

Information needs of case managers caring for persons living with HIV

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ABSTRACT

Objective The goals of this study were to explore the information needs of case managers who provide services to persons living with HIV (PLWH) and to assess the applicability of the Information Needs Event Taxonomy in a new population.

Design The study design was observational with data collection via an online survey.

Measurements Responses to open-ended survey questions about the information needs of case managers (n=94) related to PLWH of three levels of care complexity were categorized using the Information Needs Event Taxonomy.

Results The most frequently identified needs were related to patient education resources (33%), patient data (23%), and referral resources (22%) accounting for 79% of all (N=282) information needs.

Limitations Study limitations include selection bias, recall bias, and a relatively narrow focus of the study on case-manager information needs in the context of caring for PLWH.

Conclusion The study findings contribute to the evidence base regarding information needs in the context of patient interactions by: (1) supporting the applicability of the Information Needs Event Taxonomy and extending it through addition of a new generic question; (2) providing a foundation for the addition of context-specific links to external information resources within information systems; (3) applying a new approach for elicitation of information needs; and (4) expanding the literature regarding addressing information needs in community-based settings for HIV services.

INTRODUCTION

Studies on information needs in healthcare have focused primarily on physicians.^{1–2} These studies document that many healthcare workers have questions about how to care for their patients and that most questions go unanswered.³ In fact, one study found that physicians raised two questions for every three patients seen in a clinical setting, and in 70% of the cases, these questions were left unanswered.⁴ Recent studies indicate that there has been little improvement since that seminal work was published.^{5–6}

Few studies have evaluated the information needs of case managers, who link patients to medical and social services. Earlier studies mostly focused on nurse case managers who provide homecare services to patients.^{7–9} Case managers also spend considerable time addressing client needs related to social problems, including homelessness and substance abuse.¹⁰ Given the important roles that case managers play in care coordination, a clear understanding of their information needs is important.

CASE DESCRIPTION

Researchers have noted the importance of understanding the information needs of healthcare professionals before designing systems to meet those needs.¹¹ A number of approaches have focused on meeting information needs at the point of care, primarily through electronic health records, clinical information systems, and documents that cross sites such as continuity of care records.¹² Electronic access to information resources at the point of care has the potential to improve information seeking within a busy clinical setting.¹³ With the proliferation of information systems in clinical settings, it is important to determine the information needs experienced by the healthcare worker while interacting with the system and to understand how they resolve these needs. Although many information needs relate to patient data, others require accessing information from external knowledge sources (eg, diagnostic and treatment guidelines).¹⁴ While meeting information needs is especially important for high-quality patient care, there have been very few studies describing the information needs related to case-management activities¹⁵ and HIV care.¹⁶ Thus, the purpose of this study was to identify the information needs of case managers who provide services to persons living with HIV (PLWH). In addition, we sought to assess the applicability of the Information Needs Event Taxonomy in the context of HIV case management in two types of settings.

METHOD OF IMPLEMENTATION

Recruitment

After approval of the protocol by the Columbia University Institutional Review Board, case managers were recruited through direct contact by telephone, email, and distribution of invitational flyers. Upon completion of the survey, participants were emailed to ask where to send compensation and were also asked to refer their colleagues to participate in the survey. Participants were then mailed a check as compensation with a study flyer to pass on to others who may have been interested in participation.

Sample and setting

Study subjects were English-speaking case managers affiliated with agencies that provided services to members of an HIV/AIDS special needs plan. The parent study included clinicians, patients, and case managers; this case report focuses on case managers. Inclusion criteria included willingness to provide informed consent and possession of a valid email address to which the survey could be sent. The survey was completed by a voluntary,

convenience sample of 94 case managers employed at a Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 case-management agency or a Designated AIDS Center (DAC) in three boroughs of New York City: Manhattan, Bronx, and Brooklyn. COBRA case-management programs are designed for persons who have comprehensive service needs, require frequent contact with care providers, and have had difficulty accessing medical care and supportive services. COBRA case-management programs include certified home health agencies, community health centers, and other community-based organizations; they provide services for patients who receive medical care at a variety of hospitals. DACs are State-certified, hospital-based programs that serve as the hubs for a continuum of hospital and community-based care for persons with HIV infection and AIDS. Each DAC is affiliated with a single hospital.

Procedures

Data collection took place from March to June 2009. The survey was administered via email using SurveyMonkey. In two of four COBRA case-management agencies, recruitment was facilitated by a visit of an investigator who brought a laptop for data collection, since case managers at these sites had limited or no use of computers with internet access at their sites. The remaining case managers completed the survey online using their own computers. Participants were compensated \$20 for their time.

