

Sadhee Sehayth (Our Health): Experiences of Punjabi Ancestry Canadians Living with Cardiovascular Disease

Background: Cardiovascular disease (CVD) continues to be a concern for the public healthcare system as it is the leading cause of death among Canadian women and men, costing the healthcare system in excess of \$22 billion per year. Globally, the WHO estimates 23.6 million deaths from CVD by 2030 (Mendis et al, 2011); and the consequences of CVD are felt every 7 minutes when 1 Canadian dies as a result of CVD. For Canada's largest 'visible minority' community, CVD related deaths are decreasing at a significantly slower pace than their European ancestry counterparts (Yeolekar, 1998). South Asian (SA) ancestry Canadians experience coronary heart disease at a significantly younger age; have a 3-5 fold greater risk of premature death from myocardial infarctions (MI); and a higher risk of further coronary events post-MI when compared with European ancestry Canadians (Joshi et al, 2007; Singh & Gupta, 2005; Yusuf et al, 2004). The lack of conventional risk factors (i.e. absence of high fat diets, smoking and high rates of obesity (Chiu, Austin, Manuel and Tu, 2010)) to explain the higher prevalence of CVD in SA communities, consequently has been identified as the SA 'paradox'. Findings that SA individuals were 70% less likely than other Canadians to report to emergency departments 3 hours after the onset of classic MI symptoms, and typically waited more than 12 hours to seek help (King, Khan & Quan, 2009) suggests significant barriers to accessing emergency care. While epidemiological researchers have studied biological factors (i.e. metabolic syndrome, beta-cell function, deficiency of antioxidants), and health behaviour researchers have explored cultural and linguistic barriers, these explanations do not adequately explain the South Asian 'paradox.' This proposed study uniquely aims to unpack the structural and institutionalized mechanisms operating within the Canadian healthcare system that may impede healthcare access by 'ethnic' communities, and limit healthcare equity.

Research Questions: To understand how Punjabi ancestry British Columbians experience CVD healthcare, four overarching research questions will be addressed: (1) What institutionalized mechanisms act as structural barriers and facilitators to accessing CVD healthcare? (2) What perceptions and experiences do healthcare providers negotiate while providing CVD healthcare? (3) How do various social determinants of health impact CVD healthcare access (i.e. gender, ethnicity/race, class, education, migration herstory/history, income level), and (4) How do Punjabi ancestry CVD patients consider, seek, access, value, utilize and experience cardiac health services?

Theoretical Approach: Given the paucity of research regarding how SA ancestry communities experience CVD healthcare access - particularly how institutional mechanisms support or limit healthcare access - a qualitative approach will be used to uncover the embodied, lived experiences of Punjabi ancestry Canadians. Qualitative inquiry provides valuable insights to understand perceptions, values, behaviour, lifestyle, attitudes and actions, particularly useful in emerging research areas. Further, this qualitative inquiry will bridge the current knowledge gap between individual, collective and institutional factors inherent in this complex healthcare issue. The application of a critical perspective (guided by post/colonial, feminist and critical race theory) will inform the role of gender, culture and ethnicity, as well as "identifying structural forces that sustain uneven relations of power" (Anderson, Khan & Reimer-Kirkham, 2011). Gender studies will draw out the impact of gendered identities. Critical Ethnography will be utilized to understand the institutionalized public health practices and beliefs. Finally, the study will address how these elements intersect with healthcare access, delivery, prevention, promotion and uptake. My shared cultural and linguistic standpoint will assist in collecting data and deepen analysis, while the implementation of critical feminist applications will support an ethical, reflexive approach and analysis.

Methods and Procedures: Sample: South Asian ancestry Canadians comprise the largest 'visible minority' community in Canada, and India continues to be a leading source country for current and future projected migration. SA ancestry British Columbians, predominantly from the Northern Indian state of Punjab, began settling in British Columbia (BC) in the late 1800s and this well-established community has continued to grow with ongoing migration. Census data from 2001 identifies almost a million Canadians identifying their ancestry to be SA, and locates major populations to reside in British Columbia and Ontario. Given the population of Punjabi ancestry Canadians in BC, understanding the CVD healthcare access experiences of this community is essential in delivering universal and equitable healthcare.

