2024

Table of Contents

Art

Preface

Articles

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Letter from the Editors

Dear reader,

We are pleased to present to you Volume 6 Issue 1 of the University of Manitoba Journal of Medicine (*UMJM*).

UMJM is a student-run journal focused on publishing original submissions from University of Manitoba students. Since our inaugural volume in 2017, we have published seven volumes comprising 51 original pieces. We are thankful for the continued support the UM community has shown us throughout the years by the numerous submissions we receive each year as well our outstanding team of students editors and faculty reviewers.

It brings us great joy to showcase the incredible work of our University of Manitoba students as they continue to shape the field of medicine within the province. Our continuing goal remains that of providing students the opportunity to showcase their scholarly work and creativity to the larger community. This volume is a testament to their dedication towards publishing diverse and innovative scientific research and insightful perspectives on medical care, public health, undergraduate medical education, and more.

As we complete our final year as Editors-in-Chief of the *UMJM*, we would like to thank the dedicated 2023-2024 *UMJM* editorial team, comprised of 20 committed medical students. These students are an integral part of the publication process, from editing and refining articles in collaborate with authors and faculty reviewers, to drafting them for publication and engaging with the medical community over social media. We also rely on our dedicated faculty reviewers, who donate their time and make this journal possible. We would also like to extend our thanks to our faculty advisor, Dr. Joel Kettner, who has supervised the UMJM and provided invaluable assistance, and to the office of Dean Peter Nickerson for funding this project.

On behalf of the *UMJM* editorial team, we thank you and hope you enjoy Volume 6.

Happy reading,

Carrie Gu & Ina Siwach
Co-Editors-In-Chief

The impacts of schedule changes and service suspensions at the Notre Dame Health Centre emergency department

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Abstract

In July 2022, the emergency department (ED) at the Notre Dame Health Centre, Manitoba, Canada shifted its schedule from 24 hours every other day to 12 hours 7 days a week. In this paper we evaluate the impacts of scheduling changes on access to ED services. Data was reviewed for 2021-2022 and 2022-2023 fiscal years focusing on Canadian Triage and Acuity Scale (CTAS) scores, monthly patient volumes, and suspension of service notifications. We found that most patients presented during daytime hours with 93% of patients in 2021-2022 and 98% of patients in 2022-2023 presenting between 08:00-23:59. Following ED schedule changes and temporary closure of the Tiger Hills Health Centre ED monthly patient volumes were increased in comparison to the previous year. Between July 11, 2022, and June 30, 2023, 71 days were affected by service suspensions. Full day suspensions were more frequent on weekends while partial suspensions, mean duration of 2.7 hours, were more frequent on weekdays. All but 1 of the 71 affected days was caused by nursing resource shortages. Considering existing trends in when patients seek care, 69% of patients in 2022-2023 presented during the 08:00-15:59 shift which is fully encompassed in the new ED schedule. A total of 27 out of 30 partial closures occurred at the end of day when the least patients typically sought care. We identified nursing shortages to be the main source of ED closures and can serve as a target for improvement in the future. Continued efforts should be made moving forward to ensure that the ED remains open earlier on in the day.

Keywords: ER visits, rural medicine, rural emergency departments, healthcare workforce

Conflict of Interest Statement: Chief of Staff Notre Dame, St. Claude, Swan Lake, Pembina/Manitou

Introduction: Accessing emergency care in rural communities is a challenge faced by many Canadians.[1] The residents of small agricultural communities are more likely to have riskier occupations and to be hospitalised for unintentional injury in comparison to the average Manitoban.[2] This highlights the importance of maintaining small acute care facilities that can provide services to rural populations.[3] While these centres may have a narrow scope of services available, they are still relied upon as an essential service in regions where walk-in clinic same day primary care availability is greatly limited.[1] Previously established best practices have also identified that the triage, stabilisation, and transfer from a local hospital is a safe practice for injured patients requiring higher acuity care.[4] Given the geographical distance that separates rural areas from tertiary care centres in Winnipeg, smaller rural emergency centres are needed to help ensure that timely intermediate level care is available where serious injuries may occur.[3]

The community of Notre Dame de Lourdes, located 120 km southwest of Winnipeg and, has a population of 756.[5] Located in Manitoba's Southern Health Region it serves as a bilingual healthcare hub for the 8,091 residents of the Lorne/Louise/Pembina District.[2] The Centre Albert-Galliot, located in Notre Dame de Lourdes, includes a campus with several facilities, including, a primary care clinic with a variety of allied health professionals and the Notre Dame Foyer, a 60 bed long-term care facility, as well as the Notre Dame Health Centre, a 9 bed hospital with an emergency department (ED), x-ray, and phlebotomy laboratory.[6]

Historically, the ED operated from 08:00-17:00 on weekdays and shared a call schedule with the Tiger Hills Health Centre, located 25 km away in Treherne, to offer expanded coverage.[7] Each site provided 24-hour on call ED coverage beyond their standard schedule (i.e. after 17:00 and on weekends) 50% of the time. In 2021 the Prairie Mountain Health Region's Tiger Hills Health Centre was subject to staffing challenges that led to fre-

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quent closures. In July 2022 the ED at the Tiger Hills Health Centre was closed, ending the shared call schedule, causing the ED at the Notre Dame Health Centre to modify its ED schedule to 08:00-20:00, 7 days/week.[7] Since these changes were implemented, the Notre Dame Health Centre has continued to face staffing shortages that led to periodic ED suspension. The Tiger Hills Health Centre ED re-opened in January 2023 and later restored services from 07:00-18:00 weekdays and every other weekend.[8,9] The aim of this research work is to understand the impacts of these changes in the Notre Dame Health Centre ED schedule on ED access in the community and to help guide local decision-making and planning.

Methods: Summarised data was obtained from the year end reports of Notre Dame Health Centre's statistical repository for 2021-2022 and 2022-2023 fiscal years. This included monthly ED patient volumes, the Canadian Triage and Acuity Scale (CTAS) scores, which triage patients based on acuity, and the time of presentation which were all compared year to year. CTAS scores are defined as level 1 resuscitation: patients who require immediate interventions, level 2 emergent: patients who require rapid interventions, level 3 urgent: patients who could progress to needing immediate interventions, level 4 less urgent: patients who have age related conditions or require reassurance, and level 5 non-urgent: patients with minor conditions that are stable.[10]

Time of presentation data for each fiscal year was broken down into three shifts, 00:00-7:59, 08:00-15:59, and 16:00-23:59 in the original reports. During the 2021-2022 fiscal year the ED would have been open during both the 16:00-23:59 and 00:00 – 7:59 shift when on call. Starting on July 11, 2022, however, the ED would not have been open after 20:00 nor during the 00:00-7:59 shift. The 2022-2023 fiscal year data includes both when the ED was open on the shared call schedule and the current 08:00-20:00 schedule.

The notifications of suspension of services for the site from July 11, 2022, to June 30, 2023, at the Notre Dame Health Centre were reviewed and details related to dates, times, and why closures occurred were compiled. Service suspension notifications were defined as official bulletins released by Southern Health notifying the region of a planned ED closure. Suspensions were defined as ED closures that resulted in the public being unable to access care through the ED during normal scheduled hours of operation. Closures were categorised as full or partial and weekend/holiday or weekday. Partial closures were defined as a closure where ED services were still available during a given day, but not for the entire 08:00-20:00 hours of operation. Full closures were defined as days when ED services were not available. The mean duration of partial closures was also calculated. Partial closures were further categorised as start of day, end of day, or middle of day closures. Start of day closures were defined as closures starting at 08:00 with services resuming before 20:00, end of day closures were defined as starting after 08:00 and lasting until 20:00 when the ED would normally close, and middle of the day closures were defined as closures where services were unavailable for a period of time in the middle of the day but were available at 08:00 and again before 20:00.

The average number of visits per hour the ED was open was computed for July 2022 to March 2023 using the monthly patient volumes and the monthly total hours the centre was open. The percentage of expected hours of operation that were affected by suspensions were also calculated for July 2022 to March 2023. Total expected monthly hours of operation using the 08:00-20:00 daily schedule as well as the total closure hours for each month were used for this calculation.

Results: The data presented in Figure 1, summarizes the ED patient volumes for the two fiscal years, 2021-2022 and 2022-2023. Patient volumes varied between the two years with larger volumes in 2022-2023. Coinciding with the schedule modification beginning in July 2022, and the closure of the Tiger Hills Centre ED there was an increase in patient volume for every month thereafter as compared to the previous fiscal year.

The CTAS scores for the patients presenting to the Notre Dame Health Centre ED for each fiscal year is displayed in Figure 2. A total of 1507 patients sought care in 2021-2022 while 1993 patients presented in 2022-2023. A single patient left without receiving care during the 2021-2022 fiscal year compared to 4 patients during the 2022-2023 fiscal year. Between the two fiscal years the percentage of patients who presented as levels 1 and 5 were similar. There was a lower percentage of patients in acuity levels 2 and 3, and an increase in patients in acuity level 4 in the 2022-2023 fiscal year.

Figure 3 displays when patients sought care. Presenting between 08:00 to 15:59 was the most common followed by 16:00 – 23:59 and 00:00 – 7:59. Daytime presentations (08:00-23:59) were higher at 93% in 2021-2022, and 98% in 2022-2023 when compared to overnight presentations (00:00-7:59), 7% in 2021-2022 and 2% in 2022-2023.

