Exploring Tobacco Dependence and Cessation Among People Living with HIV/AIDS

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This brief report provides key findings from a study exploring the experiences, expectations and possibilities for treating tobacco dependence among tobacco users living with HIV/AIDS. The study was conducted through the Manitoba HIV program in Winnipeg, Manitoba. The study involved listening to the perspectives of people living with HIV/AIDS who are clients of the Manitoba HIV program, as well as clinic staff. A brief survey of Canadian agencies providing services to people living with HIV/AIDS was also conducted. A team of researchers from the University of Manitoba and the Health Sciences Centre collaborated on this study.

"[My dentist told me] you could have like cancer on each of the tonsils… there's all this stuff that I hear about smoking, like it scares me. That's why I want to quit."

~Client~

"I was talking to [the smoking cessation expert] today, she says well HIV isn't going to kill you, it's all the other stuff that's going on. So. Just trying to live a little longer"

~Client~

"My physician [asks if I smoke]. He's the only one. It's part of their questionnaire. No more, no less… They give you a little slap on the wrist." *~Client~*

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Background

Did you know...

Recent data indicate that the life expectancy for an adult with newly diagnosed HIV can exceed 35 years (Lohse et al., 2007).

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Even after an AIDS diagnosis, life expectancy is estimated to be almost 15 years (Walensky et al., 2006).

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Daily tobacco use has been shown to weaken the immune and virological response to antiretroviral therapies by 40% (Miguez-Burbano et al., 2003).

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Rates of tobacco use among PHAs tend to range between 47% and 80% (Benard et al., 2006; Browning et al., 2009).

<u>Why study tobacco use and cessation among people living with HIV?</u>

HIV is a virus that causes AIDS, a condition in which the immune system gradually weakens allowing for illnesses to flourish. Since the introduction of Highly Active Antiretroviral Therapy (HAART) the progression of HIV/AIDS can be slowed and people diagnosed with HIV/AIDS (PHAs) can live a substantially longer life. Now PHAs face the reality of living with a chronic disease rather than preparing for death. PHAs health needs are changing. Learning to live with a chronic disease means addressing risk factors related to aging, cardiovascular disease, cancer, and respiratory illnesses. Since the majority of PHAs smoke cigarettes, addressing tobacco use is a health priority for PHAs.

Research evidence suggests that smokers living with HIV are at a greater risk than non-smokers living with HIV to develop:

- Pneumonia
- Cancers
- Emphysema
- Heart disease
- Mouth lesions and gum disease
- Weakened immune system
- Metabolic diseases like diabetes
- AIDS dementia complex
- Acute bronchitis

<u>Research Objectives</u>

- To explore the experiences of tobacco use, dependence, and cessation with clients who use tobacco
- To describe study participants' personal smoking patterns, level of social support, depression, readiness to address tobacco use, level of tobacco dependence, and use of other substances
- To explore the experiences of tobacco use, dependence and cessation, and current practice related to treating tobacco dependence with health professionals working in the HIV Clinics

Design

Recruitment and Participation

All study recruitment and interviews/focus groups took place in Winnipeg, Manitoba. Two clinics were chosen to recruit clients: Health Sciences Centre (HSC) HIV Clinic, and Nine Circles Community Health Centre. Clients of the HSC HIV Clinic and Nine Circles who smoke were invited to participate, and staff at HSC HIV Clinic were invited to participate in the study. Additionally, a brief survey was sent to Canadian agencies that provide services to PHAs.

Interviews and Focus Groups

Client interviews and focus groups focused on:

- Experiences with tobacco use
- Changes in how they smoke since being diagnosed with HIV/AIDS
- Experiences and motivations to quit
- What would they require to stop smoking

Staff interviews and focus groups focused on:

- Practice experience related to tobacco use and cessation
- What resources are available to them for clients
- Barriers and facilitators for treating tobacco dependence within their practice
- What is the ideal situation for them to adequately treat tobacco dependence

Winnipeg Participant Questionnaires

All study participants completed a questionnaire along with their interview. Client questionnaires included their tobacco use history, a depression scale, demographics, and if they thought their tobacco use was affecting their health. Staff questionnaires assessed their smoking history and how long they had been working with people who have been diagnosed with HIV/AIDS.