Data Collection: This research will draw on two key qualitative methods: observations and semi-structured interviews. Utilizing a purposeful sampling approach, preliminary semi-structured interviews with 5-8 cardiac healthcare providers will be conducted to explore barriers and facilitators to providing culturally and linguistically specific care. Observational field notes will be compiled from 3 cardiac oriented settings (i.e. cardiac wards and cardiac rehabilitation programs), to observe how patients are responding to services, interactions with healthcare providers, and facilitators/barriers to accessing information and healthcare. Concurrently, in-depth semi-structured interviews with patients living with cardiac illness will be conducted in Punjabi/English to understand how Punjabi ancestry CVD patients experience CVD healthcare. Given the multiple methods, and the opportunity to re-interview participants, I will be recruiting 30-40 participants. This multi-layered approach will enrich the findings, uncover nuanced perspectives and expand the current paradigm regarding SA cardiac health. **Analysis:** Critical ethnography, informed by post/colonial, feminist and critical race theory, will anchor the qualitative analysis as it will go beyond conventional ethnographic methods that generally describe “what is”, to reveal “why this is” and “what can be done about it” (Cook, 2005). While all three critical perspectives call for the inclusion of subjugated knowledges and voices, post/colonial theory offers opportunities to examine “everyday experiences of marginalization, as structured by the micropolitics of power and the macrodynamics of structural and historical” processes (Kirkham & Anderson, 2002). Each digitally recorded interview will be translated and transcribed verbatim, and followed up with accuracy checks. Data analyses will proceed with reading and rereading the interviews and field notes to identify patterns of theoretical relevance using substantive coding, theoretical memoing and constant comparison approaches. I will proceed with data analysis alongside data collection to evaluate thematic saturation. Thematic saturation is achieved when nothing new is being generated by collecting further data, subsequently “there are no more emergent patterns [arising from] the data” (O’Reilly & Parker, 2012). Critical Ethnography will guide the organization and coding of the data, using the qualitative software program: NVIVO 8™. A detailed account of decisions including theme development, coding clarifications, synthesis of meaning and theorizing of relationships will be logged in a reflexive journal to strengthen analytical rigour.

Contribution to the Advancement of Knowledge: The data generated from this research project will (a) help bridge the existing gap in understanding how Punjabi ancestry British Columbians experience CVD; (b) how they access services and resources; and (c) ultimately identify what institutionalized/structural barriers impede and support CVD healthcare access. The insights will contribute to understanding the wider South Asian CVD ‘paradox’. Fundamental to this study, is the ‘real-life’ application of the findings through knowledge translation activities. To convey the findings through innovative knowledge translation techniques, such as photo voice, a separate knowledge translation grant will be submitted. Policy makers, clinicians, health educators and community members will benefit from a better understanding of how CVD healthcare is experienced, and understanding the institutionalized mechanisms that are often inscribed implicitly. In particular, understanding the context of the lived experiences, and the structural barriers that impede health equity will have a significant impact on healthcare policy and practice.

Significance to fields supported by the Canadian Institutes of Health Research (CIHR)

The data generated from this study supports CIHR’s mandate as it will contribute new knowledge regarding how Canadians of Punjabi ancestry experience CVD healthcare services and resources, and address the wider SA CVD paradox. Additionally, five of CIHR’s Institutes (Aging, Circulatory & Respiratory, Gender & Health, Health Services & Policy Research and Population a& Public Health) identify key elements that are congruent with this study including: the incorporation of societal, cultural, environmental, gender and sex based factors that influence health behaviour and utilization; the inclusion of useful health promotion initiatives; and the reduction of health inequities.

Candidate’s Role: With the mentorship and guidance of my supervisors, Dr [REDACTED] and Dr [REDACTED]; and committee member: Dr [REDACTED], I will design the research protocol; conduct data collection; theoretically informed analysis; and complete knowledge translation activities. With 12 years of qualitative health research training and experience, I will lead in the authorship of peer-reviewed articles; community based reports; and Punjabi media articles as well as present findings at academic, community and healthcare oriented forums.