Patient ethnicity and diversity research in Canada: One forecast of the future

Bejoy C. Thomas, PhD

In contrast to the 2009 Canadian Cancer Society annual cancer report, the 2020 report may not only discuss cancer incidence and mortality by age and gender but also by patient ethnicity. This reporting style would be similar to the present-day American Cancer Society (ACS) annual reports that have dedicated sections to describe the ethnic disparities in American cancer care. However, to comprehend the significance of this potential change, the complex issues that Canadian cancer care policymakers and researchers grapple with today need to be understood.

DEFINING THE POPULATION

At the time of Confederation, Canada’s population was chiefly British (60%) and French (30%). By the beginning of the 21st century, with the combination of declining birthrate and infusion of other European and non-European immigrants, the proportion of people with British, French and/or Canadian ethnic origins had dropped to less than half (46%) of the total population. Between 1991 and 2000, 2.2 million immigrants were admitted to Canada with an annual intake rate ranging between 0.6% and 0.9% of the total population and an unprecedented influx of landed refugees. This increased diversity was evident in the 2006 census, in which more than 200 different ethnic origins were reported. In 2006, 20% of Canada’s population was foreign-born, the highest proportion since 1931.

DEFINING “CANADIAN”

On the 1996 Census form, “Canadian” was added to the list of examples of ethnic origins for the first time. By 2006, one out of 3 people (or 10.1 million people) reported Canadian as either their only ethnic origin, or in combination with another ethnic origin. The majority (91%) of the population aged ≥15 who reported a Canadian origin were born in Canada and had both parents born inside Canada. After Canadian, the ethnic origins most frequently reported were English, Irish, French, Scottish, German, Italian, Chinese, North American Indian, Ukrainian and Dutch. The visible minority population accounted for 16.2% of the population, up from 4.7% in 1981.

LANGUAGE

Language diversity is also at the core of Canadian pluralism. According to the 2006 census data, English dominated as the first language (mother tongue) in 58% of the population. French came next at 22%, while the allophone category (having a mother tongue other than English or French) was 20%. The number of allophones has quickly increased — between 2001 and 2006 an increase of 18% was reported. Of the 1.1 million immigrants who settled in Canada between the 2001 and 2006 censuses, 80% were allophones.

THE INHERENT COMPLEXITY

With over 200 ethnic groups, and nearly 20% of our population being allophone, categorizing people by their reported ethnicity may not be prudent, particularly because the same individuals in 5 or 10 years time may self-report as “Canadian” or “Canadienne.” Even if this transition did not take place, no researcher or policymaker can make decisions on populations distributions such as 3 Vietnamese, 98 Germans, 13 Russians, 516 British/United Kingdom, 2 Koreans, or 9 “Africans.” This example is a partial snapshot of patient-reported ethnicity in our cancer center in a single month from the Carlson et al, study on screening. As with any other study, smaller groups are usually reassigned to larger cohorts such as “European,” “East (E) and Southeast (SE) Asian,” “Ethnicity other” or just assigned to “Non-white.” Journal reviewers frown upon such categorizations because of the “high variance in the ‘other’ group.” Yet this complex heterogeneity of our patients is something one cannot avoid — or can we? If we as cancer professionals acknowledge the uniqueness of the 200 and more cancer types, why do we assume the individuals we treat to be any less complex?

