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Educating Healthcare Professionals and The Public on Kawasaki Disease in Canada: A Scoping Review

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Final Capstone Report

**Educating Healthcare Professionals and The Public on
Kawasaki Disease in Canada: A Scoping Review**

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Chapter 1: Executive Summary

Nature of the Wicked Problem

Kawasaki Disease (KD) is an acute pediatric illness with an unknown cause that results in inflammation of the walls of small to medium-sized arteries, especially in children.¹ The disparities in KD prevalence and outcomes highlight a pressing health challenge, particularly in Canada, where it stands to be a leading cause of acquired heart disease in children under the age of 5.¹ Due to the lack of specific tests, early diagnosis and treatment are challenging.² Certain groups, such as healthcare professionals and at-risk patient populations, may lack awareness of KD symptoms and long-term implications; notably, individuals of East Asian descent are at a higher risk of acquiring KD.³ Education plays a pivotal role in addressing these disparities, both for the public and healthcare professionals. As such, how can at-risk populations and academics in Canada be educated on the preventative measures of KD?

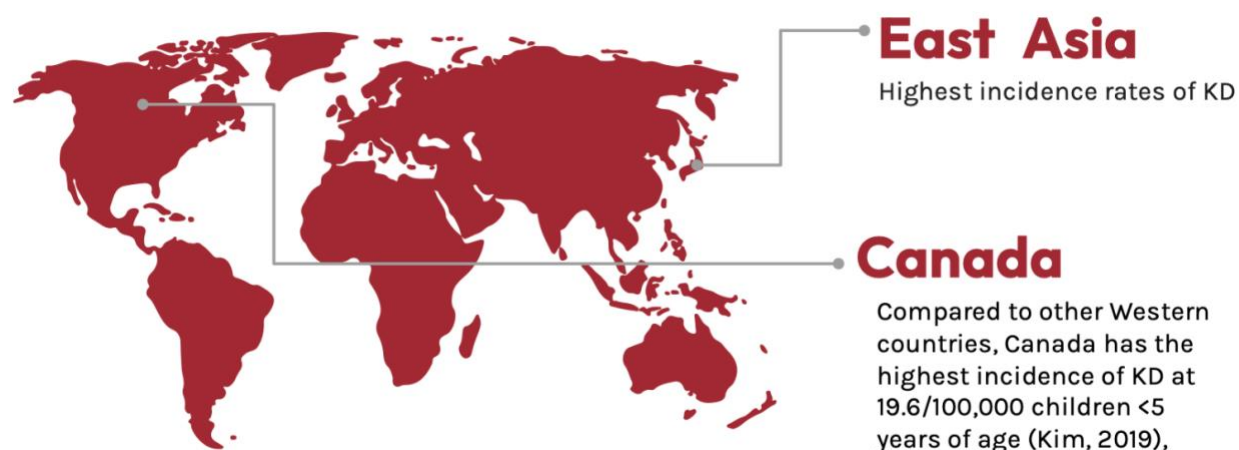


Figure 1. World map comparing annual incidence rates of East Asian countries and Canada.

Key Findings

- Kawasaki disease (KD) predominantly affects children under the age of 5, with a significant impact on Japanese individuals.
- Canada has the highest incidence of KD amongst Western countries, with rates varying significantly across its provinces and territories.
- Untreated KD cases can lead to coronary artery aneurysms, but early treatment with intravenous immunoglobulin (IVIG) can be effective.
- Lack of public and healthcare provider education contributes to delayed diagnosis and inadequate long-term support for KD patients.
- Parents play a crucial role in the early diagnosis of KD, but many lack knowledge about the disease's symptoms and long-term implications.
- Online resources have become crucial educational tools for parents seeking information about KD.
- Non-physician healthcare providers, such as dentists, can contribute to early diagnosis by recognizing atypical KD symptoms.
- Diagnostic criteria for complete and incomplete KD vary between guidelines around the world leading to diagnostic challenges.
- Technological advancements, such as machine learning and digital educational resources, can aid in the early diagnosis and management of KD.
- Long-term support for KD patients is essential to prevent major adverse cardiac events and ensure proper monitoring of heart health.

Groups Involved/Impacted

Addressing KD requires collaborative efforts where expertise, resources, and advocacy are needed to enhance early diagnosis, improve patient outcomes, and lessen the disease's burden on affected individuals and society.

