

**Addressing Racialised Disparities in Access to Health
Care and Quality of Care:
A Literature Review**

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**Together with Racialised Communities and Access to Healthcare Working Group
Toronto, January 2007**

With financial support from:

The Wellesley Institute, Toronto

Acknowledgements:

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We would like to thank Yolisa Dalamba, Julie Young, and Amanda Chafe (intern at Access Alliance) for their assistance in compiling this literature review.

We gratefully acknowledge the financial support of The Wellesley Institute.

Introduction

Racialised groups refer to non-dominant ethno-racial communities who, through the process of racialization, experience race as a key factor in their identity (Galabuzi, 2001). Racialisation is the process whereby racial categories are constructed as different and unequal in ways that result in regressive social, economic and political impacts (Galabuzi, 2001). A growing body of literature suggests that even in countries that have a 'universal health care' system, substantial disparities exist in healthcare access and outcomes based on race, immigrant status and income (Ali, 2002; American College of Physicians, 2004; Brown, 2001; Chen, Ng and Wilkins, 1996; Deri, 2004; Dunn and Dyck, 1998; Hyman, 2001; Kinnon, 1999; Lasser, 2006; Smedley, Stith, and Nelson, 2003, Wu and Schimmele, 2004). Racialised groups, especially those who are recent immigrants and from low-income backgrounds, face many barriers to accessing health care and report receiving unsatisfactory, low-quality treatment (American College of Physicians, 2004; Chen, Ng and Wilkins, 1996; Smedley, Stith, and Nelson, 2003).

In 2005 the Racialised Communities and Access to Healthcare Working Group, a multi-disciplinary research group formed under the auspices of the Regent Park Community Health Centre and Access Alliance Multicultural Community Health Centre, Toronto received an enabling grant from The Wellesley Institute to begin examining issues regarding racialized groups' perceptions and responses to differential health care.

The purpose of this literature review is (1) to examine the extent to which racialised groups experience and perceive differential access and treatment in healthcare and (2) to identify strategies to address differentials in healthcare access and treatment. We also particularly interested in exploring the use of client complaint mechanisms within health care institutions and participatory models of patient/client empowerment and anti-racist practices.

The literature review is organized along 4 themes: (1) Inequalities in Access and Quality of Health Care; (2) Perceived Quality of Healthcare among Racialised Communities; (3) Existing Client Complaint Mechanisms within Healthcare Service Providers; (4) Models of Participatory Patient Engagement and Empowerment Strategies. We conclude by identifying major research gaps and suggesting future research directions.

1. Inequalities in Access and Quality of Health Care

The last decade has seen a marked increase in research focused on inequalities in access and quality of health care. The literature points to three key factors these health care inequalities are based on: race, immigrant status, and income. A large body of published research, particularly from the U.S., suggests that even after adjusting for variables such as age, gender, education level, severity of disease, etc., disparities in health care access and quality of care based on race, immigrant status, and income persist (American College of Physicians, 2004; Chen, Ng and Wilkins, 1996; Lasser, 2006; Smedley, Stith, and Nelson, 2003).

In countries such as Canada that have publicly funded, 'universal' health care systems, health care access disparities based on income tend to be less pronounced. Indeed, studies comparing the health care systems of the U.S. and Canada reveal that income-based disparities in health care access and quality of care are lower in Canada

compared to the U.S. (see Lasser et al, 2006; Sanmartin et al, 2006).¹ However, it has been noted that income still plays a significant role in terms of access to specialist care (Wellstood et al., 2006: 122).

A comparative review of the literature points to another U.S.-Canada difference in health care research. Much of the U.S. health literature focuses on ethnic and racial population groups, with only tangential reference to immigrant status. Until recently, the opposite was true in Canada, with much of the research focusing on immigrant status and only peripheral references to ethnicity and race. This difference is constitutive of the dissimilar demographic priorities and statistical traditions in the two countries. Unlike the U.S., Canada does not have the long history and the elaborate system of collecting race-based statistics. In Canada, national and population health surveys collect data on ethnic and cultural original, but individual categories are commonly collapsed to form a 'visible minority' variable.

