Ontario HIV Outpatient Clinic Coordinators Network

Best Practices:
Optimal Care for HIV Outpatient Clinics in Ontario

Table of Contents

Introduction

Ontario has a network of 15 HIV outpatient clinics providing multidisciplinary care to People Living with HIV/AIDS (PHAs) across the province. Although the clinics share a number of common features, they each have unique programs and services designed to respond to the specific populations and communities they serve.

In 2001, the Ontario HIV Clinic Coordinators Networking Group commissioned a study to look at the experiences and perspectives on how care is provided by the clinics. Researchers conducted a number of focus group discussions with PHAs accessing the clinics and with health care professionals working in the clinics. In addition, the researchers conducted one-on-one interviews with a range of clinic staff (physicians, nurses, pharmacists, psychologists, social workers, dieticians, secretaries, chaplains and occupational therapists).

In 2003, consultants Glen Brown and Rodney Kort were engaged to review the transcripts of those focus groups and interviews and to produce a document highlighting findings that reflect 'best practices' in HIV Outpatient Clinic Care. This report reflects their conclusions.

The Context of "Best Practices" in Ontario HIV Outpatient Clinics

Before analyzing the available data and providing recommendations for "best practices" in Ontario HIV outpatient clinics, it is important to consider the following:

- The use of the term "Best Practices" or "Optimal Care" may itself be misleading. The terms have no standard definition, but imply some measure of evidence-based legitimacy. This report reflects the views and expertise of a wide range of providers and users of clinic care. One definition of best practice is provided by *Burke et al* from the Association of Ontario Health Centres: "Best practices aim to (1) adapt practice in ways that suit the particular issue and context and (2) share stories, tools and understanding so that we don't keep reinventing the wheel. Best practices include the incorporation of: philosophy and values, guidelines for practice based on evidence, indicators of positive intervention and processes of staff, volunteer and community involvement."
- Although there was significant consensus between the disciplines represented within the clinic and between clinic staff and people living with

HIV/AIDS, there were some diverging opinions expressed by study participants about what constitutes optimal care. We have attempted to note those views upon which there was major consensus, and those views upon which there were differing opinions.

- Participation in focus groups or interviews was voluntary, and therefore may not reflect the full diversity of opinion among clinic service providers and PHAs accessing the clinics.
- Some participants expressed concerns about the very notion of ”best practices” because they can sometimes be used to limit flexibility, or can be driven by cost control.
- A number of recommended “best practices” may be dependant on available resources. For example, while it may be “optimal” to have an on-site PHA peer advocate, it may not be possible given existing clinic resources and infrastructure. The research did not attempt to prioritize or rank services.
- Many participants, when asked to distinguish between “optimal care” and “minimal care” could not or would not make that distinction; several noted that the multidisciplinary mix of services provided was both essential and “optimal” – with some of course expressing the desire for additional resources, mostly in terms of staffing.

Principles of Optimal Care

The following principles reflect key underlying philosophies or values articulated by both PHAs and clinic staff in interviews and focus groups. These principles provide the foundation on which to build specific approaches and activities in delivering the best possible care to people living with HIV/AIDS in Ontario's HIV outpatient clinics.

1. One stop shopping: The delivery of a range of health and social services in the same or proximate location is of optimal benefit to PHAs and ensures better coordination and communication between service providers;
2. Confidentiality: Protecting confidentiality – both in terms of the physical design and location of the clinic, as well as the protection of personal health information - is a consistent priority among respondents. Safeguards of confidentiality should be well communicated;
3. Multidisciplinary care: An integrated clinic team from a variety of disciplines providing seamless care to PHAs is a priority for optimal care. The team should have effective internal communication and develop strong relationships with external health and social service providers;
4. Patient-centred care: Providers should build relationships of trust with patients, providing the necessary information and support so that PHAs are

able to set their own treatment strategies and identify what services they want to access;

5. Professionalism: Clinic staff should be up to date with the most current standards of clinical care, upcoming treatments, research findings and should take advantage of professional development opportunities whenever possible;
6. Culturally competent care: Services should be provided in a respectful, welcoming and non-judgemental manner irrespective of gender, sexual orientation, race/ethnicity, socio-economic class, religion or drug use;
7. Partnerships: Clinics should maintain respectful, effective relationships with other community, institutional and health care service providers to ensure continuity of care.

Clinic Location and Design

Clinics are quite diverse in their physical location and design. Many are part of hospitals, while others are stand-alone clinics. Almost all have a formal relationship with a local acute care hospital to assist with continuity of care. Following are some of the key findings as it relates to clinic location and design:

Key Findings:

- Both PHAs and clinic staff recognized a “homey” or less clinical environment is welcoming for patients, particularly those new to the clinic.
- Close proximity to other medical services, such as laboratory services or medical specialists, is important to the timeliness and quality of clinic care and the convenience of "one-stop shopping" for PHAs.
- PHAs were very concerned about confidentiality as it related to the physical location and design of the clinic and related signage; this was particularly true of PHAs from visible minority communities.
- The location within the ‘hustle and bustle’ of a typical hospital is of concern to many patients. This relates to confidentiality, as well as comfort.

