

Voices of Indigenous peoples living with chronic health issues during the COVID-19 era:

Experiences in Katarokwi
(Kingston, Ontario area)



The
Katarokwi
Indigenous
Resilience
during
COVID-19
project

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- Indigenous Cancer Care Unit, Ontario Health
- Indigenous Diabetes Health Circle
- Indigenous Health Council
- Street Health Centre, Kingston Community Health Centres
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Health



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Public Health



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OVERVIEW

Indigenous peoples living with chronic health issues during the COVID-19 era: KIRC-19 Project

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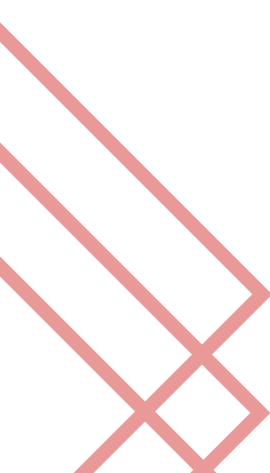
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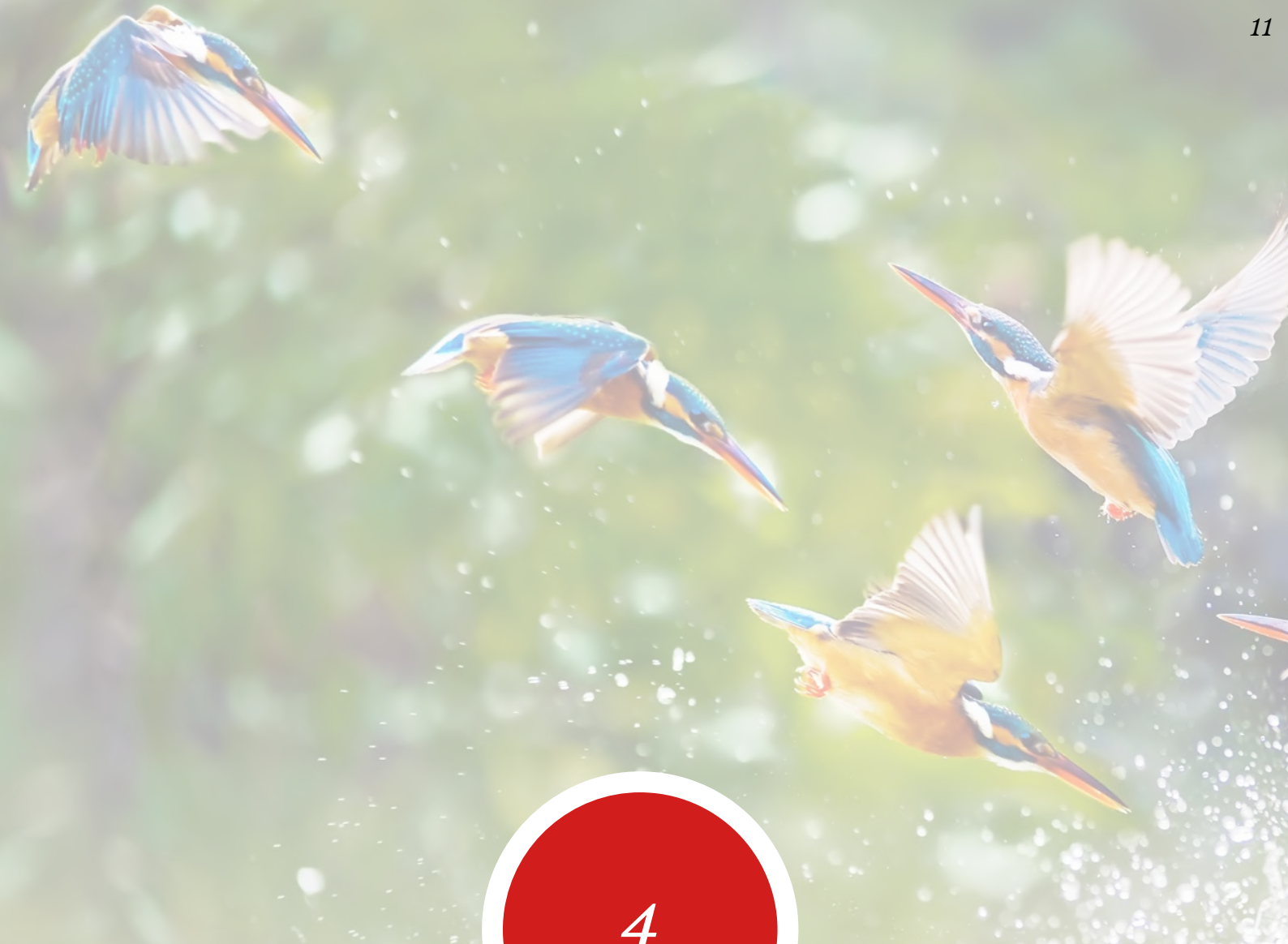
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ABSTRACT

Indigenous peoples living with chronic health issues during the COVID-19 era: KIRC-19 Project



Abstract

Background

Indigenous peoples in Canada are disproportionately impacted by chronic physical and mental health issues as a result of generations of settler colonialism (1-3). Indigenous peoples face health and social inequities, as well as significant barriers to accessing meaningful and culturally safe care (1-3). The COVID-19 pandemic has arguably magnified these challenges, for reasons including the socioeconomic, psychosocial, and societal consequences of isolation measures. However, Indigenous peoples are resilient and are exploring ways to protect their wellness from the concomitant impacts of colonialism and COVID-19.

Study Methods and Objectives

The purpose of this study is to explore the experiences of Indigenous individuals, in the context of COVID-19, who have at least one chronic illness (physical or mental) and live in the greater Kingston, Ontario (Katarokwi) area. To meet this objective, Indigenous community members, community service-providers, and academic researchers from Queen's University partnered to form the Katarokwi Indigenous Resilience during COVID-19 (KIRC-19) project. KIRC-19 has two components[1], one of which is a qualitative constructivist grounded theory study that was developed according to the principles of Ownership, Control, Access, and Possession (OCAP) (5-7). The results of this study are reported here. We conducted one-on-one telephone interviews between November 2020 and February 2021 with 22 diverse Indigenous individuals who accessed care for one or more chronic health issues in Katarokwi. During interviews, we explored areas of need for Indigenous individuals living with chronic conditions during the pandemic, in order to help identify points of intervention and areas of need. By documenting these findings through research, we can support reorientation of approaches to care and mobilization of resources and funding to meet needs. The project also highlights stories of strength, success, and resilience among Indigenous individuals in Katarokwi during the pandemic. These stories may inform other Indigenous community-based efforts to strengthen wellness during and in the aftermath of COVID-19. Finally, the academic-community partnerships being built in KIRC-19 can help ensure longstanding collaboration and community engagement going forward, thereby contributing to broader efforts of reconciliation.



[1] The KIRC-19 Project involved two concurrent studies – 1) the qualitative constructivist theory study reported here, involving interviews with Indigenous individuals living with chronic health issues, and 2) a case study, involving an examination of three Indigenous-led/Indigenous-focused organizations who provide services to Indigenous clients living with chronic health issues, to understand their experiences in adapting their operations and service delivery in the face of the COVID-19 pandemic's onset. The case study results will be reported separately.

Key Results

Participants identified several factors that facilitated or impeded access to care prior to and during the pandemic. Factors that affected access to care were related to availability, affordability, relationship, accessibility, efficacy, and necessity. Unfortunately, the number of barriers to care greatly outweighed the facilitators of care. Similarly, while some participants experienced some positive effects of the pandemic on their wellness (e.g. more time to reflect or heal), many others felt that their wellness had diminished due to the pandemic. In many cases, participants felt isolated, spiritually and/or socially disconnected, anxious, and depressed. They also experienced fluctuating moods, amplified fear and mistrust, poor sleep, and changes in eating and hygiene practices. Notably, several participants reported that their pre-existing chronic health conditions had worsened during the pandemic. The factors that impacted wellness (in positive and negative ways) were grouped into factors related to culture in community; community and personal relationships; socioeconomic determinants of health; experiences in programs, services, and institutions; cultural and personal coping behaviours; and personal identities.

Key Recommendations

Participants affirmed the need for long-term and adequate funding for community-based programs and services that support Indigenous wellness, especially those that are Indigenous-led and Indigenous-focused. Related to this, participants emphasized the need for Indigenous-led, physical spaces for people to gather to practice culture, spend time with community, and engage in ceremony to enhance their wellness. Hiring Traditional Leaders, Knowledge Keepers, and Elders in all spaces where healthcare is provided to Indigenous peoples was also highlighted as a crucial change. These are anti-colonial approaches to care that create opportunities to build Indigenous self-determination, which is a crucial aspect of wellness (4).

Participants advocated for more funding for mental health and addictions services, noting in particular the need for services that were Indigenous-focused and trauma-informed. They also identified the need for more preventative wellness services, and more programs and services in general to support families, youth, and older adults. Further, participants emphasized the need for equitable access to healthcare in rural areas where services were often missing. Participants advocated for improvement to government financial supports such as the Ontario Disability Support Program (ODSP), as well as pandemic-specific supports such as the Canada Emergency Response Benefit (CERB) for those who were financially impacted due to isolation measures. They also emphasized the need for affordable housing, as well as measures to adequately address food insecurity. In the healthcare they accessed, participants advocated for relational, community-based, and client-focused care. Participants wanted to be treated with respect while they received effective, holistic, culturally relevant care from trained practitioners. They also emphasized the need for healthcare spaces that ensured that women, girls, and 2SLGBTQ+ individuals received inclusive and safe care.

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SUMMARY

Indigenous peoples living with chronic health issues during the COVID-19 era: KIRC-19 Project

Summary

As a result of colonialism, Indigenous peoples have higher rates of chronic health conditions compared to other Canadians (1-3). Indigenous peoples also face many barriers to accessing culturally safe and culturally appropriate healthcare services in a timely manner (1-3). This places their health at even greater risk. In Kingston, Ontario and surrounding area (Katarokwi), Indigenous peoples are concerned that the COVID-19 pandemic is making their health worse. For example, COVID-19 brings new challenges including new barriers to accessing care, as well as social, mental, emotional, physical, spiritual and economic impacts from isolation measures and related lockdown restrictions.

However, Indigenous peoples in Katarokwi are strong and resilient, and they have been constantly working to resist colonialism and protect wellness. With this in mind, Indigenous community members, service providers, and academic researchers formed a partnership to create the Katarokwi Indigenous Resilience during COVID-19 (KIRC-19) project. One of the purposes of this project is to capture the experiences of Indigenous individuals living with chronic health issues in Katarokwi during the COVID-19 era. We want to understand Indigenous peoples' experiences in dealing with the COVID-19 pandemic, and experiences in interacting with health and social services during the pandemic. We want to identify the barriers and problems that exist, while highlighting and building upon the strengths. With this knowledge, we want to propose solutions and improvements so that Indigenous peoples can continue to protect their wellness, and so as to strengthen health and social services and programs in Katarokwi. To explore these questions and goals, we interviewed 22 Indigenous adults who use services in Katarokwi for a chronic health condition. Interviews were done from November 2020 until the end of February 2021.

The KIRC-19 team includes community members, service providers, and researchers. The community partner organizations include the South East Regional Cancer Program (Cancer Care Ontario), Indigenous Cancer Care Unit (Ontario Health), Indigenous Diabetes Health Circle, Indigenous Health Council, Street Health Centre (Kingston Community Health Centres), KFL&A Public Health, and Addictions and Mental Health Services of KFL&A. Importantly, the project was guided by an Indigenous Oversight Committee of Oshkaabewisag (helpers/knowledge keepers from local community) who helped ensure that research was done in an ethical way and would be meaningful for the community.

The interview findings resulted in two frameworks – the first on factors affecting access to services (facilitators and barriers to care), and the second on factors impacting wellness. They are shown visually in Figure 1 and Figure 2, and discussed below.

Factors Affecting Service Access: Facilitators and Barriers to Care

Participants identified many factors that either facilitated or acted as a barrier to care in Katarokwi before and during the pandemic. Participants identified factors related to availability, affordability, relationship, accessibility, efficacy, and necessity (each discussed below and represented visually in Figure 1). Unfortunately, there were far more barriers to care for participants than facilitators of care. This imbalance has significant implications for Indigenous peoples' wellness.

Availability

Participants acknowledged the importance of having virtual health services available during the pandemic because, these allowed them to access care despite isolation measures. Virtual services also increased access for participants who lived in rural areas where fewer health services were physically available. However, not all participants had adequate technology, or the knowledge or ability to use technology, in order to access virtual offerings.

Long wait times for appointments were also a barrier to care. Many participants felt that wait times were even longer in the pandemic, which reduced the availability of care and impacted wellness. Some participants also felt that care was at times completely unavailable to them when appointments or procedures were cancelled by service providers without rescheduling. Further, participants identified the lack of Indigenous-led and Indigenous-focused services available, as well as services and supports available for Two-Spirit Indigenous individuals. Programs and services were limited further during the pandemic. Similarly, participants felt that they were not well-represented in healthcare, and that non-Indigenous service-providers were not always equipped with cultural training to support them.

Affordability

Having access to affordable health-related programs and services is very important to wellness. In some cases, virtual services reduced the cost of care by eliminating the cost of travel to appointments. In many cases, however, participants felt that cost was a significant barrier to care. Participants mentioned the high cost of food for therapeutic diets, health-related treatments and procedures, and traveling to in-person appointments during the pandemic. Further, many participants faced job loss or hour reductions and had lower incomes during the pandemic, which made concerns about money even worse. While community programs and services for low-income individuals exist, such as food or housing supports, many participants noted that these supports were often inadequate, unsustainable, and inappropriate to meet their needs. Ultimately, living on a low income deeply impacted participants' wellness.



Relationship

Participants valued safety, trust, and respect in the programs and services they used. They also valued service-providers who used community- and person-centred approaches. Women and Two-Spirit individuals felt these values were especially important given they had often felt unsafe or mistreated in healthcare settings. Notably many participants felt most welcomed and supported by Indigenous-led or Indigenous-focused organizations.

It is well known that Indigenous peoples experience systemic racism in healthcare (5). Unfortunately, several KIRC-19 participants experienced various forms of discrimination in the care they received before and during the pandemic. They reported receiving worse care and at times did not receive care when they needed it. As a result, participants expressed fear and mistrust of many programs and services. The effects of mistrust are significant. For example, when going through COVID-19 screening processes at healthcare sites, some participants misreported their symptoms because they did not think they would receive any care if they were symptomatic. This finding reinforces the need for communication, trust, and respect between service care providers and Indigenous clients.

