Use of the Internet by oncology patients: its effect on the doctor–patient relationship

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TO THE EDITOR: The possible impact of the Internet revolution has been much discussed.[1-3] In two surveys, conducted in 1999 and 2001, we surveyed oncology patients from two teaching hospitals in central Sydney to explore the experience and impact of Internet use among Australian oncology patients.

In November 1999, a questionnaire was mailed to 240 eligible patients selected from 617 sequential registrations to the oncology units. Eligible patients were those who were alive, competent, had cancer, were of known address and whose attending medical officer was participating.

In the second survey, to obtain a more representative sample, we invited all oncology patients visiting the outpatient clinics over a three-month period (September to December 2001) to participate.

We received completed questionnaires from 142 patients (response rate, 59%) in 1999 and from 153 patients (number of refusals unknown) in 2001. Of these, 33% (47/142) in 1999 and 46% (70/153) in 2001 had accessed the Internet for information relating to their illness, either personally or through family and friends. In both surveys, most users accessed the Internet from home, the information sought was mainly in relation to treatment, and the most-visited Internet sites were those of cancer centres.

Patient perceptions of the impact of Internet-acquired information on their experience of cancer are summarised in the Box. Most patients viewed its impact as positive. The advantages of using the Internet reported by patients included its speed, convenience, privacy, currency, diversity of viewpoints, and usefulness as a support tool. Many reported that they had sought corroboration of Internet information with information from other sources, especially their doctor. Problems identified with the Internet were its impersonal nature, time costs, overabundance of information, and concerns about the discovery of inappropriate, inaccurate or distressing information. Most respondents emphasised that they were able to recognise these limitations, but, notwithstanding, considered the Internet a valuable resource. For example, one respondent wrote: "I felt my capacity to cope with the illness and treatment greatly improved because I learned enough from the Internet to challenge my oncologist and thereby learn to *trust* him and his advice."

Despite concerns expressed by many doctors, these oncology patients assessed impacts as either positive or neutral in overall influence. Increasing Internet use by patients and their families should not be viewed as a problem, but as an opportunity for patients and their treatment teams to work together, ensuring that patients have up-to-date information about their illness and its treatment and are aware that they are not alone in the fight against cancer.

1. Van Der Weyden MB, Armstrong RM, Chew M. The communication revolution: winners and losers [editorial]. *Med J Aust* 1999; 171: 512.
2. Coiera E. The Internet's challenge to health care provision [editorial]. *BMJ* 1996; 312: 3-4.
3. Ferguson T. From patients to end users [editorial]. *BMJ* 2002; 324: 555-556. ❑

Perceived influence of Internet-acquired information among oncology patients in 1999 and 2001

	Better	No change	Worse	Question not answered
1999 survey (n = 47)				
Relationship with doctor	12 (26%)	30 (64%)	0	5 (11%)
Discussions with doctor	20 (43%)	22 (47%)	0	5 (11%)
Treatment decisions	22 (47%)	19 (40%)	1 (2%)	5 (11%)
Coping with illness	26 (55%)	15 (32%)	1 (2%)	5 (11%)
2001 survey (n = 70)				
Relationship with doctor	24 (34%)	34 (49%)	2 (3%)	10 (14%)
Discussions with doctor	42 (60%)	18 (26%)	1 (1%)	9 (13%)
Treatment decisions	37 (53%)	25 (36%)	0	8 (11%)
Coping with illness	32 (46%)	31 (44%)	1 (1%)	6 (9%)

Rising cannabis use in Indigenous communities

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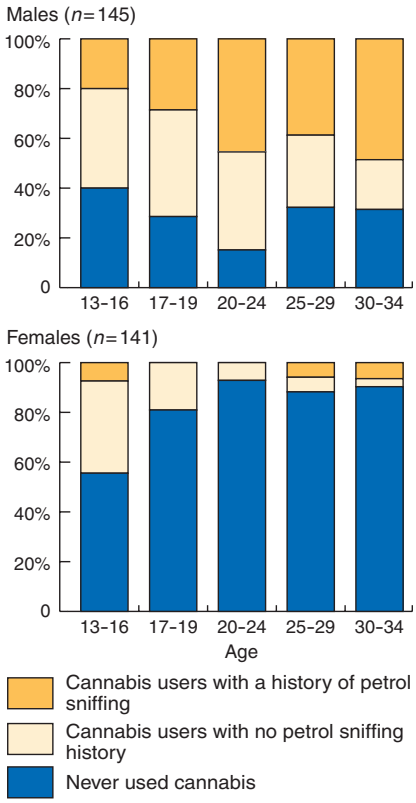
TO THE EDITOR: We write to alert policy makers and clinicians to the challenge presented by rising cannabis use in north-east Arnhem Land, in the Northern Territory, given that many current cannabis users were previously petrol sniffers. In the past five years, there has been a rise in cannabis use and evidence of expansion of supply links in the Miwatj region.[1] There are concerns that rising cannabis use is associated with social effects: increased family violence, drug–alcohol psychosis, self-harm and suicide, and community disruption. Policy makers seeking to foster

Current cannabis users among people aged 13–34 years in northeast Arnhem Land



Results for samples from two remote communities in the Miwatj region, assessed by using health worker consensus classification, self-report data, and supporting data from health clinic chart review.

initiatives to minimise harmful outcomes must develop general policies that can have local effects in a varied Northern Territory population. NT police have targeted cannabis in remote communities. A Substance Abuse Select Committee and Illicit Drugs Task Force, each with Indigenous representation, will report to the NT government during 2002.

