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Collaborative management of HIV infection in the community: an effort to improve the quality of HIV care

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Abstract *Our hospital led a multidisciplinary community team to improve the quality of care delivered to HIV-infected clients utilizing a disease management approach in a US metropolitan community of 150,000 people. Community needs assessment and client and community surveys were used to define the problems. Patient care flowcharting and the creation of an electronic patient database facilitated patient tracking across the entire community. Clinical guidelines and a consultation and referral immunology clinic standardized care practices. Measurable improvements in the quality of care were noted in multiple areas. Flowchart completion rates rose from 44% to 100%; medication adherence assessment rose from 82% to 100%; immunization rates rose from a mean of 72% to a mean of 87%; PPD screening rose from a low of 35% to a high of 87%; perinatal transmission rates fell from 31% to 4%; and Emergency Department utilization decreased. Two essential components of the effort were the establishment of a full-time leadership position in the form of a clinical nurse practitioner and the creation of an electronic database with flowcharting to standardize the measurement, delivery and tracking of care. The programme has become an example of successful disease management through hospital–community collaboration.*

Introduction

HIV/AIDS has been a growing community problem for the past two decades. New cases occur at an alarming rate despite national and local efforts to modify client behaviour (CDC, 2001; 2002; Kelly & Kalichman, 2002; McCann, 1990; Sepkowitz, 2001). No cure has been found and no vaccine is on the near horizon. However, the development of highly active antiretroviral therapy (HAART) has modified our attitude of futility to one of realization that HIV disease has become a controllable illness. It is, therefore, imperative that each community takes an active role in addressing the issues of both HIV acquisition and its management.

Federal legislation created the Ryan White CARE Act in 1990, which provided funds for community health care, treatment, support services and medication assistance for low-income

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individuals with HIV/AIDS (O'Brien, 1991). This has supplemented the support provided by the Center for Medicare & Medicaid Services (CMS). Medicaid spending on HIV/AIDS for the fiscal year 2003 was estimated at \$4.7 billion and Medicare spending at \$2.2 billion (US Department of Health and Human Services, 2002). Ryan White funds go to eligible metropolitan areas with the highest prevalence of HIV infection, and to community-based organizations with demonstrated need. Requirements for receipt of this funding include the provision for high quality, comprehensive outpatient health care and support services, including early intervention services, case management, direct medical and nursing care, substance abuse counselling, mental health services, diagnostics, treatment monitoring, prophylaxis and appropriate provision for follow-up care. While some communities have created case management and medical care coordination services as an outcome of this funding, these persons frequently do not work in full collaboration with the health services of the local hospital or with the Department of Health as part of the same continuum of care and fragmentation of services is inevitable (Andrews, 2002; Baldwin *et al.*, 1998; Begley *et al.*, 2002; Butters *et al.*, 1991; Conviser & Rounds, 2002; Kobayashi & Standridge, 2000; Lo *et al.*, 2002; London *et al.*, 1998; Morrison, 1993; Sowell, 1995; Wright *et al.*, 1993). With the support of Ryan White funding, our community sought to more collaboratively address the quality of care provided to its HIV clientele.

Assessment of the community's problem

HIV surfaced as a significant health issue in our community when a community needs survey in 1994 (conducted by the Bristol Group) identified HIV/AIDS as the health issue of greatest concern to the community. In 1995, an in-depth assessment of health indicators from the State Department of Health and Addiction Services and the State Hospital Association database was performed. Five State towns with similar population and patient demographics were chosen as the peer group. This analysis revealed that there was a 35% greater prevalence of HIV/AIDS in our community; infected patients in our community had a higher mortality compared to peer group communities (13/100,000 population as compared to 9/100,000); and the community exhibited a larger proportion of risk factors (4.2%) compared to the peer group and State averages (3.8% and 2.0%, respectively). It became evident that there was a need to more comprehensively evaluate our community's standards of prevention, access to client services, and quality of clinical practice.

Two follow-up studies were undertaken to further define the extent of need. The first was a chart review of consecutive HIV admissions at Stamford Hospital in 1996–1997. Data collection revealed that fully one-third of HIV-related admissions were preventable. Contributing factors included lack of proper outpatient follow-up, inappropriate or no prophylaxis for opportunistic infections, poor patient compliance, failure to refer appropriately and inadequate discharge planning from a prior admission.