Much of the debate in the Canadian immigrant health literature revolves around the "healthy immigrant effect." This "healthy immigrant effect" refers to the finding that recent immigrants to Canada have better health status than native-born Canadians. This has been attributed to a stringent immigrant screening process that selects for good health. The 'healthy immigrant effect' concept counters the myth that new immigrants exert excessive costs on the Canadian health care system. In fact, a growing number of studies have documented that recent immigrants face many barriers to accessing health care and tend to underutilize health services, especially mental health services and preventative care (Hyman, in press; Blais and Maiga, 1999, Chen, Ng and Wilkins, 1996; Dunn and Dyck, 1998; Hyman, 2001; Leduc and Proulx, 2004; Ng et al, 2005; Wu and Schimmele, 2004).

There is presently a consensus among health and social science researchers that many factors outside of human biology determine health. The term determinants of health (DOH) was adopted by Health Canada in 1994 to describe factors that influence population health including, income and social status, social support networks, education, employment and working conditions, physical environment, social environment, personal health practices, healthy child development, health services, gender, and culture (Health Canada, 1994). The term, 'social determinants of health,' has more recently emerged to reflect the fact that health is largely influenced by social and economic factors and thus requires health promotion and policy that move beyond biomedical and behavioral risk factor approaches (Raphael, 2004).

A recently completed literature review on the determinants of immigrant health highlighted the roles of poverty, social exclusion, racism/racial discrimination and immigration/resettlement policy (Hyman, 2006).

There is ample documentation that immigrants and racialised groups in Canada are disproportionately poorer than the population as a whole. Of particular concern, however, is the fact that recent immigrants are not catching up economically, as did their predecessors. Poverty rates for recent immigrants have increased substantially since 1980 (Statistics Canada, 2003; Picot & Hou, 2003). Despite the fact that immigrants arriving in

¹ This is in spite of the fact that the U.S. spends more on health care than Canada, both in terms of per capita spending (U.S. \$ 4,884 versus \$2,792 in 2001) and percentage of gross domestic product (14 percent versus 10 percent) (Sanmartin et al, 2006:1134).

the 1990s were the most highly educated cohort of immigrants to date, the wage gap relative to their Canadian-born counterparts has increased (McIsaac, 2003).

The impacts of social exclusion on health are also well-established, although the evidence is primarily drawn from studies of poverty – the key cause and product of social exclusion – and health (Galabuzi, 2002). In addition to the negative health effects of material deprivation, the actual experience of inequality and stress associated with dealing with exclusion is believed to have psychological effects and to impact negatively on health (Kawachi, Kennedy & Wilkinson, 2000). There has been little empirical data on the effects of social exclusion on health, partly due to difficulties in developing measures of social exclusion that can be used in population-health surveys (Galabuzi, 2002). However, there is qualitative evidence from literature reviews and community based research that confirms that racism and social exclusion contribute to mental and physical health outcomes (Agnew, 2002; Tharao & Massaquoi, 2001).

Theories abound to explain how racism affects health. It has been hypothesized that racism indirectly influences health through differential exposure to determinants of health, e.g., restricting socio-economic mobility, contributing to differential access to resources, while effects such as trauma, stress reactions, and lowered self-esteem may directly impact on health (Harris, 2006). Several studies (mostly non-Canadian) demonstrated negative associations between racial discrimination and health, including mental health, physical health (hypertension and self-reported health) and health risk behaviors (see Harris et al., 2006).

It seems clear that DOH are highly interconnected and it is the combined influence of interrelated factors that influences health and access to health care.

A large body of literature from the U.S. has documented how racialised groups, particularly Blacks and Hispanics, do not have the same access to health care, report receiving lower quality health care, tend to have more unmet health needs, and consequently have lower health status (American College of Physicians, 2004; Bhugra, Harding and Lippett, 2004, Lillie-Banton, 2000; Ngo-Metzer et al, 2004; Wood et al, 2004; Smedley, Stith and Nelson, 2003). Research conducted by the American College of Physicians (2004:226) found “ample evidence” of health disparities based on race. For example, this study found that the chance of African Americans having an angioplasty and coronary bypass surgery was half of that for White Americans, even though the mortality rate for heart disease among African Americans is about 50% higher. Many other studies have shown how disparities in care translate into lower health status and higher mortality among “minorities” (e.g., Bach et al., 1999; Peterson et al., 1997; Bennett et al., 1995). For instance, Corbi-Smith et al. (2002) discovered that Hispanics were less likely to receive blood pressure screening compared with Whites and African Americans. In their book, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Smedley et al. (2003), compiled extensive evidence of racialised minorities being excluded from necessary treatment and/or receiving lower quality care in a variety of medical settings including cardiovascular care, kidney transplantation, and diabetes, compared to in non-racialized minorities.