Table 1 summarizes the ED suspensions from July 11, 2022, to June 30, 2023. There were 54 service suspension notifications issued leading to 71 days with suspensions (see Figure 4 for a calendar of suspensions). Lack of minimum nursing resources to safely operate the ED was responsible for 70 out of the 71 total suspensions; one suspension was caused by a lack of x-ray availability. Weekends and holidays were frequently affected and usually resulted in full closure while reduced hours were more common on weekdays (see Table 1). A total of 30 partial closures with a mean duration of 2.7 hours occurred; 27 of these were end of day closures (see Tables 1 and 3). With a mean partial closure duration of 2.7 hours and considering that 27 out of 30 closures occurred at the end day the typical partial closure can be characterised as occurring from approximately 17:00-20:00.

The number of visits per hour ranged from 0.39 to 0.67 and the percentage of hours suspended ranged from 3% to 29% in 2022-2023 (see Table 2).
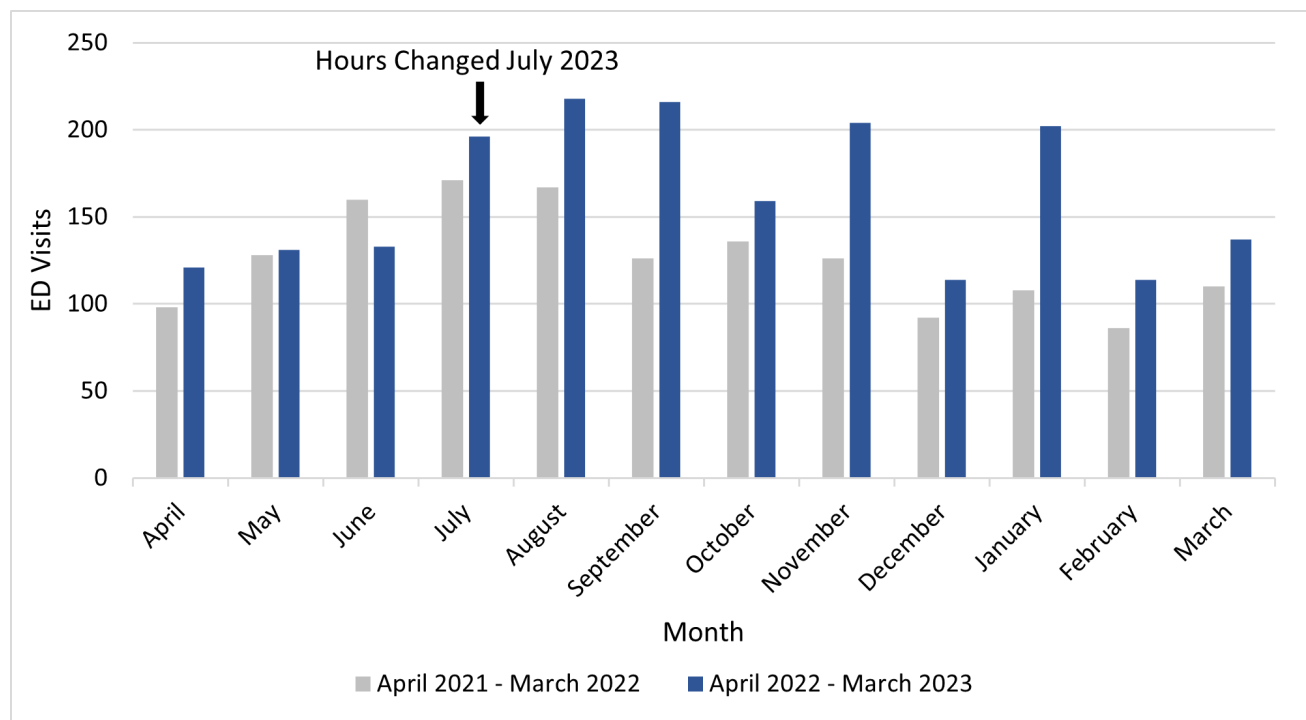
Figure 1. Number of monthly ED patient visits for the Notre Dame Health Centre 2021-2022 and 2022-2023 fiscal years (April 1-March 31).
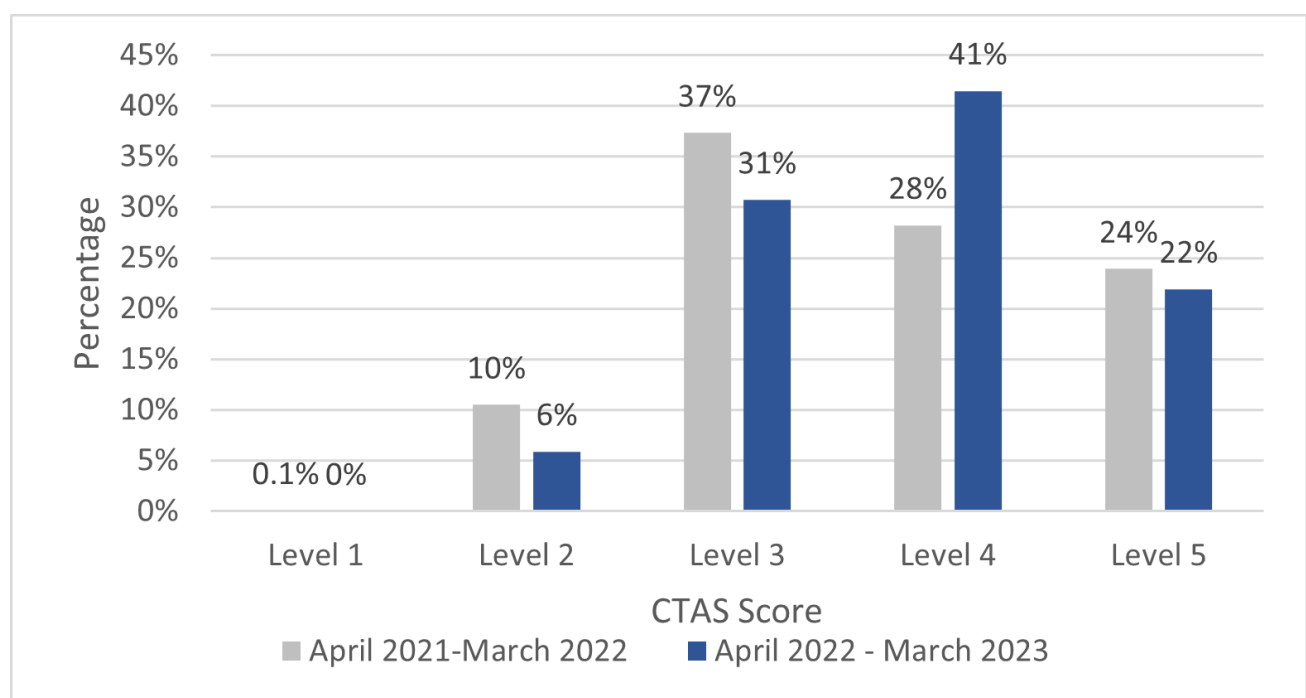

Figure 2. CTAS score percentages for patients presenting at the Notre Dame Health Centre ED between 2021-2022 and 2022-2023 fiscal years (April 1-March31).
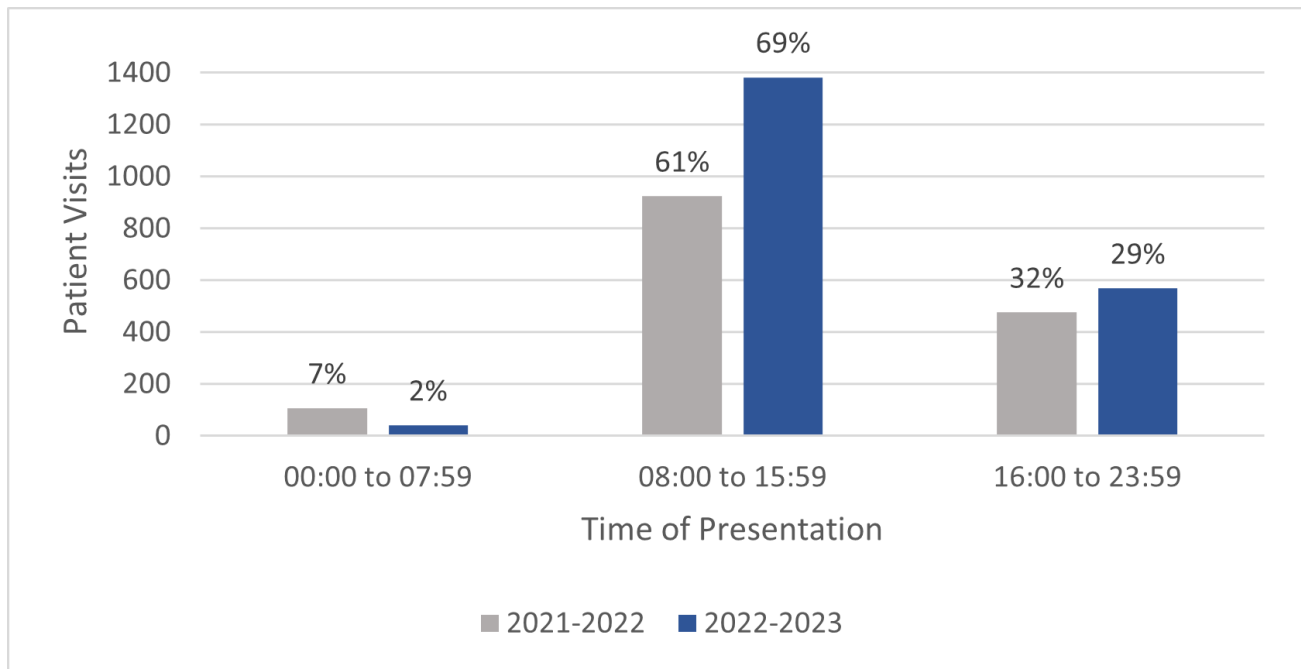
Figure 3. Total patient visits for the 2021-2022 and 2022-2023 fiscal years for each shift. Percentages are also displayed for the time intervals for each fiscal year.

