Seeking medical advice if HIV symptoms are suspected

Qualitative study of beliefs among HIV-negative gay men

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abstract

OBJECTIVE To identify beliefs associated with seeking medical advice promptly when symptoms of HIV infection are suspected among HIV-negative gay men.

DESIGN Qualitative study of beliefs among focus group participants.

SETTING Quebec city, Que, metropolitan area.

PARTICIPANTS Referred sample of 20 HIV-negative gay men 18 to 45 years old who attended bars, university, or gay associations in Quebec city.

METHOD Three focus groups of five to seven subjects were formed and each 2-hour session was tape-recorded.

MAIN OUTCOME FINDINGS Participants thought that seeking medical advice promptly when symptoms of HIV are suspected would help them be informed about their health status and would eliminate unnecessary anxiety and fear, but would force them to face reality and make major changes. Barriers were the quality of the relationship with their physicians and concern about discussing their sexual lives. Normative beliefs were sought from members of community groups, circles of close friends, health providers, and the media.

CONCLUSIONS Several beliefs could influence the motivation of seronegative gay men to seek medical advice promptly when symptoms of HIV infection are suspected. These beliefs should be integrated into programs promoting early consultation with physicians and into clinical counseling, as integration could facilitate early treatment and care. Physicians should give special attention to establishing relationships of trust with these patients.

résumé

OBJECTIF Identifier les croyances associées à une consultation médicale sans délai quand des symptômes laissent soupçonner une infection à VIH chez des homosexuels VIH séronégatifs.

CONCEPTION Une étude qualitative des croyances chez les participants d'un groupe témoin.

CONTEXTE La région métropolitaine de la ville de Québec, au Québec.

PARTICIPANTS Un échantillonnage aiguillé de 20 homosexuels VIH séronégatifs de 18 à 45 ans qui fréquentaient les bars, l'université ou des associations de gais dans la ville de Québec.

MÉTHODOLOGIE Trois groupes témoins de cinq à sept sujets ont été formés et chaque séance de deux heures avec eux a été enregistrée sur bande sonore.

PRINCIPAUX RÉSULTATS Les participants étaient d'avis qu'une consultation médicale sans délai lorsque des symptômes d'une infection à VIH étaient soupçonnés les aiderait à être informés de leur état de santé et éliminerait une anxiété et une crainte inutiles, mais les forcerait à regarder la réalité en face et à apporter des modifications majeures à leur comportement. Les obstacles dont il a été fait mention étaient la qualité de la relation avec leur médecin et une préoccupation à l'égard de discuter de leur vie sexuelle. Des croyances normatives ont été recherchées auprès de membres de groupes de la collectivité, de cercles d'amis intimes, de dispensateurs de soins de santé et des médias.

CONCLUSIONS Plusieurs croyances pourraient influencer la motivation des homosexuels VIH séronégatifs à consulter rapidement un médecin si des symptômes d'une infection à VIH étaient suspectés. Ces croyances devraient être intégrées aux programmes préconisant une consultation médicale précoce et au counseling clinique, puisqu'une telle intégration pourrait favoriser un traitement et des soins sans délai. Les médecins devraient accorder une attention spéciale à l'établissement d'une relation de confiance avec leurs patients.

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RESEARCH

Seeking medical advice if HIV symptoms are suspected

Until only a few years ago, HIV infection was a progressive lethal disease. Since late 1995, several scientific advances have led to a profound shift in the prospects of most patients receiving treatment.[1]

Recent clinical studies suggest that early treatment during primary HIV infection results in a detectable improvement in the clinical course of the disease.[2-4] Thus, the International Aids Society–USA Panel recommends managing patients who have primary HIV infection with the most powerful antiretroviral treatments, even though long-term effects are not fully known.[5]

Until recently, patients had little incentive to seek medical care, especially because several hopes and promises in the past had not had anticipated results. Evidence that early therapeutic intervention, shortly after seroconversion, could change progression of infection, however,[3,4,6,7] might lead people who suspect they have symptoms of HIV to seek medical advice promptly.

During primary infection, 50% to 80% of patients display such symptoms as fever, enlarged lymph nodes, rash, muscle aches, diarrhea, and headaches.[6,8,9] It is difficult for patients to associate these symptoms with HIV seroconversion because some symptoms are not specific or exclusive to a given health problem. Most subjects might consider the symptoms harmless; they might simply monitor the symptoms, follow the progression, and postpone clinical consultation. Motivation to seek the advice of a physician promptly when symptoms of HIV infection are suspected is not always present.[10,11]

Perceptions of and opinions about the new treatments have yet to be documented. Indeed, a literature search of MEDLINE, AIDSLINE, and PsycLit using the key terms *HIV, primary infection, gay men, attitude, medical care, treatment, and antiretroviral therapy* yielded only a few references.