Finally, when using virtual services, some participants reported some privacy concerns such as feeling as though they were being watched and recorded. Having a private area to use virtual services is not possible for all individuals, such as those who live with multiple roommates or extended family. This may be a particular issue for Indigenous peoples who are more likely to live in overcrowded housing compared to other Canadians (6-8).

Accessibility

Participants emphasized the importance of having adequate programs and services close to their homes. Having multiple providers and programs in one place (e.g. in a community health centre) also made care more accessible. In addition, access to multiple providers or programs in one space also offered a more holistic approach to care and benefited clients because it was seen as comprehensive and efficient. Participants also mentioned certain offerings that made services more accessible, such as medication and grocery delivery. However, these services are often associated with a cost and are only feasible for those who can afford them.

Participants who had physical disabilities felt that care was inaccessible at times. For example, some had chronic pain or mobility issues that limited their participation in land activities. Other participants had food allergies that excluded them from many community food supports. As mentioned earlier, technology helped some participants access virtual programs and services during the pandemic; however, some were unable to access these supports because they did not have access to technology or did not know how to use it. Participants also expressed their exhaustion and confusion when accessing healthcare services. Some experienced burnout, and this limited their ability to access care when it was needed. The influx of health-related information in the pandemic was often overwhelming, and some participants were also confused by the amount of misinformation available to them. For some, misinformation contributed to mistrust in health services during COVID-19.

Efficacy

Some participants emphasized the effective care they received from their service-providers. However, there were many instances when participants had ineffective and harmful experiences in health-related programs and services. In fact, for many, the pandemic made healthcare experiences worse by limiting the number of in-person appointments and treatments available, sometimes replacing these services with virtual offerings that were not seen as effective. In addition, participants acknowledged in-person community programming as a form of holistic care which may not be possible through virtual services alone. Ultimately, participants felt that virtual services, while a better alternative to cancelled programming, did not provide the same level of support as in-person programs and services.

Necessity

Some essential programs and services remained open and available to participants, thus facilitating service access. Further, for several participants, accessing care was medically required and deferring or prolonging treatment was not an option. Other participants were required to receive care because it was mandated as a result of incarceration. However, not all Indigenous peoples who experience incarceration in Canada are offered Indigenous-focused rehabilitation supports (9, 10).

Indigenous Wellness in Katarokwi

Colonialism is a significant social determinant of health and has created a number of social and health inequities for Indigenous peoples in Canada. In the greater Katarokwi area, Indigenous peoples have resisted and endured colonialism prior to the COVID-19 pandemic, and continue to do so while facing new and amplified stressors during the pandemic. To explore this resilience, the following section reviews the state of wellness among Indigenous participants during the COVID-19 pandemic. For the purposes of this report, we consider wellness to be the interconnection and balance of spiritual, emotional, physical, and mental health, existing within diverse cultural, social, and cosmological realities, and in relationship with a strong sense of identity (11-13).

Poor Wellness During COVID-19

The negative impacts of COVID-19 on participants' wellness were overwhelming, and greatly outweighed any benefits to wellness that happened during the pandemic. Participants felt their spiritual, emotional, physical and mental health was diminished or out of balance, and some felt their identities had been influenced as well. While a number of negative health-related outcomes were discussed, a few stood out. Participants overwhelmingly felt isolated and spiritually or socially disconnected from the world around them. Many participants experienced fluctuating moods, amplified fear and mistrust, poor sleep, changes in eating patterns and hygiene, increased anxiety and depression, and increased substance use and self-harm. Importantly, several participants reported that their pre-existing chronic health conditions had worsened during the pandemic.





Factors that Negatively Impact Indigenous Wellness

Many factors contributed to poor wellness before and during the pandemic. These factors have been grouped into categories including culture in community; community and personal relationships; socioeconomic determinants of health; programs, services, and institutions; and cultural and personal coping behaviours. They are discussed below, and also visually shown in Figure 2.

Culture and Community

Culture and community are deeply connected, and both influence Indigenous wellness and identity. In the pandemic, many community-based cultural events were cancelled, which resulted in fewer ceremonies and less time spent sharing knowledge, medicines, and other supports. While many events were able to be moved online, many others were not - such as sweat lodge ceremonies, which several felt were crucial to their wellness. Ultimately, practicing culture in community supports Indigenous peoples' wellness, and being disconnected deeply impacted participants.

Community and Personal Relationships

Participants were also spiritually, emotionally, physically, and mentally impacted by being isolated from their families and friends. On the other hand, some participants, such as those who had multiple roommates or extended family living in one home, reported more conflict during the pandemic due to spending too much time together. Several participants were especially concerned for Elders and older adults for whom they cared, who were more vulnerable to the effects of COVID-19. Participants who cared for older adults were put into difficult positions of providing crucial in-person supports while physically-distancing (if possible) to minimize the risk of spreading the virus. Unfortunately, some participants' loved ones passed away during the pandemic. Due to isolation measures, end-of-life measures were disrupted, and several participants were unable to grieve properly, cope with their losses, or properly experience and honour an important transition.

Socioeconomic Determinants of Health – Employment, Income, Food, Housing, and Education

Some participants had lower incomes during the pandemic because they had lost their jobs, had their work hours reduced, or were unable to find a job. In addition, several participants lived on low incomes prior to the onset of the pandemic. Many participants who received government financial supports such as the Ontario Disability Support Program (ODSP) stated that these were not enough to meet the cost of living. Receiving ODSP also disqualified people from receiving the \$2000 monthly CERB payment from March to September 2020 which supported many Canadians during the pandemic (14, 15). Several participants relied on community and extended relationships for childcare and transportation in order to make ends meet. In many of these cases, participants were unable to distance themselves from community relationships, thereby increasing the risk of contracting or transmitting COVID-19. Isolating from community is only a feasible public health recommendation when community members can afford to isolate themselves.

As a result of income insecurity, several participants were worried about the high cost of food during the pandemic. Though some participants accessed community supports such as food banks, others found these were inaccessible during the pandemic due to reduced hours or limited city transportation. It is also recognized that food banks had problems before the pandemic such as inconsistent stock, a lack of culturally appropriate foods, nutritionally inadequate foods, and stigma associated with accessing food banks (16). Similarly, several participants also described their experiences with unaffordable, inadequate, and/or unsafe housing prior to and during the pandemic. Some participants felt vulnerable in social housing, and also worried about those who were without a home entirely.

On the other hand, some participants were working in essential service positions during the pandemic, and, as a result, had higher demands and more stress at work. Some participants were working on the “front lines” while others worked remotely from home. Caregivers in both groups had difficulty balancing work and home life when schools closed during the pandemic and remote schooling from home started. During these times, participants felt they had more conflict with their children, and were also worried about their children’s education, development, and socialization from missed in-person schooling. There were also financial considerations with home-schooling. For example, closing in-person schooling shifted the labour and cost of teaching and caring for dependents onto caregivers, who did not always have the time or money to cover this labour. And when schools re-opened, caregivers were then faced with the decision of whether to send their children back to school where the risk of contracting COVID-19 was still present.

Finally, some participants were enrolled in post-secondary school, where they reported heavier workloads in remote-schooling formats. Participants described higher levels of stress, exhaustion, isolation, and, ultimately, burnout. Unfortunately, students who reduce their course loads to manage the workload also likely increase the length and cost of their education, because they must enrol for additional semesters to obtain their degree or diploma credits.

Programs, Services, and Institutions

Participants who did not have adequate access to health services were negatively impacted prior to and during the pandemic. Participants were also impacted when they felt neglected, overlooked, and mistreated by service providers. Many were also concerned about how Elders and older adults were treated, and reported instances of Elder abuse in certain healthcare institutions. New forms of isolation during the pandemic also negatively affected wellness. For example, health care institutions often limited the number of visitors patients could have, and, in some cases, institutions did not allow visitors at all. While limiting visitors is an important way to reduce the spread of COVID-19, it also amplified feeling of isolation which impacted wellness.

Cultural and Personal Coping Strategies

Participants who had addictions and histories of trauma reported struggling even more with substance use as a way to cope with distress during the pandemic. Other participants reported stress-eating and over-exercising to reduce anxiety, while others smoked tobacco, or blocked out their feelings altogether. These strategies can be used as a way to suppress emotions and survive past and present traumas; however, these coping mechanisms can also have harmful consequences.





Factors that Support Indigenous Wellness

While a number of factors diminished wellness, several factors protected participants' wellness. As above, factors are grouped into six categories including culture in community; community and personal relationships; socioeconomic determinants of health; programs, services, and institutions; cultural and personal coping behaviours; and personal identities. A sixth category has been added to emphasize the importance of Indigenous identity to wellness. These are discussed below, and shown visually in Figure 2.

Culture in Community

Whether remotely or physically distanced in-person, participants felt that connecting with Indigenous community and culture through events or ceremonies supported their wellness. Similarly, participants acknowledge land as an important source of strength and knowledge, prior to and during the pandemic. Many relied on the land for healing, and emphasized the importance of staying connected in spirit, heart, body, and mind to all of Creation. Further, land was understood as a provider. Several participants hunted, trapped, fished, and practiced other land-based knowledges that supported their wellness. Participants also acknowledged the importance of medicines from the land. Many participants used a variety of medicines such as tobacco, cedar, sweet grass, and sage to care for their spiritual, physical, emotional, and mental wellness.

Similarly, many described the importance of traditional teachings to their wellness. They emphasized the positive influence of Elders, Knowledge Keepers, and older family members in providing teachings. Participants also affirmed the importance of having Indigenous knowledge passed on through generations – past, present, and into the future. Some participants were especially concerned about passing on Indigenous language as a way to recover knowledge systems that have been lost as a result of colonialism. Community-engagement in Indigenous language learning was identified as a way to strengthen Indigenous individuals and communities.

Community and Personal Relationships

Participants emphasized the importance of having a supportive circle of friends and family because this support system was fundamental to their wellness. Having personal relationships was especially important for participants who suffered past traumas, and for those who lived alone or had advanced illness. In addition, several Indigenous women also discussed the significance of having spiritual, emotional, physical, and mental support from other women in the community. While having support was important, providing support to others in community also improved participants' wellness. Interestingly, some participants felt that their experiences during the pandemic had strengthened their families because they were challenged to overcome new and existing obstacles in the pandemic.

Socioeconomic Determinants of Health – Employment, Income, Food, Housing, and Education

Several participants were employed during the pandemic which supported their incomes and overall wellness. However, many others struggled with employment and had lower incomes as a result. Several participants used community-based programs and services to help them make ends meet when their incomes or government financial supports were not enough. For example, some accessed food banks and lived in social or subsidized housing. While some experiences were positive, several participants were still worried about whether they had enough money to pay their bills each month. Importantly, many participants mentioned how important Indigenous-led and Indigenous-focused community supports were to supplement their incomes and support wellness. These groups offered holistic care that was not always available in other health services and programs.

Participants who attended post-secondary school mentioned the benefits of the western education system. For example, attending school gave them valuable skills they could use in their communities, and it also provided social interaction and structure to their lives. However, as some mentioned, the western education system in many ways does not support, and in fact has actively harmed, Indigenous students.

Programs, Services, and Institutions

Participants listed a number of health-related programs, services, and institutions that supported their wellness prior to and during the pandemic including local hospitals, community-health centres, and walk-in clinics. However, few of these organizations offered Indigenous-focused programs and services, and even fewer health-related organizations in Katarokwi are Indigenous-led. Participants emphasized the importance of Indigenous-led and Indigenous-focused programs and services because they are more likely to be culturally appropriate and provide holistic care that may not be available elsewhere. These groups are also an important source of support for women and Two-Spirit individuals who do not feel safe in all healthcare spaces. Further, they allow for greater Indigenous autonomy, which is an important aspect of wellness (17). Unfortunately, some Indigenous-led and Indigenous-focused services were cancelled before the pandemic due to inadequate funding, which has deep implications for wellness.



Cultural and Personal Coping Behaviours

Participants engaged in many positive coping behaviours during the pandemic including cultural and spiritual practices such as smudging, meditation, and prayer, as well as arts-based activities including beading, leatherwork, and drumming. Taking up these practices helped many participants heal, connect with culture, find strength, and relate with community (despite isolation in the pandemic). Some participants were also able to sell their artwork, which supported them financially during the pandemic. Participants also felt they needed to keep busy with activities such as reading, knitting, and driving. Many used their time in the pandemic to learn new skills or practices. Others relied on media as a source of joy and distraction, as well as an important source of information to stay informed about the COVID-19 pandemic. However, while some benefited from staying up-to-date with COVID-19, others felt more stress from the influx of information about the pandemic that was constantly coming in. Some participants were also worried about misinformation about COVID-19.

Finally, several participants emphasized the importance of caring for their bodies, including eating well and moving their bodies regularly. For some, this meant being out on the land more often and eating healthy, traditional foods.

Personal Identities

Indigenous individuals embody complex and unique identities which support their wellness. This project highlights some of the ways in which Indigenous identity protects wellness, though it is by no means comprehensive. One way some participants felt supported was through use of their cultural names. Cultural names often showcase a person's personal gifts and responsibilities, thereby highlighting their positive qualities and grounding them in culture and community. In addition, following traditional cultural teachings helped form some participants' identities and enhanced wellness.

Participants' spirituality also contributed to their identities and wellness. Spirituality guided many participants through life, connected them with ancestors, and helped them through life's obstacles. Similarly, some participants commented on their gender and sexuality as two elements that supported their identities. Several participants described their gender roles in relation to community responsibilities and explained how these roles supported them. Others commented on how their sexualities strengthened them despite enduring discrimination for defying societal norms. Participants also demonstrated many personal traits and values that shaped their identities and influenced wellness. For example, participants showed hope, humility, optimism, humour, determination, problem-solving, responsibility, and wisdom. Overall, participants demonstrated considerable resilience which they fostered prior to the pandemic and while in the face of COVID-19.

Positive Wellness During COVID-19

While the impacts of COVID-19 on wellness were mostly negative, some participants reported positive outcomes related to wellness. Some felt that they had more time to reflect and immerse themselves in spiritual, emotional, and mental healing practices. Others felt they were able to prioritize relationships and strengthen bonds with those closest to them. Further, others experienced positive physical outcomes during the pandemic such as those who had improved wound healing, those who abstained from drugs and alcohol, or those who were able to spend time on the land more often during the pandemic.