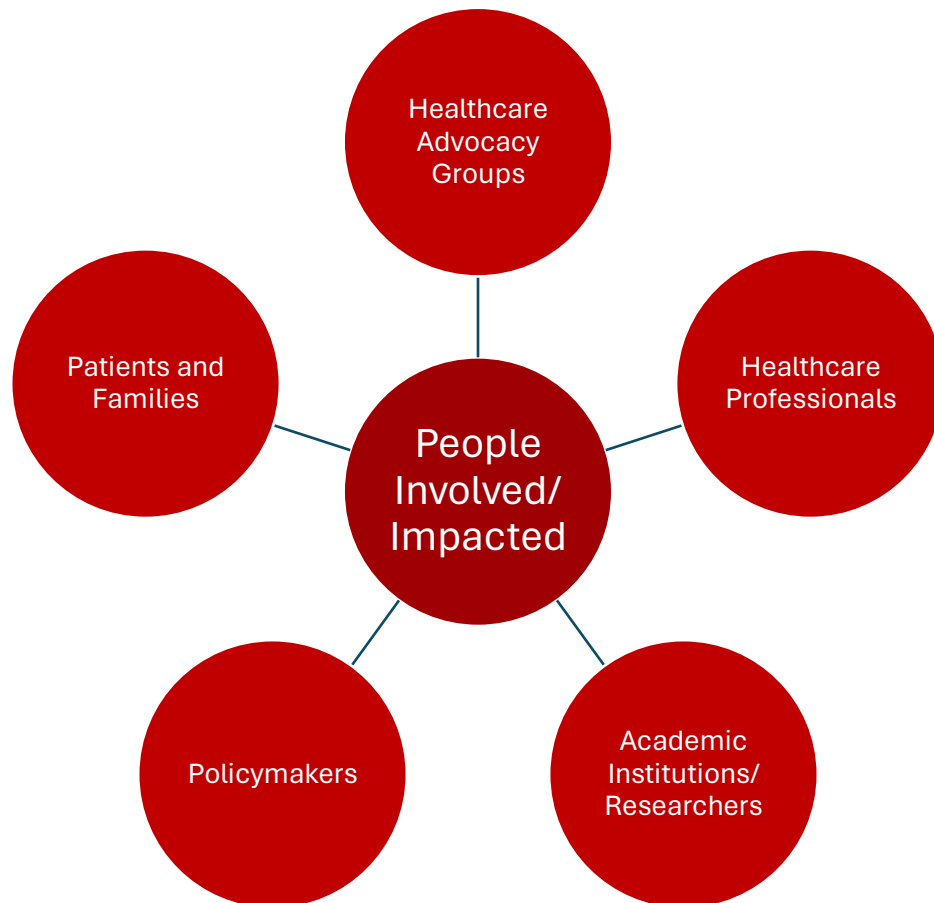


Figure 2. Groups involved and impacted in the wicked problem of Kawasaki Disease.

Healthcare Advocacy Groups

Healthcare advocacy groups, such as Kawasaki Disease Canada and the Canadian Cardiovascular Society, are vital as they actively promote awareness of KD and assist impacted families. Through planning events, providing funding, and distributing educational resources, these groups educate families about the signs and symptoms of KD, enabling prompt diagnoses and treatment.

Healthcare Professionals

Healthcare professionals, including physicians and dentists, are also vital groups involved in the fight against KD. Their awareness of the symptoms and diagnostic criteria is paramount in ensuring timely intervention. Continuing education and training programs can equip them with the necessary skills to recognize and manage KD effectively, thereby reducing the risk of long-term complications, such as coronary artery abnormalities.

Academic Institutions/ Researchers

Academic institutions contribute significantly to addressing KD. Educators and researchers continuously strive to deepen our understanding of the disease's epidemiology, etiology, and optimal treatment strategies. Innovations in diagnostic tools, such as machine learning algorithms for pattern recognition, hold promise for improving early detection and intervention.

Policymakers

Moreover, governmental bodies and policymakers play a crucial role in shaping public health policies and allocating resources for KD research, education, and patient support. By prioritizing funding and implementing initiatives to raise awareness and enhance healthcare infrastructure, they can support efforts to mitigate the burden of KD on affected individuals and the Canadian healthcare system.

Patients and Families

Finally, patients themselves and their families are perhaps the most important groups involved. Their experiences, perspectives, and advocacy efforts are invaluable in driving awareness, research, and policy changes related to KD. By actively engaging with healthcare providers, participating in support networks, and advocating for improved access to care and resources, they contribute to a more comprehensive and effective response to the challenges posed by KD.

Approach for Faster Kawasaki Disease Diagnosis and Treatment

In addressing the pressing issue of Kawasaki Disease among children, it is imperative to adopt a multi-faceted approach. Our research has examined demographic data, screening protocols, and educational initiatives targeting both the public and healthcare sectors. Moving forward, our focus lies on public education to inform at-risk populations in Canada about the prevalence of KD, its symptoms, and its long-term implications. Additionally, education is pivotal in training healthcare providers to recognize both typical and atypical presentations of KD, especially amongst vulnerable groups. This interdisciplinary strategy recognizes the diverse groups involved, including healthcare organizations and professionals, individuals in academia, policymakers, and affected individuals and families. A paradigm shift is essential, requiring collaborative efforts and innovative engagement strategies to effectively combat the challenges posed by Kawasaki Disease.

Chapter 2: Literature Review

Abstract

Background: Kawasaki disease (KD) is an inflammatory condition that impacts the walls of blood vessels, potentially leading to acquired heart disease. Notably, Canada exhibits the highest incidence of KD among children below the age of 5 from the Western countries. Early treatment with intravenous immunoglobulin (IVIG) is effective in preventing coronary artery issues, but untreated cases can result in coronary artery aneurysms, which can cause severe heart conditions. **Aim/Objective:** The purpose of this scoping review is to understand which populations are more susceptible to KD, available screening options and long-term patient support, and educational resources provided to patients, families, and healthcare providers. **Methods:** Articles from PubMed and Google Scholar databases were assessed between January 2000 and November 2023. After applying the inclusion and exclusion criteria, 34 articles were extracted. **Results:** Our findings indicate a higher KD prevalence among young children and individuals of East Asian descent. The literature highlighted a need for improved public and healthcare provider education, particularly regarding parental advocacy and sharing of KD diagnostic guidelines by physicians. There is also a gap in the long-term support for KD patients, particularly after disease treatment. **Discussion:** The need for an improved understanding of diagnostic criteria and the development of digital educational resources for KD research was emphasized. **Conclusion:** Public and professional education, combined with long-term patient support, can improve outcomes for KD patients and alleviate the burden on the Canadian healthcare system.