Several models suggest a need to identify salient beliefs.[12-15] These theories are well established and have been applied successfully to study a variety of health-related behaviours.[16] Moreover, several authors have recommended the qualitative method, known as an elicitation procedure, to design effective interventions,[17,18] because qualitative studies allow researchers to obtain "culturally specific information."[19]

According to these theories, several kinds of beliefs support decision making, mainly behavioural beliefs, normative beliefs, and control beliefs.[13,14] Behavioural beliefs are associated with the advantages and disadvantages of adopting a given behaviour. For example, a person could believe that seeking medical advice promptly if symptoms of HIV infection are suspected would help fight the disease early or would relieve anxiety. Normative beliefs come from important people or groups one considers when making decisions. For example, one might seek approval from close friends, one's lover, or others for seeking medical advice promptly if symptoms of HIV infection are suspected. Control beliefs are the perception of the presence or absence of necessary resources and opportunities, as well as anticipated obstacles or impediments to adopting given behaviours. For example, to be afraid of a positive diagnosis and to have to disclose homosexuality are such beliefs. Finally, emotions and feelings (ie, embarrassment, stress, or reassurance associated with seeking medical advice) are also important factors in deciding and need to be identified.[20]

This research aimed to identify beliefs associated with promptly seeking or not seeking medical advice when symptoms of HIV infection are suspected. This information is the first step toward developing more effective interventions to motivate patients to consult physicians promptly when symptoms of HIV infection are suspected and to help physicians counsel their patients who believe that they are HIV-positive.

METHODS

Sample

For qualitative research, participants are not selected randomly, but chosen to ensure that the sample presents the characteristics of the problem addressed. In this study, the important aspect was to be an HIV-seronegative gay man. Thus, the study population consisted of HIV-negative gay men living in the Quebec city, Que, metropolitan area.

Men aged 18 to 45 years were invited to participate in the study by the staff of MIELS-Québec, a community organization. Subjects were recruited in bars, at the university, and at social and recreational gay associations. Participants were recruited in bars through personal contact. An announcement stating the objective of the focus groups was also sent to

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various gay associations (social, recreational, and university) inviting interested men to participate in the discussion groups. In the final sample, 55% of participants were professionals, 20% were students, and 25% were non-professional workers. Forty percent were recruited in bars, 40% at social and recreational gay associations, and 20% at the university. This study was approved by the Laval University ethics committee.

Procedure for data collection

Focus groups were organized following Morgan's[21] recommendations. Three discussion groups with men of different ages (group A: 19 to 45 years, group B: 19 to 24 years, group C: 25 to 45 years) were held in January 1998. Focus groups were divided by age because epidemiologic data suggested that young gay men were engaged in riskier sexual behaviour than older gay men.[22-25] They have also been exposed to the AIDS epidemic differently; older gay men have been exposed to people dying from AIDS or living with HIV more often than young gay men. Five to seven men participated in each of the three focus groups, for a total of 20 men. A health professional and a community worker (one of the authors) explained the study's aim and directed the 2-hour tape-recorded semistructured discussion.

The analysis strategy was theory driven, that is, guided by belief categories adopted for this study as suggested by several theories of attitude.[14,15] Thus, participants were first invited to share what they knew about multi-drug therapy and treatments in the early phase of infection. Then they were presented with the following situation: "One night you go out and meet a new guy! At the end of the evening, you have unprotected anal sex. Two weeks later, you develop certain symptoms, such as fever, enlarged lymph nodes, rash, muscle aches, diarrhea, and headaches." They were asked to discuss several issues:

- perceived advantages and disadvantages of promptly seeking or not seeking medical advice when symptoms of HIV infection are suspected (ie, behavioural beliefs);
- the most important people or groups they would look to to approve or disapprove their adopting this behaviour (ie, normative beliefs);
- perceived barriers or facilitating factors that could hamper or encourage adopting this behaviour (ie, control beliefs); and
- their feelings and emotions at the thought of seeking medical advice when symptoms of HIV are suspected.

Field notes were kept by the research assistant conducting the focus group. After each focus group, questions were reviewed and main findings noted. Main findings from one focus group were not systematically used in subsequent ones, although they were useful in shaping the wording of questions. The third focus group did not generate new aspects that had not been mentioned in the first two discussion groups. Thus, it was decided that saturation of themes had been reached.