Key Recommendations for Katarokwi

SOCIETAL AND PUBLIC POLICY RECOMMENDATIONS

- Eliminate racism, sexism, transphobia, homophobia and other forms of discrimination in health services that cause Indigenous peoples to experience social exclusion and negative health outcomes
- Establish anti-colonial approaches to care which privilege Indigenous peoples in leadership roles, thereby bolstering agency and Indigenous self-determination
- Commit to relational, community-based, and Indigenous-focused programs and services where clients are treated with respect and empathy and are provided effective, trauma-informed, holistic care
- Ensure all mainstream health care spaces are safe, inclusive, and culturally appropriate for Indigenous peoples, especially for women, girls, and 2SLGBTQ+ individuals who are at higher risk of violence
- Hire Traditional Healers, Knowledge Keepers, and Elders in all spaces where health care is provided to Indigenous peoples

HEALTH AND SOCIAL SERVICES RECOMMENDATIONS

- Implement an Indigenous-led, physical space for Indigenous peoples to gather to practice their cultures and protect individual and community wellness
- Ensure long-term and adequate funding for Indigenous-led and Indigenous-focused community programming that promotes safe, inclusive, and culturally appropriate preventative health care practices
- Increase funding for mental health and addictions services for all, to support arguably higher mental health and addictions issues throughout the course of the pandemic
- Increase capacity in mental health and addictions services to ensure that programs offer Indigenous-focused care that is trauma-informed
- Increase Indigenous-focused programs and services that support families, youth, and older adults
- Ensure equitable access to health supports by increasing Indigenous-focused programs and services in underserved rural and remote areas
- Explore strategies to improve virtual care experiences for those who have limited technological literacy, as well as for those who do not have reliable access to internet or adequate space to access care privately
- Explore strategies for social supports for Indigenous individuals and communities that would be feasible and safe during the pandemic's isolation measures

Key Recommendations for Katarokwi (contd.)

SOCIOECONOMIC-CENTERED RECOMMENDATIONS

- Improve access to affordable housing for Indigenous peoples living on- and off-reserve
- Improve existing government financial support programs (e.g. ODSP)
- Re-implement financial support for those who have lower incomes as a result of the pandemic (e.g. CERB)
- Implement a universal basic income to alleviate poverty and associated food insecurity





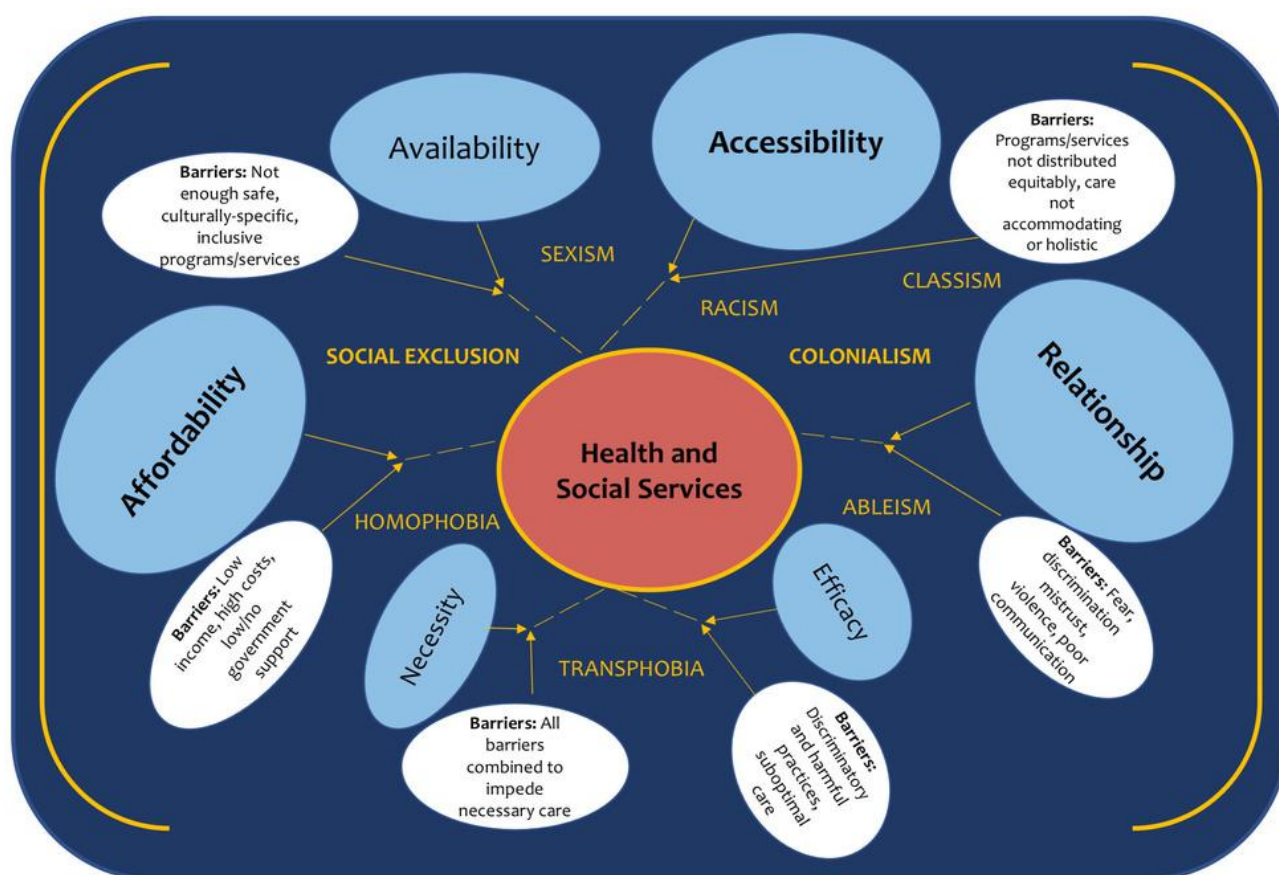
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FIGURES FOR FRAMEWORKS

Indigenous peoples living with chronic health issues during the COVID-19 era: KIRC-19 Project

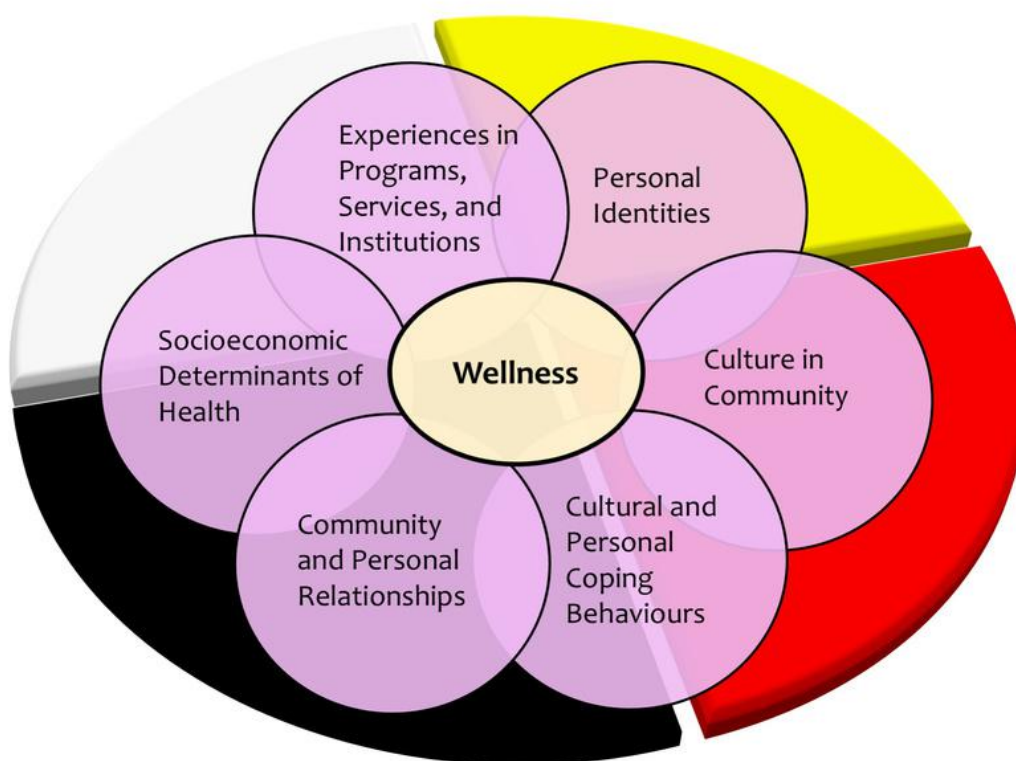
Figures for Frameworks

Figure 1: Barriers and facilitators to access to care for Indigenous peoples during COVID-19 in Katarokwi (Kingston and southeast ON)



Figures for Frameworks

Figure 2: Factors impacting Indigenous wellness during COVID-19 in Katarokwi (Kingston and southeast ON)



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FULL REPORT

Indigenous peoples living with chronic health issues during the COVID-19 era: KIRC-19 Project

Introduction

Due to historic and ongoing processes of colonialism, Indigenous peoples in Canada live with significant health inequities and face greater barriers to accessing culturally safe, adequate, and culturally appropriate care compared to other Canadians (1-3). Indigenous peoples in Kingston, Ontario (Katarokwi) are concerned that the COVID-19 pandemic has amplified these disparities, thereby worsening the state of wellness for Indigenous individuals and communities in the area. To explore these circumstances, strategize solutions, and build on existing strengths, academic researchers, service providers, and Indigenous community members partnered together to form the Katarokwi Indigenous Resilience during COVID-19 (KIRC-19) Project. The KIRC-19 Project involved two concurrent studies – 1) a qualitative constructivist theory study, involving interviews with Indigenous individuals living with chronic health issues about their experiences during the COVID-19 pandemic, and 2) a case study, involving an examination of three partner Indigenous-led/Indigenous-focussed organizations who provide services to Indigenous clients living with chronic health issues, to understand their experiences in adapting their operations and service delivery in the face of the COVID-19 pandemic's onset. This report contains key findings and recommendations from the qualitative constructivist grounded theory study. The case study results will be reported separately. We hope the results from this research can be used to improve wellness programs and services for Indigenous peoples who live with chronic health issues in this region.

Background and Significance

Indigenous peoples in Canada are disproportionately impacted by chronic physical and mental health issues including cancer, diabetes, hypertension, heart disease, COPD, depression and other mental health concerns, substance use disorders, and others (1-3). In the backdrop of colonization, Indigenous patients and communities face health and social inequities, as well as barriers to accessing meaningful and culturally safe care (1-3). The Truth and Reconciliation Commission of Canada (TRC) acknowledged these issues and also outlined seven health-specific Calls to Action (#18-24) to improve Indigenous peoples' wellness.

Despite government inaction, Indigenous Peoples have worked continuously to resist the impacts of colonialism and protect individual and community wellness.

However, since the report was released in 2015, Canada has made arguably minimal progress in responding to these recommendations (18). In addition, the health and social impacts of colonialism are arguably magnified when intersecting with current COVID-19-era challenges, including altered access patterns to health and social services, as well as the socioeconomic, psychosocial, and societal consequences of physical distancing and associated lockdown restrictions.

Despite government inaction, Indigenous peoples have worked continuously to resist the impacts of colonialism and protect individual and community wellness. This is certainly the case in Kingston, Ontario (Katarokwi) which is situated on the traditional lands of the Haudenosaunee and Anishinaabe peoples, and is home to individuals of diverse First Nations, Metis and Inuit identities and heritage. The majority of the Indigenous population in Katarokwi is made up of Ojibwe, Mohawk, Algonquin, Cree, Métis and a small proportion of Inuit.

Indigenous peoples and communities hold remarkable strength and resilience, derived in part from traditional culture as a powerful force for wellness, and from a traditional worldview of relatedness that values strong relational community connections (19). Though there are few Indigenous-led and Indigenous-focused organizations in Katarokwi, those that exist are active in cultural and health promotion activities aimed at supporting community members living with chronic health issues. Organizations include Kingston Community Health Centre and Napanee Health Centre, Street Health, the Indigenous Diabetes Health Circle, the Indigenous Patient Navigator Program of the Southeast Regional Cancer Program (Cancer Care Ontario), Tipi Moza, and Home-Based Housing.

In response to the concerns and objectives of Indigenous peoples in Katarokwi, academic researchers from Queen's University, Indigenous and mainstream service providers, and Indigenous community members have formed the Katarokwi Indigenous Resilience during COVID-19 (KIRC-19) Project. Reported here are the results of one component of KIRC-19 – namely, a study that examined experiences during the pandemic of Indigenous individuals living with chronic health issues. The goal of this component is to explore the circumstances that Indigenous peoples from Katarowki who have chronic health issues face during the COVID-19 pandemic, build on existing strengths, and explore solutions.

More specifically, this project seeks to identify:

- Possible points of intervention and areas of need for Indigenous individuals living with chronic conditions in the era of COVID-19. The goal in documenting these gaps via research evidence would be to help reorient approaches, and to mobilize resources and funding to address them.
- What is working well, and associated lessons to be learned from the strengths, successes and stories of resilience of Indigenous individuals in the Kingston area.

While focused on the Kingston area, the results of this research arguably hold generalizability to understanding Indigenous experiences in Canada more broadly. Additionally, the academic-community partnerships being built between Queen's University researchers and local Indigenous peoples for this project, can pave the way for longstanding collaboration and community engagement going forward – thus contributing to broader efforts of reconciliation.

Research Objectives

In this study, we seek to capture local experiences of Indigenous individuals in the greater Kingston area during the COVID-19 era. Specifically, our objectives and associated products are as follows:

1) To understand the experiences of Indigenous individuals living with chronic physical or mental health issues, vis-à-vis access to health and social services, in the era of COVID-19.

Product: A framework summarizing barriers and facilitators to service access.

2) To understand the impact on mental health and wellness of COVID-19 related stressors in Indigenous individuals already coping with chronic health issues.

Product: A framework summarizing factors impacting wellness in the context of COVID-19 era stressors, as well as protective factors that are sources of resilience and positive coping.

Community-based Research

In a community-based approach using academic-community partnerships, members from community organizations in Katarokwi worked together with academics from Queen's University on the research team. The project was also guided by an Indigenous Oversight Committee consisting of Oshkaabewisag (helpers/Knowledge Keepers), [11] who helped ensure that research was conducted in adherence with the principles of Ownership, Control, Access, and Possession (OCAP) in research with Indigenous peoples (5-7). The community partner organizations included:

- South East Regional Cancer Program (Cancer Care Ontario)
- Indigenous Cancer Care Unit (Ontario Health)
- Indigenous Diabetes Health Circle
- Indigenous Health Council
- Street Health Centre (Kingston Community Health Centres)
- KFL&A Public Health
- Addictions and Mental Health Services of KFL&A

Partnering community organizations and Oshkaabewisag were involved in co-constructing the project design, interview guides, recruiting participants, analyzing data, and defining dissemination strategies. Regular meetings were held between all members of the KIRC-19 team (i.e. community partners, Oshkaabewisag, and academic researchers) to ensure that a collaborative process emphasizing respect, relevance, reciprocity, responsibility, and relationship was followed (20, 21).

Study Methods

The KIRC-19 Project was approved by the Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB) at Queen's University.