Introduction

In North America, Kawasaki Disease (KD) is the leading cause of acquired heart disease in children.¹ It is an acute illness with an unknown cause that results in inflammation of the body's blood vessel walls.^{1,4} While there are no specific screening tests, KD diagnosis occurs when there is a fever for at least five days and four out of five clinical features are present: rash, swollen hands, enlarged lymph nodes in the neck, red eyes, and/or cracked lips.¹ To treat KD, intravenous immunoglobulin (IVIG) is used within ten days of fever onset as an effective preventative measure for coronary artery complications.⁵ IVIG has proven to help most children recover from KD without lifelong impacts.⁵ However, approximately one in five children develop coronary artery abnormalities if left untreated.⁵

Compared to other Western countries, Canada has the highest incidence of KD at 19.6/100,000 children less than 5 years of age.⁶ The incidence rates of KD vary significantly across the Canadian provinces and territories, with Ontario reporting the highest (24.0/100,000 kids <5 years) and Saskatchewan reporting the lowest (11.5/100,000 kids <5 years).³ Additionally, it was found that in a subpopulation of untreated children with KD, long-term inflammation of the coronary arteries causes coronary artery aneurysms (CAA).⁴ CAA is a rare and silent progressive condition that results in an abnormally wide and weak area within the blood vessel.⁴ The cardiovascular sequelae are the origin of the majority of CAA brought on by KD in children and young adults.^{4,7} If left untreated, CAA can lead to myocardial infarctions and ischaemic heart disease, making early treatment vital.⁴ Even though the risk of CAA can be reduced by IVIG treatment, there are a number of children with IVIG-resistant KD that have an increased risk of artery damage.⁴

The majority of KD patients visit a pediatrician or primary care physician, and about half are seen by cardiologists.⁸ As such, KD survivors have significantly higher long-term healthcare use and costs when compared to children with no history of KD.⁸ In Ontario, the increased incidence and costs associated with KD place a large burden on the healthcare system.⁸ Approximately 99.8% of KD cases had more than one outpatient physician visit and 15.6% were re-hospitalized within 1 year of initially being discharged.⁸ On average, patients with KD have healthcare costs of \$2466 CAD one year after discharge compared to patients without KD with a healthcare cost of \$234 CAD.⁸ KD cases incurred \$13.9 million CAD in healthcare costs within the first year post-discharge and a total of \$54.8 million CAD during follow-up, whereas non-KD cases cost \$2.2 million and \$23.9 million for non-KD cases, respectively.⁸ Thus, the rising number of KD cases and costs associated with visits have created a large burden on the Canadian healthcare system.⁸

In summary, Kawasaki Disease presents a significant health challenge, particularly in Canada, where it stands as the leading cause of acquired heart disease in children.¹ The long-term repercussions of KD, including increased healthcare costs, highlight the need for enhanced preventive and management strategies to improve outcomes for patients and alleviate the burden on the healthcare system.

The Wicked Problem

The idiopathic nature of KD leads to the lack of specific screening tests, which makes early diagnosis and treatment challenging.² Physicians and at-risk populations are unaware of KD leading to delayed diagnosis and treatment.⁹ Notably, individuals of East Asian descent face a higher risk of acquiring KD,³ yet they may lack knowledge about its signs and long-term effects. Providing the public with information about the higher

prevalence, signs, and long-term effects of KD can help all populations affected by KD, including at-risk subgroups. Furthermore, continuous education for clinicians, researchers, and healthcare trainees can facilitate earlier recognition and more effective management of this challenging disease.^{1,10-13} The gaps in knowledge are a significant barrier to timely intervention and the implementation of preventive measures.

Methods

Search Strategy, Inclusion and Exclusion Criteria

The current review searched for articles using PubMed and Google Scholar databases. Articles eligible for review were based on the following criteria: (a) written in English; (b) publications issued between January 2000 to November 2023; (c) human studies; (d) full text available; (e) focused on KD; (f) populations at high-risk of acquiring KD; (g) education needed of KD; (h) long-term support for KD patients; (i) KD guidelines. Eligible studies were restricted to East Asian and North American countries. Studies were excluded if full text was not available, or they did not fit the previously stated criteria.

Study Selection

After deduplication, 820 articles underwent title and abstract screening independently by four co-authors (AA, RK, CP, & SS). At this stage, a total of 763 articles did not meet the inclusion criteria and were excluded from the review. The full-text screening was conducted for the remaining 57 articles by the same co-authors. In total, 34 articles were eligible and included in the current review.

Results

Demographic Factors

While examining the literature, several demographic variables were found to be connected to the prevalence of KD. Age is a crucial factor in acquiring KD as the disease predominantly affects young children.¹⁴ About 80% of patients are infants or younger than 5 years of age.¹⁵ In Canada, the incidence of KD is about 20 cases per 100,000 children <5 years old.⁶ A contributing factor to disease onset is believed to be the ongoing development of a child's immune system.¹⁵ Genetically predisposed children with dysregulation of their immune system seem to be the more susceptible patients.^{16,17}

The Japanese racial and ethnic community is also among those impacted by KD.³ Japan has the highest prevalence of 308 per 100,000 children <5 years old.⁶ Analyzing the migration patterns of East-Asian countries with higher KD incidence rates than Canada (ie. Japan, South Korea, and China) may show why Canada has the highest prevalence of KD when compared to other Western countries. According to *The Canadian Magazine of Immigration*, Japanese and South Korean immigrants reside predominantly in British Columbia (48% of Japanese; 34% of South Korean), Ontario (31%; 49%), and Alberta (11%; 9%).^{18,19} Specifically, both immigrant groups reside in major cities, such as Vancouver and Toronto, while Chinese immigrants predominantly reside in British Columbia.¹⁸⁻²⁰ Based on the immigration patterns of the top three countries with the highest incidence rates of KD, children of East Asian descent are more populated in the Canadian areas that have higher KD incidence rates.

Education for the General Public

While a significant portion of the literature overlooks the absence of educational resources tailored for the general public, some studies have examined the repercussions of raising a child with KD on parents and families.^{21,22} Parents expressed concerns

regarding their child's health despite not receiving a confirmed diagnosis from their physician; however, they felt that they did not have adequate knowledge to advocate for their child.²¹ The families and parents of KD patients also exhibited symptoms of anxiety that may be linked to the lack of knowledge regarding the patient's health status and the insufficient information presented.²² Even adolescent patients with CAA reported a lack of information provided to them by physicians regarding their condition, which resulted in symptoms of anxiety and depression.²²

Additionally, parental monitoring of symptoms was reported to be one of the most important factors in the early diagnosis and treatment of KD.⁹ Although physicians make the diagnosis of KD, it is still reinforced by what parents observe.⁹ Symptoms such as rashes are easily identifiable, but parents are not educated on more obscure symptoms, including cervical lymphadenopathy.⁹ If a physician does not suspect KD and parents are not educated on how to monitor KD symptoms, the physician would have no reason to further investigate the child's illness.⁹ While this finding was not reported to be an issue in Japan,⁹ the same may not apply to countries with a lower prevalence of KD.