	Total (days affected)	Full closures (days)	Partial closures (days)	Mean duration of partial closures (hours)
Weekend/Holiday	36	27	9	1.6
Weekday	35	14	21	3.8
Total	71	41	30	2.7

Table 1. Summary of service suspension data for the Notre Dame Health Centre ED between July 11, 2022, and June 30, 2023.

Month	Ratio (visits/hour)	Percentage of Hours Suspended
Jul-22	0.56	5%
Aug-22	0.67	13%
Sep-22	0.63	5%
Oct-22	0.53	19%
Nov-22	0.65	12%
Dec-22	0.43	29%
Jan-23	0.56	3%
Feb-23	0.39	13%
Mar-23	0.39	7%

Table 2. Visits per hour during which the ED was open and percentage of expected hours where services were suspended at the Notre Dame Health Centre ED from July 2022 to March 2023.

Partial Suspensions		
Start of Day	**End of Day**	**Middle of Day**
2	27	1

Table 3. Summary of time course for partial service suspension at the Notre Dame Health Centre ED between July 11, 2022, and June 30, 2023.

Discussion: Despite changes in the Notre Dame Health Center ED schedule and frequent service suspensions due to staffing challenges, overall visit numbers increased during the 2022-2023 fiscal year, suggesting service provision continued and local access to care was maintained. The increase in monthly volumes between the 2021-2022 and 2022-2023 fiscal years is an interesting trend when we consider that the volume increase continued after the Treherne site re-opened in January 2023.[8] This could also be representative of changing healthcare needs as a result of the COVID-19 pandemic.[11] Since in the past the Notre Dame ED shared a call schedule with Treherne the new more consistent schedule and increased volume could suggest that with regular ED hours those seeking care could do so more consistently at the same centre.[7] The initial increase could also suggest that service suspensions at other centres caused an increase in patients now accessing care at the Notre Dame Health Centre.[12] The increase in CTAS 4 presentations may represent a shift in care where acute cases preferentially seek care at regional sites with 24-hour coverage and additional services. Alternatively, a lack of access to ED services after 20:00 may have resulted in a deterioration of their condition leading to a more acute presentation at a regional centre with 24/7 ED services.[3] With limited resources this may reflect more appropriate use of a community ED, like the one in Notre Dame. Our work did not consider access to primary care which likely also plays a role.

Moving forward, looking at region-wide ED volumes so see if the volume trends seen at the Notre Dame Health Centre ED are similar to those at other sites across the region would be beneficial. This could characterise if the changes were seen at all sites or only at the sites where significant schedule changes occurred. The prevalence of seasonal illnesses should also be considered. Region-wide data could also highlight the effects that closing one ED has on neighbouring centres such as the Carman Memorial Hospital ED and the Boundary Trails Health Centre ED. When services are suspended patients must seek care at larger EDs that remain in operation, further increasing the patient load that other sites must address.[3] Other research has demonstrated how closures have a wide-reaching impact and how it is imperative to ensure that some redundancy is available in the system.[3,13]

Since 70 of the 71 suspensions were caused by a shortage of sufficient nursing staff needed to safely operate the ED a clear resource gap has been identified. Since the full day suspensions were more frequent on weekends and holidays solutions that target these temporal trends would likely be beneficial. Recruiting staff to work rurally has been a longstanding challenge however and other solutions should also be considered.[3] Considering visit volumes and prioritizing current staff resources to ensure coverage during busier times or reconsidering sharing staffing resources could be considered to improve patient access to healthcare resources. Literature suggests that developing a local strategy that is tailored to the unique circumstances at the Notre Dame Health Centre would be likely be beneficial.[1]

Partial day suspensions were more likely to occur later in the day when less patients typically presented. The data also suggests that closures that take place from 08:00 to 15:59 are the most disruptive since this is when patients most commonly seek care. Since closures during the 08:00 to 15:59 shift was the least frequent however, disruptions are already being minimized. Focusing on ensuring that service suspensions do not take place earlier on the in the day would help continue this trend. The small number of patients who presented overnight in the 2021-2022 fiscal year also demonstrates that closing the ED from 20:00-08:00 was a reasonable option. Given the finite nursing resources, maintaining the old schedule could have resulted in more schedule inconsistencies since more nursing duty hours would have been required. The schedule modification ultimately prioritised shorter but more consistent hours leading to a more stable schedule. Since full closures were more frequent during weekends and local primary care access was limited on weekends, gathering weekend volume data would play a vital role in further characterising the impacts of suspensions. Considering the role other options like virtual care may have in ensuring consistent access to same day primary care is also warranted.

The CTAS scores compiled demonstrate that more than half of patients had acuity levels of 4 or 5. These concerns can often be addressed in different settings such as in primary care and could suggest a lack of primary care access.[10,14] Thirty-seven percent of presentations in 2022-2023 had CTAS acuity score of 1-3 indicating urgent and emergent care needs for a significant portion of patients.[10] This highlights the need for maintaining access to emergency care in smaller rural communities like Notre Dame de Lourdes. Our data is limited as CTAS scores were not broken down by time. Identifying if trends exist regarding when acuity levels 1-3 patients are more likely to seek care is important to consider in fully assessing the repercussions of modifying ED availability. Ensuring that appropriate care is available when the most acute cases present is important in addressing rural health inequities.

Visits per hour and the percentage of total hours suspended were variable. This reflects the nature of an ED, where it is often difficult to predict patient volumes accurately.[15] Other research has demonstrated that travel time is a major influence in deciding where to seek care and could help explain why patients seek care locally despite an, at times, inconsistent schedule.[16] The monthly variation in the number of closures is also of interest since if these patterns repeat themselves in subsequent years, it could be used to predict times to prioritize for additional staffing. For example, in December 2022, 29% of expected hours were suspended which could suggest additional challenges during the holiday season when staff are more likely to be on vacation. Looking closely at staff schedules and seeing if this trend repeats itself in the future could help confirm this suspicion and assist in guiding targeted

recruitment and retention efforts.

While this study revealed many interesting findings it did have several limitations. This work only focused on the last two fiscal years, with a more detailed focus on the time since the schedule was modified. This is still a relatively new change and looking at the volumes and suspensions from a single year may not be sufficient. This short time frame could be subject to confounding factors that originated from the recent changes such as staff adjusting to these variations, and the community being unfamiliar with the service fluctuations. Continuing to monitor patient volumes and looking at changes to service suspensions in the coming years are still necessary. The data also lacked the granularity needed to determine the exact number of patients who presented outside of the current schedule and did not provide us with information on when the most acute patients, levels 1-3, were most likely to present. Subsequent research with a multi-year focus that addresses the limitations of this work would help further guide the efficient use of limited resources in rural areas.

Modifying the schedule allowed staffing resources to be re-purposed towards keeping the ED open when most patient seek care while ensuring that physician resources were still available for primary care. The previous schedule would have put significant strain on nursing resources and likely would have led to a more unpredictable schedule. Prioritising shorter but more consistent hours resulted in a more stable schedule in the ED. With this comes a better staff experience, more consistent patient care, and the potential for improved care such as through less interfacility transfers.[13] This work shows that despite a significant schedule change and suspensions the provision of care was still frequently available for the local community. Continuing to evaluate service availability and considering changes such as bolstered nursing resources when needed would help further improve health of the region, enhance the care experience, advance health equity, and bridge the inequities between urban and rural populations.[17]

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Community-based gender-affirming medical care

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Abstract

In Manitoba, extensive waitlists for gender-affirming medical care disproportionately affects rural residents.[1] Disparities arise due to limited approved providers and a concentration of services in Winnipeg. Patients pursuing gender-affirming surgeries are faced with further barriers in Manitoba Health's policies, which require a diagnosis of Gender Dysphoria by an approved list of health and mental health professionals for the procedure to be covered. This case explores a 20-year-old transgender male's successful gender-affirming care journey in rural Manitoba. The patient's journey, encompassing social, legal, and medical transitions, highlights the effectiveness of community-based primary care providers (PCP) delivering gender-affirming medical care.

From a broader context, the case report also delves into the heightened risks faced by transgender individuals, further emphasizing the need for accessible gender-affirming care. This report challenges the "approved provider" system arguing that it undermines the patient-physician relationship and contradicts Manitoba's self-regulated medical practice. This case study advocates for increased resources and policy changes to better serve Manitoba's gender-diverse population by underscoring successful gender-affirming care delivery in a community-based setting.

Keywords: gender-affirming care, transgender, health disparities, Manitoba

Introduction: Within gender-affirming healthcare in Canada, disparities continue to persist.[2] In Manitoba extensive waitlists and limited providers create significant barriers to accessing essential medical care for gender-diverse individuals.[3,4] This paper delves into the case of a 20-year-old transgender male navigating his gender-affirming care journey in rural Manitoba. Through his experiences, we explore the efficacy of community-based primary care providers (PCPs) in delivering comprehensive gender-affirming medical care.