For this component, we used a method of qualitative research called “constructivist grounded theory” for the study. “Grounded theory” is concerned with developing a theory regarding a phenomenon, based on data and the views and knowledge of research participants. In “constructivist” grounded theory, the researchers seek the standpoints of the participants, as well as the historical circumstances and social experiences that shape their opinions. A constructivist approach recognizes the existence of multiple interpretations of a situation according to societal context (22). A constructivist approach also affirms that knowledge is co-produced by all members in the research process (i.e. researchers and participants alike) (23). In this way, constructivism has similarities to Indigenous methodologies which are centred on knowledge produced in relationship (24).

We used a variety of recruitment strategies in the project, which were tailored based on discussion within the KIRC-19 team. For example, we invited eligible participants using digital fliers on social media sites such as Facebook and Twitter. Staff at community partner organizations identified eligible patients/clients and provided them with information about the study. Community partners also distributed information about the project widely in their greater Katarokwi networks. Participants were eligible to join the project if they self-identified as Indigenous, had a diagnosis of at least one chronic health issue (physical or mental), were able to converse in English, and were at least 18 years old.

A research associate conducted one-on-one interviews with Indigenous individuals over the phone using an interview guide developed in consultation with three community-partner agencies, three Oshkaabewisag, and all academic research partners.

Participants



One-on-one telephone interviews were conducted with 22 Indigenous adults living in Katarokwi who had at least one chronic health condition (physical or mental) from November 2020 until February 2021 (inclusive). The participants we spoke with came from diverse backgrounds, allowing for a wide range of perspectives to be heard and documented (see Appendix later in this document for characteristics).

Summary of Study Results

Factors Affecting Service Access: Facilitators and Barriers to Care

Participants identified a number of factors that either facilitated or impeded access to care in the Katarokwi area, both prior to and during the pandemic. In this report, barriers and facilitators have been grouped into six major categories including factors related to 1) availability, 2) affordability, 3) relationship, 4) accessibility, 5) efficacy, and 6) necessity. These have been visually summarized in Figure 1. Unfortunately, fewer facilitators of service access were identified compared to barriers to care that Indigenous participants face. In the discussion below, we examine factors based on whether they existed exclusively before the COVID-19 pandemic, whether they were pre-existing factors that were amplified during the pandemic, and whether they developed specifically during the pandemic. It is important to note that the majority of the facilitators that were identified were found to be present prior to the onset of the pandemic and were eliminated or limited as a result of the pandemic.

Availability

Facilitators of Service Access

Many participants were able to access care due to the availability of remote services (i.e. services provided over telephone or online conferencing platforms). Several in-person programs and services were cancelled or modified during the pandemic, and as a result, participants reported attending more remote programs and/or attending physically-distanced, in-person programming instead. For example, participants reported attending telephone appointments with their family doctors or videoconference counselling sessions on Zoom with organizations such as Lanark, Leeds and Grenville Addictions and Mental Health.

Making care available virtually has allowed many Indigenous peoples in Katarokwi to access the care they need during the pandemic. Interestingly, some participants preferred counselling and other services/programs through remote platforms rather than in-person. One woman commented, “The phone calls are really nice because I don’t have to leave my house. I can just have them from the comfort of my own home.” Some participants also received home-delivery from their service care providers, which made remote programs involving cooking, crafting, and ceremony possible and enjoyable.

Importantly, many participants relied on Indigenous-led and Indigenous-focused remote services that were available, including online sharing circles, workshops, Indigenous language classes, beading groups, and appointments with Elders offered through organizations such as Four Directions Indigenous Student Centre, Kingston Indigenous Language Nest, Métis Nation of Ontario, and Mohawks of the Bay of Quinte.

With that said, it is important to acknowledge that few Indigenous-led and Indigenous-focused programs and services are available in Katarokwi overall (in a pre-pandemic context and amidst the pandemic), and this was a major concern for participants (as discussed later in more detail).

Barriers that Existed before the COVID-19 Pandemic

One significant barrier that several participants mentioned was the lack of resources available where they lived. For example, a few rural-dwelling participants reported travelling long distances for health-related services. One participant required access to a wound care specialist, but due to the long distance they needed to travel for their appointments, they ultimately decided to cancel their care. Having fewer healthcare resources in rural compared to urban areas in Canada may impact whether a rural client receives care, especially when combined with complications such as inadequate transportation, unfavourable weather conditions, poor mobility, and having a high-risk health condition (25).

Pre-existing Barriers that were Amplified during the Pandemic

Long wait times for appointments and procedures may be a significant barrier to adequate care. Long appointment wait times were an issue for many prior to the pandemic, such as for various specialist services in Ontario (26). Unfortunately, participants felt that wait times for their healthcare appointments were even longer than usual during the pandemic. Due to extended wait times, some participants were forced to delay treatments which impacted their overall health. One man commented on his experiences with wait times, noting:

“Lack of access to [...] non-urgent healthcare during the pandemic meant that I just... had to put [treatment] down the road while I’ve been... dealing with the effects of long-term celiac [...] I think what I was waiting for the longest was an endoscopy for confirmation of my diagnosis.”

Similarly, one woman noted, “I had cancer treatment, and I was not able to have the necessary follow-up exams, as they were cut-off due to COVID. And just recently, I’ve had the last exam, which was probably 4 months – 4 or 5 months – overdue.”

Participants felt that delayed care was also in-part due to organizations’ limited resources, time, and capacity to provide care. Unfortunately, this led some participants to feel that they and their family members were being “put on a back-burner” during the pandemic, and that their health was ultimately suffering as a result.

In terms of Indigenous-led and Indigenous-focused programs and services, many participants identified the absence of these crucial forms of care in Katarokwi overall. Some participants reported that, before the pandemic, a few of the Indigenous-led and Indigenous-focused programs and services that they relied on were cancelled. For example, as one participant reported, a Three Sister’s Group that was offered through

Interval House in Kingston was cancelled before the pandemic started. In addition, another Indigenous-led resource, the Katarokwi Native Friendship Centre, also closed prior to the pandemic due to inadequate long-term funding. Unfortunately, cancelling Indigenous-led and focused programs and services may have significant implications to Indigenous wellbeing and identity (as discussed later in this report) (27).

Related to this, one participant also reported the lack of healthcare supports available for Two-Spirit Indigenous individuals in Katarokwi. This was an issue prior to the pandemic and has been arguably made worse in the context of the pandemic, as one Two-Spirit person noted:

“I have never, ever seen a group for Two-Spirit people in this community... Like, I’ve never walked into a doctor’s office and ever seen any support for Two-Spirit people up on the wall... It’s almost like there’s no place for us.”

One woman expressed the difficulty of finding Indigenous representation and/or cultural safety in the services they access in Katarokwi, noting, “It’s hard to find a doctor as well, that understands ADHD, [let] alone find a doctor that also understands the implications of being Indigenous.” Indigenous peoples are underrepresented in the workforce of healthcare systems in Canada; adequate representation of Indigenous peoples in the services they access is vitally important to ensure they receive effective and culturally safe care (28).

Unfortunately, the pandemic caused many Indigenous-led and Indigenous-focused programs and services to temporarily or permanently cease. For example, the following programs were impacted by the pandemic: Indigenous language programs offered by Kingston Indigenous Languages Nest (KILN), full moon and sweat lodge ceremonies offered through Four Directions Indigenous Student Centre (Four Directions), and drumming and



other events offered through Métis Nation of Ontario (MNO). Though some in-person offerings were transferred to online platforms (e.g. language groups online with KILN), not all offerings were able to translate to remote settings (e.g. sweat lodge or other ceremonies). Further, not all participants had access to online programming due to financial constraints or technological barriers (to be reviewed in further detail later in this report).

Barriers that Developed during the COVID-19 Pandemic

When in-person programs and services were cancelled, some participants thought that care was no longer available to them at all. For example, one man reported that he did not have access to his family doctor for several months at the onset of the pandemic. Other participants stated that regular check-ups and certain treatments were cancelled. Further, some participants reported that their appointment times had been reduced, and they were therefore receiving less care overall. For example, one woman reported that their physiotherapy appointments were shortened in order to accommodate the cleaning protocols necessary to reduce the risk for COVID-19 transmission among clients. She noted:

“They said don’t arrive until your appointment time. But then when I arrived at my appointment time, and I get in there, it interferes with my 30-minute appointment that I have for treatment.”

Affordability

Facilitators of Service Access

Many participants highlighted the importance of affordability of the programs and services they access. For example, one participant noted, “It’s what stuff is provided out there for you that you can access that doesn’t have a price on it for your wellbeing.”

Considering affordability, remote services may reduce some of the costs associated with care, such as the cost of transportation. For example, one woman commented, “It’s been beneficial because they were able to have... a phone call for an appointment instead of having to find a ride or spend money for gas to come into Kingston.”

Barriers that Existed before the COVID-19 Pandemic


While there were some instances where the cost of care was reduced, many participants reported financial barriers associated with their care. For example, one woman reported the higher cost of food required for their lactose and gluten-free, low fibre therapeutic diet (prior to and during the pandemic). Similarly, another participant reported the high cost of treating their chronic back pain with a periodic lidocaine infusion, noting, “I won’t feel the results today, but by tomorrow I will. So, I only get 6 days-worth out of that, but it’s worth the \$30.00.” Further, simply attending services, programs, and appointments is difficult if a person cannot afford adequate transportation, which was the case for some of the participants. Instead, these participants chose resources that were in close proximity to their homes and missed out on other community supports that existed (but were too far away to access). One woman put this dilemma into perspective, noting, “So, the reality is that [...] a lot of our community members can’t afford transportation. So [...] in Kingston, are you going to get on a bus? No. Do you have the funding to get on a bus? No.”

Importantly, many participants relied on Indigenous-led and Indigenous-focused remote services that were available, including online sharing circles, workshops, Indigenous language classes, beading groups, and appointments with Elders offered through organizations such as Four Directions Indigenous Student Centre, Kingston Indigenous Language Nest, Métis Nation of Ontario, and Mohawks of the Bay of Quinte.

Pre-existing Barriers that were Amplified during the Pandemic and Barriers that Developed during the COVID-19 Pandemic

Some participants mentioned that their income was reduced during the pandemic due to job loss or hour reductions at work. Several participants whose incomes were lower during the pandemic were worried about the cost of food, transportation, childcare, and other costs of living. Inability to afford transportation, as discussed earlier, was reported as a barrier to accessing care.

“It’s been beneficial because they were able to have... a phone call for an appointment instead of having to find a ride or spend money for gas to come into Kingston.”



However, lower income had a greater negative impact on participants' overall wellness (e.g. higher levels of stress, suboptimal diets, or amplified exhaustion) than it did on access to health-related programs and services. In fact, low income was unfortunately a facilitator of program and service use, as participants often cited using programs and services for which they were eligible in order to make ends meet (e.g. food banks and social housing). The impacts of low income on Indigenous wellness are discussed in more detail later in this report.

Relationship: “It comes down to trust”

Facilitators of Service Access

Safety, trust, and respect were significant relational facilitators of service use among participants. Safety and trust were both values that were especially emphasized by women and Two-Spirit participants, as some of these participants often felt unsafe in healthcare settings. For example, a Two-Spirit individual noted:

“If I have a personal crisis, who am I going to call? [...] I'll call [the Indigenous] crisis line first because that's where I'm going to get my answers. That's where I'm going to get my help. That's where I feel safe. That's where I have my trust.”

Participants reported using the resources from service providers whom they respected and who showed them respect in return. A significant indicator of respect that participants mentioned was non-judgemental care. Participants also consistently used community resources from service providers and organizations when they felt genuinely supported by them.

For example, a participant who utilized resources from Mohawks of the Bay of Quinte reported the regular support they received from the organization, noting, “There's people who are actually there for you to pour your problems on their shoulders. And they don't mind because they're very strong people that will and are willing to listen...”

When describing their interactions with service care providers whom they trusted, respected, and with whom they felt safe, participants often described providers who used community and person-centered approaches in their care. For example, one participant described a moment where on-reserve home supports offered them free food delivery and simply ‘checked-in’ with them. Another participant highlighted the sense of community present in the programs and services they accessed, noting,

“The United Way, the Salvation Army, everybody – it’s community. Everybody helps everybody in that social area.”

There were also several participants who felt most welcomed and supported by Indigenous-led organizations or in organizations with Indigenous-focused programs and services. A Two-Spirit individual noted,

“Every Indigenous leader or event that’s put on in this town involves Two-Spirit people. Yes, the powwows, everything. The Indigenous and Two-Spirit are OK in this town [...] They don’t judge you.”

Barriers that Existed before the COVID-19 Pandemic

While relationship was important to many, some participants mentioned that their own connections to community (both in professional and personal contexts) were barriers to receiving care. For example, one participant explained that connection to community members in their professional role deterred them from attending community-based events/programs.

She noted,

“...a lot of the clients that I worked with also went to the Indigenous ceremonies and had taken programs [...] so it just didn’t feel, like I didn’t want to make them feel uncomfortable...”

Pre-existing barriers that were amplified during the pandemic

It is well known that Indigenous peoples experience systemic racism in healthcare (5). For example, healthcare in Indigenous communities in Canada has been consistently underfunded, and preventative action by mainstream governments was arguably lacking to strengthen Indigenous communities to protect them against COVID-19 (29).

This is despite the fact that Indigenous peoples have historically experienced higher infection rates, greater severity of symptoms, and more cases of death during other pandemics in Canada (e.g. small pox, tuberculosis, H1N1) (30). In alignment with these findings, KIRC-19 participants reported experiences of racism, homophobia, and other forms of discrimination (both pre-pandemic and during the pandemic), which impacted the quality of care they received or whether they received care at all.

One participant summarized their views of how Indigenous peoples are treated in healthcare, noting,

“You know, I still get the feeling that we’re pushed to the back of the bus as Indigenous [people].”

Public health recommendations for the prevention of COVID-19 transmission involve actions that not all Indigenous people are able to take due to disparities in the social determinants of health. For example, physical-distancing and regular handwashing may not be possible for Indigenous peoples who live in overcrowded housing or do not have adequate access to water (31). Fortunately, many Indigenous Nations have successfully advocated for more government funding to support their communities, and have also taken public health measures into their own hands by controlling access to their territories and modifying ceremonies and social gatherings (32). These and other measures resulted in Indigenous peoples' experiencing lower COVID-19 rates during the first wave compared to the wider Canadian population (29).

Unsurprisingly, in the context of systemic racism in healthcare and other colonial institutions, several KIRC-19 participants expressed significant mistrust in government, healthcare, food systems, employers, and society overall – all of which impacted which programs and services they chose to use and which ones they avoided. For example, one woman voiced their mistrust of her employer, noting,

“Yeah, I don’t trust anything that’s...put in place through our employer [...] I just didn’t have any faith that [my information] would be... not held against me...”