Due to a high number of parents feeling a lack of understanding of their child's diagnosis, many of them turned to online resources to educate themselves.²¹ Using online resources as an educational tool can be due to the lack of lay language used by professionals when discussing a KD diagnosis, leading to a parent's feelings of confusion.²¹ The number of search queries for KD during the COVID-19 pandemic was the highest compared to other childhood diseases.²³ When alerted of the symptoms of KD, patients and their families sought out information that was readily available and easy to understand.

Education for Healthcare Professionals and Academics

We identified three articles that examined the diagnostic criteria of complete KD, incomplete KD, and atypical KD. In the American Heart Association's (AHA) diagnostic guidelines, complete KD is diagnosed by the presence of a fever for five days with four of five principle clinical features of KD.^{1,24} The well-established criteria can vary with the clinical features that are present during the patient's initial assessment. Patients who do not meet these clinical criteria can be diagnosed with incomplete KD (iKD)¹; however, the AHA 2004 diagnostic algorithm for iKD was not effective in clinical practice.²⁴ With this critique in mind, in 2017 McCrindle *et al.* provided an updated algorithm and defined iKD (also referred to as atypical KD) as an individual with unexplained prolonged fever, less than four of the principle clinical features of KD, and a positive echocardiograph. By contrast, Japan's 6th diagnostic guidelines for KD considers iKD to be cases where three principal symptoms with coronary artery lesions are present, and cases with four KD signs without coronary artery lesions.²⁵

Upon the diagnosis of KD, the standard treatment is IVIG with an aspirin dose.^{10,11,26-28} The IVIG therapy has been heavily relied on for the initial treatment of KD; however, there are many speculations about the importance of corticosteroids as an adjunct therapy to IVIG.^{10,11,26-28} Although the AHA does not support the use of corticosteroids for KD treatment, utilizing a tapering steroid therapy for 2-3 weeks along with IVIG and aspirin when a patient is IVIG-resistant.²⁸ Another alternative treatment for IVIG-resistant patients, which has been discussed in Japan, is the use of plasma exchange—removal of inflammatory cytokines, chemokines, and proinflammatory factors from the blood.¹⁰ Positive results have been established using this technique and it has been added to the 2020 version of the *Guidelines for the Medical Treatment of Acute KD* in Japan.¹⁰

However, the plasma exchange technique has yet to be incorporated into the AHA guidelines.

Within recent years, researchers have created tools to promote better clinical and research KD practices. To aid with knowledge translation for medical school students, a digital educational resource was created and piloted. The interactive platform was beneficial for the retention and revision of information about KD.¹² The dissemination of more complex concepts related to KD has been achieved through Knowledge Graphs—an AI approach to compiling various data resources.²⁹ The graphs integrate clinical guidelines and trials, medical literature, etc. to share disease-specific graphs that allow for in-depth exploration of factors impacting KD. For example, it has created a discussion on potential biomarkers of KD.²⁹ Lastly, KD diagnosis heavily relies on a physician's ability to notice the clinical signs and symptoms of KD.^{10,26-28} However, to mitigate the misdiagnosis of KD from other febrile diseases, in 2023 Tsai *et al.* implemented the use of machine learning. Their prediction model utilized objective laboratory tests as predictors for KD and was able to differentiate KD with “excellent sensitivity, specificity, and accuracy”.¹³

Although patient and family education are vital to screen for and diagnose KD, another area that is not well studied is the education of dentists. A study conducted by Verma *et al.* in 2018 focused on the role of dentists in observing the oropharyngeal symptoms of KD. They discussed a case study in which a patient presented with lower lip swelling, an uncommon symptom of KD.³⁰ The process of identifying and referring to a physician can be replicated in cases with hallmark KD symptoms, such as oropharyngeal mucositis.³⁰ By incorporating KD-specific education into the curriculum of

dentists, less common symptoms can be identified sooner, and patients can seek faster treatment.

Screening and Long-Term Support

Examination of the literature further revealed the lack of screening methods for patients with KD. Currently, KD has no definitive screening tests and as such, the disease is difficult to diagnose.² Diagnosis is generally made through clinical observation, where patients who present with at least four of the five principal clinical features are deemed to have complete KD.¹ Laboratory findings supplement clinical diagnoses by evaluating whether a patient presents with leukocytosis, anemia, and/or elevated acute-phase reactants, however, these findings alone are not substantial enough to make a diagnosis.³¹ Patients who have KD are promptly treated with IVIG, which has been shown to be effective in helping most patients recover.⁵ Issues arise when patients do not present with sufficient clinical and laboratory findings, shifting the diagnosis to iKD. iKD is a risk factor for delayed diagnosis and treatment; thus, patients presenting with iKD are at a higher risk of developing cardiac complications.³² The algorithm proposed by the AHA and updated by McCrindle *et al.* in 2017, has been successful in highlighting patients at the highest risk of CAA to be given IVIG treatment. Although effective, the algorithm has shown difficulties in diagnosing a subset population of children, specifically infants less than 6 months and adolescents.³² Further updates to the algorithm and diagnosing process must be made to better encompass the larger population of patients presenting with KD or iKD. Echocardiograms must also be implemented into diagnostic measures for suspected iKD, as they are mainly performed for patients with suspected complete KD.³³