Summary Analysis

- There was strong consensus between PHAs and clinic staff on the need to make the clinic environment as welcoming and comfortable as possible;
- Although proximity to other health care services was recognized by both groups as an important asset in providing optimal clinic care and "one-stop shopping", the advantages were balanced by PHA concerns that the level of

activity around the clinic may have a detrimental effect on patient confidentiality and personal anonymity.

Best Practices - Clinic Location and Design:

1. Clinic design and location should ensure that patients in the clinic waiting room cannot be seen by passers-by;

2. Clinic signage should use terms such as "immunodeficiency clinic" or similar generic terms to limit visual references to HIV/AIDS;

3. Comfortable seating, donated artwork and low-cost beverages should be available in the clinic waiting room;

4. The clinic should be located in close proximity to other medical services such as laboratories, medical specialists and other services;

5. Clinic design should ensure appropriate physical privacy from other clinics and medical departments in the same institution.

Clinic Services & Staff Disciplines

There is a range of services and clinical disciplines offered within the Ontario HIV Clinic Network. Most offer a similar range of core services, with other services and disciplines varying according to resources, client needs, and relationships with related service providers and institutions.

Key Findings:

- HIV specialist physicians, nurses, social workers, psychologists, dieticians/nutritionists and medical/clerical secretaries are seen as vital to the multidisciplinary team. In most clinics, the clinic director is an infectious disease specialist, although the scarcity of ID specialists does not always allow for this.
- A pharmacist with expertise in HIV medications is seen to be of great benefit to the team, with a role in reinforcing and assessing adherence. Having a pharmacist on-site can also alleviate concerns about confidentiality or stigma that clients might experience in visiting a community pharmacy.
- Clinical research capacity is important in linking clinics to ongoing provincial, national and international research efforts, providing additional staffing support within the clinic and ensuring PHAs have access to trials of potentially beneficial experimental drugs.

- Those clinics associated with teaching hospitals benefited greatly from the participation of residents/students.
- Both PHAs and clinic staff expressed a desire for a wider range of staff, should resources permit. Among some of the expressed needs were:
    - More addiction/harm reduction counselors
    - Spiritual/pastoral care providers
    - Home care workers
    - People to assist with transportation to the clinic for those unable to come on their own
    - Complementary/Alternative Medicine practitioners
    - Peer counselors, who might assist with monitoring standards of care, compliance, referrals, etc.
- Many participants noted that it was important to develop smooth referrals and relationships with a variety of specialists as part of their extended clinical team beyond the on-site clinic.

Summary Analysis

- There was strong consensus between PHAs and clinic staff on the need to ensure a wide mix of disciplines were part of the clinic, offering PHAs a single point of access to meet the complex medical, psychosocial and health system issues raised by HIV/AIDS;
- Pharmacists are increasingly critical to the multidisciplinary team, both due to their role in promoting and assessing adherence and their knowledge of the complex world of HIV drug interactions. As new infections are occurring predominantly among populations with pre-existing health issues, knowledge of HIV drugs, and of interactions between HIV drugs and other therapeutic agents has become even more important;
- Clinical research trials and clinical research nurses were also seen as important to clinic operations by PHAs and clinic staff, although this varied depending on the importance placed on clinical research from clinic to clinic;
- Access to medical specialists from a variety of disciplines is important to ensure appropriate care;
- Both clinic staff and PHAs recognized that additional resources in pastoral care, peer counsellors, addictions counselling and other areas would be important to provide optimal care.

Best Practices: Clinic Services and Staff Disciplines

1. HIV Outpatient Clinics in Ontario should include the following staff in the mix of disciplines:
   - Infectious disease specialist **or** experienced HIV primary care physician
   - Nursing staff (both Registered Nurses and Nurse Practitioners)
   - Psychologist
   - Dietician/Nutritionist
   - Social Worker
   - Pharmacist
   - Clinical Research Nurse/Coordinator
   - Administrative staff;

2. Where relevant to the clinic population, the following staff should also be part of the clinic team:
   - Addiction/harm reduction counsellor
   - Peer counsellor;

3. Clinics should establish a pre-screened roster of pastoral care providers in their community to ensure they are able to refer PHAs for appropriate care upon request (e.g. Aboriginal elders, rabbis, ministers, hospital chaplains, etc.);

4. Clinic staff should establish a roster of reputable complementary health care providers including (but not limited to):
   - Aboriginal healers
   - Naturopaths
   - Homeopaths
   - Registered Massage Therapists (RMTs)
   - Traditional Chinese Medicine practitioners;

5. Clinics should establish a roster of HIV-knowledgeable medical specialists to refer patients to when necessary, including:
   - Endocrinologists
   - Cardiologists
   - Gynecologists
   - Oncologists
   - Dermatologists
   - Psychiatrists;

5. Clinics should participate, whenever possible, in clinical research trials and ensure notices for new trials or compassionate access programs are prominently displayed in the clinic.