Canadian HIV Agency Email Survey

We identified 86 eligible agencies from the Canadian AIDS Society website membership list. Agencies were emailed a survey that focused on assessment of tobacco use at their agency, advice offered around tobacco use, what supports they offer to clients, if costs of these services are subsidized and by whom. The response rate was 28%; a total of 24 agencies from across Canada. At least one agency from each province or regional area responded with the exception of the northern territories. On a final note, due to funding limitations the survey was only available in English.

Insights from these data sources shed light on how tobacco use and cessation is addressed within HIV/AIDS clinics.

Winnipeg Participants

29 CLIENTS were interviewed/participated in a focus group

- Age range: 28-63 years
- Almost 3/4 were men
- 28 clients were daily smokers
- 18 clients reported smoking for 20 years or more
- The clients started smoking between the ages of 6 and 17
- 18 clients reported a high level of dependence and giving up their first cigarette of the day was least preferable over all others
- 20 clients have 3 or more friends/family that they see weekly who smoke
- 7 clients reported a high level of depression based on the CES Depression Scale

4 CLINIC STAFF were interviewed/participated in a focus group

- Years working with individuals with HIV/AIDS: 0.5—20
- 2 are former smokers

Study Findings: Client Experiences and Thoughts about Smoking

Co-Addictions

Many of the clients are not only addicted to tobacco, they have co-addictions to other substances.

- Marijuana—19 clients used illicit drugs in the last 30 days
- Alcohol—10 clients consumed more than 5 drinks in a single sitting in the last month
- Coffee

How they get cigarettes

Most clients have how they obtain cigarettes down to a science. They know where to get the cheapest cigarettes, good places to go to pick up butts and who to ask to bum cigarettes.

- Most buy cigarettes; some buy premade cigarettes and others buy loose tobacco and roll their own
- Only one person picked up cigarette butts to smoke, another picks them for friends
- Rare situations: bum cigarettes off others, family members buy cigarettes for them, get cheaper cigarettes from a reserve

Habits around smoking

Some also have specific habits around smoking, such as not smoking around non-smokers, smoking outside, or smoking after their morning coffee.

"I have to smoke as soon as I wake up. The first thing I do is reach for my cigarette. I have to smoke after I eat, or when I'm in bed or going to bed. It's just I like smoking, but I shouldn't."

"I don't smoke first thing in the morning. I smoke more and more towards the evening."

Framing Tobacco Use

Clients we interviewed said they smoke because they enjoy it, it's something to do when they are bored, it helps them deal with stress, they are sometimes influenced by their peers to smoke, but also because it helps distract them from their diagnosis.

"if I get a upsetting phone call or, it seems any excuse I can find I will go and have a cigarette"

Attitudes clients have around their tobacco use:

- Some say they are addicted, while others say it's just a nasty habit
- Don't like the smell
- Waste of money, too expensive
- More socially acceptable than other addictions
- Wish they had never started
- Smoking has nothing to do with HIV

Researcher: "So do you ever think about quitting now?" Client: "No, I'm too addicted."

"quite frankly I'm a little bit ashamed that I started smoking again after quitting for so long"

"my addictions are not as big as other people's"

"people on welfare can't afford to smoke, yet it's so addictive"

Family and friends play a role in the client's smoking status. Most clients have family and friends around them who smoke. In fact, 13 clients have partners who smoke. Some clients were allowed or encouraged as early as 6 years old to start smoking by relatives. On the other hand, numerous clients have had family members pass away from cancer due to smoking, which has not influenced their opinions and decisions about their own smoking.

Many talked about facing restrictions related to smoking:

- While incarcerated, some clients said that not smoking was not a bother and they simply just dealt with not smoking. Others learned tricks like how to turn a patch into a cigarette. All returned to smoking immediately after being released from prison.
- Some talked about finding ways to smoke in their home where smoking was not allowed. This includes group home settings.
- Some clients talked about appreciating legislated restrictions, because it helps them cut back on their smoking.
- When people are on limited incomes, once the money is gone and they can't buy cigarettes they just don't smoke; this is their way of life.

"Stick your head out the window, use a sheet and stick it out the window."

Study Findings: Client Health Concerns

Did you know...

Within 20 minutes of last cigarette blood pressure may drop to normal level, pulse rate drops to normal rate, and body temperature of hands and feet increase to normal.

Within 8 hours the carbon monoxide level in blood drops and oxygen level in blood increases.

Within 24 hours the chance of a heart attack may reduce.

Within 48 hours the ability to smell and taste is enhanced.

Within 3 days lung capacity increases, bronchial tubes relax and if they are not damaged, breathing is easier.