The second follow-up initiative was a survey of providers (86), clients (42) and physicians (29). Questionnaires were delivered to clients (patients) by Department of Health outreach workers or physicians, and were mailed to community physicians and other providers. This survey revealed that there was a lack of awareness in both the provider and client community regarding the HIV resources available; a deficit in clinical knowledge at all levels; and low rates of referrals to case management services, partner notification services, drug assistance programmes, support groups and counselling services. Furthermore, infected individuals were failing to seek follow-up after being informed of the HIV test results (45% of clients failed to seek help for more than one year after being informed of their positive HIV status).

Methods

In response to the community need for improved HIV care, we assembled a team of Health System physicians and nurses, community providers and clients who were interested in defining and addressing these issues. The initial multidisciplinary team was created in March 1996. Membership consisted of physicians and nurses from the two local hospitals (merged into a Health System in 1998), the Department of Health and Human Services and the unaffiliated Community Health centre; community HIV service providers from other venues; and clients (patients). All HIV teams included a team leader and facilitator. Team reports were provided directly to the Hospital Quality Council, and the Medical Staff leadership through the Quality Improvement Coordinating Committee and Medical Executive Committee. Subsequent creation of a Clinical Effectiveness Programme accountable to the Clinical Leadership Council of the Medical staff supplanted the earlier reporting structure. A sub-committee of the Board of Directors was formed to oversee quality improvement efforts throughout the system, known as the System Quality and Service Committee. To help the organization achieve its mission of improving the health of the community, it had adopted the principle of continuous quality improvement using the FOCUS-PDCA model. In 1997, a hospital-wide Clinical Effectiveness Programme was begun using published best clinical practices to improve outcomes of care in high-risk as well as high-volume patient populations. The specific HIV initiative described herein was one of several disease management projects of the Clinical Effectiveness Programme.

The team focused outcome measurement efforts on specific indicators to assess the quality of clinical management in our HIV-infected clientele. Outcome measures were grouped in several categories:

- *Adequacy of prophylaxis* (influenza and pneumococcal vaccination rates, hepatitis A and B vaccination when appropriate, percentage of patients having TB testing, OI prophylaxis where appropriate);
- *Success in patient management indicators* (the number of ED visits, preventable admissions for opportunistic infections, HIV inpatient cost and length of stay, perinatal transmission rates, individual and aggregate CD4 and viral load changes);
- *Adherence indicators* (total numbers of patients attending HIV speciality clinic, clinic no-show rate and self-reported adherence to medications using a standardized tool);
- *Quality of life indicators* (Karnofsky scoring, patient satisfaction surveys);
- *Overall management indicators* (flowchart completion rates).

Manual data collection began prospectively in 1998 and through a confidential electronic database in 1999. However, some earlier data were available through retrospective analysis of the hospital information systems database and the survey data previously collected. Wherever possible, data were collected by computer (e.g. financial and length of stay data), but medical record review and manual tabulation were also used (e.g. medication adherence in the outpatient setting).

Most of the data were screened and collected by a single individual (the HIV nurse practitioner or, in the case of adherence issues, the adherence counsellor) to minimize observer variation. The dedicated HIV programme nurse practitioner was central to the data collection process by overseeing data collection and managing the electronic database. Most indicators were entered into the database designed for the purpose of managing the patient rather than purely data analysis.

Flowcharting provided standardized data sets and the creation of an electronic database in 1999 allowed retrieval of more timely data, permitting the flowcharts to be more easily kept

current. In addition, the flowcharts provided effective longitudinal information and helped to assure completeness of data collection through graphic means. In addition to flowcharting, standard templates for assessing adherence and quality of life were used at each patient visit.

Most outcome and performance measures were assessed for all known clients, or clients were selected based on study focus (e.g. pregnant clients, non-adherent clients). The nurse practitioner visited clients at multiple venues throughout the city so as not to deselect those who preferred care outside the Health System. Obviously, the large number of asymptomatic clients not seeking care created an underestimate of our denominator, i.e. the total HIV-infected population. Some clients may have been cared for outside the system, but very few were cared for by primary care physicians and thus most symptomatic patients were known to us.