Beyond the individual narrative, this paper contextualizes the broader healthcare landscape for gender-diverse individuals in Canada. Alarming statistics underscore the heightened risks of mental health struggles and suicidality within this population, highlighting the urgent need for accessible and gender-affirming medical services. Furthermore, the discussion delves into the systemic barriers perpetuated by Manitoba Health's "approved provider" system, which not only undermines patient-physician relationships but also contradicts the principles of self-regulated medical practice.

This paper advocates for tangible reforms in Manitoba's healthcare system. Proposals for increased resources, policy revisions, and enhanced medical education aim to dismantle existing barriers and foster a more inclusive and patient-centered approach to gender-affirming care delivery.

Case History: The patient is a 20-year-old transgender male living in rural Southern Manitoba who sought ongoing gender-affirming care from a community-based Primary Care Provider (PCP). The patient presented with a multi-year history of gender dysphoria, characterized by incongruence with their experienced/expressed gender, secondary sexual characteristics misalignment, and a strong desire to alleviate feminine voice and features.

The patient had initiated their social transition four years before finding a community-based PCP. They also attempted to seek out gender-affirming care in Winnipeg and endured an eight-month waitlist before having their intake appointment. This was followed by another five-month wait for an available appointment

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before being able to initiate testosterone treatment. Although the testosterone was initiated, the patient found it difficult to receive follow-up for ongoing adjustment. Once they heard a community-based PCP was available, they completely transitioned their care to their rural community.

Upon introduction, the patient used their preferred name and pronouns when meeting the community-based PCP. The patients' outward appearance was masculine, congruent with their described gender. Regular lab work was completed throughout this patient's treatment to track their testosterone levels. Routine follow-up was completed by the PCP to track blood pressure, potential side effects from testosterone, and the patient's well-being. The patient had support for ongoing titration of medications, management of side effects, and achieving further goals for masculinization through their PCP. Of note, the patient described how important it was for their breakthrough menstrual bleeding to be managed, which was handled in the community setting.

Not only did the bulk of their medical transition take place locally, but the patient also successfully went through their legal transition with assistance from the community-based PCP. The patient sought a legal name change to better represent their identity on their government-issued ID. This was initiated early in treatment and successfully completed after being connected with the community-based PCP.

As the final steps in the patient's gender affirming journey, this patient underwent gender-affirming surgery. The community-based PCP facilitated the surgical readiness assessment for the patient and provided necessary pre-operative evaluations prior to chest masculinization and complete hysterectomy surgeries which were successfully completed in Manitoba in early 2022 and early 2023 respectively. The community-based PCP was only able to assess and refer for procedural gender-affirming care as they were one of the few "approved providers" in Manitoba able to generate a referral for gender-affirming procedures.[5]

Patient Experience: In discussion with the patient about their experience receiving gender-affirming care outside of their home community compared to within their home community, several important factors were discussed. Of note, the lack of access with the treatments only being available in Winnipeg, the waitlist for treatment, and the financial burdens and time associated with the commute to Winnipeg were significant barriers in this case that were remedied by transitioning to community-based gender-affirming care.

When initially seeking gender-affirming care, one of the major challenges for the patient was that care was only available in Winnipeg, precluding the patient from initiating medical treatment until after the age of 18 despite their social transition. This delay was due to travel and transportation constraints experienced by the patient in their home community and was in part mitigated after the patient was able to relocate seasonally to Winnipeg for post-secondary studies and acquired personal transportation. After the patient-initiated referral, they spent over a year on the waitlist prior to initiation of gender-affirming care. The patient stated the long wait time was a significant challenge, in part attributed to their gender dysphoria and struggles with anxiety and depression, both of which significantly improved after initiating hormonal transition, and by later completing gender-affirming surgery.

Exclusively receiving gender-affirming care within Winnipeg presented a significant financial burden, geographic barrier, and added time commitment and stress for the patient. The patient detailed having to miss an entire shift of work whenever there was an appointment scheduled in addition to the cost of fuel and wear to the vehicle. An appointment in Winnipeg would routinely take three to four hours of allotted time for the patient, after considering the average travel time and appointment time. Conversely, an appointment within their home community would take an hour and could be easily scheduled around their work shifts. Given the extreme climate of Manitoba, adverse driving conditions would also need to be anticipated as severe weather could greatly impact their ability to arrive safely and on-time to appointments. Considering the financial strain, both through direct transportation costs and lost wages, as well as overall stress from the commute, the patient shared several pragmatic concerns in their ability to pursue gender-affirming care long-term if services remained limited to Winnipeg.

The transition to receiving gender-affirming care within their rural community addressed challenges and barriers that the patient faced by commuting to Winnipeg for treatment. Having a community-based PCP for gender-affirming care meant the patient was not required to routinely travel extended distances to receive care and they missed less work shifts, therefore alleviating the associated financial and occupational stress caused by commuting for treatment. In addition, the patient was able to interact more regularly and consistently with their community-based PCP compared to when travelling to receive care, resulting in a stronger patient-physician relationship which the patient felt positively impacted the quality of their care.

Throughout our discussion the patient reiterated that having community-based gender-affirming care through a community-based PCP notably improved their overall well-being and eased both psychological and financial stress throughout their transition. Additionally, the community-based PCP helped by fostering a more inclusive and accepting home community by visibly supporting and advocating for gender-diversity through various local networks. Living within a rural community can often be an isolating experience for gender-diverse individuals, and the patient noted having a special appreciation for how their PCP was part of their home community and supported their efforts throughout their transition.

Discussion: In Canada, suicide ranks as the second leading cause of death among adolescents and young adults aged 15-34 years.[6] A study conducted in 2022

focusing on Canadian adolescents aged 15-17 revealed transgender adolescents showed 5 times the risk of suicidal ideation and 7.6 times the risk of a suicide attempt than when compared with cisgender, heterosexual adolescents.[7] These findings are supported by a meta-analysis and systematic review that found in the world's transgender community, the prevalence of suicidal thoughts overall was approximately 48%, with 39% in the past month, 45% in the past year and a 50% lifetime risk.[8] These alarming statistics underscore that transgender and gender-diverse persons are part of a vulnerable population and further substantiate why sexual orientation, gender identity and gender expression are protected classes under the Canadian Charter of Human Rights and Freedoms.

A sampling study completed in Ontario, Canada, highlighted the positive impact of access to medical transition, broadly defined as hormonal and/or surgical gender-affirming care. The study demonstrated a 62% relative risk reduction in suicidal ideation among transgender individuals who had undergone medical transition compared to those awaiting transition.[9] Additionally, this study estimated that access to medical therapy, when desired by patients, would correspond to preventing 170 cases of suicidal ideation per 1000 transgender persons and further prevent 240 suicide attempts per 1000 transgender persons with suicidal ideation.[9] A systematic review looking at psychosocial functioning post gender-affirming hormone therapy in transgender persons found consistent evidence that both feminizing and masculinizing hormone therapy resulted in decreased psychological distress and decreased depressive symptoms in the transgender population.[10] These studies support that receiving accessible and timely gender-affirming care significantly improves the overall mental health and quality of life of gender-diverse individuals. Studies support that risks of depression and suicidality may be mitigated with receipt of gender-affirming medications over the relatively short time frame of 1 year.[11]

A cross-sectional survey completed in 2019 looking at healthcare access for transgender and non-binary people in Canada found that Manitoba respondents who were receiving but not completed gender-affirming care had an adjusted predicted probability of 48.9% of being on a waitlist for gender-affirming care, where gender-affirming care was defined as including mental health assessments, puberty-blockers, hormones or surgery.[4] This means about half of Manitoban gender-diverse people seeking gender-affirming care are on waitlists for gender-affirming surgery, hormonal transitioning, and mental health assessments. Furthermore, barriers such as transportation costs and time off work to attend appointments further compounds the inaccessibility of care for patients who may otherwise have minimal to no other resources.

The health disparities experienced by gender-diverse individuals in Canada has necessitated research into the medical education of physicians of gender-affirming medical care.[2] When surveying current medical students across Canada the majority expressed that they felt insufficiently prepared to address the health concerns of gender-diverse individuals and therefore reported a lack of comfort in providing care to the gender-diverse community.[12] This is reflective of the limited training in medical school and residency,[12,13] which may in turn leave local Manitoba physicians feeling ill-equipped nor supported to include gender-affirming medical care within their practice. This contributes directly to the lack of access to practitioners that many gender-diverse Manitoban's contend with, and the affect is compounded when considering the overall physician shortage experienced by Manitobans.[3]

