How clients choices influence cancer care in northern Aboriginal communities

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ABSTRACT
Objectives. To illustrate how personal choice, or client self-reliance, is a determining factor in the management of cancer patients’ care in northern Aboriginal communities. Study design. Multiple-site study done in the northwestern part of the Canadian Province of Ontario. Method. In-depth interviews with professionals and paraprofessionals involved in community-based delivery of cancer care. Results. Study details how perceived care options, gender, awareness of disease and treatment, reaction to system-linked problems in care delivery, as well as cultural preferences influence clients’ choices and care outcomes. Conclusion. The study underlines the interdependence between personal choice and the health care system; "bad" experiences with the system cause clients to disengage from care, while client disengagement results in reduced care options.

Key Words: Aboriginal health. Cancer care, Client self-reliance

INTRODUCTION
Personal choice, or client self-reliance, is a significant factor in how any cancer patient’s case is managed. For aboriginal people in the north, however, experiences with a stretched and, hence, inflexible health care system, together with distance-linked barriers to access, make clients’ decisions more important than is generally the case. Moreover, such widely shared factors are compounded by individuals’ situations and responsibilities. Results from a study done in the northwestern part of the province of Ontario, Canada, illustrate the combined effect that system-linked and/or situationally-driven decisions have on care outcomes (1). The study, basis for the present paper, looked at oncology services for aboriginal clients in several rural, but diverse northern contexts: differing sized communities, various distances from tertiary referral centres, some road-accessible, but others that can be reached only by air.

Recognition of patients’ inherent right to decide is a relatively recent phenomenon in health-care, the result of emerging awareness of socio-cultural, ethical and legal considerations (2). Significant research has been done on dimensions of the issue over the past 15 years; from interactional styles of nurses and physicians seeking to influence patients’ choices (3) to measuring and improving decision-related outcomes (4). Several studies focus on ways care-givers can assist patients in the process (5,6); as well, disease and situation-specific factors have been identified in peoples’ non-compliance with therapeutic regimen (7). However, despite increasing expectations of patient involvement, relatively little is known about how they actually make choices (8).

METHODS
Although the incidence of cancer in the study population has yet to be determined, the high self-report rates published in the Ontario First Nations Regional Health survey (9) for the province as a whole signalled possible cause for concern in northern districts where there is a higher propor-
tion of aboriginal people. Consequently, Chiefs of the region’s Nishnawbe-Aski First Nations passed a resolution supporting research on the delivery of oncology care. This idea was endorsed in the neighbouring Grand Council Treaty #3 area by individuals advocating at the community level. Six communities from both regions agreed to participate in the study.

The research team, which included three aboriginal health professionals, designed the project to respect aboriginal people’s preference for direct involvement in any research in their communities. During the development phase, members of the team met with community leaders and care providers to discuss the project. Subsequently, three aboriginal university students were hired as research assistants to conduct in-depth interviews with the professional and paraprofessional care providers who serve each of the communities, both within and from outside. The resulting narrative data were subjected to analysis by team members working independently of one another and, then, consensually validated. This process identified three broad categories of factors – geographic, systemic, and situational – which bear on oncology patients’ decisions about their care and, thus, their health outcomes.

RESULTS AND DISCUSSION

Geographic Influences
In northwestern Ontario there are 67 Cree and Ojibway communities scattered over a vast track of subarctic boreal forest, equal in size to Germany. Just 46,847 people live in them, with fewer than 100 residents in some places, but as many as 1,600 in others. Several communities along the southern boundary of the area are road-accessible, but most can be reached only by aeroplane. So geography dictates what health services are available, as well as the routes of access to and utilization of them. Where there are roads, patients can easily reach a number of neighbouring industrial towns, each with a comparatively good compliment of health resources. However, for primary care those in more remote communities must depend on staff at the local nursing station, together with physicians who fly in on a monthly basis, or fly out for tertiary treatment at one of the region’s larger centres.

The geographic imperative is evident in the treatment altering decisions made by patients from each type of location, respectively. Those from the road-accessible communities, blessed with multiple options in different towns, routinely “shop” for care, rather than maintaining contact with one provider. This practice has numerous consequences. A complete medical record is not generated and, thus, not available to physicians or other care providers in any of the locales. So these professionals tend to deal only with presenting symptoms, rather than providing care based on a full understanding of the patients’ past history. Subsequently, continuing care is disrupted when the patients fail to keep follow-up appointments, reportedly a common occurrence. Moreover, if health professionals do not see themselves as the usual or principal care provider, they may not do routine health assessments, so patients miss having normal screening and diagnostic tests done for extended periods of time.