“ACCESS” AS A CANADIAN RIGHT

Another significant reason why we do not have the legislation in place to identify ethnic-based outcomes is that the Canadian Health Act (CHA) mandates “accessibility.” The ACS highlighted the fact that the underlying cause of “disparity” in the US is poverty, lack of resources or the existence of socioeconomic barriers that prevent optimal access to care. If this was the case, it would be reasonable to assume that disparity does not exist in a public health system. The first point being made is that this assumption has not been tested and hence cannot be assumed as a corollary. The second equally important point is that access is not the same as utilization. You may have a world-class tertiary cancer care centre at your doorstep, but your “consumers” need to feel that the service you provide caters to their needs. While

Bejoy C. Thomas, PhD is an associate professor at the Department of Oncology, Faculty of Medicine, University of Calgary, and at the Department of Psychosocial Resources, Tom Baker Cancer Centre; and a research scientist at the Associate Cancer Centres and Community Oncology (ACCCO), Alberta Health Services Cancer Care, Calgary, Alberta. E-mail: Bejoy.Thomas@albertahealthservices.ca

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this ideology may be more apt in the business world or perhaps in the US, which functions on a fee-for-service basis, in publicly-funded Canadian healthcare we the care providers are accountable to all of our constituency, not just the 75% majority. The operative term is “patient-centred care.”

**A POTENTIAL SOLUTION**

It is a common assumption that remedying the allophone’s presumed limited ability to speak the host language is a sign of institutional responsiveness, hence the availability of interpretation services. However, even the impression of being an allophone often signals a distinct set of patient attitudes, experiences and beliefs which could be critical in understanding what informs and influences cancer care behaviour.11,12 For the healthcare provider, the stimulus of being an allophone often signals a distinct set of patient of institutional responsiveness, hence the availability of presumed limited ability to speak the host language is a sign of potential solution. Individuals in Group 3 may have a phenotype similar to that of the host population. However, they could comprise an “audible minority” — we hear the accent or are informed of their non-Canadian roots (e.g. a cancer patient originally from Italy who speaks fluent English may consider himself Italian first and Canadian second). The individuals in Group 4 are what may be considered the bulk of the “classic visible minority” population. Some of them may be proficient in English, have lived the major part of their lives in Canada, and may consider themselves “Canadian.” The advantage of this 2x2 framework is that all of the patients, and the reader, are able to pinpoint the exact quadrant to which they belong.

**CURRENT RESEARCH**

While this line of research is not blind to potential variability within each group, it creates the first step to move away from the labelling chaos, in order to ask meaningful questions so that the healthcare delivery system can adapt and improve utilization. Current work looks at patients from each of these 4 groups and how each progresses along their cancer journey. It is like watching a race with 4 runners — they all have the same set track but each has his or her own unique pace. In our snapshot on symptom burden on these 4 groups, despite the level playing field of access to existing resources, there are disparities on levels of anxiety, depression, pain and fatigue. It is imperative that we develop an understanding of why such disparities exist. Is it a cultural response to the cancer diagnosis or journey, or might it be a disparity prevalent in non-cancer populations as well?

**CLINICAL IMPLICATIONS**

If there is a gap between the apparent patient need (e.g. high levels of anxiety and depression) and the actual uptake of a service that could ameliorate it (e.g. counselling, psychotropics or a drop-in fatigue class) we as healthcare providers need to revisit the way we care for our patients. Our care paths need to be revamped to meet the needs of our constituency — and all our constituents. There are 3 steps that we need to follow to make our services relevant to our patients. We are dutiful in the first step, where we design programs that are targeted at a specific subpopulation or cohort. (e.g. resources on nutrition or fatigue, pain clinics and psychosocial services), yet program attendance is not representative of those in need. Thus, in the second step, these programs need to be adapted or tailor-made to address variations within the group (e.g. services in other languages). The third step is to adjust these processes to meet individual-specific needs (e.g. a Muslim women not wanting to be seen by a non-Muslim male practitioner or a Punjabi gentleman of the Sikh faith not wanting to shave his beard prior
to surgery). True, this may sound like a daunting task, and no, we do not have to bend over backwards to accommodate differences. The objective is to find a middle ground (i.e., an agreement of patient and practitioner expectations) and to communicate in a proactive way that we are respectful and ready to engage with all people irrespective of their religious or ethnic backgrounds. If the business world has figured out how best to operate within a multicultural context, shouldn’t we do the same in healthcare?

References
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