Another participant expressed their concern with the people around them who were not following safety recommendations related to COVID-19, as well as with people who did not believe the virus existed. Ultimately, several participants expressed significant mistrust in institutions connected to their wellness, which fundamentally impacted their experience of care and/or whether they received care at all.

Another barrier to care that participants mentioned was inadequate communication with their service providers when trying to access care. Some participants mentioned that they had a harder time reaching their family doctors or specialists when trying to schedule appointments. Some participants also expressed feeling “rushed” on the phone or like a second priority when speaking with their service-providers. On the other hand, some participants reported not wanting to reach out to service providers or community supports for help because they did not want burden other people. Unfortunately, due to physical-distancing recommendations, some participants were also reluctant to reach out to friends or family for help when they needed it. In fact, some participants commented on how communication with their loved ones had diminished in general during the pandemic.

One man noted, “...My daughter used to drop the grandkids off all the time, spend the weekends with me [...] And ah, once that happened – this pandemic started up [...] she stopped bringing them.”

Barriers that Developed during the COVID-19 Pandemic

Some participants perceived COVID-19 screening processes at healthcare sites as a barrier to care, and therefore misreported their symptoms in order to ensure they received care. These actions highlight feelings of mistrust in the healthcare system, as well as Indigenous participants' perception that they would not receive care if they reported their symptoms. This finding reinforces the need for communication between service care providers and Indigenous clients. It also confirms the need to create healthcare environments that make Indigenous peoples feel safe and respected, and that they can trust their care providers.

Some participants also expressed privacy concerns that they had with remote programs and services. For example, when discussing telephone appointments with their doctor, one woman noted, "What I don't like, though, is that, because the phone calls, I have to be, like, somewhere private to take them. Whereas if they were appointments, I would have... to go to the office and have the appointment." Having a private area to use services is not possible for all individuals, such as those who live with multiple roommates or extended family. This may be a particular issue for Indigenous peoples who are more likely to live in overcrowded housing compared to other Canadians (6-8).

Another participant reported privacy concerns with online programs and services. One woman mentioned, "...for this support group... they got to make sure that there's no men in the room, other people listening... so the camera has to be on the whole time, and I just feel like people are looking at me..." Although some groups require that participants' cameras and audio be left on during service-use, not all programs require this. As a result, there is an increased privacy risk when using these forms of online services.

Fear of contracting the virus was also identified as a barrier to care. For example, some participants mentioned that they had access to some in-person healthcare services during the pandemic. However, due to heightened risk and fear of contracting COVID-19, some participants reported avoiding these services regardless of their availability. For example, one man reported, "I probably would have seen somebody already for this weird pain in my side [...] I don't want to do unnecessary contact with people, anyone, or whatever."



Accessibility

Facilitators of Service Access

Many participants appreciated programs and services that had greater accessibility. For example, participants reported the benefits of having their medications delivered and/or prepared in weekly blister-packs. During the pandemic, having medication delivered reduced the frequency at which a high-risk participant needed to leave their home for necessities, thereby reducing their risk of contracting COVID-19. Similarly, some participants used grocery delivery services to minimize their exposure risk as well. With that said, other participants also perceived grocery and medication delivery costs as expensive; these services are only available to those who can afford them.

Participants also commented on the benefits of select service providers as “one-stop-shops”, such as the Kingston Community Health Centre. One woman noted, “...the health centre is great, where they have extra support, you know? Like, they have [occupational therapy]. They have a dietitian. They have the pharmacist. They have a diabetic nurse.” Having integrated services (or a more holistic approach to care) benefits clients because it promotes comprehensive and efficient care, and enhances communication between service providers (33). Accessing a one-stop-shop may also improve patients’ subjective health outcomes such as anxiety (34).

As mentioned earlier, participants also reported using services that were located in close proximity to where they lived. For example, one man noted, “I live in Kingston, so I was lucky that way. I could [access] urgent things. Emergency – I could go right to the hospital.” However, proximity of services was less of an issue for some participants during the pandemic with the availability of remote offerings.

Barriers that Existed before the COVID-19 Pandemic

Several participants who had physical disabilities felt that care was inaccessible at times. For example, suffering with chronic pain limited where and how often several participants accessed health-related programs and services. One participant who had multiple health conditions, including chronic pain, had difficulty leaving their home to access care. A few participants were unable to attend community land-based events due to issues with mobility and pain.

Participants who had food sensitivities/allergies were also unable to access all food-related community supports. For example, one woman discussed food supports in the Katarokwi area such as those available through local churches. However, due to dietary restrictions and requirements, she was unable to utilize the available services because her needs were not accommodated. She commented, “Well, because of my dietary restrictions, I don’t go to get food at any churches or anything like that. I can’t eat most of it anyways, so why take what somebody else can have?”

Pre-existing Barriers that were Amplified during the Pandemic

Some participants expressed feeling confused, overwhelmed, and exhausted by certain aspects of their care. For example, a few participants felt burnt out from managing their own care or their loved ones' care. In fact, a few participants described feel exhausted to the point of wanting to stop care altogether. For example, one man commented, "So, I was just having a hard time [...] Going in for this appointment, that appointment. I just was getting tired..." Burnout or significant fatigue may be a major barrier to accessing life-saving care for some patients/clients (35).

Similarly, several participants were confused about public health recommendations in the pandemic and unsure of how to keep themselves safe. One man commented, "[I'm] confused. Like, they're saying they're working on vaccines. That and confused about the different zones: green zone, yellow, orange, red." This confusion contributed to several participants' feelings of exhausting and being overwhelmed.

"So, I was just having a hard time [...] Going in for this appointment, that appointment. I just was getting tired..."

Barriers that Developed during the COVID-19 Pandemic

Some participants have been unable to join remote programs due to limited access to technology and/or limited technological literacy. For example, for some participants, the cost of having and using technology was a barrier (e.g. high cost of device(s) and internet). Other participants reported technological issues as a barrier to service access (e.g. inconsistent and unstable internet access depending on geographical location). Other participants reported that they did not use technology because they did not know how to. One man noted, "When my wife passed away... she was the one that did all the computer stuff. I know how to answer a phone and send messages and talk. I don't have anything." In these cases, online services are not an option.

Some programs and services were also being offered in-person following physical distancing guidelines. However, participants highlighted barriers to these alternative programs as well. For example, one woman noted that some outdoor programs and events are not accessible because they are not accommodating for people with physical disabilities. In-person gatherings were also not possible during provincial "Stay At Home" orders.

"When my wife passed away... she was the one that did all the computer stuff. I know how to answer a phone and send messages and talk. I don't have anything..."

Efficacy

Facilitators of Service Access

Participants acknowledged programs and services where effective care was provided. For example, some participants expressed confidence in their family doctors and the care they received. Effective care seemed to be strongly connected to effective service provider communication. In particular, participants appreciated receiving updates from their care providers about COVID-19 with instructions on how to stay safe during the pandemic. Regular phone calls from their service providers were also emphasized as important to participants' wellness. Ultimately, many participants wanted connection and wanted to be heard while receiving care. One Two-Spirit person noted, "Ask them, simply, 'What are your needs? What needs aren't being met in your community? Are your needs being met?' [...] And then you'll hear their needs because they'll tell you."



Pre-existing barriers that were amplified during the Pandemic

Some participants described difficult experiences with healthcare that had been intensified as a result of the pandemic. For example, one woman described the ineffective and frustrating care they and their dependent received during the pandemic:

"...We've been on the wait list for special services for diagnostics since he was 18 months old. And that would have happened during the pandemic and it is done by the phone. So we don't...we still don't have a diagnosis. And we still don't have...any consistent services. Like, they did an OT appointment by phone with a 4-year-old. Like, that's not going to help, right?"

Barriers that Developed during the COVID-19 Pandemic

Some participants who transitioned to virtual services described them as less effective compared to in-person care. For example, one man discussed his experience with counselling over the phone, noting, “It’s not the same [...] In person you’re face to face... you’re more comfortable talking.” Participants also worried that their care providers were missing important information about their health when using virtual services such as telephone visits. One woman commented:

“...I was taught you looked at the whole picture. You can’t even look at the whole picture when talking to somebody on the phone [...] You look at somebody’s gait because they might forget to tell you that, ‘Oh, I have a big callus on the outside of my foot, so I don’t walk right.’”

Many participants acknowledged that it was nice to have virtual services as an option during the pandemic, but preferred in-person programs and services. In-person community programming also offered participants holistic care which may not be possible through remote services alone. For example, almost all participants mentioned the relational benefits of attending community programs in-person and felt they were missing these connections online. One woman noted, “Cooking classes and stuff like that, it’s just – it sucks not being able to be around people, you know what I mean? Like, not being able to talk and actually work together.” Participants felt that remote services, while a better alternative to cancelled programming, did not provide the same level of support as in-person programs and services.





Necessity

Facilitators of Service Access

Some participants accessed care during the pandemic because it was medically required, and deferring treatment was not an option. Other participants were required to receive care because it was mandated as a result of incarceration. For example, one man described having access to weekly Elder-support, which was organized through corrections and their Indigenous support worker. He pointed out an unjust and inequitable reality, noting,

“Where if I wasn’t – if I wasn’t in the correctional system, I probably wouldn’t have these supports.”

It is important to note that not all Indigenous peoples who experience incarceration in Canada are offered these Indigenous-focused rehabilitation supports (9, 10).

Indigenous Wellness in Katarokwi

Indigenous peoples in Canada have experienced many impacts of settler colonialism which have affected their lifeways, identities, and overall wellness. In the context of colonialism, Indigenous peoples have endured forced removal from their traditional territories; laws and policies that stripped them of their rights; racism and discrimination; as well as education, social, and health-related institutions which have been operationalized to assimilate and erase Indigenous Nations (36). As a result of historical (and ongoing) colonial oppression, Indigenous peoples in Canada face inequities in housing, education, employment, income, and food security, all of which impact their wellness and have resulted in higher rates of morbidity and mortality compared to Canadian counterparts (37).

Indigenous peoples resisted and endured these health and socio-economic inequities prior to the COVID-19 pandemic, and continue to do so while facing new and amplified stressors during the pandemic. Speaking with participants in the KIRC-19 project, many described the background of colonial violence that impacted their lives prior to and during the pandemic. For example, participants shared stories of traumatic experiences in the residential school system and in foster care. Several participants described their negative experiences living under the Indian Act in a colonial reserve system. On the other hand, many participants had also been rejected by the Indian Act due to colonial measurements of blood quantum, which reduced their access to federal health-related supports. Ultimately, it was clear that participants entered the pandemic dealing with historical health inequities and barriers to their wellness already in place.

With this in mind, the following section reviews the state of wellbeing among participants during the COVID-19 pandemic. For the purposes of this report, we consider wellbeing to be the interconnection and balance of spiritual, emotional, physical, and mental health, existing within diverse cultural, social, and cosmological realities, and in relationship with a strong sense of identity (11-13).



Poor Wellness During COVID-19

Participants described the impacts of COVID-19 on their overall spiritual, emotional, physical, and mental wellness. In terms of participants' spiritual health, many expressed that they were disconnected from their spirits or the spirit of others and their surroundings. Several participants reported feeling spiritually isolated and broken, which contributed to feelings of sadness and loneliness. One participant even expressed losing their sense of purpose in life during the pandemic as a result of spiritual and social disconnect. Further, another participant discussed how distancing from others fostered feelings of fear and mistrust of others.

Participants reported experiencing a range of emotions during the pandemic. Most significantly, almost all participants felt heightened anxiety and/or depression. Participants' distress was influenced by a multitude of factors, such as having amplified financial constraints, as well as feeling hopeless and vulnerable during a global crisis and being increasingly concerned about family and friends' health. Some participants reported new anxiety and depression, while others who experienced anxiety and depression prior to the pandemic felt that their symptoms had significantly worsened throughout the pandemic.

Participants also reported feeling frustration, anger, and fluctuating moods during the pandemic. Some participants expressed feeling frustrated over lockdown restrictions (e.g. not being able to see family members), and/or over other people not following public health guidelines during the pandemic. Participants were also angry with their working conditions, with some concurrently feeling exhausted from higher workloads during the pandemic. Participants also reported feeling frustrated about the delay of COVID-19 vaccinations, especially those who belonged to higher-risk groups (e.g. essential workers, those with highest-risk chronic health conditions). Several participants described their emotional experience during the pandemic as an accelerated roller coaster ride going “all over the map.”



Some participants also felt guilty during the pandemic because they had positive supports in their lives such as adequate or high incomes, and/or family and friends who supported them. One woman noted,

“You almost feel guilty... as well, for being so happy and living such a good life if somebody is having such a terrible time.”

On the other hand, some participants who received help from family and families also felt guilty because they felt like they were burdening their loved ones. Further, some participants who supported older family members or friends also felt guilty because they worried about exposing them to COVID-19 with in-person contact. While in these complicated situations, it was clear that many participants felt deep empathy for their relations who were in need during the pandemic.

While some participants openly expressed their feelings, others suppressed their emotions. For example, one woman described holding back emotions, noting, **“I can’t really say what...makes me feel good. Just, absolutely not thinking about anything, because then I’m... I’m just not feeling.”** Suppressing emotion can be a way for people to survive distressing experiences, but it can also have long-term consequences to wellness (38, 39).

Participants’ physical health was also negatively impacted as a result of the pandemic. Notably, many participants’ pre-existing chronic health conditions worsened during the pandemic as a result of factors such as delayed or cancelled health appointments, procedures, therapies, and tests. For example, some participants reported sub-optimal blood sugar management, increased pain, or impaired healing. However, with this in mind, some participants voluntarily cancelled or delayed health appointments due to fear of contracting the virus. Participants who had higher-risk health conditions, such as immunosuppression, are especially vulnerable to the physical health impacts of COVID-19 and had to weigh the risks before accessing care.





Participants also reported having worse sleep, higher levels of fatigue, altered eating habits (e.g. not eating enough, or eating more than they thought they should), reduced physical activity, and worse hygiene during the pandemic. As a result of changes to their wellness, some participants also reported higher substance use (e.g. alcohol, opioids, stimulants, and others), as well as incidences of self-harm and attempted or completed suicide (for themselves, and/or friends and family members).

Participants experienced many changes to their mental wellness during the pandemic, as well. One notable outcome was the fear that overwhelmed many participants. Several participants expressed their 'worst-case scenarios' that seemed to invade their thoughts while dealing with the pandemic. One woman questioned,

“Some of the anxiety [involves] fearing what’s next – the unknown. Is it going to get worse? Is it going to affect someone in my family? When will this ever end?”

Several participants felt that not knowing why the virus was impacting their lives, or how it would affect the future, deeply impacted their wellness. Further, many participants feared the invisibility of the virus, afraid of what may be all around them without their knowing. These thought processes further contributed to participants' anxiety and depression, as well as their fear of others and isolation from society.