When looking at the long-term support for patients with KD, the literature shows that there are gaps in care for patients once they are treated for KD. Patients presenting with KD are at risk of developing coronary arteritis within the first four to six weeks of disease onset.³³ CAA has been well-documented to occur following coronary arteritis in both untreated and treated populations, with incidence rates of 25% and 5%, respectively.³⁴ Although patients with transient or no CAA have been reported not to be at risk of long-term cardiac complications, the subgroup of patients who have presented with CAA require life-long clinical follow-up and management.³⁴ Furthermore, a secondary subset of patients exists with IVIG-resistant KD, putting them at an increased risk of artery damage.⁴ The size of a CAA is the main predictor of long-term health outcomes in patients as difficulties in long-term support stem from care discrepancies based on CAA size.³⁴ Although rare, patients with CAA categorized as 'giant' are at the highest risk of severe life-long complications resulting in ischemic heart disease.³⁴ Patients with giant CAA require thromboprophylaxis and revascularization and must be closely monitored.³⁴ Discrepancies in long-term support arise when dealing with a non-giant CAA, which has a small to medium size and makes up the majority of cases. The non-giant CAA have been recorded to regress within 155 days on average, with small CAA regressing in approximately 74% of cases and medium CAA regressing in approximately 24%.³⁵ Rigorous follow-up is only conducted with patients whose CAA has not regressed, resulting in the loss of patient follow-up for patients with non-giant CAA as they transition to adulthood.³⁴ With how little data is available on the long-term outcomes and cardiovascular risks of non-giant CAA, the loss of this population for testing and long-term support puts them at a heightened risk for major adverse cardiac events. The failure to

retain patients is outlined by Johnson *et al.* in their 2021 review of adherence to AHA guidelines. Patients and their families have been shown to have low adherence to AHA guidelines regarding echocardiograms, with only 14% of a study cohort completely adhering to said guidelines.³⁶

Discussion

From the literature, a critical aspect of KD that emerges is the role of demographic variables in its susceptibility. One of the pivotal demographic factors influencing KD prevalence is age. As demonstrated by Newburger *et al.* in 2016, KD predominantly affects young children, with approximately 80% of patients being younger than 5 years old, including infants. Genetic predisposition has been suggested as a key factor in KD susceptibility, with children who exhibit immune system dysregulation being at a higher risk.^{16,17} The interplay between age and genetic predisposition emerges as a central aspect influencing KD prevalence, which emphasizes the significance of focused interventions and educational programs for at-risk groups in Canada.

Another significant demographic factor associated with KD prevalence is racial and ethnic background, particularly those of Japanese origin.³ Japan stands out with the highest global prevalence of KD, necessitating explanations for the comparatively elevated incidence of KD in Canada. An important consideration is the migration patterns of East Asian countries with high KD incidence rates. Japanese and South Korean immigrants are concentrated in specific regions of Canada, particularly in British Columbia, Ontario, and Alberta, with significant populations residing in major urban centers like Vancouver and Toronto.^{18,19} Analyzing these immigration patterns reveals a correlation between the regions with high KD incidence rates and the presence of Asian

immigrant populations. The correlation suggests that the prevalence of KD in Canada may be influenced by the racial and ethnic demographics of the population, with children of Asian descent being more concentrated in regions with elevated KD incidence rates. The scoping review highlights the intricate relationship between demographic variables and KD prevalence in Canada. Age, race, and ethnicity emerge as significant factors influencing susceptibility to KD. Understanding these demographic factors is crucial for tailoring educational and healthcare efforts to effectively address the challenges posed by this wicked problem within at-risk populations in Canada.

Delayed diagnosis of KD can lead to long-term heart issues, such as CAA, due to delayed IVIG treatment. If the symptoms of KD and the populations that it adversely affects are not well known, the disease could progress without treatment and give rise to more severe complications.⁹ Educating both the general public and healthcare professionals on the disease and those at risk is critical to make sure all affected patients receive diagnosis and treatment in a timely manner. Certain demographics are at higher risk of developing KD,³ but if these groups are not aware of this, they may ignore their symptoms or wait longer to seek medical care. Similarly, healthcare professionals cannot diagnose patients with KD if they are not aware of its unique symptoms to differentiate KD from other similarly presenting febrile diseases. Even if physicians are well-trained, there are no definitive screening tests that currently exist², which may delay the diagnosis of KD by the physician. In cases of iKD, diagnosis is even more delayed as a result of inadequate lab findings for a KD diagnosis.¹ To bridge these knowledge gaps, we propose that a system be put in place to educate the public and healthcare professionals to quickly identify and diagnose KD. A system that educates families coming to Canada from

regions with high KD prevalence could provide them with knowledge of the symptoms, allowing them to identify the disease onset and seek medical care faster. Continuing to develop educational tools for physicians, such as AI for pattern recognition and detection of relationships, can go a long way in disseminating information between professionals on a global scale. Ultimately, addressing the knowledge gaps regarding KD will allow patients to seek medical care before reaching the late stages of the disease, give physicians the knowledge and tools to diagnose KD efficiently, and guide patient care regarding KD in high prevalence regions.

Educating the general public could lead to increased awareness of the symptoms and forms of KD, which can lead to faster diagnosis and treatment. When spreading information on KD, it is important to do so broadly instead of focusing solely on the at-risk populations; certain populations will always be at further risk of acquiring KD, but KD can be diagnosed in any individual. Focusing on one population can lead to a lack of awareness in other groups, making general public education crucial. Based on research conducted in past studies, parental knowledge of the symptoms of KD has led to quicker diagnosis, which is important in regions outside of East Asia where physicians are less inclined to search for KD-specific symptoms.⁹ Additionally, it is important for adjacent healthcare professionals, such as dentists, to be educated on the less common oral symptoms of KD. As such, they may suspect KD and subsequently refer patients to physicians for diagnosis and treatment.³⁰ In situations where a patient presents oral KD symptoms, dentists would most likely be the first to notice them during a routine checkup. The amount of knowledge a dentist has on KD and its symptoms could directly correlate to the speed of making a diagnosis and starting treatment.³⁰

The *Kawasaki Disease Foundation* is a parent-based organization that works to spread awareness of KD and provide support for families.³⁷ They have created many initiatives to allocate funds, create documentaries and educational videos, facilitate a network of support workers, and conduct regional educational conferences for families to attend.³⁷ These initiatives have spread awareness of the symptoms and forms of KD, as well as provided families with a support system to continuously receive information about their child's diagnosis in an easily digestible manner.