These findings suggest that health inequalities and differential treatment are widespread but similar studies have not been conducted in Canada. Given differences between the U.S and Canada in the organization of health services and the emergence of racialized communities as a result of immigration, further research is required to fully

understand the multiple and complex ways in which racialised communities experience differential access and quality of care.

2. Perceptions Among Racialised Groups about Access and Quality of Health Care

To the extent that studies have documented systemic access barriers and differential treatments in healthcare based on race, it becomes important to understand how racialised groups themselves perceive and respond to these disparities. What kinds of impressions are racialised communities beginning to form regarding how accessible health care is to them compared to non-racialised people? How satisfied are racialised people with the quality of care they receive? How do racialised groups respond to and cope with differential access and treatment in healthcare? To what extent do previous negative encounters with health care practitioners deter racialised people from accessing needed health care? To what extent is the general public, including non-racialised groups, aware of disparities in health status and health care treatment?

Here again, most of the findings come from U.S. research. Many studies in the U.S. have documented that racialised groups perceive that they are receiving lower quality of treatment compared to non-racialised groups, and thus are quite dissatisfied with the health care system. In a study by Wood et al. (2005) African-Americans reported significantly lower rates of satisfaction compared to non-Hispanic white Americans for six of 16 questions regarding satisfaction during hospitalization care. Similarly, Bhugra, Harding and Lippett (2004) found that African Americans were more likely than Whites to be dissatisfied with primary care. Ngo-Metzer et al. (2004:112), using multivariable analyses, reported that Asian-Americans were less likely than Whites to report that they were very satisfied with care. In the same study, when asked about the last visit, Ngo-Metzer et al., (2004) found that Asian Americans were more likely to report that their doctors did not listen, spend as much time, or involve them in decisions about care as much as they wanted. In a research study conducted by the Agency for Healthcare Research and Quality, three ethnically diverse patient groups (61 Blacks, 45 Latinos and 55 non-Latino Whites) noted that they were dissatisfied with physicians who did not demonstrate sensitivity to their historical/cultural backgrounds, including awareness of varied values systems, critical view of stereotypes, sensitivity to complementary and/or /alternative medicines, and language barriers (Napoles-Springer et al, 2005). A number of studies, including Lavieste and Nuru-Zetter (2002) and Napoles-Springer et al., (2005), reported that racialised groups experienced greater satisfaction with physicians who are from the same race.

Public perceptions about health care disparities, including among non-racialised groups, are equally important to capture. A survey by Lillie-Banton et al. (2000) found that most people in the U.S. were unaware that Blacks have a higher infant mortality rate and lower life expectancy than Whites. These researchers also found that Whites do not perceive that minority Americans receive a lower quality of care than they do.

The Canadian literature on perceptions of health care among racialised groups is thin, highlighting the need for further research in this direction. Much of the research focused on identifying barriers to health care for racialised groups, rather than perceptions of the quality of care received. Dissatisfaction with health care services was mostly described in terms of an “over-willingness” of Western practitioners to prescribe pharmaceuticals, perceived “dismissive attitude and lack of time from physicians in

previous encounters,” cultural mismatches, a Euro-centric orientation of mainstream services, stigmatization, and the loss or devaluation of language and culture (Whitley et al., 2006; Hrycak and Jacubec, 2006). It must be noted that this result may, with one exception, be due to the fact that racism wasn’t asked about directly. In Ali et al. (2003), on the impact of racism on access, almost 1 in 5 of the participants (N = 81) reported that they experienced racism in the health care system; 8.6% found doctors to be culturally insensitive or ignorant; and 6.2% reported receiving an inferior quality of care. These experiences ranged from cultural insensitivity or ignorance from their doctors to name calling or racial slurs, and included the receipt of inferior care. As cited by a study participant,