Similarly, several participants were confused by messaging about the virus. They were unsure about vaccine safety and roll-out timelines, provincial lockdown guidelines, and where to access reliable information. Constantly wading through new information about the pandemic, as well as their spiritual, emotional, and physical responses to the pandemic, left many participants feeling mentally exhausted. In addition, many participants also simultaneously dealt with the mental work of healing from traumatic events from the past; being physically and socially isolated has exacerbated negative mental and emotional symptoms for many during the pandemic (40-42).

Some participants also emphasized that their spiritual, emotional, physical, and mental health were interconnected; if one aspect is out of balance, then the others will be impacted as well. Some participants' sense of identity was also impacted by their state of wellness. After being disconnected from the spiritual, isolated from others, overwhelmed with negative emotion, damaged physically, and exhausted mentally, several participants voiced that they did not feel like their full selves.

Factors that Negatively Impact Indigenous Wellness

It is clear that participants experienced overwhelming impacts to their wellness during COVID-19. The following section reviews the factors that negatively impacted participants' wellness, including those that existed prior to the pandemic and those that developed as a result of the pandemic. These factors are discussed within the following categories, which are also visually represented in Figure 2: 1) culture in community, 2) community and personal relationships, 3) socioeconomic determinants of health 4) programs, services, and institutions, and 5) cultural and personal coping behaviours. These categories are overlapping and interconnected but have been defined for the purposes of discussion within this report.



1) Culture in Community

Culture and community are inextricably intertwined and contribute to many Indigenous peoples' identities and wellness. Unfortunately, many cultural and community-based events and programs were cancelled during the COVID-19 pandemic. Events and ceremonies such as powwows, sweat lodge ceremonies, language courses, land activities, and cooking groups were all permanently cancelled or postponed during the pandemic. Cultural events provide opportunities for knowledge transfer among community members, and cancelling these events may have negative consequences for Indigenous peoples' wellness and identity (43). Community events were also a source of Indigenous medicines for some participants, and therefore some struggled to access medicines during the pandemic without their usual supports in place.

While select programs and events were able to run remotely or in-person with physical-distancing protocols during the pandemic, others were not - such as community fasting or sweat lodge ceremonies. Ultimately, cultural disconnection in community deeply impacted many participants, with one woman noting, "I think being part of the community is what makes you Indigenous, right? Like, heritage of course too, but it's that connection [...] It's really difficult to connect with your whole self when you're not connected to your community." Similarly, another woman commented,

"As a culture, we come together [...] With the pandemic, it's separated us all... We've lost that connective power."

2) Community and Personal Relationships

Just as participants were affected by cancelled community events, they were also spiritually, emotionally, physically, and mentally impacted by being separated from their families and friends in smaller gatherings. However, despite missing their loved ones, participants also cared deeply about their friends' and families' wellbeing and were motivated to prevent them from contracting COVID-19. As a result, many participants reported connecting with their relations remotely via telephone or online videoconferencing. While this was an option for some, participants also felt that remote connection did not fully replace time with their loved ones in-person. One woman noted, "The personal stuff, face-to-face, the hugs, the family time, the grandkids-time, the sister time, the brothers time, the mother time, the father time [...] They've been separated from that and some need that." Many participants viewed themselves as deeply relational and interconnected, and being separated from their loved ones impacted them deeply.

Participants were especially concerned for the wellbeing of Elders and older family and community members, which in turn elevated their own feelings of anxiety. Due to physical distancing recommendations, several participants felt that they could not provide the same support to their older loved ones that they once had prior to the pandemic. Simultaneously, participants emphasized their responsibility to support Elders and family members during the pandemic, due to their heightened vulnerability to the virus. These participants were placed in difficult situations where they had to provide in-person supports while physically-distancing whenever possible. Balancing these conflicting responsibilities contributed to amplified anxiety for these participants.

Some participants had family and friends who passed away during the pandemic. A few participants described how end-of-life processes were disrupted by the pandemic, which negatively impacted participants' abilities to grieve, cope with their losses, and/or acknowledge an important transition. One woman noted,

"...my grandfather [...] had brain cancer and he was blind. So, we went up to see him before we went into lockdown and he ended up passing away while we were in lockdown... We didn't get to say goodbye."

Participants also described social conflict which arose due to conditions of the pandemic. Namely, having multiple roommates or many family members in one home resulted in more conflict, because household members felt constrained and overwhelmed by lockdown restrictions. One woman noted, "One roommate...has bad anxiety, but the kind where it's definitely implemented on everyone else. So, I think when you're stuck in a house with someone, and you aren't able to... leave and go somewhere else..."

3) Socioeconomic Determinants of Health

i) Employment

Many participants lost their jobs (temporarily or permanently), closed their businesses, had their working hours reduced, and/or were unable to find a job during the COVID-19 pandemic. While many participants experienced varying levels of job loss, others reported increased demands at work due to the pandemic. For example, a few participants had healthcare-related positions, and they felt frustrated and overwhelmed by their increased workloads associated with the pandemic. One woman noted, “There was stress of dealing with the long wait-lists and trying to accommodate the backlog of patients.” Another woman also explained that “...trying to work and make referrals to other service providers has become more difficult because a lot of them weren’t (or still aren’t) doing, like, face-to-face or they’re very limited...” Several participants were also worried about contracting the virus at work, and one reported leaving their essential service job due to fear and anxiety related to COVID-19. Some participants also described their experiences working from home throughout the pandemic, which was a physical-distancing measure that was implemented by their employers. Participants reported several issues with working from home including a struggle to remain productive and stay focused.

Other participants described difficulties managing job demands with home responsibilities, including providing care for dependents who were home due to school closures in the pandemic. One woman also felt that issues at work were more difficult to resolve in remote settings, noting, “So, when something bad happens, for example, at work, it’s very difficult to deal with the situation directly because everything is distanced. So, you don’t know how bad it is...”

Further, for one participant, the pandemic highlighted inadequacies and fragmentation in their employee health insurance. They described the difficulty obtaining mental health supports covered by their workplace, noting, “You have to call this number where they then will decide if you get counselling. And then they will put you in touch with someone. It could take months. It’s ridiculous.” Participants who experience worse mental health during the pandemic need to be supported by the healthcare system and by their employers who can make accessing care easier or more difficult.

ii) Low income (Pre-existing and Pandemic specific)

Several participants reported living on low income prior to the onset of the pandemic. For example, one woman explained,

“...I’m only on disability. I get \$1220 every month and, so, I’m left with \$100... maybe \$110 left after I pay all my bills...”

During the pandemic, several participants who had low incomes felt that they needed to be even more careful with their money. This concern may have been related to financial uncertainties associated with provincial lockdowns, changes in government financial supports (e.g. ambiguity around Canada Emergency Response Benefit (CERB) payments), general mistrust of government, and/or an overall heightened anxiety among participants during the pandemic.

Participants who received government financial supports such as the Ontario Disability Support Program (ODSP) stated that these were inadequate to support them prior to and during the pandemic. People who receive ODSP have elsewhere reported that ODSP does not cover the cost of living (15). Further, receiving ODSP also disqualified people from receiving the \$2000 monthly CERB payment, which many other Canadians received from March – September 2020 (14, 15). Participants also reported that Ontario Works did not fully support their needs, as their health-related claims were often denied. One woman noted, “I don’t have no partial [dentures], because I can’t afford to get it. I applied for it, but it wasn’t approved or something. So, now I don’t smile like I used to, you know?”

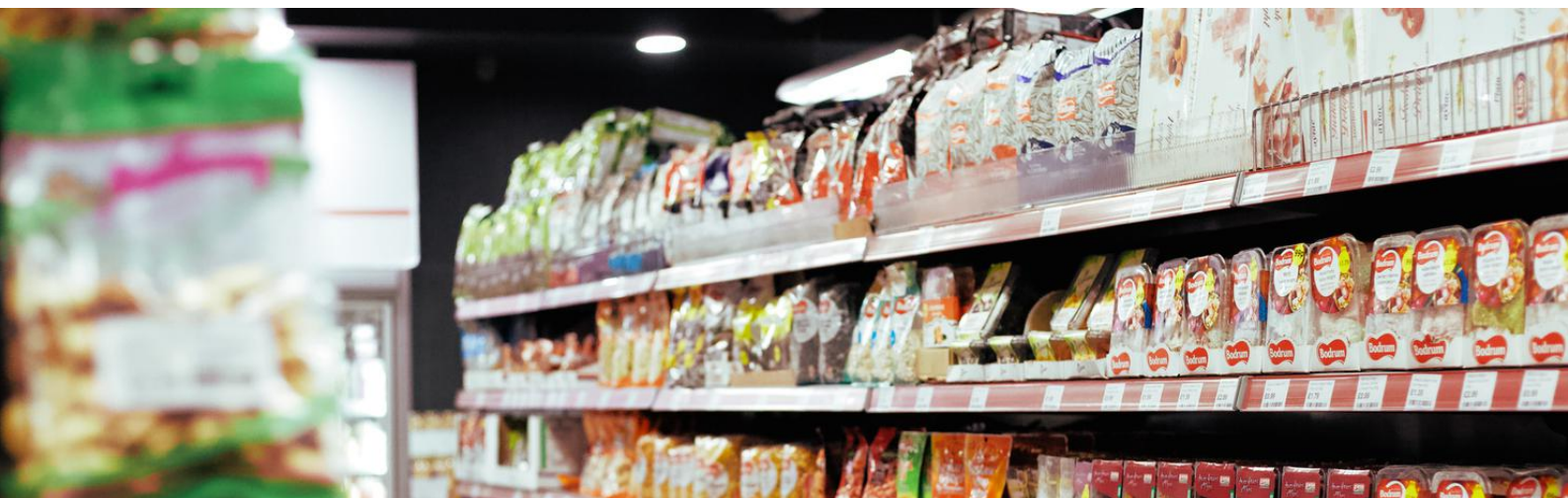
Several participants reported relying on community and extended relationships to make ends meet. For example, some women depended on other women in the community for childcare, and others supported community members by running errands, providing people with a place to stay, or offering financial support. In many of these cases, participants were unable to physically-distance from community relationships, thereby increasing the risk of spreading or contracting COVID-19. Isolating from community per public health recommendations is only feasible when community members can afford to isolate themselves.

iii) Food Insecurity

Several participants were especially worried about the cost of food during the pandemic. One woman commented,

“When the pandemic came, I was very, very frightened [...] I thought that we were going to starve.”

Participants reported accessing food banks or other community food supports both prior to and during the pandemic. However, they also noted that food supports were less accessible during the pandemic due to reduced hours or limited city transportation. These barriers are combined with those that existed prior to the pandemic such as inconsistent stock, lack of culturally appropriate and nutritionally inadequate foods, and stigma associated with accessing food banks (16). While community food services provided some participants with fragmented support prior to and during the pandemic, it is clear that food banks are not a sufficient or long-term solution for those with low incomes who experience food insecurity.



iv) Housing Insecurity

Several participants discussed their experiences with inadequate, unsafe, or unaffordable housing prior to and during the pandemic. For example, participants who lived in social housing throughout the greater Katarokwi area explained the conditions they experienced before and/or during the pandemic. One woman commented,

“Housing doesn’t give support. Sorry, I’ve been living in housing for 23 years now. And it’s a nightmare.”

Some participants also voiced concerns about community members who were without a home entirely, citing tent communities and the growing homeless population in the region.

v) Education

Some participants were taking care of children who attended elementary schools that were closed down intermittently throughout the pandemic. In some cases, having children at home full-time put a strain on child-caregiver relationships. For example, participants reported having more arguments with their dependents, and higher levels of stress and fatigue while caring for dependents and/or teaching dependents during the pandemic. Anxiety and exhaustion seemed to be especially prevalent among caregivers whose children had chronic health conditions or disabilities. For example, one woman noted,

“The school schedule also has been erratic and that – that can be very difficult to deal with because we are raising a child with special needs and we don’t have the supports [...] that school provides...”

Similarly, caregivers were also worried about their children’s development and socialization, and felt that children were missing out on important moments and milestones.

Having children in home-school also raised financial concerns for some families. For example, some participants described how school also served as childcare. Closing schools shifted the labour and associated costs of teaching and caring for dependents onto caregivers at home, who did not have the time or financial stability to pick up this extra labour. One woman noted,

“My grandson goes to school [at home] from 8am–2pm. What do you do if there is no one able to be home to help? Does the babysitter do it? Can they afford a babysitter?”

On the other hand, when schools re-opened, caregivers were faced with dilemma of whether to send their children back to school (where they are at higher risk of contracting COVID-19) or continue home-schooling (which proved unfeasible for some households). Some participants were enrolled in post-secondary school, where they reported heavier workloads in remote-schooling formats. Participants described higher levels of stress, exhaustion, isolation, and ultimately, burnout. Unfortunately, students who reduce their course loads to manage the workload also likely increase the length and cost of their education, because they must enrol for additional semesters to obtain their degree or diploma credits.

4) Programs, Services, and Institutions

All participants had at least one chronic health condition prior to and during the pandemic, for which they accessed health-related programs, services, and institutions. Unfortunately, some participants' experiences of healthcare negatively impacted their overall wellness. Notably, not having access to adequate health-related services negatively impacted participants. The barriers to care have been reviewed in detail earlier in this report.

Participants also reported being negatively impacted when they felt neglected, overlooked, inadequately supported, or mistreated in their interactions with service providers. For example, one woman commented, "...A psychiatrist threw me on medication and just threw me out [...] I wasn't feeling great about just being put on meds with no help." Participants were also concerned about the treatment of Elders and older adults by some health-related programs, services, and institutions, reporting that they knew of some Elders who were being "abused" in the healthcare system. One woman noted:

"Some people... are really good at it, at their job because then you know they like their job. And then you have those ones that come in and just do it for a pay cheque. [...] Like, that...to me that's a form of abuse [...] I've seen the... the Elders being abused, and I feel sorry for them."

Finally, a few participants also described other forms of isolation in healthcare institutions that they experienced during the pandemic. Due to physical-distancing recommendations, in some hospitals, only one family member was allowed to visit a loved one every-other-day. In other hospitals, no visitors were allowed at all. One woman noted, "I was hospitalized over the summer. And at that point...it was quite a serious event, and my family was not able to enter the hospital. And...basically, I was alone..." Limiting the number of visitors in hospital is an important strategy to limit the spread of COVID-19; while it may keep people safe from the virus, it has also amplified feelings of isolation, which impact wellness.

5) Cultural and Personal Coping Strategies

As a result of historical traumas in the context of colonialism, Indigenous peoples in Canada have higher rates of addictions compared to other groups in Canada (44). Substance use has been arguably exacerbated in the context of COVID-19 as people struggle to cope with previous trauma, as well as isolation and worsened mental health during the pandemic (45). In this project, a few participants reported substance use to cope with life prior to and during the pandemic.