Despite the clear benefits, gender-affirming care remains a limited resource in Manitoba. Presently gender-affirming care, including hormone initiation and management, is being initiated by select providers, contributing to the long wait times experienced by patients seeking gender-affirming care.[4] This has occurred even though gender-affirming hormone therapy can be safely initiated and monitored within the primary care setting and PCPs are an ideal choice to support patients longitudinally. This is in part attributable to the unnecessarily restrictive steps required to support a patient for gender-affirming care. Manitoba Health has approved certain health professionals (physicians) and mental health professionals (physician or psychologist) who can assess the candidacy of patients seeking "transgender health procedures" and can make referrals for "transgender surgery." Only then will Manitoba Health provide coverage for these medically required services. However, to determine if a transgender health service is medically required, and therefore covered by the provincial health insurance plan, Manitoba Health requires the following: 1) "A referral letter from a Manitoba Health-approved physician to the surgeon that provides an assessment of the patient's candidacy for surgery and recommends the particular surgery as treatment for their specific symptoms of gender dysphoria;" and 2) "A brief letter from an Manitoba Health-approved mental health professional that provides a diagnosis of gender dysphoria, and advises on the appropriateness of surgery to treat the patient's specific symptoms of gender dysphoria." Manitoba Health has also stated "An interim agreement is currently in place to reduce the current requirement of two different Manitoba Health-approved professionals to one Manitoba Health-approved provider for adults, when the Manitoba Health-approved provider has been approved as both a mental health professional and a health professional for the following services only: chest masculinization, chest feminization, and laser hair removal services." Currently, there are only four locations with 'approved' health professionals in Manitoba, two are located in Winnipeg, one in Brandon, and one in Portage la Prairie.[5] Manitoba Health has mechanisms that determine which physician providers are 'approved'; one must be a health professional (physician) and then apply for approval from the government with separate applications and reviews for adult patients versus chil-

dren and adolescent patients. The "approved provider" list means a patient's family doctor, who has a longitudinally established relationship with the patient, is not able to generate a referral to a surgeon for many gender-affirming procedures unless they are one of the few "approved providers" by Manitoba Health. As a result, even if a provider supported a patient with hormone initiation and monitoring, they are not eligible to refer them directly for a gender-affirming procedure. This has further perpetuated the notion that gender-affirming care is outside the scope of most primary care providers.

The lack of providers and geographical restrictions creates unnecessary obstacles for gender-diverse patients to overcome. An obvious step to address this would be to review Manitoba Health Insured Benefits "approved providers" system. Community-based PCPs must be able to generate referrals for gender-affirming procedures, which is required for Manitoba Health to provide insurance coverage for patient seeking gender-affirming surgery. Due to the "approved provider" system it often requires another referral to be made and further extends the wait period for gender-diverse patients. These policies can undermine and damage patient-physician relationships, discourage community-based physicians from providing gender-affirming care, and create unnecessary backlogs in Manitoba's taxed healthcare system.

The "approved provider" list is both concerning and does not reflect how we practise medicine in Manitoba. Medicine is a self-regulated practise, and The Regulated Healthcare Providers Act established by the Manitoba Legislature gives authority to The College of Physicians and Surgeons of Manitoba in the development, establishment and maintaining standards of practice and ethics by members.[14] The "approved provider" list is at odds with this, as an external agency should not be determining which physicians can provide referrals for gender-affirming surgery under threat of Manitoba Health authorizing coverage for gender-affirming surgeries versus not. As stated earlier, gender-affirming care is well within the expected scope of practise of PCPs and therefore generating referrals for gender-affirming surgery should fall within the scope of practise as well. It is discriminatory that this requirement of an "approved provider" adds an unnecessary barrier to accessing gender-affirming care.

Furthermore, the "approved provider" system is focussed on gender-diverse patients being required to complete mental health assessments as Manitoba Health requires patients to receive a diagnosis of Gender Dysphoria for gender-affirming surgeries to be funded. The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition details diagnostic criteria for Gender Dysphoria, contributing to the narrative that being trans is a psychiatric diagnosis. The "approved provider" requirements set by Manitoba Health continue to require gender-diverse patients to 'prove' that they have a psychiatric diagnosis before being able to seek aspects of gender-affirming care. This continues to pathologize trans and gender-diverse persons by relying on the false assumption that psychological distress is an inherent aspect of being transgender and that every gender-diverse persons' experiences are the same. Advocacy groups have pushed for a change in the health care model of gender-diverse patients, moving from psychiatric assessment process to an informed decision-making approach.[15].

Conclusion: Gender-diverse individuals are a vulnerable population at increased risk of self-harm and suicide attempts when compared to their peers. Research supports that when transgender and gender-diverse persons receive gender affirming care, we see substantial decreases in suicidal ideation and suicide attempts as well as improved quality of life. Gender-affirming care includes but is not limited to access to safe and inclusive healthcare providers, gender-affirming hormone therapy, and gender-affirming surgical procedures.

Increasing access to gender-affirming care within Manitoba through improved medical school education for future physicians and removal of the "approved provider" system would help close the gap in care for this vulnerable population. Both aforementioned factors would contribute to more PCP's including gender-affirming care within their practises. Additionally, it creates a more inclusive environment for both physicians to provide care and for patients to receive care, fostering more long-term patient-physician relationships and improving continuity for transgender and gender diverse patients; all factors that are shown to improve quality of care.

The patient case study discussed in this paper shows that gender affirming care can be handled successfully within a community-based healthcare setting. This case highlights the potential benefits of utilizing community-based PCP as an avenue for providing gender-affirming care within a rural community setting. Increasing resources for community-based gender-affirming care, removal of the approved providers list, and improving medical education of gender-affirming care offers feasible avenues which both increases access and improves care for our Manitoba gender-diverse and transgender population.

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Patient and/or caregiver experiences of interprofessional team-based primary care

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Abstract

Due to its current fragmentation, much of the current work being done to reform primary health care is focused on creating continuous, integrated care that incorporates the expertise of professionals from across different professional disciplines. Although attractive in theory, the reality of implementing such change often results in some patients 'falling through the cracks,' – that is, not receiving the care they need due to getting lost between different healthcare providers. The only way for these situations to come to the forefront is when individuals and researchers stop to listen to the voices, stories, and experiences of patients and their caregivers. This research sought to better understand patient/caregiver experiences of interprofessional, team-based primary health care. After conducting semi-structured qualitative interviews using interpretative phenomenological analysis, three key themes emerged regarding participant experiences: communication (between patients and their providers), functioning/activities (of the providers direct towards the patient), and roles (of the each of the different healthcare professionals). Communication followed a gradient, with some respondents not aware of any communication between providers, while others had a clear understanding of what occurred. Interprofessional functioning in primary care was perceived as positive as participants felt they had access to a greater array of opinions. The roles of each healthcare provider were generally known by participants. Future research is needed to complement this work with the providers' perspective to provide a more complete picture of interprofessional primary care.

Addressing complex patient needs has become a key area of focus for healthcare systems in Canada. Reform began by introducing interprofessional (IP) teams of providers into health settings[1]. In theory, having multiple providers can seem favourable as it increases accessibility, efficiency, and can provide holistic care[1]. Yet, it has been noted that introducing more than one provider can lead to continuity problems[2]. Patients can get 'lost' between providers, which leaves their health concerns unaddressed. Hence, primary care has been an emphasis when studying integrated care, as these settings are often the first point of contact for patients and act as 'threads' to keep care continuous across the vast healthcare systemi[1]. This study aims to understand patient and/or caregiver experiences of receiving IP team-based primary care.

Keywords: interprofessional, primary care, team-based, experiences

Conflict of Interest Statement: The authors declare no conflict of interest.

Methods

Setting

Recruitment was done at the Northern Connections Medical Clinic, located in Winnipeg, Manitoba, as well as through the Manitoba Primary and Integrated Healthcare Innovation Network (MB PIHCI) email newsletter. Northern Connections is an interdisciplinary primary care clinic and teaching site which integrates family physicians, family medicine residents, nurses, a registered dietitian, a pharmacist and a social worker. MB PIHCI is a network of patients who have identified themselves as being interested in being recruited for future research.

Recruitment and Sample

Meetings were held with clinic staff to inform them of the study. Staff were supportive of the initiative and were provided with a recruitment script. Study posters

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were also displayed. The researchers went to the clinic on two separate afternoons to speak to potential participants and conduct on-site interviews. Any interested participants recruited from MB PIHCI contacted the researchers directly by email to arrange for a virtual interview.

Convenience sampling of patients and/or caregivers was used to select participants based on those who agreed to an in-person or virtual interviews. All successful participants had to have been receiving (or caring for someone who was/is receiving) IP, team-based primary care from at least two providers from different professional disciplines. Written consent or verbal assent was obtained. All participants were given a $20 gift card to thank them for their time.

Data Collection and Analysis

Interviews were recorded and transcribed by Zoom or Microsoft Word software. The data was anonymized using a date-numbering system and stored on a secure hard drive. Seven key domains were prompted during the interview: 1.) general definition and role of the team, 2.) family caregiver involvement (as applicable), 3.) accessing other team members, 4.) personal and professional interactions, 5.) access and coordination across the continuum, 6.) patient-centred care processes, and 7.) team and individual responsiveness. Refer to Appendix 1 for the complete interview guide.

The data was analyzed using interpretive phenomenological analysis (IPA). IPA is a qualitative methodology that concerns itself with the examination of the personal and lived experiences of participants by looking at each individual interview/case in detail for key themes and codes[3]. Once each participant's lived experience has been examined, IPA looks for patterns across all the interviews[3].

This study has been approved by the Health Research Ethics Board at the University of Manitoba, Research Ethics Bannatyne Campus, Ethics number: HS25146 (H2021:318). Additional approval from Shared Health was obtained to conduct the research at Northern Connections Medical Clinic.

Results

A total of seven interviews were conducted, two on site at Northern Connections Medical Clinic and five done virtually over Zoom. The average age of the participants was 58.1 years with five being between 63–90 and the remaining two being 22 and 28. One identified as a male and six as female. Two participants were caregivers to a family member and five were patients. The participants averaged 8.4 clinical visits within the last year and took an average of three medications per day. The primary healthcare providers (PHC) seen by the participants included family physicians, a sports medicine physician, physician assistants, a geriatrician, nurses (including registered nurses, nurse practitioners, and psychiatric nurses), dietitians, an occupational therapist, a social worker, a respiratory technologist, a psychologist, and a massage therapist.