“They were coming from a completely different culture... They didn’t understand my culture and it didn’t seem like they made an effort either. It was more just like, ‘Well, it shouldn’t be that way,’ and it’s almost like my own culture was being put down.” (Ali et al., 2003, p. 28)

In summary, the literature reviewed suggested that racialised people are quite aware and very critical of the low quality treatment and racism they experience in accessing health care. At the same time, perceptions about differential treatment appear to be case specific, rather than comparative or systemic; thus, most of the criticisms revolve around the failure of health professionals to understand a patient’s specific individual and cultural context. As Lillie-Banton et al. (2000) point out, more research and dissemination work is needed to generate public awareness among racialised and non-racialised communities about the systemic nature of racialised inequalities in health care access and quality of treatment. Additional research can also help us to better understand how perceptions of health care inequities may vary between subpopulations and by class, age, gender, and health status within the same populations. Thus, for example, wealthier cohorts from racialised groups may be more concerned about long wait times, and may indicate that they are willing to pay for quicker service.

3. Existing Client Complaint Mechanisms within Healthcare Providers

Well designed client complaint mechanisms within healthcare providers could potentially help to identify and overcome some of the access barriers and differential treatment that racialised groups face in healthcare. It is thus worth exploring the kinds of client complaint mechanisms that exist within healthcare providers. Drawing on existing literature and a small informal survey of major healthcare providers in Toronto, this section explores the types and quality of client complaints/feedback processes that currently exist among healthcare service providers.

Several researchers highlighted the constructive role that well designed client complaint mechanisms can play in improving access and quality of treatment (Higgs, 2001; Street et al, 2005; Smedely et al., 2003). At the least, complaints mechanisms provide avenues for dealing with specific cases of malpractice and discrimination. Complaint mechanisms operating within regulatory/umbrella organizations can help to promote uniformity in health care quality across institutions and regions.

A comparative study conducted by the Health Professions Regulatory Advisory Council of Canada (2005) found that the UK, Australia and New Zealand have a more

centralized and “patient-centred” complaint system, while complaint mechanisms in the U.S. and Canada tend to vary widely between provinces and health professions. Each state or territory in Australia and New Zealand has its own Office of Health Care Complaints Commissioner (HCCC) or Ombudsman, an independent statutory body that serves as a ‘one-stop-shop’ for resolving complaints in a fair and unbiased manner (Health Professions Regulatory Advisory Council, 2005: executive summary). Patient advocates are widely used in Australia, New Zealand and the UK to ensure that patients are involved throughout the proceedings; patients in these countries report “high satisfaction rates” with existing complaint mechanisms (Health Professions Regulatory Advisory Council, 2005). By contrast, little effort is made in the U.S. to involve patients in complaint procedures, and complaints are pursued only if filed in writing. The complaint mechanisms in Canada lie somewhere between the Australia/New Zealand/UK model and the U.S. model (Health Professions Regulatory Advisory Council, 2005).

Our quick survey of major health care providers in Toronto found that most of them have some form of client complaint mechanism, or at least a “complaints box” in place. Three questions are worth exploring further in this regard. First, how effective and genuine are these complaint mechanisms in terms of addressing and incorporating patient feedback? Second, to what extent do racialised people utilize these complaint mechanisms, particularly in regard to complaints related to differential access and treatment? Third, to what extent are existing complaints mechanisms equipped to address complaints regarding racialised disparities in health care access and quality of treatment?

The hospitals under the University Health Network (Toronto General Hospital, Princess Margaret Hospital, and Toronto Western Hospital) have a systematic complaints process in place through its Patient Relations office. Complaints about unsatisfactory care can be filed with the Patient Relations Office. Complaints are organized into four categories: care, attitude, communication, and other. The inpatient complaint rate can vary widely every month. For example, the inpatient complaint rate for the University Health Network for November 2004 was 32.6 per 1000 separations, while for December 2004 it went down to 10.4 per 1000 separations. Similarly, Mount Sinai hospital has a client complaints process that is closely tied to their Diversity and Human Rights Policy.