Where measurements were made on samples of the population, efforts were made to select sequential clients, comparable time periods and adequate sample sizes to improve reliability, minimize bias and ensure sufficient power to detect differences over time. Data were collected on a continuous basis and were aggregated yearly for evaluation. Areas which appeared to show little improvement were then re-analyzed for other variables offering potential for new initiatives (e.g. the perinatal HIV team). Nurses, physicians and support staff were aware of the nurse practitioner's role as contact person for questions regarding care of all HIV-infected clients within our community. Staff were encouraged to call her with any concerns or suggestions for improving the existing process.

Resources for funding this initiative were incorporated into staff budgets from the hospital and also the local Ryan-White agency. The Clinical Effectiveness Programme has been funded as an institution-wide resource. The Infectious Disease physicians donated time and expertise to this project. Two full-time employees were hired by the hospital to work on the HIV initiative. The nurse practitioner and adherence counsellor salaries were largely supplied from Ryan-White funds. Clinic costs were minimally increased as the patients' appointments were merely reorganized.

Results

Implementation

From the inception of the HIV performance improvement team in 1995 to its present operation, the following interventions have been designed and implemented:

1. Creation of HIV Service Assessment and HIV Clinical Flowcharts (Parry *et al.*, 1997) to standardize practice, data collection and communication across multiple provider venues. Flowcharts provide longitudinal information to facilitate clinical decisions by attending physicians, residents and nurse practitioners; facilitate continuity of care by easily displaying historical data to multiple providers; clarify next steps by graphically displaying trends and changes in status (e.g. viral load values and CD4 counts); identify possible adherence problems by showing data variation; and provide visual information for patient education and to reinforce the value of adherence to the treatment regimen.
2. Recruitment of a dedicated HIV programme nurse practitioner to provide direct clinical care, improve medication and follow-up adherence, and systematically collect data. The HIV nurse practitioner role ensures consistency and continuity of patient management and data collection across multiple venues using the flowcharts,

- data collection tools and clinical guidelines developed by the team; and she provides a personal link between all provider agencies in the community.
3. Dissemination of evidenced-based guidelines to reduce practice variation and improve clinical outcomes. Clinical guidelines were adapted and updated regularly from published literature (AIDS Info, 2002; Yeni *et al.*, 2002) by the interdisciplinary team. They were distributed to providers to assist in patient care for initial treatment plans, prevention and treatment of opportunistic infections, prevention of perinatal transmission and post-exposure neonatal guidelines.
 4. Formation of a multidisciplinary speciality consultation clinic (Adult Immunology Clinic) for all newly diagnosed HIV patients and for 12 month and as needed follow-up visits for all patients diagnosed with HIV. Referrals come from all community sites. The clinic links new patients to primary care physicians or resident continuity clinics for ongoing care. Efforts are made to maintain existing patient/physician relationships if appropriate. Case management and social work services, nutritional services, psychology and pharmacy services, as well as direct supervision by infectious disease physicians, the HIV NP and adherence counsellor are provided onsite. Primary care residents also participate in the clinic. Each client's care is transitioned into the resident's continuity clinics when medical stability is achieved.
 5. Establishment of an electronic database to track clinical information for all clients. The nurse practitioner has access to this database, which contains up-to-date clinical information, from all sites where care is delivered in the community.
 6. Hiring of an adherence nurse counsellor to assist patients who have difficulty with adhering to antiretroviral therapy; to promote positive attitude and patient self-management; to provide treatment facilitators (medication cues, pill boxes, etc.); to provide directly observed therapy; introduce alternative therapies, nutrition, psychiatric support; to explore innovative therapies, e.g. once-daily regimens; to supply clinic visit reminders.
 7. Creation of separate multidisciplinary extension teams to address the specific issues of perinatal HIV transmission prevention, medication adherence and HIV/HCV co-infection.

Outcomes

Specific outcome indicators (outlined above) were selected to assess the value of the programme and to measure improvement in clinical management.

Adherence indicators. Yearly trends in the total numbers of patients who attend the HIV speciality clinic and the percentage of patients showing up for their speciality clinic appointments are monitored. Clinic 'no-show' rates have been relatively constant, averaging about 23% of scheduled appointments. This compared favourably to general medical clinic no-show rates. The hiring of an adherence coordinator has increased assessment of medication adherence in patients attending the speciality clinic to 100% (Fig. 1).

