

22nd Health & Human Rights Conference: Stigmatization in Healthcare

Research Competition Abstract Booklet



Novel Patient Education Infographic on Palliative Care: A Qualitative Pilot Study

Ana Constantin - presenting in-person

Objective: Palliative care (PC) is still stigmatized and misunderstood among patients with advanced cancer. Objectives of the current study were to assess the patients' understanding of PC and the utility of a novel patient-education infographic.

Design: This is a qualitative pilot study conducted in one outpatient palliative care clinic at a mid sized hospital in Eastern Ontario.

Participants: Patients with a lung cancer diagnosis referred to the Palliative Care Unit at the Cancer Care Southeastern Ontario (CCSEO) Clinic, and specialist health providers.

Methods: Infographic was mailed to new referrals prior to their first appointment at CCSEO. Semi-structured interviews were conducted with patients and health providers. The data set included patients interviewed without (n = 5), and with (n = 3), the infographic. Health providers were interviewed twice; pre- (n = 3) and post-infographic (n = 2). A theoretical thematic analysis was done on a semantic level to identify major themes and subthemes.

Results: This pilot study found four central themes and 13 subthemes. Patients have a limited understanding of PC with some admitting common misconceptions (i.e., imminent death). They have similar referral experiences of anxiety and confusion and often rely on specialists to clarify the role of PC, having little prior knowledge. Those who read the infographic found it contributed to their understanding and was useful in preparing them for that first appointment. Patients and health providers recommend its distribution to other advanced cancer referrals.

Conclusions: This pilot study provides insight on patient and specialist health provider perspectives on the utility of a PC infographic in referrals. Results informed the strengths and weaknesses of this educational tool, and how its utility can be further evaluated. Future directions should assess the impact of the infographic to patients with other advanced cancers and across multiple sites in Ontario."

Indigenous Youth and Resilience in Canada and the USA: a Scoping Review

Olivia Heid - presenting in-person

Relative to non-Indigenous youth, Indigenous youth have been under-represented when studying pathways to mental wellness. Yet, a broad range of adversity is acknowledged, from intergenerational and ongoing trauma arising from colonial policies. This scoping review explores resilience definitions, measures, key stressors, and what Indigenous youth identify as pathways to their wellness, based on quantitative and qualitative peer-reviewed literature in Canada and the Continental United States. Eight databases (EBSCO, PsycINFO, Science Direct, Social Science Citation Index, Web of Science, PsycARTICLES, and EMBASE) and hand searches of 7 relevant journals were conducted to ensure literature coverage. Two independent reviewers screened each article, with one Indigenous screener per article. The final scoping review analysis included 44 articles. In articles, no Indigenous term for resilience was found, but related concepts were identified (“walking a good path,” “good mind,” Grandfathers’ teachings on 7 values, decision-making for 7 generations into the future, etc.). Few Indigenous-specific measures of resilience exist, with studies relying on Western measures of psychological resilience. Qualitative approaches supporting youth-led resilience definitions yielded important insights. Youth stressors included the following: substance use, family instability, and loss of cultural identity. Youth resilience strategies included the following: having a future orientation, cultural pride, learning from the natural world, and interacting with community members (e.g., relationship with Elders, being in community and on the land). Indigenous traditional knowledge and cultural continuity serve as prominent pathways to Indigenous youth resilience. More research is needed to yield a holistic, youth-centered measure of resilience that includes traditional practices.

Stigmatization and Racism in Disease Nomenclature: A Literature Review

Peter Anto Johnson - presenting virtually

Introduction: Racialized groups are at a particularly vulnerable position, as the names and language we associate with diseases i.e., COVID and its strains, can inadvertently propagate racism, xenophobia, and systemic violence. This was widely evidenced by COVID-based stigma and discrimination have been seen worldwide since the start of the pandemic. We aimed to evaluate health stigmatization and racism outcomes of disease nomenclature.

Methods: We performed a qualitative literature review following ENTREQ guidelines and utilizing Google Scholar, EMBASE, and Medline/PubMed databases to identify health stigmatization and racism outcomes of disease nomenclature.

Results: We included 12 articles in our synthesis. Race-associated language used when naming diseases, especially of the infectious sort, is nothing novel. For instance, the naming of the Spanish influenza in 1890 and the Middle East Respiratory Syndrome first reported in Saudi Arabia in 2012 both had the unintended consequences for stigmatizing certain communities. Most often, these names are not issued by the scientific community but rather popularized by common usage in social media and the Internet. Unfortunately, stigmatization and discrimination have also seeped its way into language, policy, and even mere association with race. Within the population of India, for instance, there have also been cases of prejudice and othering based on geography, class, and religion. There have been growing concerns over naming strains of SARS-CoV-2 based on geographic origin i.e. “Indian variant,” “Brazilian variant,” “African variant,” etc. Gene sequence labels like B.1.617.2 are not used in everyday exchanges and do not blend well with the public vernacular. Dangerous geographic variants were thus associated with fearmongering and race-blaming.