The Strata of Communication

On the Other Side of the Door

Participants described not knowing about the communication between providers because much of it happened 'on the other side of the door' – that is, it did not happen during a time/place that allowed the participant to be aware of it. Participant 15-1 indicated that they did not know if a report was sent after the initial referral from the physician to the dietitian to update the other provider. The feeling was also described by a caregiver who was not present in the same appointment when information was being conveyed by a healthcare provider. Even when the two providers were physically present in one appointment, communication was sometimes done on the other side of the door, leaving the patient unaware of what was being discussed. When asked about whether they saw the interactions between two providers providing the care, participant 14-1 responded "not really, 'cause usually they leave the room and talk." When asked about whether they observed two providers coming to a common decision about their care or having differing opinions, participant 25-1 expressed that it was something they would not be aware of, and that decisions were simply communicated to them.

Assumptions of Communication

Communication between providers was assumed (but not confirmed) by some participants. For example, participant 25-1 indicated that after they no longer had need for home care, they had "presumed" that the clinic they were going to was notified of the change. In other circumstances, patients were aware that communication should have taken place, but they did not observe it themselves and were left presupposing that it had happened. It was often communicated with participants when they were being referred by one provider to another, but whether the referral was sent and reviewed, and how it was sent was often unknown. Participant 24-1 indicated that their provider "says she's going to do it [send a referral], and I assume that she will." In another instance, when commenting on the interactions between the nurse and the physician in the same clinic, they mentioned that "I just don't know specifically ... I assume that she actually spoke with her personally, but it could have been by telephone it could have been an email ... there was communication, I just don't know how it happened." Similar sentiments were echoed by participant 25-1, who could not cite "a specific example of how that's done, or how [they knew] about it" with regards to the communication between the physician and physician assistant, but who had "expectations" that they communicated as it was their "impression."

These assumptions about providers dialoguing with each other were often made by participants due to diverse observations of other aspects of their care. Par-

ticipant 14-2 cited physical co-location between the occupational therapist and doctor as the reason they surmised that there were interactions between them regarding their care. Participant 24-1 anecdotally described their experience of communication between the nurse and the physician by saying that they knew "that the nurse noticed something because she mentioned it to me. So, I'm assuming that she consulted with the doctor later because the prescription was telephoned into the pharmacy that I use."

Based on the conversations participant 25-1 had with each provider separately, they deduced that the physician and physician assistant were communicating. Each provider was aware of 25-1's situation, it was clear to them that they were communicating "back and forth."

Patient as Intermediary, Caregiver as Coordinator

It was found that as an intermediary, patients are sometimes the ones monitoring the communication between providers (such as following up on a referral) or facilitating the exchange of information between providers (informing one provider of what was done/discussed with another provider). Participant 24-1 indicated that once a referral is sent, they will follow up if they have not heard anything within three months to check "with the office just to make ... sure the referral actually went out." When steering between a family doctor and sports medicine doctor, participant 16-1 recalled having to repeat their medical history to both practitioners and being asked similar questions by both regarding a stress fracture that they had sustained. Although it is sometimes normal for different providers to ask similar questions, this patient felt that the repetition was an indication that their providers had not communicated adequately regarding their case. In addition, one of the providers specifically asked the patient to independently follow up with their family doctor regarding some concerns around blood work and medication interactions. When the patient went to go see the family physician, they discussed "what [the] sport medicine doctor was concerned about." The participant cited being the one to bring this information forward to their family physician. Participant 16-1 had similar experiences with their psychologist and family physician, stating that: "I'm kind of relaying whatever the other person says, and any information I get from my GP I usually bring to my psychologist to work through. But that's all done myself." It should be noted, however, that participant 16-1 also cited that being an intermediary between different providers "empowered" them to "take that step in [their] own health." They believed that it was their job to follow up with the providers and that being able to repeat their medical information allowed them to explain their condition in their own words instead of through a clinical note.

For caregivers, being an intermediary also manifested itself as being a coordinator for the care of their family members. When asked about whether they felt as though their family member had fallen through the cracks, participant 21-1 stated that it would be more difficult to navigate the healthcare system for those not familiar with how it operates. It would be more likely that 'balls would drop' in between the cracks. Caregiver 15-1 also felt as though they "held the pieces together" and within their parents' specific clinic, were accepted as "part of the care team." They also described their role as being a "connector" between the doctor and the dietitian. Upon reflection, they reported that they were not sure if the interactions between the dietitian and physician would have "gone very far" had they not been acting as a caregiver/connector and "been the dialoguing person" between the two of them. It was also speculated that because they were doing a lot of the "collaborating" between the providers, there was not as much collaboration between the providers themselves.

Evidence of Communication

Clear communication between the different health care providers was made evident to patients in a variety of ways. For some, the providers explicitly told the patients of the communication that had taken place. Participant 14-2 recounted this when describing the method by which the occupational therapist told them that they were keeping the doctor updated. For multiple participants, provider dialogue and the passing on of information was done through clinical notes. The occupational therapist was also making notes that the physician could see later, another way that participant 14-2 knew that there were exchanges happening between the two of them. Information on medications was communicated through clinical notes for participant 16-1 and any background information on the patients was relayed through the patient chart according to participant 25-1. When two or more providers were both in the room during a patient's appointment, communication was also evident to the participants. Participant 21-1 described it as having "both players on the team [having] the same information." This was deemed beneficial because if one provider needed something followed up on by another, they would both be "working from the same starting point." In participant 14-1's experience, when two providers were in the room, one was taking notes and the other was speaking to them directly. They felt as though the right questions were being asked when it was done this way.

In a more complex pathway, communication was described as a "chain" by caregiver 21-1. Between the nurse and the geriatrician, the nurse would do an assessment of the patient before the appointment, relay the results to the geriatrician, and then they would both be present in the appointment room together. In other circumstances, the nurse would follow up with the patient on their medications and then communicate that information to the geriatrician as needed. Some clinics have more robust communication – for example, one caregiver (15-1) was aware that the clinical staff on site had large, regularly scheduled team meetings, as was told to them by one of the nurses. They would discuss each of their patients amongst each other, and the caregiver stated that: "I never felt that I had to call the doctor and tell her anything because she would

have heard it from, from the other doctor, as they were discussing the case very often."

Functioning/Activities

Ease of Co-location

Three different participants (15-1, 21-1, 24-1) commented on the benefits of all their PHC providers being at one location. Knowing where to go each time and what was going to happen, rather than having a new experience each time they saw a different provider, was perceived as easier for the patients by their caregivers. Not only did it allow for many different services to be accessed and coordinated in one spot, but it was also said to lower anxiety and aid patients who may get their sense of location distorted. In one instance, the familiarity grew to the point that the atmosphere at the clinic "felt like family" (15-1). Participant 24-1 had a differing opinion as to why different providers being in the same place was beneficial. They believed that "close physical proximity makes a difference because they're more likely to be reminded that they have to pass the information along." They stated that busy providers can be reminded to exchange information when they see other professionals.

Inter-provider Expertise

Positive comments were made about the diversity of perspectives that interprofessional collaboration (IPC) brings to patient care. There was confidence that patient concerns were being looked at from "different angles" (16-1) because each provider focuses on different aspects of health. In addition, there was a consensus that each professional cannot know everything, making the diversity of providers an asset to patients.

Addressing Patient Needs

When asked about the ability of IPC to provide patients with care that adequately addressed their needs, perceptions were positive. When speaking about their family member, caregiver 15-1 mentioned that having more than one PHC provider allowed them to "[look] after more of their basic needs than if they would have been in a setting where there was only a doctor." One caregiver (21-1) attributed the patient's needs being met to providers having access to the same information when they were both present in the appointments, stating that they "valued that both of [the providers] did have access to information because I think that really does help provide better care. If [providers] have their information ... in silos and don't connect, things get lost." The same participant also indicated that having the professionals in the room at the same time made their family member more comfortable sharing their concerns, providing a more accurate picture of their medical condition. It was considered a safe space where they could ask questions. With all relevant providers in the room at the same time, participants expressed not having to repeat their medical information, making the process simpler.

When asked why IP primary healthcare (PHC) was used in their care, participants perceived two distinct reasons. Some believed IPC was utilized because providers needed the expertise of their colleagues. Others believed IPC was employed because one professional needed the support of another due to time constraints. This meant that more professionals were needed to provide the patient with the care they needed. For example, participant 21-1 indicated that the nurse conveyed certain information about a cancer diagnosis because the doctor could not be present at the time. Similar observations were mentioned by two other participants who talked about how providers often do not have the time to do everything the patient needs. The role of professions like that of the physician assistant was perceived as being in support of the doctor if they could not take on a particular task. Any teamwork that participant 14-1 saw between the physician and physician assistant was them dividing tasks, such as one provider making notes during the appointment while the other was speaking to the patient and asking them questions. This complements the experience of participant 14-2 who stated that the physician often relied on the dietitian to provide support to the patient regarding their diet, as well as the occupational therapist to assist the patient with managing their pain.