Along with educating the public, professionals must stay well-informed on the current global clinical guidelines and research initiatives on KD. KD is a rare and potentially serious condition as its etiology is not yet understood. Therefore, diagnostic criteria and optimal management strategies will continue to be critiqued and compared leading to meaningful guideline revisions.^{25,28,38} These dynamic guidelines provide a framework for standardized care, which is especially important for KD, where timely intervention can prevent serious long-term complications. Being aware of international recommendations may help improve local understanding of the disease and potential treatments. KD may present differently in various regions and populations; thus, global collaboration may optimize patient-specific treatment. Professionals in the field should continuously critically appraise, revise, and share KD diagnostic guidelines, standard treatments, and novel innovations on a global level as this directly impacts the well-being and quality of care patients receive.

Furthermore, healthcare professionals must stay up to date with continuously evolving screening methods and provide updates for early KD diagnosis. The lack of specific diagnostic measures has made screening for the differing forms of KD a technical

challenge, with iKD being the hardest to diagnose in subpopulations of patients. The use of further education to improve current iKD detection algorithms would provide the highest benefit for undiagnosed patients. Additionally, educating healthcare professionals on the consistent and continued use of echocardiograms/echocardiography would help improve the detection and diagnosis of iKD.

As the intricacies of KD are being uncovered, academics should actively utilize new technological resources to enhance our understanding and clinical management of KD. Technology allows researchers and educators to access and disseminate information efficiently, as seen with Song and Tombs' digital educational resource created in 2023. Moreover, interactive online platforms make it easier for a diverse range of learners, from students to experienced clinicians, to access information on KD. Technology can also facilitate global interdisciplinary collaboration, creating connections between ideas and expertise. The Knowledge Graphs created by Huang *et al.* in 2021 demonstrate this by utilizing AI approaches to discover new patterns to promote a more comprehensive appreciation for the disease. Continuing the development of new resources that educate a broad spectrum of learners and detect relationships beyond human intellect can help improve diagnosis and patient care.

Finally, it is essential that both the public and professionals be better educated on the long-term health outcomes that stem from KD, and in turn, the long-term support that is required for patients to live free of major adverse cardiac events. Patient families must be informed of the importance of adhering to health guidelines as outlined by the AHA, as only a small percentage of this population follows it completely. With how complicated KD is, how little is known about its etiology, and the uncertainty surrounding post-KD health

outcomes, it is imperative that patients maintain a link to their healthcare providers so that adequate monitoring can be conducted. Support must be better implemented for all levels of CAA as well so that patient retention can remain high, allowing for improved monitoring of heart health. Furthermore, poor long-term support for patients cured of KD and those who are transitioning into adulthood must be further investigated, as the complications that may arise are still unknown to healthcare providers.³⁴

Chapter 3: Recommendations and Call-to-Action

Focus 1: Educating the General Public on Kawasaki Disease for the Faster Diagnosis and Treatment

Recommendation: Pamphlets/Handbooks from Kawasaki Disease Foundation Disseminated to Hospital/Clinic Waiting Areas

A major reflection from parents of KD patients is the lack of available information on the disease and the anxiety associated with it, necessitating educational material.²² Although physicians should be the main source of information, parents often report feeling confused about their child's diagnosis and how to manage the condition.²¹ Parents often refer to external sources, such as websites and forums, when their child's physician is not using language that is easy for them to understand.²¹

One measure that should be implemented to better disseminate data to the public is creating informational pamphlets and handbooks to distribute in hospital waiting areas. The resources will contain information about the disease, how parents can best support their children, and parent-specific resources, such as support groups or sites with peer-reviewed educational information. By clearly outlining information from accredited organizations, these pamphlets and handbooks will prevent any misinformation that parents may receive from external sources. The informational material will utilize lay terms and be readily available in areas frequented by KD patients and families. Learning about KD will become more accessible and help mitigate anxieties that arise from a KD diagnosis.

Recommendation: School Curriculum Integration for Early Childhood Educators

Oftentimes, patients diagnosed with KD and their families are not aware of its symptoms, which delays diagnosis and treatment.⁹ To prevent long-term complications, a timely diagnosis is crucial through effective monitoring of KD symptoms. Thus, teachers

and caregivers, individuals who often spend the most time with children apart from parents, will benefit from education on KD.

A second recommendation is to integrate information on KD into the training of early childhood educators. In terms of educating teachers, adding modules to their curriculum will be helpful; these modules will include which high-risk KD populations, its principal symptoms, and the importance of early diagnosis and treatment. This education will provide teachers with the knowledge they need to monitor the health of their students, as well as educate them on how to better advocate for their students if they are presenting with KD symptoms.

Focus 2: Education for Healthcare Professionals and Academics on Kawasaki Disease for Faster Diagnosis and Treatment

Recommendation: Incorporation of Kawasaki Disease Education into the Curriculum for Canadian Dentists

Although KD often presents with various symptoms, such as fever, rash, swollen hands, enlarged lymph nodes in the neck, red eyes, and/or cracked lips,¹ there are more obscure symptoms such as lower lip swelling and oropharyngeal mucositis,³⁰ which may not always be easily observed in clinical settings. In situations where a patient may exhibit oral symptoms more than traditional symptoms, professionals such as dentists would be the first to observe these clinical features. Identification of these symptoms and subsequent referral to a specialist will contribute to decreasing diagnosis time for KD.³⁰ However, if dentists are not aware of KD symptoms, they would not know what to look for and may assume these symptoms are indicative of another condition.