Conclusion: Amidst the climate of political and scientifically disconcerting times, we must act in good faith when building language around diseases and strains to avoid it from being used for derogation and guilt induction.

Reducing stigmatized healthcare experiences for Indigenous peoples: A scoping review

Aishwarya Rajesh Krishnan - presenting in-person

Background: Stigma in healthcare has led to medical malpractices, mistrust of Western healthcare, and a disproportionate burden of medical conditions among the Indigenous population. A lack of culturally competent care compromises equitable healthcare and cultivates a white saviour complex, exacerbating harm to health. Few studies have analyzed strategies in peer-reviewed literature to reduce stigmatized healthcare experiences in the Arctic and Subarctic regions. This study aims to highlight approaches to reduce stigmatized healthcare experiences for Indigenous peoples in the Circumpolar Arctic and Subarctic regions.

Methods: A systematic literature review using MEDLINE was performed to derive current strategies for addressing stigmatized healthcare experiences for Indigenous peoples in the Circumpolar Arctic and Subarctic regions. Articles were uploaded into NVivo to facilitate thematic analysis.

Results/Discussion: There were 130 hits from database searches, and 66 met established inclusion and exclusion criteria. Two repetitive themes appeared within the literature review: interpersonal-level interventions, including cultural safety training for healthcare professionals and institutional-level interventions, including Indigenous-led healthcare clinics. Cultural safety training platforms aim to increase knowledge of Indigenous history and self-awareness of biases while strengthening the skills of culturally safe care provision for those who work directly or indirectly with Indigenous peoples. Beyond this, Indigenous-led healthcare service partnerships improve holistic health outcomes for the Indigenous population by improving equitable access to care, healthy behaviours and adherence to care plans.

Conclusion: The strategies to address stigmatization in healthcare outlined in this study demonstrate a promise to close the gap in healthcare for Indigenous peoples. Deriving the best practices from these approaches will facilitate future research and policies to improve the health and well-being of Indigenous peoples. Ensuring Indigenous perspectives are at the center of all discussions and actions, establishing partnerships with Indigenous peoples, and increasing awareness of culturally-relevant health services may reduce stigmatized healthcare experiences among Indigenous communities.

Objective Structured Clinical Examinations (OSCE) with individuals with IDD as simulated patients early in medical education

Isis Lunsky - presenting in-person

PURPOSE

Individuals with Intellectual and Developmental Disabilities (IDD) face unique physical and mental health needs. Yet, they are medically underserved and face numerous barriers. Furthermore, medical professionals often do not receive adequate training early in their careers serving individuals with IDD. This study aimed to address this gap by developing and implementing an Objective Structured Clinical Examinations (OSCE) with individuals with IDD as patient educators (PEs) for first and second-year medical students.

METHODS

This was a pilot observational study, with first and second-year medical students (n=25), participating in a virtual OSCE with individuals with IDD as PEs. Also, senior medical students and medical residents were recruited to assess all student-PE interactions as objective observers (OOs). The OSCE was conducted over Zoom and consisted of five virtual stations featuring cases developed by the PEs. During the OSCE, OOs assessed student's performance using a Prediger scale. Pre- and post-OSCE, the students completed a self-report scale and a Prediger scale. Then, students participated in a semi-structured interview to collect qualitative data. The assessment scale scores were analyzed using descriptive statistics and effect size using Cohen D (d) analysis. The qualitative data was analyzed using NVivo with two independent reviewers.

RESULTS

Students reported a significant large effect size ($d > 0.8$), comparing their post-OSCE to their pre-OSCE scores (Self-report: $d = 1.96$, $p < 0.0001$; Prediger: $d = 1.34$, $p < 0.0001$). OOs consistently reported significantly higher scores for students. Qualitative analysis yielded the following common themes: positive experience, development of personal awareness and changes in perspective.

CONCLUSION

The results of this study suggested that this OSCE promoted the development of confidence and important self-realizations and changes in perspective about serving individuals with IDD. Thus, this study should encourage curriculum developers to include individuals with IDD into medical education.