Data analysis

Content analysis was performed by two persons (the research assistant who conducted the focus group and one of the authors). First, each person listened to the 2-hour recording independently. Then the tapes were transcribed into text and the principal elements were identified by each of the two analysts. The process of coding was one of constant comparison: moving back and forth between interview material and analysis, uncovering similarities and differences within and between focus groups. This procedure generated categories and subcategories as defined by the belief-based system adopted. The two analysts had to reach agreement on the most-often mentioned themes and on labeling themes extracted: behavioural beliefs, normative beliefs, control beliefs, and emotions and feelings. Finally, the representativeness of the themes extracted was confirmed by community members who reviewed the findings.

FINDINGS

Behavioural beliefs

To be informed about one's health. Participants indicated that seeking medical advice promptly when symptoms of HIV infection were suspected would help them be informed about their health. Several participants believed that it was important to know what condition one might have, to know the nature of one's discomfort, and to avoid living with uncertainty.

Consulting promptly was also related to the hope of recovery by fighting the disease early, by slowing disease progression, and by having access to new treatments. Participants believed that response to treatment might be greater if treatment is started early. One participant stated, "If I don't seek medical advice, I will never know what I have. One should not live with uncertainty.… If you have a cold or a flu, you don't wait until it degenerates into pneumonia. It is important to know what's wrong." Another person expressed similar feelings, "By consulting early, I can

identify the problem and have access to treatment;… it could help slow down the disease's progression."

Anxiety and fear. Diminution of unnecessary anxiety and elimination of unnecessary fear were other perceived advantages of seeking medical advice when HIV infection was suspected. Prompt reassurance, after someone has had unprotected sexual intercourse, would eliminate doubts and fear as to their HIV status. Some participants also indicated that living for months with anxiety could have a negative psychological effect. They believed that, if someone learned that he was seropositive, at least he would know where he stood and would thus avoid having unnecessary doubts and unnecessary psychological side effects.

I don't understand not wanting to consult. I would not be able to say to myself, "I won't consult because I am afraid to learn that the result of the test is positive; I will be anxious in any case, so instead of living with this anxiety, I would rather face the truth." If the result is negative, the balloon will deflate. If the result is positive, I will have to learn to live with this situation as any other problem in life.

Safer sexual practices. More than one third of the men also reported that finding out their HIV status as soon as possible would enhance adoption of safer sexual practices. They would thus avoid infecting others and feeling guilty. Several men indicated that their physicians could help them be conscious of the situation and of the risk of transmission to other partners. They believed that it was crucial to take responsibility and to adopt socially responsible behaviour.

You have to think about those with whom you have sex. An infected person who has unprotected sex with others should not transmit the virus to others. I don't think this would help him to have a better quality of life. It is better to find out as soon as possible if one has the virus, instead of infecting everybody and then feeling guilty.

Facing reality. Reasons reported for not seeking medical advice promptly when symptoms of HIV infection are suspected were that it would force them to face reality and would result in great changes in their lives. Most participants believed that they would have to reorganize all aspects of their lives if they learned that they were seropositive. They thought their future would turn upside down and their projects would suddenly fall apart. A young man explained, "If tomorrow morning I learn that I have the HIV virus, what do I do? I am in the middle of my studies; do I stop my education? I have a good job; do I quit my employment? I have to make major changes in my life." Another participant expressed his thoughts, "Delaying consulting a physician will let me continue to live the same way. I will not have to make major changes in my life; I will not have to wear condoms; I will not have to deal with any stress; I will not have to question myself."

Normative beliefs

The most important people or group who would approve seeking medical advice promptly if symptoms are suspected were close friends and sexual partners. One participant said, "I would first talk about it with my partners and close friends. If those persons were not available for one reason or another, I would seek the opinion of community groups that I trust because of their experience and their credibility."

Some men also noted that knowing someone who was HIV-positive would probably prompt them to consult a physician. Being in contact with other seropositive gay men would help them to be aware of what is happening to them; otherwise their only source of information would be the media. The important role that television and other media could play in providing information on the advantages of consulting rapidly was raised by several participants. Finally, the social influence of family members and health professionals was also mentioned, but to a lesser extent than the other groups.