One recommendation regarding professional education on KD is collaborating with policymakers to integrate KD-specific training into the dentistry curriculum. By adding topics related to KD, dentists will be provided with a background on KD and how it

manifests, as well as their specific role in observing and identifying a KD-specific symptom and referring the patient to the appropriate specialist for diagnosis. Additionally, this curriculum will establish frameworks that all dentists can adopt within their own practices to uniformly screen their pediatric patients for oral KD symptoms.

Recommendation: Creating an Online Learning Module on the Continuing Medical Education (CME) and the Maintenance of Certification Program Platforms

Across the globe, there are differing guidelines and standards for KD diagnosis, treatment, and long-term management.³⁹ The dynamic landscape of KD management requires a means to stay well-informed as new information comes to light. For this reason, creating online learning modules is a highly recommended strategy that offers benefits for the healthcare system, healthcare professionals, and medical trainees.⁴⁰

E-learning provides a flexible and accessible mode of education. Healthcare professionals can access the modules at their convenience, allowing them to learn at their own pace and incorporate continued learning into their busy schedules. Furthermore, online modules can be designed to cater to various learning styles by incorporating various elements, such as videos, interactive quizzes, case studies, and external resources. Presenting information in different formats will ensure that the content resonates with a wide range of learning preferences. The promotion of this educational tool will offer practitioners across healthcare institutions and geographical regions the opportunity for standardized education. In turn, the variability in quality of care would be reduced resulting in improved patient outcomes.⁴¹ To accommodate new developments in the field of KD, the online platform can be regularly updated to reflect advancements in KD research and clinical guidelines. The platform will allow healthcare professionals to

be well-informed, consider new evidence-based practices in their treatment plans, and be empowered to maintain high-quality care that aligns with the latest standards of practice.

The online module will be added to the *Continuing Medical Education (CME)* and the *Maintenance of Certification* programs where physicians and trainees in Canada can use online learning materials to maintain and further their understanding of their given specialty.⁴⁰ It is recommended that the Royal College Specialty Committees including pediatricians, cardiologists, and general practitioners, update their *CME* and *Maintenance of Certification* policies to include a KD-specific module. The topics included will examine national and global information concerning KD's definition, its signs and symptoms, current treatments, incidence and prevalence rates, case study examples, and gaps in knowledge. Furthermore, the module will highlight the Canadian-specific subpopulations, demographic factors, and geographic locations that are at higher risk of developing KD.

The implications of establishing an e-learning module for KD education are extensive. Equipping healthcare professionals in all geographic locations with comprehensive knowledge of KD can contribute to earlier diagnosis, more effective treatment interventions, and better long-term management of KD. Increased physician competence can result in decreased complications, shorter hospital stays, and mitigation of life-long health impacts.⁴² Ultimately, this recommendation will lower the associated economic burden on the healthcare system.⁴²

Recommendation: Additional Required Training for Family Medicine, Internal Medicine, and Pediatric Residents in Nova Scotia, Ontario, and British Columbia

In Canada, the provinces with the highest rates of KD include Nova Scotia, Ontario, and British Columbia.³⁴ Therefore, it would be beneficial for educational policymakers to update medical trainee curriculums within their respective provinces to include KD

identification and treatment plans. Continuous development and refinement of trainee curriculums are required to maintain the trainees' understanding of prevalent issues within their area of study. The specialties that most frequently encounter KD are pediatrics, family medicine, and internal medicine.⁸ The additional training will cover the current Canadian diagnostic criteria for KD and iKD, and their respective signs, symptoms, and treatment plans. Trainees will also be made aware of the demographic variables that increase one's risk of developing KD, such as individuals of East Asian descent, children under the age of 5, and those with immune system dysregulation.^{17,16}

Specialty-specific training is of high importance as it aims to improve patient outcomes. Clinicians will have a deeper understanding of KD, which enables them to provide efficient, patient-centred care. Additionally, a common language surrounding KD diagnoses will be established as national standards and guidelines will be disseminated to trainees. Healthcare providers could effectively collaborate and coordinate comprehensive patient care with the standardized language. Most importantly, with higher awareness about KD risks, manifestations, and complications, physicians can more accurately identify and treat KD to improve patient outcomes. Healthcare is constantly evolving; thus, clinicians must stay educated with the latest developments and best practices in the KD field.

Recommendation: Hosting Events such as Conferences, Webinars, Workshops, and Seminars Covering the Latest Research on Kawasaki Disease

Hosting collaborative events such as conferences, webinars, workshops, and seminars regarding advancements in KD research is crucial for understanding the disease at hand. Targeted specialties would include pediatricians, pediatric cardiologists, family doctors, and general cardiologists as they see the majority of KD cases.⁸ Through

these events, collaborative efforts about the progression of KD research can be shared by individuals in academia and clinicians alike to explore new hypotheses into the complexities of KD. The interdisciplinary approach is imperative and may result in novel methods of diagnosis and treatment. By facilitating these in-person and virtual events, healthcare professionals and researchers around the world have access to updates on the global trends of KD. Once these events garner more support from clinicians, researchers, and advocacy groups, an Annual General Meeting can be organized to allow for a centralized meeting to share novel advancements in the field of KD.

The promotion of these events has many positive implications for KD patients. By fostering collaboration among researchers and clinicians on a global scale, scientific discovery can be accelerated. Collaboration is beneficial for breakthroughs in understanding the underlying mechanisms of the disease or the development of therapeutic approaches. Also, the pre-clinical knowledge can be translated into clinical impacts, resulting in improved patient outcomes through early and accurate diagnosis, and timely intervention. The strategy will advance scientific knowledge and overall awareness about this rare, but significant pediatric condition.