2 weeks to 3 months later circulation improves, walking is easier, and lung function may increase up to 20%.

1 month to 9 months later coughing, sinus congestion, fatigue, shortness of breath may decrease markedly over a number of weeks.

At 1 year the risk of heart disease is reduced by half.

At 2 years cervical cancer risk is reduced compared to continuing smokers, and bladder cancer risk is halved compared to continuing smokers.

At 5-15 years the risk for stroke is reduced to that of someone who has never smoked.

(RNAO Nursing Best Practice Guidelines, 2007)

Health and HIV

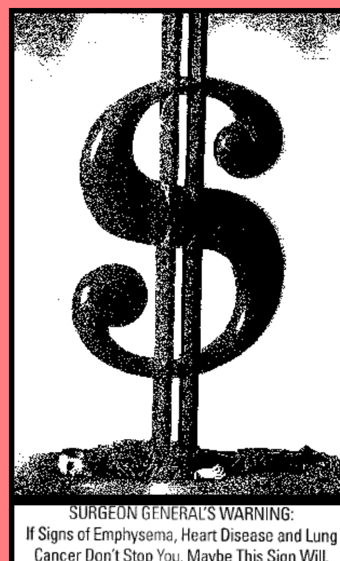
The clients talked about several health concerns. Common worries mentioned were: asthma, emphysema, COPD, pneumonia, bronchitis, difficulty breathing, their heart, and their energy level.

When talking to clients about health risks associated with smoking, only one was aware that smoking increased the risks of health conditions related to having HIV and taking HIV medications. Clients talked about quitting smoking because of their lung disease or heart disease not because of health risks related to living with HIV. When asked if thoughts about stopping smoking had changed since being diagnosed with HIV, participants' response was no. Clients appeared unaware of health risks related to being a smoker living with HIV beyond lung or heart conditions.

During interviews some clients mentioned that being diagnosed with cancer could result in *starting* to think about stopping smoking. For many smoking is not an addiction, rather it is something they thoroughly enjoy and something very serious would have to happen to them to give up something they love so much.

"...my nurse said; you have the beginnings of emphysema... I said that means quit smoking. And she said yes."

"Like I'm feeling so worn out. And exhausted and I know smoking a cigarette aint going to give me any energy."



"Every time I have a cigarette, I feel like I'm putting one nail in my coffin"

"I just wanted to stop getting pneumonia... I have a history of bronchitis and pulmonary embolisms... also combined with my asthma."

"I have asthma... And now I have heart problems. I had a stroke."

Study Findings: Client Experiences of Quitting

In the past, 23 of the 29 clients interviewed had tried to quit smoking. 17 of the 23 clients had quit for 6 months or less, and 6 had quit for 1 year or more.

Clients have had different and opposing experiences with health providers concerning their smoking and quitting:

- Most were *asked* if they smoke
- Concerning *advice*: some feel nagged and others said they received minimal advice to quit, or asked if they are interested in quitting
- *Supports* are there if they want them and others felt there isn't a lot of support available
- A common *support* offered was medication
- Cessation expert talks to them a lot, and is planting seeds with them
- A few attended a group program
- Resources posted around clinic about smoking

"I also know already that if I do need help and I am struggling, I can get a hold of [the smoking cessation expert] and get into that or she has there that program"

"my worker… when she goes out for a smoke break, she gives me a cigarette."

"they said that it would be a good idea if I did quit, but cutting down even makes a big difference."

"Every time [the smoking cessation expert] walks in that room she says you got to quit smoking."

"they ask me if I smoke and how much I smoke per day and that's about it."

Experiences with nicotine replacement therapy (NRT) are similar to those with health providers; opinions are split. Some say they work, and others say they don't work, taste horrible or they have a bad reaction to medications. Clients have tried Champix (Varenicline), Zyban (Buproprion), the patch, gum, and lozenges. It came across strongly that the cost of NRT and other treatment options prevents clients from trying products or retrying a product. Finding the funds to pay for both cigarettes and NRT while in the process of trying to stop smoking is too much for some; they simply cannot afford it.

"I tried the Patch and it didn't do anything. I didn't feel like I was getting any, anything to help the craving."

"I think like Nicotine Patches are the most effective thing around now."

"but Champix works. Ahh, it kills the urge for a cigarette."

"I've tried the Patch; I've tried acupuncture; I've been trying for a long time."