Role of Patient Navigators in Addressing Racially Stigmatized Health Disparities in Obstetrical Care: A Systematic Review

Han Shu Pu - presenting in-person

The 1946 WHO Constitution acknowledges healthcare as a human right where the highest attainable standard of health must be achieved for all, and each state must support the right to health without discrimination. This is not the current standard in North America in which institutionalized racially driven stigma disproportionately harms pregnant black, Indigenous, and people of colour (BIPOC) individuals. They often experience an increased risk of labour induction, maternal transfusion, ICU admissions, and difficulties accessing available health services. Patient Navigators (PNs), first pioneered in oncology, is a regulated profession with well-defined roles in Canada and acts as an advocate and proficient communicator for marginalized patients. Despite being in the infancy stages, they are essential to interprofessional collaborative healthcare delivery, offering longitudinal patient-centred services to the most vulnerable.

This review includes 24 studies which have met the PRISMA 2020 checklist. They have been identified through Google Scholar, MEDLINE, and the Cochrane Library database searches, as well as the references of included articles.

The prevention of adverse outcomes, including pre-eclampsia, embolism, and hemorrhaging, are common process measures, but few studies assessed the patient experience. PNs are an effective measure to combat this racial health inequity, assuming responsibilities such as assisting with health literacy and psychosocial support for patients. Prominent factors in medicalized racism are coded to be (1) language and cultural barriers, (2) intergenerational trauma, and (3) systemic colonial perspectives.

PNs are proving to be an essential allied health profession, providing a humanistic barrier-focused approach and linkages to resources in a society engrained with Western-centric perspectives. There is a promising future for PNs and BIPOC patients, where some Canadian jurisdictions are evolving towards having culturally sensitive PNs representative of the patient demographic.

The IMPACT Cross-Sectional Study: The socioeconomic experiences of US and non-US immigrants in Canada in the midst of the COVID-19 pandemic

Anwar Subhani - presenting in-person

Background: The COVID-19 pandemic has exacerbated socioeconomic deficiencies within Canada's immigrant populations, yet the difference between immigrants from countries with similar language and resources (such as the US) and those from a different background (non-US countries) is not well understood. Accordingly, the IMPACT study at the centre of this article included a Canadian national survey that compared key domains of life in US immigrants with non-US immigrants to provide policymakers with a research-based path toward delivering culturally targeted and socially competent services.

Methods: Potential participants were recruited from newcomer support services centers to complete the IMPACT survey which assess participants' self-perceived impacts of COVID-19 on various socioeconomic markers. For each socioeconomic variable, we analyzed the experiential differences between US vs non-US immigrant subgroups. A chi-square analysis was used to analyze the differences between these geographic subgroups (significance level $\alpha=0.05$).

Results: On average, non-US immigrants in Canada were less likely to disclose their COVID-19 health status; this trend was correlated with reported concerns over discontinuation of one's income. Qualitative themes within the non-US immigrant subgroup elucidated a mentality of "making it on [one's]own", and consequently, a reluctance to seek out external resources. Surprisingly, the US immigrant subgroup was subject to a comparatively greater post-pandemic decrease in socioeconomic well-being, resulting in proportionally greater food and financial insecurities than non-US immigrants.

Conclusion: The study highlighted two key findings: (1) US immigrants faced a proportionally increased instability of their socioeconomic well-being; whilst (2) non-US immigrants faced greater social and intrapersonal barriers to external supports and experienced a greater incidence of COVID-19 infections, likely resulting from this cohorts reluctance to miss employment income. Government-funded immigration resources, newcomer support centers, and researchers require evidence-based, demographically-targeted initiatives to aid the diverse needs of Canadian immigrants and in the post-pandemic recovery period and in future public health emergencies.

Critical Illness in Migrant Workers in the Windsor-Essex Region

Alex Zhou - presenting virtually

Background

In 2020, the Windsor-Essex region (WER) hosted approximately 10,000 migrant workers. Despite their essential role in Canadian agriculture, they face numerous healthcare barriers. There is a knowledge gap on healthcare experiences of migrant farm workers with critical illness.

Methods

This is a retrospective chart review on health care encounters of migrant workers with critical illness at the Windsor Regional Hospital (WRH) between December 31st, 2011 and December 31st, 2021. Critical illness was defined as any condition life-threatening if left untreated. A list of greenhouse addresses in WER was created through an online search. Patient charts from those addresses were retrieved. Migrant worker status was confirmed by reviewing social history. Patients were excluded if their social history is missing or if it states non-migrant worker status. The study was cleared by WRH ethics board.

Results

We identified fourteen migrant workers who presented to WRH with critical illness during this period. Median age was 41 years. All were males. The most common diagnosis was acute leukemia in 5 of 14 patients (36%). Migrant workers often visited the emergency room as their first point of contact for healthcare suggesting lack of access to primary care. Seven of the fourteen patients were repatriated and their outcome unknown.

Discussion

Migrant workers with critical illness face several challenges, including limited healthcare coverage and loss of continuity of care. Our review is far from exhaustive and we recommend further work to identify healthcare experiences of majority of the migrant workers with critical illness in the WER.