Focus 3: Improving Long-Term Support for Patients and their Families

Recommendation: Creating Transition Pamphlets to Assist Individuals Throughout their Healthcare Journey After Diagnosis

As mentioned previously, KD treatment is heavily reliant on early diagnosis, in which complications can occur if the condition is not treated promptly.⁴³ Taking this into consideration, patients missing the window for effective treatment are at risk for further complications later in life, which is exacerbated by the poor retention rate of patients following treatment who exhibit CAA.⁴³ As stated in the literature review, rigorous follow-

up is only conducted in patients who have not shown CAA regression or giant CAA. Considering that long-term health outcomes of KD are not well known, this failure to retain non-giant CAA patient follow-ups opens the risk for potential cardiac complications later in life.

To combat these concerns, a pamphlet outlining a patient's change in care is suggested. The pamphlet would be given out to all patients, and it would outline many important aspects that patients should be made aware of following a diagnosis of KD. One of the major points that would be highlighted within the pamphlet would be the need for patients to return for reassessment one and two years after diagnosis. Firstly, it would ensure that the patient is aware of potential cardiac conditions. There has been a large emphasis placed within this paper highlighting the difficulty in diagnosing KD, and as such, there is a large variance in how long-term KD implications may present themselves later in life due to varied treatment times. Having checkups over the course of two years would mitigate the potential risk of developing surprise conditions. The second benefit of these checkups is ensuring the complete regression of any CAA. With how little follow-up is conducted for patients with non-giant CAA, combined with the prolonged time it takes for the regression of a CAA, the risk of thrombosis and/or rupture is unknown to the patient. The proposed checkups would help mitigate this issue by keeping the patient informed of their potentially changing health conditions. Another key goal of this pamphlet would be to inform the patient and their family of the importance of disclosing their diagnosis whenever interacting with a healthcare provider. With so many KD patients surviving to adulthood, there needs to be an increased involvement from adult cardiologists to better determine guidelines in treating patients who have previously

exhibited KD.⁴⁴ By keeping healthcare providers aware of previous KD cases, they can point patients to the correct specialist and establish foundational knowledge, which can aid in developing new methods for treating patients with similar medical histories.

There are numerous benefits of a pamphlet as it can help patients and their families. Firstly, the pamphlet would help patients transition into adult care with an understanding of their previous condition and how it can impact them. Being knowledgeable about their condition would help increase their health outcomes later in life by advocating for their own health. Secondly, by keeping the family informed of recommended checkup times, patients with CAA of all sizes can be monitored and treated accordingly, which will heavily mitigate the chance of a non-regressing CAA from going unnoticed.

Recommendation: Establishing Patient Support Groups to Foster Mentorship and a Sense of Community

Another recommendation is the creation of support groups for both KD patients and their families. Multiple studies have shown the mental toll a KD diagnosis can have on all family members involved in the diagnosis. For KD patients, like with any disease, there remains the possibility for mental health issues to arise such as depression or anxiety later in life if their condition is not completely treated.⁴³ Similar outcomes are seen in the parents of patients with KD, as anxiety builds over the possibility of more serious complications such as CAA and other cardiac concerns.²¹ To amend this, support groups could be implemented where individuals with similar experiences can get together and share their stories. The support groups would be spearheaded by healthcare advocacy groups, such as Kawasaki Disease Canada and the Canadian Cardiovascular Society. Having a community would allow patients to receive guidance from others who are in the same position or have been treated.

There has been strong evidence that supports the establishment and impact of support groups, as they have been consistently shown to improve mental health.⁴⁵ Given that many parents complain about the complex terminology used in clinics, these support groups would also provide families with the opportunity to voice concerns, aiding them in understanding KD better.²¹ As with the previous recommendation, implementing support groups would have a large impact on lessening the burden of a KD diagnosis. While not directly aiding in the treatment of the condition, having methods of coping with the subsidiary aspects that come along with a KD diagnosis will help lessen the burden families may feel from a diagnosis. Furthermore, this would allow them to be better prepared mentally to deal with the challenges of KD.

As a whole, both of these recommendations serve to enhance the treatment of KD, however, they do so in a manner that does not directly treat the condition. The strategies have the added benefit of being flexible and can be incorporated alongside any method of treatment, allowing for new treatments of KD to become available without impacting the effect of the proposed recommendations.

Chapter 4: Conclusion & Next Steps

Based on the current evidence surrounding KD, it appears that a larger emphasis must be placed on educating both the public and healthcare professionals regarding multiple aspects of the disease. This review highlights the critical role that demographic variables play in KD prevalence in Canada. Age, genetic predisposition, race, and ethnicity are all suggested to influence susceptibility to KD, and as such, targeted education for at-risk groups must be created. Broad public education is also paramount in establishing early diagnosis of KD for all populations. Healthcare professionals should stay informed and collaborate globally to improve current care surrounding KD. Specifically, healthcare professionals should further their understanding of guidelines, technologies, screening methods, and long-term care to disseminate this knowledge to their patients. Furthermore, academics and researchers should incorporate new technological resources to enhance the understanding of KD and fill the gaps in knowledge about the etiology of the disease. For these goals to be met, this review emphasizes three main recommendations: educating the general public on KD for faster diagnosis and treatment, educating academics on KD for faster diagnosis and treatment, and improving long-term support for KD patients and their families.

To reach these proposed goals, there are distinct next steps that should be taken to see progress in KD care. For the general public, efforts must be made to collaborate with policymakers to better incorporate KD-specific information within the curriculum for educators, as well as work with patients and families to create educational pamphlets. In terms of academics, provincial and territorial training guidelines should be frequently updated to reflect the evolving prevalence of KD across Canada. Additionally, alongside

national webinars and conferences, global partnerships are needed to establish an interdisciplinary approach to standardize KD care. Finally, collaboration with healthcare advocacy groups must be established to begin working on transition pamphlets and initiate the creation of support groups. Overall, by incorporating these changes, efforts will be made to bridge gaps in the diagnosis and treatment of KD.

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