One woman noted,

“People use substances to cope... to stay alive, in a way, even though it’s hurting them. And people also do it because of loneliness, isolation, and boredom, which is made even worse because of the pandemic.”

One participant reported smoking cigarettes as a way to deal with stress, which was intensified during the pandemic. A few participants also discussed stress-eating and over-exercising to reduce anxiety (though it often produced more anxiety for those who used these coping strategies). Similarly, a few participants also reported “numbing” themselves to their emotions as a way to survive past and present traumas.



For many participants, having positive coping strategies removed from daily life as a result of the pandemic had a significant impact on wellness. For example, being disconnected from community and culture had a major negative impact on participants’ wellness. One woman noted,

"Not being able to be with the community makes it worse. And then when something bad happens, I feel like I have too much space to ruminate and not enough space to go out and connect with people."

In addition, not being able to interact in their usual physical spaces (e.g. parks, stores, restaurants) had an impact on several participants.

Factors that Support Indigenous Wellness

While there were many factors that negatively impacted participants' wellness, there were also several factors that protected wellness. As above, protectors of wellness are discussed within the following distinct (yet overlapping) categories, which are also visually represented in Figure 2: 1) culture in community, 2) community and personal relationships, 3) socioeconomic determinants of health, 4) programs, services, and institutions, 5) cultural and personal coping behaviours, and 6) identity. The sixth category has been added in this section to review and emphasize the importance of Indigenous identity to wellness that was clearly demonstrated in KIRC-19.

1) Culture in Community

Participants expressed that connecting with Indigenous community and culture protected and supported their wellness. For example, attending community events and ceremonies (whether in-person prior to the pandemic or remotely/physically-distanced during the pandemic) was a significant source of strength for many participants. Participants also reported that practicing culture in community was the main reason why they felt welcome, safe, and happy, despite ultimately living in a colonial society that was designed to erase Indigenous peoples.

Importantly, many participants acknowledged land as a source of support, strength, and knowledge for them, prior to and during the pandemic. Participants expressed their interconnection with land, stating that their life and wellness were inseparable from the land. Some participants returned to the land when they needed healing, and acknowledged the importance of staying connected (i.e. in spirit, heart, body, and mind) or returning to the land during the pandemic when more support was needed.

Several participants emphasized that land is the ultimate provider, as one Two-Spirit participant noted,

“Everything that we need is already given to us. You just got to find it [...] A beautiful gift that the Creator has given us.”

Further, several participants described hunting, fishing, trapping and other land-related knowledges and practices that supported their wellness. These participants possessed land and food knowledge that was passed through generations, and they had learned recipes and food practices to support themselves, their relations, and future generations. In this way, participants highlighted land as the ultimate teacher, as well as a source of intergenerational resilience and mental and intellectual wellness.

Medicines from the land were also reported as a source of support for Indigenous wellness. One man noted, “I do sage, sweet grass. I get up early in the morning and I just cleanse the house and my body.” One woman noted, “I appreciate my life today and I put asemaa (tobacco) down every day to thank the Creator for the gifts he’s put into my life.”

Participants used a variety of Indigenous medicines in different ways. Some participants drank cedar tea or hung cedar from their doors. Others wore medicine pouches and/or used stones for guidance. Participants used medicines for spiritual cleansing and to communicate with their Ancestors. Participants used medicines on their own, as well as with other people in ceremony (both prior to and during the pandemic). Medicines were used for spiritual, physical, emotional, and intellectual wellness.

Participants also described the importance of receiving traditional teachings as a way to support their wellness, prior to and during the pandemic. In particular, participants emphasized the benefit of receiving teachings from Elders, Knowledge Keepers, and older family members. Participants also mentioned following various cultural teachings such as the Seven Grandfather Teachings, as well as the teachings of the Medicine Wheel to support them in life. Further, given that the greater Katarokwi area is home to many Indigenous Nations, one participant identified the benefit of being able to learn from and support one another with the diverse Indigenous knowledges and practices thriving in the area.

Teachings were transmitted in a variety of ways. Participants mentioned story-telling, dreaming, land-based learning, and ceremony as ways in which knowledge was passed to them. Some participants also described the benefit of teachings others, and were proud when younger generations took up traditional teachings and practices. For example, one man noted, “I taught my grandkids how to [trap] and how to hunt [...] The girls do and they have their own guns and everything else, yeah. They’re true Mohawk women...”

Similarly, participants also expressed the importance of learning and speaking their Indigenous languages as a way to recover knowledge systems that have been lost through generations of settler colonial assimilation. Learning the language was also a way to bring Knowledge Keepers, Elders, and all community members together to strengthen the community. In addition, some participants felt supported by Indigenous literature (related to language or otherwise). Literature by Indigenous authors may be a relatively accessible way for some Indigenous individuals to stay connected with their Indigenous culture while separated from community during the COVID-19 pandemic.

“

“I appreciate my life today and I put asemaa (tobacco) down every day to thank the Creator for the gifts he’s put into my life.”



2) Community and Personal Relationships

One participant summarized the importance of relationship by stating, “Culturally, we’re a people-people.” Participants described the relational networks that supported them in the Katarokwi area and how these relationships enhanced their wellness. Overall, they felt supported by their friendships, partnerships, and families prior to and during the pandemic. Despite physical separation from people during the pandemic, many participants were able to stay connected with friends and family through remote communication during the pandemic. Personal relationships were especially a source of support for participants who suffered past traumas and needed help healing. Participants emphasized the importance of having a supportive circle of friends and family around, stating that this support system was fundamental to their wellness.

Many participants emphasized the importance of caring for others in the community, which, in turn, supported their own wellness. For example, participants mentioned checking in on loved ones and community members. Some participants also reported that family and friends ran errands for them, picked up their groceries, or drove them to health appointments. Having friends and family during the pandemic was especially important for participants who lived alone or who lived with advanced illness. Notably, multiple women in the study reported the importance of Indigenous women supporting other Indigenous women in community. Several women described belonging to women’s support groups and providing childcare for one another when needed. Families often overlapped to create large networks of families hosted by strong Indigenous women. Having strong relationships can be a major protector for Indigenous wellness.

Interestingly, some participants felt that their experiences during the pandemic had strengthened their families. One woman noted:

“I don’t want to see them going through what I went through as a kid, and I want to be there through this pandemic for them, you know what I mean? I want to be their number one support and help them and make them understand how serious this COVID stuff is [...] So, with the pandemic...I’ve made my family stronger.”

3) Socioeconomic Determinants of Health

i) Employment Income and Government Financial Supports

Several participants were employed during the pandemic, which provided financial stability and supported wellness. One woman noted, “We’re very fortunate in that our jobs have allowed us to adapt to the pandemic and maintain the income that we had before (almost).” Some participants also discussed budgeting strategies that allowed them to optimize their incomes and cover the costs of living. Further, some participants also felt that their intellectual health was supported by their work during the pandemic, as participants faced new challenges and new work settings with the conditions of COVID-19.

However, as mentioned earlier, several participants had low incomes prior to the pandemic, which made making ends meet difficult or near impossible during the pandemic. Some participants received government financial supports such as the Ontario Disability Support Program (ODSP) to help them pay for the cost of living. While some participants acknowledged the help that government funding provided, many more commented on the inadequacies of this funding to meet their needs.



ii) Supplemental Community Supports – Food, Housing, and More

Many participants also listed several community-based organizations that helped them make ends meet when their incomes or government financial supports were inadequate. Participants listed a variety of programs and associations including The Elizabeth Fry Society, Kingston and Lanark County Interval Houses, Kingston and Napanee Area Community Health Centres (KCHC and NACHC), The Salvation Army, food banks, and churches which provided income supplements such as food and/or shelter for some participants.

A few participants who lived in social or subsidized housing reported feeling well-supported. One participant noted, “Yes, I live in housing. That’s where Elizabeth Fry comes in [...] And they’re my support system out here.” However, while living in subsidized housing, some participants were still worried about whether they had enough money to pay their bills each month.

iii) Supplemental Indigenous-led or Indigenous-focused Community Supports – Food, Housing, and More

Many participants underscored the importance of Indigenous-led and Indigenous-focused community supports to assist their income and protect their wellness. Organizations such as the Mohawks of the Bay of Quinte, Kingston Interval House, KCHC and NACHC, Métis Nation of Ontario (MNO), Kingston Indigenous Languages Nest, The Elizabeth Fry Society, and Four Directions Indigenous Student Centre were among those listed that provided participants with supports such as food and housing. Further, events that were run by Indigenous-led groups such as the Kingston Indigenous Languages Nest (KILN) often provided food at events as a traditional cultural practice. This practice offered an opportunity for people to access food supports without any stigma. For example, one woman commented on an event they regularly attended, noting,

“...there was always a healthy snack. There was always coffee and tea and juice. So, it was option of food, so if you didn’t have healthy food at home, you at least had it here, right?”

Several participants commented on the holistic and excellent care that Indigenous-led and Indigenous-focused groups provided, in comparison to organizations that did not take Indigenous views of wellness into account.



iv) Education

Participants who attended post-secondary school mentioned the benefits of being in the western education system. For example, attending school provided social interaction prior to the pandemic that supported wellness. Attending school in person also provided more structure to some participants’ lives, which they valued. Attending school also provided some participants with valuable skills that they were able to utilize in their communities such as training in various healthcare fields. Further, during the pandemic, some participants also mentioned reading books and novels to support their wellness and pass the time.

4) Programs, Services, and Institutions

i) Mainstream Health and Related Services

Participants listed a number of health-related programs, services, and institutions that supported their wellness prior to and during the pandemic. For example, participants mentioned using services from institutions such as Addiction and Mental Health (KFL&A and LLG counties), Kingston Institute for Psychology and Neurofeedback, Queen's Student Wellness Services, Napanee Crisis Centre, KCHC and NACHC, local hospitals including Kingston Health Sciences Centre, Street Health, CDK Family Medicine and Walk-in Clinic, Kingston Orthopaedic Pain Institute, HIV/AIDS Regional Services (HARS), as well as family doctors and multiple crisis lines. During the pandemic, many of these organizations offered remote counselling sessions over telephone, Ontario Telemedicine Network (OTN), or Zoom for participants who needed their services.

In addition to primary care, many of these organizations also provided programming directed at managing mental and physical health conditions in community settings (e.g. Better Beginnings through KCHC). Participants also accessed community programming through support groups in local churches, and relied on health messaging from their local public health units for updates about COVID-19 and how to remain healthy and safe during the pandemic.

ii) Indigenous-led and Indigenous-focused Programs and Services

Many community-supports available to participants did not offer Indigenous-focused programs and services. The few organizations that offered Indigenous-focused community supports that participants reported included Kingston and Lanark County Interval Houses, KCHC and NACHC, the Elizabeth Fry Society, the Katarokwi Learning Centre, the Southeast Regional Cancer Program (Indigenous Patient Navigator), and HARS. Unsurprisingly, participants also mentioned the dearth of Indigenous-led health programs and services available in the wide geography of the greater Katarokwi area. A few that were mentioned include Four Directions Indigenous Student Centre, KILN, MNO, Mohawks of the Bay of Quinte, and the Indigenous Diabetes Health Circle. Indigenous-led programs and services are important because they allow for greater Indigenous autonomy in planning and providing care services in Indigenous communities. Further, given that Indigenous-led services are more likely to be culturally appropriate for Indigenous service-users, they also offer forms of support that may not be possible through other healthcare mediums (46).

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“Every Indigenous leader or event that’s put on in this town involves Two-Spirited people [...] We all take care of each other. Yeah, we’ve always been told to take care of each other.”

Participants commended several Indigenous-led and Indigenous-focused programs for offering holistic forms of care. For example, participants mentioned that the Métis Nation of Ontario provided services such as drumming circles, crafting programs, cooking workshops, and other social activities which helped improve participants' wellness. One participant also emphasized Indigenous-led initiatives in the community as a supportive space for Two-Spirit Indigenous individuals who may not be represented, acknowledged, or welcomed in other healthcare spaces. One Two-Spirit individual noted, "Every Indigenous leader or event that's put on in this town involves Two-Spirited people [...] We all take care of each other. Yeah, we've always been told to take care of each other."

While a few Indigenous-led and Indigenous-focused services exist in the greater Katarokwi Indigenous community, multiple Indigenous-specific services are being cancelled due to inadequate funding. For example, the Katarokwi Native Friendship Centre was open from 1992-2013 and closed due to inadequate long-term funding (47). This centre was the sole cultural hub for many Indigenous peoples in the area. These closures are devastating because many participants emphasized the need for Indigenous-led and Indigenous-focused care for their wellness.

5) Cultural and Personal Coping Behaviours

Participants listed a number of activities they used to cope with isolation and impacted wellness during the pandemic. For example, participants described a variety of cultural, artistic, and creative practices that supported them including beading, painting, leatherwork, birch bark work, sewing, and more. Participants also made regalia and other clothing, snowshoes, canvas art, and various crafts. Participating in art-based cultural practices helped several participants heal, connect with their culture, find strength, feel grounded, and stay rooted in community (despite being physically separated during the pandemic). Some participants who had access to technology were also able to attend workshops and events online and learn new skills and practices to help them during the pandemic.

Making and listening to music was another significant way that participants stayed well during the pandemic. For example, several participants mentioned drumming as a source of wellness, with one woman noting, "As I started to heal... the drum actually was part of my healing." Further, one Two-Spirit person stated,

"When I drum, I become one with my drum. That drum – what you hear is my heartbeat."

Ultimately, participants reported feeling good when they had ways to express their feelings (whether it be by talking with friends or family or through various art practices). Some participants also started selling artwork during the pandemic as a way to supplement their incomes and/or to create new, profitable businesses to continue past the pandemic.

Many participants practiced other cultural and spiritual activities to help with their wellness such as smudging, meditation, connecting with Ancestors, and prayer. Some participants cited prayer or ceremony as protection against negative coping mechanisms such as substance use. Similarly, several participants emphasized the importance of caring for their bodies. Participants expressed the need to eat well and move their bodies regularly as a way to cope with stress and improve their physical health. For some participants, the pandemic was an opportunity to be out on the land more and eat healthier foods at home more often. Participants also expressed a need to “keep busy” during the pandemic as a way to safeguard their wellbeing. For example, participants reported keeping busy with activities such as reading, knitting, crocheting, cooking and eating comfort foods, or driving. While many of these activities were practices that participants had prior to the pandemic, some participants reported trying to learn new activities remotely during the pandemic as a way to keep busy.