Control beliefs

Physician-patient relationships. Several participants stated that one of the most important barriers to seeking medical advice promptly was the physician's reaction. The quality of the relationship with a physician is reported to influence men's decision to seek care when they believe they are HIV-positive. Several men were worried about having to find an understanding and competent doctor whom they trusted as well as having to face a doctor's prejudice. Several participants voiced the concern that some physicians were unreceptive and had prejudices against gay men. Participants' opinions are illustrated by this statement: "Physicians are human beings, and some of them are not very receptive; they are prejudiced against gay men. It is important to find a good doctor. In medical school they don't learn how to deal with homosexuality."

A few participants thought that, when a gay man consults a doctor who dislikes homosexuals, he suffers the consequences. For example, one participant said, "If I felt from the beginning that I was not accepted, the

relation that I will develop with my physician would start off on the wrong foot."

Fear of ridicule. Another important concern was ridicule; because the symptoms of primary infection are very similar to other diseases, such as the flu, participants worried that physicians would not take them seriously, would not understand their preoccupation. One person emphasized, "There is also the fear of ridicule, especially when the doctor asks you why you are preoccupied by a simple cold, and tells you that you have to learn how to deal with little health problems."

Disclosure of sexual identity. Other obstacles difficult to circumvent in seeking medical advice were to have to reveal sexual orientation and to disclose unsafe sexual practices. Many participants believed that talking about sexual behaviours with their physicians or telling their physicians that they have had unsafe sexual practices was not a simple task. It could be an important barrier, particularly if a physician were uncomfortable with the situation. Some men also thought that a non-identified gay man or a married man would never dare to consult a doctor to talk about his sexual life.

> For me to talk openly about my sexual behaviour with my doctor is not easy; to have to tell him that I had risky behaviour is a problem.... The fear that I will be discovered, to be obliged to admit my infidelity, will prevent me from consulting.... It is embarrassing.

Fear of positive test results. Finally, the fear of finding out the result of the test was another barrier. Several men would refuse to consult promptly because they believed they were unable to deal with positive test results. By not knowing what they had, they could continue to believe that they were still healthy. During the discussion, the following arguments were presented: "There is also the risk of being confirmed as seropositive, the fear of the reality… to have to receive a diagnosis." "If a person is not able to face a positive result, he is going to tell himself that he prefers not knowing the result because he is not able to deal with this answer that he dreads. It is easier for him to not know and live with magical thoughts."

Emotions and feelings

Mixed emotions were also associated with the intention to consult a physician promptly when symptoms of HIV infection were suspected after unsafe sexual practices. On one hand, seeking medical advice could be embarrassing, frightening, shameful, stressful, and unpleasant. Several men mentioned the fear of being discovered and the obligation to admit their infidelity, particularly married men or gay men with steady partners. They also talked about the stress and fear associated with confronting death. One participant expressed his emotions and feelings as "the fear to be discovered, to be obliged to admit infidelity, for example, a married man with three children, a gay man with a steady partner and who has secret sexual encounters." Another man indicated, "There is the fear. You have to know how to face that fear. It is embarrassing: the anxiety, the distress, the panic to be confronted with death, the despair to learn that you might die soon."

On the other hand, some participants thought that it could be comforting and reassuring to find out the nature of the symptoms and to eliminate unnecessary anxiety about being infected. One man stated, "The week after consulting the physicians, the fear may increase, but when you find out that the result is negative, you feel relieved and reassured."

DISCUSSION

Gay men reported several beliefs and barriers regarding seeking medical care promptly when symptoms of HIV were suspected. These should be taken into consideration within clinical settings as well as in programs promoting seeking early advice from a physician.

In the literature, understanding the motivation of people who suspect they are HIV-positive for consulting promptly or delaying seeing a physician is poorly documented because active antiretroviral treatments for the primary infection stage are recent.[9] Few studies have attempted to understand the psychosocial factors associated with gay men's decisions to seek HIV testing.[10,26,27]

Although these two behaviours have some similarity, differences could be crucial. Tests for HIV infection can be taken anonymously and do not necessarily involve physician-patient interaction, whereas consulting a physician implies personal contact. Important reasons reported for avoiding HIV testing were fear of encountering AIDS-related discrimination,[26] desire for anonymity, self-perceived health, no perceived benefits, denial,[10] negative attitudes, and poor behavioural control.[27]

In this study, the main advantages of consulting a physician promptly when symptoms of HIV were

suspected were the perception that this would improve health outcome, would lower fear and anxiety, and would favour adoption of safer sexual practices. An important perceived disadvantage was that this would force participants to make great changes in their lives. As pointed out by Siegel and associates,[28] factors associated with treatment initiation could change over time. More emphasis should be placed on positive health outcomes following early treatment and on positive attitudes toward changes in life. Siegel and associates[28] reported similarly that the decision to initiate treatment for HIV infection among a group of urban gay men was associated with adopting a more positive approach to dealing with their HIV status and with an attempt to influence their health outcomes.