Components of Clinical Care

Clinical care, for the purposes of this document, includes not only medical assessment, diagnostic and referral processes, but also the manner in which care is delivered within the clinics.

Key Findings:

- Friendly, compassionate, culturally competent staff are key to establishing and maintaining a level of comfort and trust for PHAs. This includes everyone from the individual answering the telephone to the medical director and other professional staff.
- An initial intake assessment is required to establish a baseline medical history, including treatment history, HIV and non-HIV related health issues and other clinical and psychosocial issues that may have an impact on clinical care.
- Ongoing clinical care is supported by appropriate follow-up (particularly following implementation of a new drug regimen), referral and regular check-ups.
- Clinic staff noted the extensive and time-consuming paperwork required for drug approvals, insurance/disability forms, referrals and other medical services.
- Crisis intervention is increasingly required of clinic staff, particularly among multi-diagnosed populations and/or those in unstable housing.
- Both PHAs and clinic staff noted the importance of nutritionists and dieticians in assessing the nutritional health of PHAs and advising on strategies to maintain general health, boost the immune system, respond to infections and manage the complications of medications.
- Both PHAs and clinic staff noted the importance of ensuring appropriate information and counselling regarding HIV medications. Physicians, pharmacists, social workers, nurses and psychologists can all play important roles in supporting PHAs to make informed decisions regarding drug regimens.
- Many clinic staff noted that a key part of their role was liaison and education with a variety of other institutions and community groups (hospitals, schools, CCAC nurses, social service agencies, AIDS organizations, etc.)

Summary Analysis

- Having friendly, welcoming staff who are respectful and deliver care in a compassionate and non-judgmental manner is critical for establishing relationships of trust between PHAs and health care providers;
- Clinic staff should provide consistent procedures for assessing patients and providing appropriate follow-up and support for a wide range of clinical and psychosocial issues;
- Strong relationships with external health and social service providers is essential to ensuring an appropriate continuum of care for each patient;
- Clinic staff need to be knowledgeable of appropriate crisis intervention strategies and have protocols in place for responding to emergency situations.

Best Practices - Clinical Care

1. Clinic staff should receive regular training in cultural competence and develop appropriate policies and complaint procedures for the Clinic and its host institutions. Where relevant for the clinic population, services should be available in multiple languages;
2. Initial Assessment: Initial intake assessment by the physician and other clinic staff should include:
    - a complete physical exam;
    - a review of whether the PHA may have other health conditions such as other STDs, Hepatitis C, B and A, mental health issues, etc;
    - a review of other medications currently prescribed;
    - substance use;
    - laboratory work (CD4, CD8, ratios, viral load, liver enzymes, testosterone levels, etc.); additional testing may be required depending on clinical history and current health issues (e.g. bone density tests, drug resistance testing, BMI, etc.);
    - information on safer sex and drug injection practices;
    - information on local HIV-related health and social services including services available through the HIV clinic (e.g. nutritional and psychological counselling);
3. Ongoing Care: ongoing/follow-up care should include:
    - an annual health exam
    - scheduling of appropriate injections/immunizations
    - standard laboratory work every 3 - 6 months;

4. Starting/Changing Antiretroviral Therapy: When starting a new anti-retroviral drug regimen there should be a staggered schedule of appointments to ensure appropriate follow-up at:
    - 2 weeks, 4 weeks, 8 weeks, 12 weeks, and then every 3 - 6 months;
5. Clinic staff should receive crisis intervention training and standard protocols should be developed to ensure staff respond and triage calls appropriately. Protocols should include referrals to the clinic social worker or psychologist;
6. Nutrition Counselling: Access to dieticians should be an option for the PHA, and should include either one-time or on-going nutritional advice;
7. Clinics should establish and maintain a current list of local health and social services relevant to their patient population, including individual contact information at each agency. The list should include, but not be limited to:
    - community-based AIDS organization(s)
    - hospices and respite care agencies experienced with HIV/AIDS
    - Community Care Access Centres (for home and attendant care)
    - subsidized housing
    - Disability support agencies/programs (both those offered through the Ministry of Community and Social Services as well as independent agencies)
    - food banks and clothing banks;
8. Clinic staff should, wherever possible, establish relationships with individuals at local health and social service agencies to facilitate access to these services on behalf of their patients;
9. Clinics should maintain a current list of support groups provided locally for specific populations including, but not limited to:
    - HIV positive pregnant women,
    - HIV positive children
    - HIV positive injection drug users
    - HIV positive gay men
    - HIV positive prisoners.
    - Co-infected (Hep C, etc) PHAs