Reference Providers

Despite the benefits of having an IP group of providers looking after their care, it was also revealed that one provider (often the physician) is seen as the most trusted for the participant and was often the one leading their care. For example, when opinions differed between a physician and a dietitian, participant 14-2 trusted the physician over the dietitian, stating that: "maybe, Dr. X knows ... exactly ... what to look for as a doctor." There was also a preference towards specialist physicians for health conditions that were perceived by the patient to be more niche. Participant 16-1 mentioned that they were more confident in going to see a sports medicine doctor rather than their general practitioner for an issue related to their foot, indicating that they would not have been "confident going to [their] family doctor for a stress fracture or an orthopedic related injury." In particular, family physicians were found to oversee a patient's care, with participant 21-1 stating that: "it was a family doctor that was sort of in charge of all the care."

Roles

Many participants could clearly articulate the role that each provider played in their care, citing specific examples related to their diagnoses. However, it was noted that many participants did not know the exact role or title of the provider they were seeing. This was most common among the different nursing specialties. Participant 15-1 stated that they saw "some nurse" when asked about the different providers they interacted with. Participant 21-1 did not know whether the nurse they were seeing was a nurse practitioner or an advanced practice nurse, and participant 24-1 could not tell whether their nurse was a nurse practitioner or a

psychiatric nurse. When asked about their role in providing care, participant 25-1 was unable to state what the role of the nurse was in the home care process. The same participant had a limited understanding of the role of the physician assistant, assuming that by virtue of their title, they were accountable to the doctor.

Discussion

Roles, functioning/activities, and communication were the three key themes that emerged from this research. Within communication, four main strata were uncovered: on the other side of the door, assumptions of communication, patient as intermediary/caregiver as coordinator, and evidence of communication. Preliminary research from Denmark on collaborative communication (CC) between general practitioners (GP), care managers (CM), and psychiatrists during a mental health intervention uncovered additional strata of communication that exist between providers[4]. Communication was categorized as either making a report (a transfer of information from one professional to the other), communication by proxy (one provider attending a meeting and briefing the providers not in attendance), and communication that develops as a result of shared knowledge (using the information from the other provider to arrive at a more complete perspective of the patient during a peer-to-peer discussion)[4]. Communication via making a report and by proxy were observed. For example, participant 14-2 noted that communication between the occupational therapist and physician often occurred through clinical notes, and participant 16-1 noted that any updates regarding their medications were often communicated by the doctor via notes as well. Information was also shared by proxy, with caregiver 21-1 describing information transfer from the nurse to the geriatrician as being like a 'chain'. The nurse would often meet with the patient first to gather the information that would then be relayed to the doctor (who was not present during the first half of the appointment). Communication that develops because of shared knowledge was rarely experienced. Although participant 15-1 explained that they were aware of regularly scheduled meetings that happened between the doctor and the nurse, they could not comment on how the providers were using the information from other providers to arrive at a more complete perspective of the patient. They merely described that these meetings would be an opportunity for information to be shared by proxy, as described by Overbeck et al. (2019)[4]. Similarly, other patients that experienced communication between providers only saw it as a means of sharing information or as a vehicle for dividing the workload (14-1, 16-1, 25-2). Even if communication did develop because of shared knowledge, none of the patients were privy to that information. Speculation as to why that was case can be difficult to determine, but it may be because it either did not happen between providers, or if it did, it was not shared with the patient.

It should also be noted that ideal communication or activities as defined in the literature may not be applicable in practice for a variety of situational and interpersonal factors. For example, time is often limited during appointments, making robust communication pathways between an IP group of professionals and the patient difficult and unsustainable. Findings from Overbeck et al. (2019)[4] confirm this, citing that care managers sensed that GPs wanted reporting systems that did not take long but that still provided the relevant details. Depending on the medical condition being addressed, more than one provider might not be needed to care for the patient. Judgements around what warrants an IPC versus single provider care are likely made by the provider, and more research is required to determine the nature of such decisions. Despite what is recommended in the literature, some providers have actually been found to prefer more "informal, unplanned communication 'in the doorway' because they felt this was flexible and reflected their working style"[4]. Patient preferences must also be considered. Depending on their education, familiarity with the healthcare system, and health status, patients may refuse or feel no need to discuss their medical conditions with another provider[5]. Their cognitive ability to repeat their medical history may also have implications for the communication that happens both during and after an appointment[5].

To improve patient-centred care, continuity of care should be considered with regards to the functioning within PHC[6]. Defined as the extent to which distinct healthcare events are experienced as cohesive for the patient, continuity of care is often broken down into three key areas: informational continuity (providers know what has happened previously), management continuity (an agreed upon plan), and relational continuity (patients knowing who will care for them in the future)[7].

Informational continuity is the common link between one patient and their various providers[7]. As was discussed prior, the degree of communication required between providers depends not only on what may be recommended in the literature, but on several factors specific to each individual. Whether or not patients have to repeat their medical history (and their desire to do so) is often implicated in informational continuity. For example, patient 16-1 felt empowered when they would repeat their history to more than one provider, citing that it felt as though it was their responsibility to do so. This was a sentiment shared by caregivers as well. 15-1 felt that they were often 'holding the pieces together' of their family member's care, which made them feel like a member of the care team. Despite these circumstances, many patients were often not aware of communication that had or had not occurred between their healthcare professionals. It was assumed or inferred based on external factors, such as when patient 14-2 assumed that the doctor and the occupational therapist communicated simply because they worked in the same office. This was the same for caregiver 25-1 who assumed that the clinic was informed when home care for their family member was stopped. In-

formational continuity, or a lack thereof is perceived differently by different patients/caregivers, and largely depends on their capacity and willingness to be the intermediary.

Management continuity involves delivering flexible and timely healthcare services in ways that complement each other and reflect a clear plan[7]. These findings revealed that patients perceived two reasons that an additional provider was required for their care. Either more expertise was needed (such as the doctor relying in the dietitian and occupational therapist to provide more support to patient 14-2), or the referring provider did not have enough time (such as in the case of participant 21-1 where the nurse conveyed information regarding the diagnosis because the doctor could not be present). More research is required to look at the different circumstances in which another professional is utilized for their knowledge/skills versus time constraints. In situations where management continuity is broken (such as when two providers have different opinions), the findings of this current study suggest that patients often defer to one provider, which is often the physician. This was discussed in greater depth in the Reference Provider section of the results. Deferring to a single provider is likely done because patients need to feel that they have one person who is in control to help mitigate the dissonance they may be experiencing. Despite its function, this may lead to the construction of hierarchies with the physician on top. More research would be required to explore this phenomenon further.

Relational continuity provides patients with a sense of "predictability and coherence"[7] when the same providers are seen over long periods of time and ongoing relationships are established. This level of continuity may not always required for every patient, as it depends on their health condition. For example, someone who is young and healthy and only interacts with the healthcare system sporadically for routine checks is less likely to need an IP group of providers looking after their care. This compares with someone who has a chronic condition with many comorbidities and requires more healthcare services, a larger number of healthcare visits, and a greater diversity of providers. Further research to explore the extent of the need for IPC given the complexity of patient cases would be an asset to the literature.

Although the results highlighted four strata of communication, four domains of functioning/activities, and information regarding roles, optimal communication, functioning/activities, and roles were things that participants could not speak to. This research focused solely on patient/caregiver experiences, which are limited in only being able to describe what happens on one side of the door. That is, there might be more collaboration between providers that was not described by this research because of its emphasis on patient perspectives. More research is needed to complement this work, using provider perspectives to give a clearer understanding of what happens on their side of the door, as well as the qualities, infrastructure, and activities needed for optimal collaborative practice in primary care.

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Appendix 1

Interview Guide

Eliciting perceptions as well as substantive, concrete examples of team-based care and how it was experienced in a primary healthcare setting.

1. **General definition and role of the team**

   a. Can you tell me about all the different health care providers you see and what role they play in your care?

      i. Tell me about how those people come together to solve your problems? Was the advice the same? Were they talking in the same way? Did they have the same info and the same understanding of what was going on?

      ii. Did they solve your problems?

      iii. Do they address your needs?

2. **Family <u>Caregiver</u> Involvement (as applicable)**

   a. How does your role as a caregiver for your family member/friend interact with the role/function of the members of the healthcare team?

      i. Do you have input?

      ii. Do they take your concerns into account?

3. **<u>Accessing</u> other Team Members**

   a. Do you feel that you are able to access other healthcare providers in a timely manner? Please explain why or why not.

      i. Are you given adequate information on different providers?

      ii. Do you know what other providers do outside of the ones you are currently seeing?

4. **Personal and Professional <u>Interactions</u>**

   a. How well do the interprofessional providers that provide care to you interact with/communicate each other?

      i. Do they communicate often?

      ii. Do you have to repeat your medical history each time?

      iii. Are they properly briefed on your case?

5. **Access and <u>coordination</u> across the continuum**

   a. Do you feel that your health care is continuous/coordinated? Please explain why it is, or is not.

      i. Do you get your test results and are your providers aware of your results?

      ii. Does your primary care provider know about the other appointments you have had and the outcomes of those appointments?

      iii. Do different providers give you different opinions?

      iv. How do you know that a referral has been sent and that you have an appointment with a different provider?

      v. Do you feel "lost" between the cracks of the healthcare system?

      vi. Think about a time when you were sent to get a test result back: did you get results fast, etc.?