Adequacy of prophylaxis. This measurement assessed vaccination rates for the HIV-infected clinic patients, including influenza and pneumococcal vaccines (Fig. 2). Guidelines recommend vaccination against hepatitis A and B for clients who are co-infected with hepatitis C and HIV. For this reason hepatitis C serology was also used as an important indicator for care. TB testing (PPD) was evaluated as an indication of appropriate screening

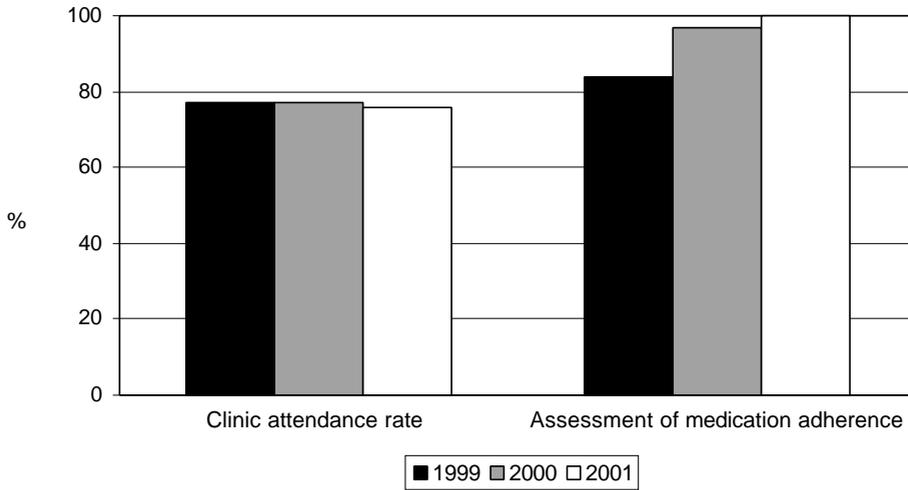


FIG. 1. Adherence indicators, 1999–2001.

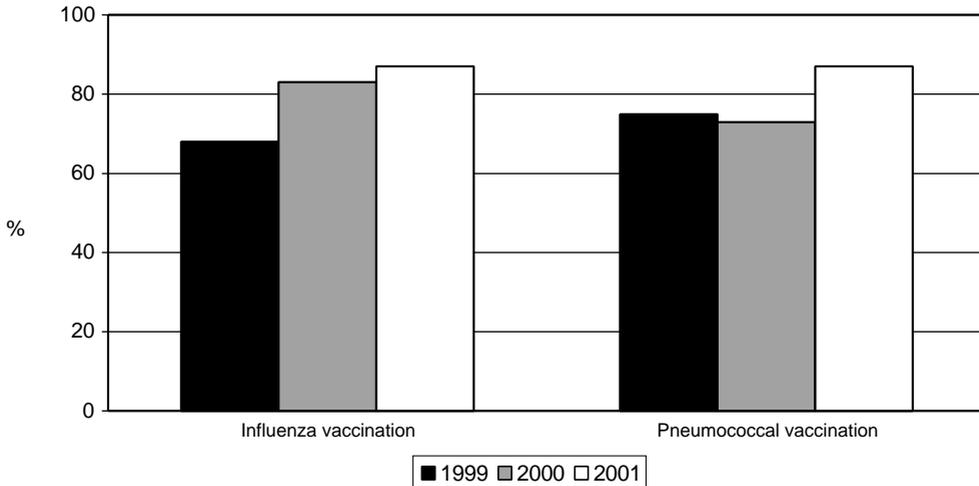


FIG. 2. Vaccination rates, 1999–2001.

for prophylaxis. Between 1994–1998 these measures were poor and inconsistent until after the improvement project was begun. PPD screening rose from a low of 35% to a high of 87% (Fig. 3).