In contrast, the limited choice for those in remote communities necessitates travel out for some screening (e.g. mammograms) and advanced diagnostic tests, as well as any complex treatments (e.g. chemotherapy). At the time of the study, the Canadian government still covered the cost of transportation for the patient and, if required, an escort. However, because of the high cost of travel and accommodation, other family members usually cannot afford to accompany them, so patients facing a significant health crisis often find themselves alone or with a single companion, in an unfamiliar town hundreds of kilometres away from their loved ones and extended support group. Even if they are able to return to their home communities at intervals, the regimen of care requires that they repeatedly undertake the long trip south. Faced with this reality, the researchers heard of case after case where individuals opted not to follow their plan of care, either electing to return home before completing a
course of treatment, or refusing to return for follow-up care. The possible consequences of disengaging in this manner seem to be accepted with a stoical preference – if they were going to die, then they wish to do so at home.

**Systemic Influences**

The low population density of the region translates into a health system where physical and human resources are scarce, not per capita but due to geographical dispersion. The system is stretched, literally and figuratively, to meet people’s needs.

The difficulty recruiting human resources is particularly serious at the moment. Attracting health professionals to work in northern communities is a chronic problem that has turned acute. This is true for physicians working in towns proximate to the region’s road-accessible communities, and for both nurses and physicians serving more northerly sites. At the time of the study, one fly-in community had 42 different nurses in and out over a year-long period. Because care providers are short-term, the care horizon is also. Presenting symptoms are dealt with, follow-up is not. Indeed, staff shortages shift the system’s orientation exclusively to treatment; programs like the well-women’s clinic, responsible for screening (e.g. pap smears), are put on hold.

Staffing deficits can have a significant impact on patients’ decisions. They tire of having to repeatedly recount their symptoms and history every time there is a new person and, frustrated, sometimes simply stop going to the nursing station for follow-up care. Or, if they do keep their appointments, they do not restate essential facts during the history taking stage, since they told the last doctor or nurse and assume that the information has been passed along. Unfortunately, the flow of client information is not guaranteed when busy clinicians are reliant on a charting system where multiple care-givers have made entries. As a result, the risk of symptoms being missed increases.

**Personal Influences**

Factors which might be characterized as "personal" in nature fall into three categories: gender-linked preferences, cultural practices, and disease awareness. While varying from individual to individual, obviously, each has the potential to affect decisions in a significant way.

A reluctance to access care was noted across our interview sites; this was found to be true for both men and women. Early detection among males is rare since men avoid having such routine screening as rectal exams done and tend to ignore warning signs. They present only when the symptoms become acute, often not until the disease course is well advanced. Similarly, there are obstacles convincing women to have Pap smears done. Respondents pointed to shyness as a cause, although apprehension about exposing themselves to strangers has been attributed to demeaning residential school experiences in the case of older women, or sexual abuse for those who are younger (10).

Practices rooted in their culture form the basis on which key care decisions are made. Many individuals, especially those who are older, continue the time-honoured economic pursuits of their people, living for extended periods in the bush on their fur trapping lines. But the wish to do so poses a dilemma for cancer patients; it is difficult to maintain a regimen of care that depends on frequent medical appointments when one is out on the land. Cultural beliefs also inform their choices. Some people prefer traditional medicines rather than physician-prescribed treatments; they stop the latter, relying instead on traditional methods of healing. Others seek to blend both traditional and western medical practices; this approach was endorsed by practitioners, who noted the importance of spiritual and emotional well-being in treatment.

Clients’ awareness about the disease and the potential efficacy of treatment courses are key determinants in the decisions they make. Respondents felt that patients had little awareness of the treatments available and were prone to view the diagnosis of cancer as a death sentence. As a result they sink into denial or avoidance behaviours, rather than actively exploring their options. Moreover, there is a stigma associated with the illness, perhaps due to the assumption of mortality, so pa-
tients conceal the information. By not revealing their condition, however, they effectively deny themselves support from within the community.

The antidotes to the above — communication and education — although they may be categorized as systemic in nature, are made personal through experience. Consider, for example, the challenge of discussing with a patient their pancreatic cancer when there is no word in the Oji-Cree language for pancreas. Or having to rely on translators who themselves may not really understand in English the medical information they are being asked to convey. Such impediments can affect the personal choices made by cancer clients and, hence, affect the process of care.

CONCLUSION
The study underlines the interdependence between personal choice and the health care system; “bad” experiences with the system cause clients to disengage from care, while client disengagement results in reduced care options. Although geographic realities and some systemic stressors, like staffing shortages, will persist, they can be offset through better communication and education. In this regard, community members who are part of the system of care, like Community Health Representatives (CHRs), appear to be underutilized resources. As a case in point, a doctor from an industrial town, discouraged by patient non-compliance, reports that the problem disappeared when his office (with the patients’ permission) informed their community’s CHR about follow-up appointments. She made sure that these were kept. The paraprofessionals’ role could be much greater, however. Not only is health education part of their mandate, but with their knowledge of the language, culture and communities’ sensitivities, they are well situated to take a lead in helping to make cancer patients’ personal choices informed choices.

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