We recently began collecting baseline data to allow us to evaluate the effects on patterns of use of cannabis (and related harm) of community-wide interventions. These interventions will be similar to those implemented for petrol sniffing,[2] but with a focus on improved availability of appropriate drug education. We have selected a random sample of about a third of the residents (aged 13–34 years) from two communities. From this sample, current cannabis users (at least weekly) and past petrol sniffers have been identified by using health worker consensus classification, supported by data from review of the health clinic chart and self-report, if available. These data for 145 males and 141 females are presented in the Figure. Among males aged 20–34 years, 74% are current cannabis users and, of these, 60% are former petrol sniffers. To date, 57 cannabis users have agreed to interview (34 males and 23 females) and, of these, 38 met DSM-IV criteria for cannabis dependence.[3]

A particular health concern is that persistent cannabis use may compound any residual cognitive impairment from petrol sniffing.

Competing interests: None identified.

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1. Clough AR, Guyula T, Yunupingu M, Burns CB. Diversity of substance use in eastern Arnhem Land (Australia): patterns and recent changes. *Drug Alcohol Rev.* In press, 2002.
2. Burns CB, Currie BJ, Clough A, Wuridjal R. Evaluation of strategies used by a remote Aboriginal community to eliminate petrol sniffing. *Med J Aust* 1995; 163: 82-86.
3. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed. Washington, DC: American Psychiatric Press, 1994. ❑

Corrections

Re "Thiazolidinediones and type 2 diabetes: new drugs for an old disease", the New Drugs, Old Drugs article by Trisha M O'Moore-Sullivan and Johannes B Prins in the 15 April issue of the Journal (*Med J Aust* 2002; 176: 381-386), in which an editing error resulted in the word "tryglyceride" replacing "total cholesterol". Thus, on page 383, under the subheading "Both drugs increase HDL and LDL and decrease FFA levels; pioglitazone lowers triglyceride levels", the first sentence in the second dot point should read "Rosiglitazone also tends to increase total cholesterol level and studies have reported variable effects on ratios of **total cholesterol** to high-density lipoprotein (HDL) and of LDL to HDL." ❑

Re the article "The contribution of airway structure to early childhood asthma", by McKay KO and Hogg JC, in the 16 September supplement to the Journal, *Early childhood asthma: what we know and what we need to know* (*Med J Aust* 2002; 177: S45-S47). The last two lines of the figure caption on page S46 were omitted. The full caption should read:
"The vessels in the submucosa (a) are smaller than the vessels in the adventitia (c), and the vessels that pass through the muscle layer (b) connect them. These two sets of vessels are perfused in series, providing a basis for a difference in the nature of the inflammatory reaction in the submucosa and lumen compared with the peribronchiolar space."
The article, with correct caption, appears on our website. ❑

Hepatitis C virus seroconverters: help wanted

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TO THE EDITOR: In Australia, an estimated 11 000 people become infected with hepatitis C virus (HCV) each year.[1] Most are injecting drug users.

The Early Hepatitis C Intervention Project was a collaboration between the STD Services Surveillance Unit, Drug and Alcohol Resource Unit and Infectious Diseases Unit at the Royal Adelaide Hospital, Adelaide, South Australia. Its objectives were to manage people who had seroconverted in the preceding 12 months and to provide standard treatments for drug use and dependence. Services included information and education on HCV, referral, counselling, psychosocial support and three-monthly clinical evaluation. The project was approved by the Ethics Committee of the Royal Adelaide Hospital and funded by the Department of Human Services for 18 months.

The attendance rate was low. Of 88 people with HCV seroconversion who were identified as eligible for enrolment by the Surveillance Unit (from the mandatory notification scheme), 57 agreed to further contact by mail or telephone, and 12 attended for risk assessment. Of these, eight enrolled in the project (10% of those eligible).

Despite demographic variation within the group, similarities included difficulties with accommodation, finances, mental health and social integration. Seven of the eight participants had injecting drug use as the risk factor for HCV infection. Most participants also used alcohol and cannabis. During the program, half decreased their risk-taking behaviour: four reduced injecting drug use, and four reduced alcohol use, reaching low risk levels. Characteristics of participants at their last interview are summarised in the Box. Two participants are maintaining regular contact with the Drug and Alcohol Resource Unit.

Despite encouragement, few of the target group engaged in the program. We do not know why so few people who agreed to attend a first appointment failed to do so. We did not have their permission or the resources to contact them again. Maintaining contact with participants also proved challenging, and was in part unsuccessful because of complex, multifaceted social issues aside from HCV infection (Box). These included unstable accommodation, use of health services only when in crisis, mental health problems, financial difficulties, polydrug use and continued risk-taking behaviours despite harm-reduction information.

In conclusion, the Australian epidemic of HCV infection, driven by injecting drug use, is likely to continue unless a new approach to harm minimisation is developed. Such an approach will recognise that comorbidities and social dislocation influence risk of infection. Unless treatment programs address coexisting problems, it will be futile to offer definitive treatment for HCV infection.[2]

Within the limited objectives and resources of this project, we were unable to support these people comprehensively. We believe that a "one-stop shop" that includes active and intensive case management by a flexible, multidisciplinary team and deals with social, economic and mental health