Patient management indicators. The total number of emergency department visits stayed relatively constant over four years. This was due, at least in part it was felt, to better clinical management since there was an absolute increase in the number of clinic patients registered over the time period evaluated. The ratio of ED patients to the total number of inpatient admissions has, therefore, declined (Fig. 4). The opportunistic infection rate has also decreased due to improvement in CD4 counts and greater use of prophylaxis. In 1998, 25% of the admissions were for opportunistic infections; while in 2000, only 17% of the admissions were due to opportunistic infections. Furthermore, many of these were the presenting

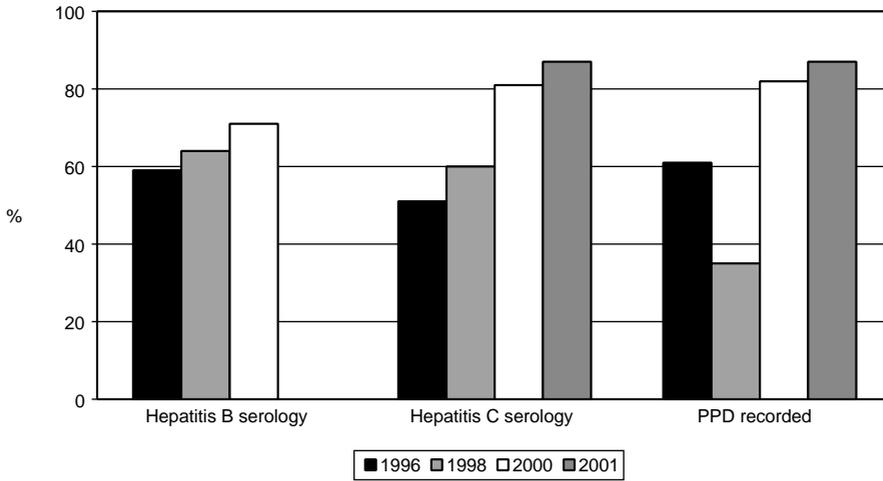


FIG. 3. Screening for underlying illnesses, 1996–2001.

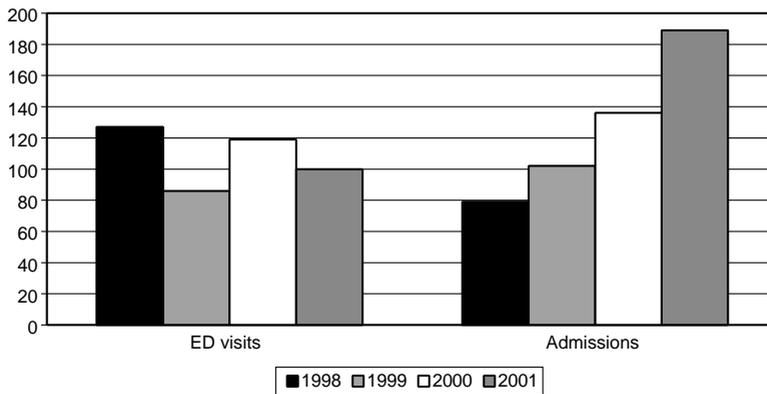


FIG. 4. Hospital utilization: Emergency Department (ED) visits and hospital admissions for primary diagnosis coded HIV, 1998–2001.

diagnosis for a new patient and were, therefore, not classified as preventable. Currently, patients admitted for HIV-related conditions have more co-morbidities and higher acuity. Hence, although the average length of stay has decreased from 9.5 days in 1998 to 7.5 days in 2001, hospital costs have remained relatively flat. With our improved management of the HIV-infected perinatal patient, including treatment with HAART, the rate of transmission of HIV to the infants exposed has dropped below national averages (Fig. 5). In 1999, there was a single case of transmission (4% transmission rate, down from 31%) which was believed to be related to advanced AIDS, lack of prenatal care and poor adherence to medical management. Patients are individually managed using surrogate markers including CD4 counts and HIV viral load. These markers are tracked over time with each patient as an indicator of their disease status. In active clinic patients over three years, 95% had stable or increased CD4 counts, 90% had decreased viral loads and 93% had stable or increased weight. These indicators are useful to confirm the efficacy of the programme, although no control group is available.