Finally, participants also mentioned that various forms of media supported their wellness during the pandemic. Media was a source of joy and distraction for some participants, and it was also a source of informative health-related information. Some participants found media helpful when trying to learn more about their health conditions (e.g. health-related websites), or while staying up-to-date with the COVID-19 pandemic. Several participants felt that it was their responsibility to stay informed, and it helped reduce stress. On the other hand, some participants experienced higher levels of stress due to the influx of information about the pandemic that was constantly available to them. Some were also concerned about the amount of misinformation available online.

6) Personal Identities

Participants expressed aspects of their identities that supported their wellness prior to and during the pandemic. In the greater Katarokwi area, there are many Indigenous Nations that are comprised of diverse populations of Indigenous peoples. Indigenous individuals engage with their Indigenous identities in unique ways, and this section describes some of the ways in which Indigenous participants’ identities supported their overall wellness. For example, some participants shared their cultural names, explaining how these names were given to them by other members of the community, and showcased their own personal gifts and strengths. Cultural names helped highlight the positive qualities of participants, especially as they related to community involvement and interconnection. In addition, following traditional Indigenous teachings helped shape some participants’ identities and enhanced wellbeing. One Two-Spirit individual noted,

“When I went back onto the red road, it became my healing tool. It became my way of life. So, I live and try to live by the Seven Grandfather Teachings.”

i) Spirituality

Contributing to many participants’ identities was a sense of spirituality, and spirituality was also a key component to many participants’ wellness. For example, participants described how spirituality had helped them and others who struggled with addictions and mental health issues (as discussed earlier).

Several participants felt guided by their spirit in daily life, emphasizing that their spirit was a major source of strength. One man noted,

“I guarantee it’s my beliefs and my culture is what’s been getting me through this.”

Some participants also acknowledged their spirit as fundamentally connected to others around them, and those spiritual connections gave them strength. On the other hand, a few participants shared words of caution about religion and certain spiritual practices as they shared traumatic experiences from the past. In some cases, participants’ past experiences with religion deterred them from spirituality (in its diverse forms) almost entirely.

ii) Gender and Sexuality

Participants also commented on their gender and sexuality as two elements that structured their identities and supported their wellness. Some participants articulated their strength and power as it related to their gender and gender roles. For example, one participant viewed her mother as a role model, and therefore took on similar working roles and home responsibilities in order to embody strength and respect. Other women commented on their gender identities as formed by traditional views of land in relation to women.

For example, one participant commented on,

“...how much power as women we have because of the water.”

Similarly, one participant commented on their gender and sexuality noting,

“Years ago, you know...at one time, Two-Spirited were very [highly regarded] in the Indigenous community. Like, those teachings have been lost over the years [...] they were considered very sacred.”

Even after facing constant discrimination, one participant showcased incredible strength, noting,

“I’ve felt homophobia all my life from all different walks of life, ok? So, it doesn’t matter to me. I just push right through it.”

ii) Personal practices and values

Participants also demonstrated several personal practices and values that shaped their identities and contributed to wellness. Participants showed combinations of traits and actions such as forgiveness, gratitude, hope, humility, optimism, humour, determination, problem-solving, self-reflection, respect, self-respect, self-preservation, self-love, independence, responsibility, and wisdom. Many participants also placed significant emphasis on the importance of helping others in their families and wider community.

Overall participants demonstrated considerable resilience during the COVID-19 pandemic, as well as responsibility and hope for future generations of Indigenous community members. For example, one woman noted,

“I think we’re stuck and we’re going, ‘Poor us, poor us.’ Now, it is poor us, but you know what? We can grow and learn together and move away, so that the next generation doesn’t get affected the way we were.”



Positive Wellness During COVID-19

While the negative impacts to participants' wellness were overwhelming, some participants expressed positive outcomes related to their wellness during the pandemic. Some participants felt that cancelling events, gatherings, and appointments created space for spiritual and emotional healing during the pandemic. Having fewer day-to-day responsibilities allowed some participants to slow down and reflect on their past and present. Similarly, with greater time to reflect, some participants felt they were able to reconnect with their spirits, realign their priorities, and find emotional and mental contentment.

While many participants reported feeling strain in their relationships, some participants felt their relationships improved during the pandemic. For example, because public health guidelines limited the number of people that participants were able to see in-person, some participants prioritized relationships with family and close friends, thereby strengthening these select relationships.

A few participants also mentioned some of the positive physical outcomes of the pandemic. For example, a few people who suffered from addictions abstained from drugs and alcohol during the pandemic, with one participant explaining that keeping her daughter safe from COVID-19 was her biggest motivation for quitting. Other participants explained that their physical health had improved because they were able to get out on the land more often and be more physically active than they had prior to the pandemic. Further, one participant attributed their accelerated wound healing to having more time to relax at home. Finally, being at home more often also gave some participants the opportunity to develop hobbies and skills (as noted earlier) which helped improve wellness.

Summary of Recommendations: Ways Forward in COVID-19 and Beyond

Participants commented on what they thought service-providers, community groups, leaders, or governments could do to address the needs of Indigenous peoples living in Katarokwi who have chronic health conditions. Participants offered multiple recommendations, which we have grouped into those that primarily involved either proximal, intermediate, or distal determinants of health for Indigenous peoples. Proximal determinants of health are those that have a direct impact on a person's wellness (48). They include factors such as health behaviours, physical environments, employment and income, education, and food security.

Intermediate determinants are those that are primarily located at a systems-level and can influence proximal determinants of health (49). Intermediate determinants include health care systems; education systems; community resources, infrastructure, and capacity; environmental stewardship; and cultural continuity (48). Finally, distal determinants are the historic, political, social, cultural, and economic contexts that impact the ideologies, health and social structures, and collective and individual practices which ultimately impact a person's wellness (49). They include colonialism, social exclusion (as a result of racism and its intersections with sexism, transphobia, homophobia, ableism, and classism), and self-determination (48). Distal determinants influence both intermediate and proximal determinants of health.

Ultimately, a multi-pronged approach, involving action across distal, intermediate, and proximal determinants, is required.

We have decided to begin the discussion by looking at participants' recommendations as they relate to distal determinants of health; while colonialism, social exclusion, and self-determination are more difficult to address, they arguably have the greatest impact on the lives and wellness of Indigenous peoples.

Recommendations Addressing Distal Determinants of Health

Colonialism intersects with racism, sexism, transphobia, homophobia, ableism, classism and other forms of discrimination to privilege white, straight, able-bodied cis-gendered men and their acquisition of land, resources, and power (50). People who most resemble this privileged identity are granted access to more resources than those who do not (51). People who stray from this favoured identity pattern are excluded from accessing the same level of physical, economic, financial, and political resources; as a result, they are more likely to experience health and social inequities, and they are less likely to be listened to when advocating for equality (52).

Historically, mainstream health services and programs have been paternalistic and damaging to health, and have ultimately impacted Indigenous peoples' agency and self-determination as a result (53). In this project and elsewhere, Indigenous peoples have

responded by firmly stating: “Nothing about us, without us.” For example, in this project, there was a common and resounding recommendation for more Indigenous-led and Indigenous-focused programs, services, and institutions in the Katarokwi area. Implementing more Indigenous-led programs and services creates opportunities to build greater agency and self-determination among Indigenous communities; Indigenous self-determination is an important goal in reconciliation and a crucial aspect of Indigenous wellness (4).

Similarly, hiring Traditional Healers, Knowledge Keepers, and Elders was also identified as an important change in order to ensure that care is being provided in a good way, and clients have access to supports that care for more than just physical health. Hiring Traditional Healers, Elders, and Knowledge Keepers in all institutions that provide healthcare was suggested as an important step forward in caring for Indigenous and non-Indigenous peoples with chronic health issues. Further, this change acknowledges the legitimacy of Indigenous knowledge and practices and is aligned with the TRC’s Calls to Action #22 and #23 (54).

Participants also emphasized the need for care that is inclusive and safe for women, girls, and 2SLGBTQ+ individuals who may be at-risk or feel unwelcome in other health-related spaces in Katarokwi. In fact, participants called on federal, provincial, and municipal governments to take greater action in protecting 2SLGBTQ+ individuals, women, and girls from colonial violence in general as they felt many people were still at risk. Several participants came forward and reported facing gender-based violence in the area and in other parts of the country as well. One woman noted, “I had a lot of friends in my past die. And they would be considered a prostitute or someone who ran away and didn’t care about themselves [...] They need more support.” These individuals need a space to feel supported in the Katarokwi area. Implementing more Indigenous-led services could help ensure that safe, inclusive, culturally appropriate, holistic care is provided (4).

Recommendations Addressing Intermediate Determinants of Health

Many participants emphasized the need for an Indigenous-led, physical space in community for Indigenous peoples to gather to practice their cultures. Some described the potential space as a welcoming, communal location for healing, sharing, teaching, and learning. The recommendation to implement a funded space for Indigenous peoples is aligned with the Truth and Reconciliation Commission of Canada (TRC) Call to Action #21 (54). Ultimately, implementing more Indigenous-led services and a designated space for Indigenous peoples in Katarokwi would also contribute to Indigenous self-determination (as discussed earlier).

Participants defined key areas of healthcare that needed to be improved, such as mental health and addictions services throughout the greater Katarokwi area. Participants felt that these areas were underfunded, and therefore underservicing the populations that need these supports. Participants also noted that mental health and addiction were likely worsened due to the pandemic, and people needed support now more than ever. However, adequate support was often difficult to access (e.g. due to extended wait times or technological issues) prior to and during the pandemic.

While virtual care worked well for some (due to the convenience of not needing to travel for in-person care), others highlighted the challenges of virtual care including technological issues, unreliable internet access, and lack of private space to use virtual care services. These highlight the importance of further research and action around strategies to improve virtual care access and experiences among Indigenous (and other) clients.

Further exploration is also warranted on how to maintain critical social supports for individuals in the midst of isolation measures. Participants also highlighted the need for more culturally relevant family supports, youth programming, and older adult supports in their communities. Participants additionally reported the need for more preventative health programs so that they could self-manage their wellness. They also noted that having more preventative health programs may free-up services, thereby ensuring those with advanced illness receive institutionalized healthcare when they need it. Further, participants felt that resources were concentrated in urban areas such as downtown Kingston, and advocated for more resources in rural areas to minimize geographical barriers to accessing care. Similarly, participants also emphasized the importance of enhancing communication between service-providers in order to improve continuity of care and minimize burden on clients with chronic health issues in the healthcare system.

Finally, participants emphasized the need for holistic care in the programs and services they accessed, noting the importance of caring for the whole spirit, heart, body, and mind interaction. In order to treat the whole person, care-providers must implement individualized and client-centred care, and see the client in the context of their community-connections as well. One participant summarized the sentiment saying it was like, “being treated like you matter – like all of you matters.” Participants hoped for an empathetic, understanding approach from their service-providers, instead of feeling attacked, discriminated against, and seen as a financial burden on the healthcare system.

Recommendations Addressing Proximal Determinants of Health

Several participants expressed a dire need for improved access to affordable housing for Indigenous peoples living in the Katarokwi area (both on and off-reserve), as well as more food supports during and after the pandemic is over. While community

charity/grant-based food programs and services (e.g. food banks, community gardens) were important for some participants, there is evidence that these supports are inadequate to address low income and poverty, which is the root cause of food insecurity (55). Instead, other strategies have been proposed such as a universal basic income for all Canadians, which may help to ensure that all people have enough money to cover the costs of living (56, 57).

Participants emphasized the need to improve existing government financial support programs such as ODSP which does not cover the cost of living for many (15). Participants also advocated for financial supports for people who lost their jobs or who have a low income as a result of the pandemic; CERB is now closed despite ongoing, intermittent provincial lockdowns (14). Participants also highlighted the need for long-term funding for community programs and services in order to promote Indigenous wellness in Katarokwi.



Conclusions

The Katarokwi Indigenous Resilience during COVID-19 (KIRC-19) Project was developed as a way to explore the experiences of Indigenous peoples living with chronic health issues in Katarokwi during the COVID-19 pandemic. We found that Indigenous peoples living in Katarokwi experience difficult socio-economic and health conditions which have been amplified during the course of the pandemic and have been detrimental to individual and community wellness. Indigenous adults with chronic health conditions in Katarokwi also experience many barriers to accessing safe, adequate, and culturally appropriate care. In addition to the many pre-existing barriers that have been intensified due to COVID-19, the pandemic has also created new barriers to care for Indigenous peoples. Ultimately, these barriers threaten the wellness of Indigenous peoples in Katarokwi, along with the distinct impacts of COVID-19 on wellness.

However, Indigenous peoples are incredibly resilient and have found ways to protect themselves from COVID-19 and the stressors of the pandemic. Indigenous culture, community, relationship, and identity all interact to protect Indigenous wellness. KIRC-19 participants also identified important strategies to protect their health during the pandemic and beyond. One pressing need that participants identified was to ensure adequate, long-term funding for Indigenous-led and Indigenous-focused programs and services in Katarokwi. While Indigenous peoples are strong and have resisted the impacts of colonialism and other social determinants of health which impact their wellness, mainstream governments must also be accountable in their role in safeguarding public health (including Indigenous health and wellness). Being resilient is not a fair or adequate solution to health and social inequity.

We hope that the recommendations made by participants and supported with academic literature can be used to implement changes in Katarokwi that benefit Indigenous peoples' wellness. Further, we hope that the academic-community partnerships that were developed in KIRC-19 can be carried into future projects that continue to work towards enhancing Indigenous wellness in the greater Katarokwi area.



8

APPENDIX

Indigenous peoples living with chronic health issues during the COVID-19 era: KIRC-19 Project

Appendix – Participant Demographics

22 self-identifying Indigenous adults (18 years and older) who had at least one chronic health issue (physical or mental) and lived in the greater Katarokwi area participated in this project. 16 participants identified as women, 5 identified as men, and 1 identified as Two-Spirit. 20 participants identified as First Nations, 1 participant identified as Métis, and 1 participant identified as Inuk. Of the participants, 16 lived in Kingston, 2 lived on reserve, 2 lived in cities or towns outside of Kingston in the greater Katarokwi area and 2 lived currently outside of the Katarokwi area but accessed health-related programs and services in Kingston. 6 participants had access to Non-Insured Health Benefits. Participants' ages ranged from 20-65 years. Most participants were either in their 20s (n=8) or 50s (n=6). One participant chose not to provide their age.

3 participants identified as being in a common-law relationship, 2 were widowed, 8 were single (never married), 5 were divorced and single, 3 were married, and 1 was in a relationship (not living together). 9 participants reported having children who were now over 18 years old and no longer lived with them, while 6 participants were caring for children who were under 18 and still living with them.

3 participants were students without paid employment and 2 were students with paid employment (e.g. part-time or casual contracts). 2 participants were retired, while the remaining participants had varying levels of employment including full-time, part-time, contract work, temporary unemployment, or were off work permanently due to a disability. Several participants also volunteered without pay. Participants had varying levels of income and education, with all major income and educational categories represented in the diverse group.



9

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