Case managers were asked to report their demographic information, including: age, gender, ethnicity, race, internet usage, and computer experience. Internet usage was assessed by how often case managers used the internet (daily, weekly, monthly), and computer experience was measured by when respondents began using a computer (in the past 6 months, in the past year, etc). Respondents were asked to think back to three clients they saw on the day of survey completion. Open-ended questions asked the case managers to recall information needs (eg, correct interpretation of a laboratory result, expected medication side effects) that they had experienced during case-management activities for clients of three complexity levels (simple, moderate, complex) without revealing any protected health information regarding the patient. The purpose of specifying the complexity levels was to encourage respondents to

think about information needs across a variety of patients rather than only focusing on the most memorable.

Data analysis

Multiple methods were applied to analyze the data. Participant characteristics were summarized using descriptive statistics. Case managers' information needs were categorized using a coding framework, the Information Needs Event Taxonomy, previously developed to study the information needs of physicians and nurses (personal communication, Currie LM. Infobutton Project Coding Guidelines, 2007). The framework comprises 16 generic questions that were created based upon 10 of Ely's generic questions,¹⁷ a review of the literature, and studies of physicians and nurses. Information needs were categorized by one investigator (RS) and reviewed by a second (SB).

RESULTS

A total of 131 surveys were emailed to potential participants, and 94 surveys were completed, yielding a response rate of 71.8%. Of the eight sites that participated in the survey, four were COBRA case-management agencies, and four were DACs. Site response rates varied from 20 to 100%. Case managers at COBRA case-management agencies (77.5%) were more likely to participate than case managers at DACs (59.5%) ($\chi^2=19.9$, $p<0.0001$). The highest response rates (94.1% and 100%) were in agencies in which recruitment was facilitated by a visit of an investigator and research assistant.

Demographics

The majority of respondents were females (80%) between the ages of 20 and 40 years old. Respondents were predominantly Black (41%) followed by White (34%); 38% identified their ethnicity as Hispanic. The most frequently cited job title was case manager (44%), followed by social worker (17%). Most respondents used the internet at least once per day (79%), and all used the internet at least once per month. Nearly all respondents started using the computer more than 2 years ago (94%).

Information needs

Table 1 lists the frequencies, percentages, and examples of generic questions from the Information Needs Event Taxonomy

Table 1 Number and examples of generic questions from the information needs event taxonomy in this study

Generic question (N = 282)	N (%)	Example
1. Can drug x cause (adverse) finding y?	11 (3.9)	'Client was given his current labs and was told that he needed to start medications. He was not sure of what side effects to expect and should he start medications as recommended by PCP.'
2. How should I manage condition x (not specifying diagnostic or therapeutic)?	1 (0.4)	'Explanation of why there are special concerns for severe vision deterioration for a client with HIV, what specific issues may be causing the drastic change'
3. How should I treat condition x (not limited to drug treatment)?	0 (0.0)	—
4. What is the cause of physical finding x?	2 (0.7)	'Reason for epilepsy occurrence'
5. What is the cause of test finding x?	19 (6.7)	'A client requested information on liver enzymes results that were deemed abnormal'
6. What is the dose of drug x?	0 (0.0)	—
7. What is the drug of choice for condition x?	0 (0.0)	—
8. What test is indicated in situation x?	1 (0.4)	'Discussion of a procedure: PET scan'
9. What is the cause of symptom x?	0 (0.0)	—
10. Could this patient have condition x?	0 (0.0)	—
11. What is normal in this situation?	0 (0.0)	—
12. What are my patient's data?	66 (23)	'Clients last CD4/viral load counts were needed to explain to client what it means'
13. How is this done at this institution?	20 (7.1)	'Client needed a medical appointment, and medical referrals scheduled'
14. What are the patient education resources related to X?	94 (33)	'Client was asking me which of his medications were prescribed for what purpose'
15. What is this (unfamiliar) domain-specific information?	6 (2.1)	'Diagnostic definition'
16. How do I administer drug X?	0 (0.0)	—
17. What are the referral resources related to X?	62 (22)	'A referral for (food) pantry and shelter'

that were found in our study (personal communication, Currie LM. Infobutton Project Coding Guidelines, 2007). There were a total of 282 comments, of which 220 could be coded into nine of the 16 original existing generic questions. One question was added to accommodate the remaining 62 questions that did not fall into the original generic questions: 'What are the referral resources related to X?'

