsythe et al.<sup>21</sup> found that explicit requests in the form of questions were only a portion of all actual information needs. Requests were often indirect and not immediately apparent from the transcripts of clinicians' interactions during morning rounds.

The spread of the AIDS epidemic makes it necessary for a broad base of health care workers to deal with HIV-infected patients. Future research will have to consider the needs of diverse groups of health care professionals, categorize existing information sources based on their suitability for different tasks, establish guidelines for the creation and integration of new medical knowledge, and develop mechanisms that facilitate patient care by making up-to-date information available at the right time and in the appropriate form.

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#### APPENDIX

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