Reasons they have quit in the past:

- Pregnant
- Offered a reward to quit smoking
- Preparing to run a marathon
- Incarcerated
- Going for surgery
- For their young children
- Health concerns, such as asthma

"when I was pregnant with my children, it was more of – what's nine months out of my life for their life."

Techniques they used to cut down :

- Chew chewing gum
- Willpower
- Cut down with spouse
- Watched for triggers
- Using a NRT or medication
- Buying a 20 pack of cigarettes vs. a 25 pack
- Didn't have the money to buy cigarettes
- Cold weather keeps them inside where they don't smoke
- Going to the gym
- Keep busy
- Stop drinking
- Roll their own cigarettes—it's a chore and so they smoke less
- Smoke one cigarette over the course of the day

"That time I quit smoking is when I quit drinking."

"I eat sunflower seeds just to keep my mind off the cigarettes sometimes."

"it's just money wise more or less that's cut me down"

" I'm trying to use more willpower then anything else."

Study Findings: Client Expectations of Quitting

Participants are interested in quitting. Of the 29 clients interviewed 12 expressed a desire to quit within the next 30 days, and another 6 in the next 6 months. Still, they also face significant barriers that prevent stopping smoking from becoming a reality.

- Cost of NRT, unable to cover costs of both NRT and cigarettes while trying to quit
- Scared of their mood swings and the effect this has on their relationships
- Worried about gaining weight if stopping smoking
- Hard to quit when everyone around them smokes

"But, the doctor wants me to quit of course. But I can't. I just can't do it on my own."

"But I didn't want to get fat. I don't want to put on all this weight."

Clients talked about what might support quitting smoking:

- Free NRT
- To be kept busy, either physically or mentally
- Willpower
- Constant support
- To have a very serious health condition
- Social support; making a commitment to someone else

"Throat cancer or something like that"

"I wish there was just a magic pill."

"If I run out of money…. I mean that could change tomorrow if I get emphysema and I can't and I'm on a respirator"

"A new life."

"I just can't imagine quitting."

Ultimately, clients feel it is up to them to decide when they are ready to quit, but they also acknowledge that when they are ready support will be required. There are benefits from health care providers continuing to "pester" them and telling them about medications. But they want health care to include support groups and help lines. Clients think it would be appropriate for the government to partially or fully pay for people to quit smoking, for example through providing NRT.

"They should help you out with, if you're going to quit. I mean maybe not pay the whole price of the [NRT]… but give you some kind of a discount. I mean you even pay taxes on top of that. That's how greedy they are for the money. I mean they should give the, the person who is trying to quit a bit of a break… even take the tax off… I'm not asking for the moon, just something that shows that at least they support you."

"it's a great idea that umm, that the medical field's getting more into helping people deal with their addiction of, of tobacco."

Client thoughts about quitting now:

- Some were interested in quitting but it has to be their decision to quit, they won't quit just because a health provider told them to
- Don't feel they have the support needed to quit and know they can't do it on their own
- Want to quit because of the smell, the cost, and future job prospects
- Won't quit unless forced by a health issue
- Have tried NRT and they didn't work
- Might try NRT if it were free
- Would like to try Champix but unable to afford it
- Might stop using cigarettes but not marijuana
- Scared to quit after smoking for so long
- Only seems possible when money disappears or other situations with no option (like incarceration)

"I think if something like that Champix was covered by umm, Manitoba Health… Or even through the welfare. I would probably give that, give that a shot."

Study Findings:
National Email Survey & Health Professionals

National Email Survey

We received 25 completed surveys from 24 agencies from across Canada who provide services to PHAs. One agency completed two surveys to reflect different agency programs.

Offering Assessment and Advice

	Yes	Sometimes	No
Assess Tobacco Use	6	7	12
Assess Social and Emotional Support	9	6	9
Advise to Reduce Tobacco Use	12	6	7
Advise to Quit	8	8	8

Counseling and Group Support

	Yes	Sometimes	No
Regular Counselor	6	8	8
Counselor with Cessation Training	4	3	15
Group Cessation Program	2	6	12
Cessation Workshop	1	5	13

Counseling sessions were available more than once a week and group programs were offered as weekly meetings. Workshop delivery varied. All of these services were offered at no cost to clients. Also, just over half of the agencies at least sometimes referred clients to the Smokers' Helpline.