The most frequently assigned generic question was, 'What are the patient education resources related to X (33%)?' Case managers frequently identified three types of educational resources that were needed to meet information needs: drug information (n=22), adherence (n=17), and substance abuse (n=14). The next most frequently assigned generic question was, 'What are my patient's data (23%)?' and included: laboratory results (n=25), medications (n=20), and appointments (n=7). The third most frequently assigned generic question was, 'What are the referral resources related to X (22%)?' Referral resources that were sought included: housing (n=31), public assistance (eg, Medicaid, social security) (n=8), and food (n=6). The three most frequently assigned generic questions accounted for 79% (n=222) of case managers' stated information needs.

DISCUSSION

The study findings contribute to the evidence base regarding information needs in the context of patient interactions in four ways. First, the study findings support the applicability of the Information Needs Event Taxonomy in a new domain by demonstrating that some of the generic questions that were generated from earlier clinician studies are also relevant to case managers' information needs. In addition, our study found that 22% of the information needs were related to referral resources, and thus, we extended the Information Needs Event Taxonomy by the addition of a new generic question. Since a primary function of case managers is to link clients to medical and social services,¹⁸ the ability to refer clients for such services is particularly important. Therefore, it is not surprising that the third most frequently reported information need in our survey was related to referral resources, which is similar to findings in earlier study focused on homecare case managers.¹⁵ The important role of case managers in educating PLWH and addressing treatment adherence issues is also reflected by the top-ranking information need. In contrast to the classic study on supplemental information seeking by cardiovascular nurses,¹⁹ patient-specific data ranked second in our study instead of first. This is likely due to differences in role rather than setting.

Second, the fact that most case-manager information needs clustered into only a few generic questions suggests that a targeted set of resources may meet most needs. This finding provides a foundation for the addition of context-specific links to external information resources within information systems such as electronic health records and continuity of care records through approaches such as the Infobutton Manager.²⁰

Third, this study also contributes methodologically to studies of information needs by providing a new approach to studying this area. Earlier studies have used focus groups,¹ observations,^{21–23} literature reviews,² interviews, and in-person questionnaires.⁴ An online survey with anchors to stimulate recall of information needs encountered while interacting with clients during a particular day offers the advantages of flexibility and non-obtrusiveness in a care setting.

Fourth, the study adds to the literature regarding addressing information needs in community-based settings for HIV services. The National Library of Medicine has made a substantial investment in HIV/AIDS information outreach for the last 16 years

focused on PLWH and their care givers.²⁴ Our study's approach to explicating information needs during patient interactions complements the HIV/AIDS information outreach projects' critical attention to access, training, and resource development.

There are several limitations to the study; these include selection bias, recall bias, and a relatively narrow focus of the study. The primary limitation of the study is selection bias, since all case-manager participants were internet users and willing to complete an online survey. However, there is no reason to anticipate that the information needs of case managers who use the internet are different from those who do not. Internet use is more likely to relate to strategies for meeting information needs. Moreover, although the sample was primarily female, the respondents were diverse from a racial and ethnic perspective. Another possible limitation is that our survey approach for eliciting information needs is subject to recall bias, but the methods applied partially addressed this concern by anchoring the recall questions in types of patients of varying complexity seen on the specific day of data collection. Our study focused only on case-manager information needs, but there is no doubt that patient information needs and case-manager information needs are related, given that case managers are responsible for linking patients to medical and social resources, and are often involved in explaining clinical findings and medication information to their patients.¹⁸ The narrow focus on case managers precluded identification of a broader set of information needs that occur during case-manager–patient interactions or between other healthcare workers and patients.

Case managers in COBRA and DAC settings provide essential services to PLWH. To ensure high quality of care, it is essential to characterize case managers' information needs in the context of patient interactions and to design informatics-based solutions to address those needs.

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Competing interests None.

Ethics approval Ethics approval was provided by the Columbia University Medical Center.

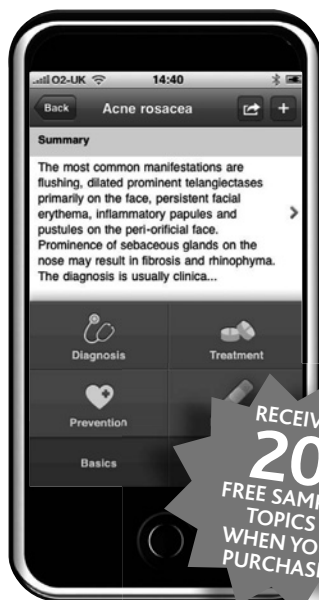
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