Internal Communication & Resources

Key Findings

- Most clinic staff noted that a database with the patient's detailed treatment, medication and other health information, accessible to all parties that are involved in treatment, is vital for comprehensive care.
- Clinic staff reported that weekly team meetings and/or rounds to discuss both clinical and administrative issues were integral to internal coordination and communication and the provision of optimal patient care. Many team members stress that they could be more effective if they were available to the clinic on a fulltime basis.
- Clinic providers note that it is important to "touch base" with other team members about a PHA's situation and needs. For example, it may be valuable for the physician to hear the social worker's assessment of the PHA prior to the clinical assessment.
- Clinic staff expressed a strong desire for educational opportunities to ensure that their standards of care were current and optimal.
- While most communication is informal, Clinics also had systems in place to ensure appropriate coordination, referrals and follow up of patients.
- High staff turnover can pose a problem because there is not the same familiarity with the client. Many clients have encountered administrative mix-ups as a result, especially during an emergency.
- All respondents reported a need for additional resources that would provide a wider array of services, ensure ongoing professional development of staff, and expand and retain knowledgeable and experienced staff.

Summary Analysis:

- Clinics need an information system including electronic health record, secure email and integrated patient database to reduce paperwork, facilitate communication between health care providers and support research;
- Regular weekly meetings among the multidisciplinary team are key to providing integrated patient care and follow-up;
- Additional funding/resources are required in the clinics in order to secure the necessary mix of disciplines, expand the role of existing team members, and ensure appropriate systems support for patient care;
- Professional development opportunities are important in ensuring knowledgeable, experienced clinic staff.

Best Practices - Internal Communication & Resources

1. Implementation of a comprehensive, secure information technology solution is required to support clinic administration;

2. Clinics should establish regular meetings for the entire multidisciplinary team to raise questions and share information about specific patients, provide updates on new or emerging treatment issues, and ensure individual team members are aware of any changes in HIV programs and services provided by government or local service agencies;
3. Each clinic staff member should complete an annual professional development plan, outlining relevant conferences, meetings, journal subscriptions or other education opportunities required to remain current with the latest advances in HIV clinical and psychosocial care.

External Coordination, Communication and Advocacy

Many respondents noted that referrals to, communications with and knowledge about other health and social service providers are key to providing optimal care, including those delivered by government ministries and departments. Although a portion of this relates to clinical care and is addressed in that section of this document, other health and social services are equally important to quality of life for PHAs.

Key Findings

- Some clinics have representatives on multi-agency coordination committees;
- Clinics report varying waiting times to access labs, specialists, and other related services;
- While some staff expressed concern about the extent to which their institution's management supported the clinic, others indicated significant support from the institution's management;
- Clinics which engaged in research noted the need for efficient relationships with research coordinators and data collectors;
- PHAs in particular, but also clinic staff, noted the need for improved access to government drug, disability and income support programs;
- A number of PHAs suggested the need for PHA advocates – systemic and individual. Some believe these should be PHA peers.

Summary Analysis

- Clinic staff participation on local committees or planning councils which provide HIV-related programs and services is useful in establishing relationships with other service provides and improving service coordination;

- Clinics play a significant advocacy role for individual PHAs in facilitating access to services, although this function has not been formalized within the clinic staff disciplines and clinic mandate.

Best Practices - External Coordination, Communication & Advocacy

1. Clinic staff should participate on local, regional provincial and national committees and boards which are responsible for improving clinical care and health and social service delivery to PHAs and other marginalized populations;
2. Clinics should establish a protocol for establishing and maintaining current information on HIV-related programs and services provided by both government and community-based agencies;
3. Clinics should consider retaining voluntary or (where resources allow) paid PHA peer advocates to help facilitate access to drug, disability, income support and social housing programs

Conclusion

It is important to note that the recommended "Best Practices" outlined in this document substantively reflect current policies and procedures at the 15 HIV outpatient clinics in Ontario. The data from focus groups and key informant interviews reveal a profound commitment from the clinic staff to ongoing self-evaluation and improvement and a significant level of satisfaction from the PHAs served by the clinics.

The authors of this document are hopeful that, by identifying policies and procedures that have developed and refined over time, *Best Practices: Optimal Care for HIV Outpatient Clinics in Ontario* will provide a helpful reference tool for the clinic staff who continue to provide unparalleled care and treatment in an epidemic that has presented Ontario with unprecedented clinical, social and economic challenges.