Medications Available

	Yes	Sometimes	No
NRT Gum	8	1	13
NRT Patch	7	3	12
NRT Inhaler	6	1	15
NRT Lozenge	6	2	14
NRT Spray	4	1	15
Zyban (Buproprion)	5	4	12
Champix (Varenicline)	5	4	12

Costs for medications were offered at some level of cost subsidy to a client, which appears to be primarily a result of mechanisms within the agency or through government organization support. The NRT gum was available through a variety of health providers or counselors but the remainder of the NRT medications were prescribed by either a physician or a trained cessation counselor. Zyban and Champix were only available through a physician prescription.

Alternate Therapies: The majority of agencies were not offering or accessing alternate therapies; 72% said no to offering laser therapy, 60% to acupuncture and 64% to herbal supplements. Agencies reporting accessibility for these therapies reported either complete or partial subsidized costs.

Health Professionals

Clients with HIV/AIDS and Smoking

- Smoking is a long time coping mechanism to deal with stress and anxiety
- Some clients do not view smoking as an addiction or even harmful
- Smoking is normalized in society—can buy cigarettes at a store—so no worries for some clients
- Sometimes clients will choose cigarettes over food
- Clients will *say* they want to quit but are looking for a magic bullet

"Because often we have people who have no money… they'll take the cigarettes over food sometimes."

Framing Priorities

Tobacco use is not always addressed, especially upon first diagnosis because of competing priorities for PHAs. Stabilization of the client's life is most important by addressing housing, nutrition, energy level (fatigue), other addictions, understanding the diagnosis, and social network issues. With stabilization of these issues, an interest in becoming healthier emerges and tobacco becomes a priority.

"There are probably ahh days when people come in really sick – we just need to focus on the immediate medical issue. So taking a longer history from them for anything that day other than the immediate symptoms are not, not appropriate."

"if you're living under the bridge, ok, that's priority – needs to get a house."

"Well, I think with some of our patients, they're, tobacco is the least of their concerns. Because they are dealing with a lot of other very serious addictions in terms of either solvent or alcohol ahh or needles. … I don't think they view tobacco as an addiction or anything even harmful because it's so common."

Study Findings: Health Professionals

Tobacco Use, Health and their Practice

- Aware of the long term health effects of smoking, living with HIV and HAART medications
- Thought they needed to be better translators of health effects with clients
- On initial visit to the clinic most clients are asked if they smoke at a minimum
- At subsequent visits:
  - Clients may be asked if they continue to smoke
  - About their smoking/quitting history
  - If interested in reducing or stopping smoking
- For clients interested in reducing:
  - They are offered an appointment with the clinic smoking cessation expert
  - Possibly at that time or during a future visit

"[If the client is interested in quitting….] we'll again try and follow them up with [the smoking cessation expert]. And if some people want to stop, start that day… we can get them on the Champix or the Wellbutrin."

"And we know very clearly the benefits to stop smoking. And how it can improve general health. One health. Ahh increase your longevity. Umm, so there are benefits that we know. We need to I think to better translate that. To our patients."

What Prevents Treating Tobacco Dependence

- *PHAs'* level of stress, lack of stability, or inaccessibility of treatment options due to lack of money, disbelief in medications, or living in rural settings.
- *Clinic staff* believe clients do not want to talk about tobacco use, other co-addictions need to be addressed first, and that there are competing priorities.
- *Clinic structures* lack support for tobacco dependence treatment being a priority through: lack of space for counseling clients about tobacco and limited time to spend with clients regarding tobacco use because of demands related to multiple appointments and priorities.
- *Governmental support* for coverage of medications and resource support for clinic structure does not reflect the importance of treating tobacco dependence. Why are they not using taxes to cover costs of treating tobacco dependence?

"Like [the smoking cessation expert] has to book sometimes outside [clinic] time. So you know it's hard sometimes for her to get the clinic room."

"But, I also see it as you know what, it's not a priority for the hospital. You know. So if it's not a health care priority, for an institution you know even from the government level you know to have these medications covered. I mean what kind of message does that send overall."

What is working now:

- Door is always open to readdress tobacco use at each appointment
- Cessation expert within the clinic is a resource to work with clients and has influenced health professional practice through knowledge/ skill in approaching the topic
- Tobacco dependence treatment fits within the clinic's mission
- The clinic has a good supply of cessation material for clients

"Our ahh waiting area is full of smoking cessation resources."

What is needed to improve clinic practice:

- Another smoking cessation expert
- More space for counseling
- Tobacco dependence medications at no cost to clients
- More time to spend with clients on prevention priorities
- Cue in the client chart as a reminder to address smoking at each visit

"You need more people. Basically you know we need another [smoking cessation expert]. And then we'd need more space. You know. For counseling and you know, so it can actually be addressed. And free NRT."