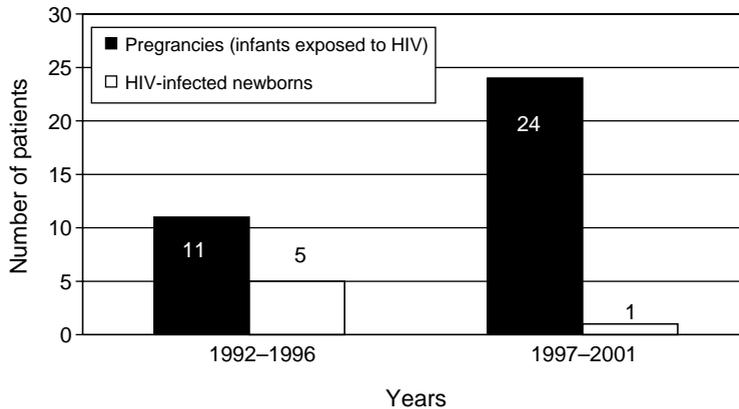


FIG. 5. Perinatal transmission of HIV, 1992-1996 and 1997-2001.

Quality of life indicators. These assessments were made using Karnofsky scoring and patient satisfaction surveys. As the effort progressed, it became clear that the Karnofsky system was too insensitive to detect subtle changes in quality of life and it was not effectively used. Rise in overall clinic volume and relatively low no-show rates relative to other medical clinics was also used as surrogate evidence of the impact of the programme and patients' satisfaction. Formal satisfaction surveys are to be planned in conjunction with the local Ryan-White agency.

Overall management indicators. The overall management of outpatients is tracked through the confidential electronic database. Key parameters of care were followed and laboratory results were graphically displayed in flowchart format (Parry *et al.*, 1997). Flowchart completion rates, used as evidence of thorough assessment of patient progress by the clinical staff involved in their care, rose from 45% in 1998 to 100% in 2001. The flowchart is quickly available to review the patients' past history, medications, vaccination history and surrogate lab markers.

Discussion

The focus of our initiative was to improve the clinical care of HIV-infected adults in our community. Prior to the programme, HIV-infected clients were cared for in a variety of settings by individuals with a variety of clinical skill levels. There were no formal mechanisms for communication between patients, providers and support agencies. Clinical guidelines for effective medical care were not well developed, nor were they consistent with current literature. No outcome measures were being tracked and disease outcomes were far from optimal. It became evident from these observations and from the formal surveys we performed, that there was a need to comprehensively overhaul our community's standards of HIV care for all practitioners.

At a local level, there are only two realistic approaches to managing the HIV/AIDS issue: (1) create educational and social support programmes to modify individual behaviour and prevent transmission (i.e. new cases); and (2) optimize the clinical management of already infected patients through intervention at multiple levels. The first challenge had already been met in large part due to the efforts of the Red Cross, the Department of Health and Human Services and a non-profit HIV/AIDS support organization providing emergency assistance, counselling, testing and case management services. The second challenge, to address the

problems we defined in our surveys, required a new and multidisciplinary approach. This was the emphasis of our initiative.

The outcomes we measured reflect those items generally included as national standards for appropriate clinical care (Franchi & Wenzel, 1998; Journot *et al.*, 2001; Lehrman *et al.*, 2001; Marshall *et al.*, 2000). Most clinical and programmatic parameters have shown significant improvement since the programme began. Unfortunately, many clients present clinical compliance and medication adherence challenges not unique to our community (Chesney, 2000; Chesney *et al.*, 1999; Crespo-Fierro, 1997; Williams & Friedland, 1997). These have been difficult to surmount.

Our HIV programme has become the model for disease management (Weingarten *et al.*, 2002) within the Health System. Key components of the implementation plan were the establishment of a full-time leadership position for the effort in the form of a clinical nurse practitioner and the creation of clinical pathways utilizing flowcharts for standardization of care delivery. These two items were central to achieving the goal of improving the direct delivery of care to HIV-infected clients. Sub-committees were created to address specific problems and incorporated other clinicians pertinent to new or unsolved issues: for example, the Perinatal HIV Transmission Prevention Committee and HIV/Hepatitis C Co-infection Committee. The timeline evolved as the process matured and outcome data were generated. The addition of a specialized medication adherence nurse counsellor to assist patients identified as needing assistance with antiretroviral therapy has been another asset to the patients and the overall programme.

The programme has entered its fifth year of operation. It remains a model for disease management and has received state and national recognition. Federal funding continues to support the clinical nurse practitioner and medication adherence counsellor roles, which have been vital to our success. We hope that the measurable benefits of similar programmes will generate continued federal and public support for these efforts.

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