Regulatory institutions overseeing certain health sector professionals also have complaints processes in place. For example, the College of Medical Radiation Technologists of Ontario has a Complaints Committee which meets three times a year to address patient complaints against staff working in the medical radiation field. Complaints are organized in four categories: communication problems, physical and verbal abuse, sexual abuse, and authoritative acts. In 2004, 10 complaints were filed with the Complaints Committee and two from 2003 were carried over. From this set of complaints, two were dismissed; for another two, relevant members were being asked to appear before a council to be cautioned; and eight complaints were continuing to be investigated. The College of Nurses in Ontario (CNO) has a comprehensive and thoughtful complaints process overseen by a Complaints Committee comprised of RNs, RPNs, and members of the public. The College is required to investigate every complaint that it receives in a timely manner. The actions that the Complaints Committee may take range from ‘no action,’ if the reported nurse’s conduct is deemed to be not breaching the standards of practice, to withdrawal of the right to practice, if the complaint is determined to be very serious. The CNO also has a “Participate Resolution Process” in place, in

which the nurse, complainant, facility and CNO work collaboratively to negotiate a solution. In 2004, the CNO conducted 596 formal investigations. The College of Physicians and Surgeons of Ontario (CPSO) also has a rigorous complaints process in place. Patients can also file complaints with the Health Professions Appeal and Review Board, the final legislated venue for reviewing complaints related to the health profession. In 2004, the Health Professions Appeal and Review Board received a total of 612 complaints.

Further research is needed to better understand what types of people access existing complaints processes, the challenges involved in access, and the impact that these mechanisms have on complainants and the health care service practitioners and providers concerned.

A key limitation that applies to most of the existing complaint mechanisms is that they do not openly or clearly identify ethnic/racial discrimination as a legitimate area of complaint. In absence of clearly articulated policies to address complaints related to racialised disparities and discriminations, racialised communities may be hesitant to make use of these systems. Moreover, the body reviewing the complaints may be ill-equipped to properly address complaints from racialised clients regarding differential access and treatment. Further research is required to understand racialised people's experience with using client complaint mechanisms.

4. Models of Patient Empowerment Strategies and Anti-Racism Policies

While client complaint mechanisms can help to identify and reduce some of the inequalities in access and differential treatment that racialised groups face, such procedural steps are not sufficient by themselves to overcome the systemic causes of racialised disparities in healthcare. Even if comprehensive client complaint mechanisms are in place, racialised communities may face many barriers (such as language barriers or time constraints) or may be hesitant (for fear of further reprisal and stigma) in accessing these resources; in other words the same barriers that prevent racialised people from having equal access and quality treatment may bar them from accessing client complaint mechanisms.

Contesting systemic causes of racialised disparities in healthcare access and treatment needs to go beyond mere procedural changes. What is required are more proactive, participatory, systems approaches of patient engagement and empowerment, ones that (1) actively inform and empower people, particularly excluded groups, to exercise their rights to quality healthcare with dignity, and (2) mobilize collaborations among patients, healthcare providers, and policy makers to overcome not just the obvious/reported cases of differential access and treatment, but also the hidden, systemic structures that perpetuate differential access and discriminatory practices based on race. Also needed is an institution-wide commitment to promoting anti-racism, diversity and human rights at the everyday practice level, not just on a case by case basis. Research conducted by Ryan and Burke (2000), Finucane and Caress (1990), and Rathore et al. (2000) illustrate that in the absence of proactive anti-racism policies, even well-intentioned health care practitioners may inadvertently end up making biased medical diagnoses and treatments for racialised people. These institutional transformations need to be put in place irrespective of whether racialised clients are filing complaints about differential access and treatment in healthcare.

Several studies on patient engagement and patient-provider relationships have documented that strengthening patient participation and patient-physician communication leads not just to greater satisfaction among patients, but also to improved health care services in general (Dault, Lomas and Barer, 2004; Health Canada, 1999; Smedley, Stith, and Nelson, 2003; Street et al., 2005). Higgs, Bay and Murphy (2001) highlight that, “consumer input is critical in understanding local issues in health care and is part of the circular feedback loop of findings and policy decisions.” Based on a cross-sectional analysis of 279 patient-physician interactions, Street et al. (2005) found that “more facilitative communication” from physicians is key to enhancing patient participation and satisfaction, particularly from minority patients. They stress that, “physicians could more effectively facilitate patient involvement by more frequently using partnership-building and supportive communication.”