Treating Tobacco Dependence: Gaps & Possibilities

In Canada there are six provinces/ territories that provide at least some coverage for NRTs and Champix. The provinces are: British Columbia, Saskatchewan, Ontario, Prince Edward Island, Quebec, and the Yukon. Manitoba is now considering this coverage.

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The benefit of covering costs of medication means immediate increased funds for housing, food, and other stabilizing factors within PHAs lives. All of which will also have a positive influence on PHAs health and will decrease the likelihood of developing additional health conditions.

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Nurturing open lines of communication concerning tobacco dependence is an important health priority.

Health and Priorities: Shedding light on disconnected dots…

We know PHAs' life expectancy now commonly spans several decades after initial diagnosis and as a result their health care needs now focus on learning to live with a chronic condition. Yet, they are at greater risk for a variety of health conditions. While the increased risk is a result of living with HIV and taking HAART medications, the level of risk is commonly compounded by other factors. For PHAs one key factor is tobacco use. Based on research evidence, it is easy to argue that treating tobacco dependence is a health priority among PHAs.

- The health professionals involved in this study were aware of this argument but also acknowledge that their effort in translating this information to clients is lacking.
- The client stories heard in this study, suggest a disconnect between tobacco use, living with HIV and increased health risks. This disconnect confirms the health professionals acknowledgment.
- From our study, this is further demonstrated by what health professionals identified as a trigger to addressing tobacco use, which was seeing early signs of heart or lung disease. This is a reactive approach, whereas if the practice standard was more proactive, then health conditions could be prevented or at least deferred.
- From the interviews, we hear that health providers frame housing and nutrition as higher priorities than treating tobacco dependence. We wonder though, if clients stopped smoking not only would they have positive health effects, but they would also have more money available for housing or nutrition. With this in mind, might treating tobacco dependence become a higher priority for PHAs health care?

Treating Tobacco Dependence

Clients involved in this study indicated an interest in quitting, which is reflected in the literature specific to PHAs who use tobacco.

Significant barriers to treating tobacco dependence identified by participants were:

- Competing with other priorities and accessibility of health care services
- Having costs of treatments covered will be essential for PHAs
- Clients require support beyond medication in overcoming their addiction to tobacco
  - ⇒ Survey results demonstrate that a minority of agencies are finding avenues to having treatment costs covered for their clients

While a decision to stop smoking must come from the client, for most there was some level of interest in wanting to stop and several welcomed ongoing encouragement to stop. The challenge arising is to create a health care service context for PHAs that is rich with possibilities to explore addressing tobacco dependence. Subsequently, how to have tobacco dependence treatment become a health priority in practice to match what is clearly articulated in the literature.

Conclusion

Next Steps

- Meet with study sites to discuss findings
- Publication of findings in peer-reviewed academic journal

Contact Information

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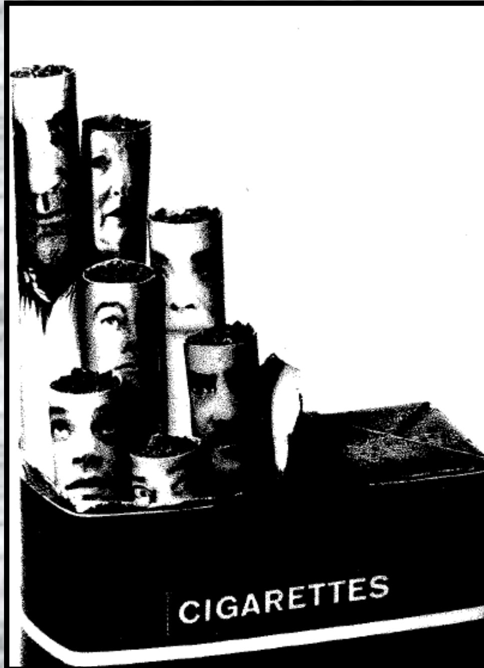
This report and others by Dr. Annette Schultz can be found on the following webpage: http://www.sbrc.ca/content/blogcategory/275/335/



SURGEON GENERAL'S WARNING:
Don't Be Taken in by the Rest of the Pack.

SURGEON GENERAL'S WARNING:
Some People Just Can't Quit.

We would like to hear from you. Send us an email at:

HIV_smoking_study@yahoo.ca

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Health Sciences Centre Foundation
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