Two main barriers emerged during these focus groups: the quality of relationships with physicians and concern about discussing their sexual lives. The positive association between the physician-patient relation and compliance with medical recommendations for treatment of HIV infection was observed in a study of long-term AIDS survivors[29] and among HIV-seropositive people.[11] Siegel and associates[28] also reported that, during unstructured interviews, several seropositive men said they had chosen not to receive medical treatment because of their distrust of doctors and of the medical establishment.

For patients to seek medical advice promptly, they must first establish trusting relationships with their physicians. Thus, practitioners should focus on establishing trusting and understanding relations with their patients, especially those who report high-risk behaviours for HIV infection. This might result in more careful monitoring of HIV symptoms and early intervention as reported by O'Brien and colleagues.[30] Moreover, Makadon and Silin[31] highlighted several barriers that could explain physicians' lack of involvement in clinical HIV prevention. Among these barriers were physicians' discomfort with issues raised by HIV and AIDS, such as human sexuality and drug use, and physicians' attitudes toward patients living with HIV. Interventions promoting early identification of HIV infection will need to address the issue of patient-physician relationships.[11] No doubt enhancing physicians' skills in taking sexual histories would be very relevant for HIV prevention.[32] Including HIV risk assessment in regular physical examinations should also be emphasized.

Participants pointed out that several people or groups could influence their decisions to seek medical advice promptly. Besides the close circle of friends and their partners, it should be noted that community organizations, health providers, and the media in general could have an important role. Several studies have shown that family physicians are cited by the public as the most trusted source of health information[33] and that patients heed their health-related

Key points

- Because early intervention with new anti-HIV drugs can confer great benefit on HIV-positive men, family physicians have an important role in diagnosing, managing, and preventing HIV.
- Gay men recognized the advantages of consulting early for suspected HIV infection: improved health outcomes, reduced fear and anxiety, and adoption of safer sexual practices.
- Participants were also wary that such consultation might force them to make important alterations in their lives and be associated with anxiety, guilt, and shame.
- Physicians' negative attitudes toward gay people and discomfort discussing sexuality were identified as serious barriers to these patients' seeking early care.

Points de repère

- Parce qu'une intervention précoce au moyen de nouveaux médicaments contre le VIH peut se traduire par des bénéfices considérables pour les hommes VIH séropositifs, les médecins de famille ont un rôle important à jouer dans le diagnostic, la prise en charge et la prévention du VIH.
- Les homosexuels reconnaissent les avantages de consulter sans délai si une infection à VIH est soupçonnée: une meilleure issue médicale, la réduction de la crainte et de l'anxiété, et l'adoption de pratiques sexuelles moins risquées.
- Les participants se doutaient aussi qu'une telle consultation pourrait les forcer à faire des changements importants dans leur vie et pourrait être associée à de l'anxiété, de la culpabilité et de la honte.
- Les attitudes négatives des médecins à l'endroit des homosexuels et le malaise ressenti à discuter de sexualité étaient identifiés comme de sérieux obstacles à une consultation médicale sans délai par ces patients.

messages.[34] Thus, intervention programs should integrate these key groups, particularly family physicians, who could help people at increased risk of HIV infection to seek early medical intervention.

Results reported in this study represent the opinion of a group of seronegative gay men living in a French Canadian community. They do not represent the spectrum of opinions in other cultural settings or in other groups, such as women or intravenous drug users.

This information could be useful to health care professionals, however, in understanding the concerns and motivation of patients who are likely to consult them promptly when symptoms of HIV infection are suspected. Because early intervention could have important benefits for infected people,[5] family physicians can play a critical role in diagnosing, managing, and preventing HIV infection. Clinicians can better achieve this objective if they are aware of the beliefs prevailing among gay men regarding seeking medical advice promptly when symptoms of HIV infection are suspected.

CONCLUSION

This study has highlighted several factors that could influence seronegative gay men to seek medical advice promptly. These salient beliefs should be considered in developing programs promoting early consultation with physicians to facilitate early treatment and care of men who are seropositive. Special attention should be given to establishing trusting relationships with patients. Finally, further investigation is needed to better understand the attitudes and beliefs of family physicians regarding early medical intervention in management of HIV infection.

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