Other studies highlighted how the provision of interpretation services and an increase in representation of minorities in health care professions can substantially boost the level of participation and satisfaction among racialised groups (Bauer et al, 2000; Brown, 2001; Health Canada, 1999; Lavieste and Nuru-Zetter, 2002; Smedley, Stith, and Nelson, 2003; Street et al, 2005). Brown (2001) points out that, “language, rather than cultural beliefs and practices of patients, may be the most significant barrier to initial contact with health services.” Progressive health education programs and proactive health promotions can not only help to inform excluded racialised people of their rights to equitable and dignified health care, but also contribute in dispelling negative public perceptions about health care utilization and access (Lillie-Blanton et al, 2000; Health Canada, 1999).

It is equally important for health care institutions to tackle issues of racism head on. Doing so requires developing policies and practices of anti-racism and human rights at an institution-wide, “everyday” level, not just on a case by case basis. As noted earlier, most health care institutions have advanced little in terms of developing comprehensive anti-racism and human rights policies. A few institutions are beginning to head towards this direction and their experiences are worth exploring further.

The Medical Council of Canada appears to be making some efforts at tackling issues of discrimination. Sporadic initiatives have been introduced by other Toronto hospitals. For example, Mt. Sinai Hospital in Toronto developed a very thoughtful Diversity and Human Rights Policy and Procedure in order to promote a health care system that is anti-racist, anti-oppressive, and grounded on equity and human rights. As part of the policy implementation, it offers education and organizational training and development programs for its staff on anti-racism, diversity and human rights. Further research is required to understand the strategies and challenges of promoting such strong anti-racism and human rights policies, so that they can be replicated.

Future Research Directions

This review found a dearth of literature about racialised peoples’ experience with accessing quality health care in Canada. It would be erroneous to assume that the minimal published literature exploring inequalities in health care based on race is indicative that racialised groups in Canada do not face any significant differences in terms of access and quality of care compared to non-racialised groups; rather, it underscores a major research gap in this area.

Socio-economic predictors and trends suggest that racialised disparities in access to and the quality of healthcare exist in Canada, and are increasing. Some of these socio-economic predictors include: (1) the growth in racialised population (by 2017, over half of the population of Toronto and Vancouver will comprise of racialised groups); (2) the over-representation of racialised groups in low-wage sectors and under-served neighborhoods; (3) the racialization of poverty (according to Michael Ornstein, “all twenty of the poorest ethno-racial groups in the Toronto CMA are non-European”); (4) the under-representation of racialised people in health care professions; (5) and the growing percentage of an immigrant population who do not speak English or French. Further research is required to better understand how these racialised inequalities, operating at the broader scale, generate disparate health status and health care needs. More research is also needed to understand the extent to which existing health care providers are equipped to address these varied health needs.

Within racialised groups, special attention needs to be paid to vulnerable and excluded subpopulations (e.g., refugees, youth) in order to better comprehend their specific health needs and the barriers they face in accessing needed care.

It would be problematic to assume that racialised inequalities in health care access in Canada mirror those in the U.S.. Several studies suggest that the causes of unmet health care needs and for health disparities in general maybe different for Canada compared to the U.S.. For example, Sanmartin et al (2006:1138) found that while the key reason for unmet health care needs in the U.S. was cost (53 percent), for Canada it was “excessively long” wait times (32 percent). Research priorities identified by Health Canada (1999) and the Canadian Health Service Research Foundation (2004) for the Canadian context include issues of long wait times, rushed examination procedures, the maintenance of steady relations with primary care givers, access to specialist care, and access to mental health services.

Additionally, it is important to avoid replicating the rigid, homogenizing, race-based statistical categories used in the U.S.. Any research investigating ethno-racial parameters needs to consider the heterogeneous and dynamic nature of racialised communities; in other words, the task at hand is to progressively deconstruct, rather than entrench, racial categories and racialisation. Community-based participatory methodologies are particularly suited for such research due to their potential to recognize racialised people as producers of health knowledge and empower them within and through the research process.

As noted earlier, there is pressing need for more research, both in the Canadian and U.S. context, on client complaint mechanisms, patient participation/empowerment frameworks, and anti-racism policies as bases to promote more equitable health care systems.

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