6. **<u>Patient-centred</u> Care Processes**

   a. If you needed to see another health care provider, is that another appointment or would you have same-day access to a consultation? How far would you have to travel to see another health care provider? How convenient is it for you to see another health care provider?

        i. Have you encountered a time when you needed to see another provider, tell me about that experience?

    b. What role does finances or insurance coverage have in being able to access other team members?

    c. If you experienced limitations, what other options were available to you?

    d. Do all of the different team members provide information to you? Are your questions answered?

    e. Were you usually aware of the next steps in your care? The overall plan? Did you feel like the care you would receive from other health care providers was well mapped out?

7. **Team and Individual Responsiveness**

    a. How timely are your healthcare providers in responding to your healthcare needs, either minor or urgent (non-emergency) concerns?

        i. What do you do when you have a minor injury?

        ii. What do you do when you have an urgent concern that does not need hospitalization?

8. **Wrap up**

    a. Is there anything that has come to mind that you would like to go back to, share or discuss/question further?

Appendix 2

Consent Form

Patient and/or Caregiver Experiences of Interprofessional Team-Based Primary Care

Student Investigator:	Miray Eskandar
	Rady Faculty of Health Sciences
	c/o P219 – 770 Bannatyne Ave.
	Winnipeg, MB R3E 0W3
Supervisor:	Dr. Gayle Halas, Assistant Professor
	Rady Chair Interprofessional Collaborative Practice
	Dept of Family Medicine Research Office
	P219 – 770 Bannatyne Ave.
	Winnipeg, MB R3E 0W3
Funder / Sponsor:	Not Applicable

You are being asked to participate in a research study involving participation in an interview. Please take your time to review this consent form and discuss any questions you may have with the student investigator.

Purpose of this Study

This research study is being conducted to provide a better understanding of patient and/or their caregivers' experiences of team-based, primary health care in a large primary care clinic based in Winnipeg, Manitoba.

Participants Selection

A total of 20 individuals from one clinical practice site will be asked to participate. The clinical practice site is the Northern Connections Medical Clinic.

Study Procedures

The method of data collection for this study will be through one-to-one interviews lasting approximately one hour. The interview will be conducted by Miray Eskandar, who will ask you to complete a short demographic form (approximately 5 minutes) followed by a number of questions regarding your experiences with team-based care.

The interviews will be conducted online or in-person at Seven Oaks General Hospital, based on each individual's preference and in compliance with pandemic-related regulations (evidence of vaccination, symptom-free, wearing a mask and physical distancing). The interview will be recorded and transcribed by a professional transcriber, who will sign a form stating that he/she will not discuss any item on the tape with anyone other than the researchers.

Your name will be removed from all the transcripts. The audio will be stored securely in the Dept of Family Medicine Research Office (with Dr Halas) after being transcribed. Tapes will be destroyed after the analysis is completed and the transcripts will be deleted at the end of the study. If you would like to review your transcripts, you can arrange a time with Dr. Halas.

If you decide to participate in the study, a summary of the study will be provided to you on request.

Risks and Discomforts

There are very few risks for participating in this study. If at any time during the interview you feel uncomfortable with the questions being asked, you can choose not to answer those questions without any negative impact. You are also encouraged to contact any member of our research team should you experience any negative feelings after the interview. If you have concerns with the care provided at the clinic or have questions regarding your ongoing care, you are encouraged to speak with your primary care provider(s).

Benefits

There may be no direct benefits to participating in this study. The information from this study will be summarized and may be used to develop initial recommendations for enhancing the quality of team approaches to patient care.

Costs

There is no cost to you to participate in the focus group.

Payment for Participation

You will be given a $20 gift card in appreciation for your time to complete the interview. Any incurred parking expenses will also be reimbursed.

Confidentiality

We will do everything possible to keep your personal information confidential. Your name or other identifying information will not be used or revealed. A list of names and addresses of participants will be kept in a secure file, separate from any data. Audio files of the individual interview will be typed and used to prepare a report. The audio files and typed notes will be kept in a secure data server and/or locked file cabinet within the Dept of Family Medicine Research office. Only Dr Halas will have access to them and know your name and will only be accessible only by the two above-named researchers. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law (i.e. illegal or dangerous situations).

Some people or groups may need to check the study records to make sure all the information is correct. All of these people have a professional responsibility to protect your privacy. These people are members of the Health Research Ethics Board of the University of Manitoba, which is responsible for the protection of people in research and has reviewed this study for ethical acceptability. If any of your research records need to be submitted to the Health Research Ethics Board of the University of Manitoba any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

This study will use the Zoom platform to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available here: https://explore.zoom.us/docs/en-us/privacy.html While the University of Manitoba Health Research Ethics Board has approved using the platform to collect data for this study, there is a small risk of a privacy breach for data collected on external servers.

All records of your participation in this project, including paper records of transcripts and communication notes will be destroyed 5 years following the completion of the study.

Permission to Quote:

We may wish to quote your words directly in reports and publications resulting from this. With regards to being quoted, please check yes or no for each of the following statements:

Researchers may publish documents that contain quotations by me under the following conditions:		
Yes	No	I agree to be quoted directly if my name is not published (I remain anonymous).
Yes	No	I agree to be quoted directly if a made-up name (pseudonym) is used.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your participation or discontinuance in the study will not be known to anyone at the clinic and will not affect your care in any way.

Questions

If any questions come up during or after the study contact the study supervisor, Dr. Gayle Halas at (204) 977-5666 or by email at Gayle.Halas@umanitoba.ca. For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Consent Signatures:

1. I have read all 4 pages of the consent form.
2. I have had a chance to ask questions and have received satisfactory answers to all of my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication.
6. I understand I will be provided with a copy of the consent form for my records.
7. I agree to participate in the study.

I would like to receive a summary of the study findings upon completion.

- **By email**_____

- **By postal mail**_____

(If in-person) Participant signature_____ **Date** _____

(day/month/year)

Participant printed name: _____

I, the undersigned, believe that the participant named above has had an opportunity to discuss this research study and has knowingly given his/her consent.

Printed Name: _____

Date:_____

(day/month/year)

Signature: _____

Role in the study: _____

Gaps in healthcare policy throughout COVID-19 with respect to disabled individuals: a screener's perspective

Kaitlyn A. Merrill [*†‡]

Abstract

The medical community holds great responsibility to the public, including that the needs of each patient are met through the tenants of justice, beneficence, non-maleficence and autonomy.[1] Indeed, the balance of ensuring individual health needs are met, while also considering societal health needs is, and always has been, an important component of the healthcare system. This principle was made evident during the COVID-19 pandemic, and achieving this balance was no simple task.

Several blanket policies and recommendations from multiple levels of Canadian government were enacted, adjusted, and upheld throughout the everchanging pandemic.[2,3] Due to a lack of consideration regarding accessibility during the "one size fits all" governmental policy making, disabled individuals, including people with physical and cognitive disabilities, and their caregivers were left to navigate the healthcare system without their usual, though imperfect, supports. Importantly, pre-pandemic barriers to obtaining proper medical care, including unreliable transportation and stigmatization by healthcare personnel[4,5], were both highlighted and exacerbated by new challenges posed by the pandemic. This is cause for concern as, without necessary supports, disabled patients' safety is put at an even higher risk.

Ultimately, this commentary will provide insight to the effect of federal recommendations and provincial healthcare policies on disabled populations in Manitoba. Such insight may help guide responses to the next pandemic. Research into the experiences of disabled individuals, other marginalized, and disenfranchised communities during COVID-19 is sorely needed in order to learn from this pandemic and shape our emergency policies during the next one.

Keywords: COVID-19, disability, essential care partner, policy, restrictions

Conflict of Interest Statement: The authors declare no conflict of interest.

The COVID-19 pandemic introduced many changes and challenges to everyday life. As demonstrated by previous pandemics and crises, vulnerable populations, including disabled people, are disproportionately impacted.[6] Policies and recommendations were brought forward by the various levels of governments in Canada to minimize the spread of the virus, while mitigating the challenges faced by the public, including specific recommendations regarding disabled people.[7] These policies were produced quickly, and in hopes of protecting the most people, while ideally posing the fewest issues. Unfortunately, as is the case in many blanket policies, there were disparities, which gave rise to critical health-related problems in the lives of disabled people. My interest in this topic stems from my personal experience as a COVID-19 entry-point screener at a Winnipeg hospital, and the inequities I witnessed. In this position, I was responsible for upholding current COVID-19 restrictions, which involved communicating with staff to determine who required an essential care partner to remain with them throughout their stay in the department. The purpose of an essential care partner was to ensure specific groups of people, such as those with disabilities, could obtain medical care safely and effectively. Unfortunately, in my experience, the need for this support was often debated, and inconsistently granted. It is known that disabled people seeking medical care are more likely to suffer an adverse medical outcome due to negligence by hospital staff, even prior to COVID-19 when support workers and family members were allowed to be present. Therefore, it is an especially important topic to consider in light of the

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COVID-19 pandemic.[8,9]

First, I would like to draw attention to the cases which initiated the creation of some of the policies specific to disabled people receiving healthcare during the COVID-19 pandemic. At the onset of the pandemic, hospitals and care homes began closing doors to visitors. Therefore, people requiring medical treatment were to go to acute care facilities, clinics, and appointments alone.[10,11] Since these policies were developed quickly, as necessary by the state of emergency, the policies that generally worked for able-bodied individuals accessing healthcare left gaps for those outside the "norm". The death of Ariis Knight in April 2020 sparked outrage from the disability community. Knight, a non-verbal woman with cerebral palsy living in British Columbia, was refused the supports she needed to effectively communicate with medical staff, as the policy at the time had no mention of an amendment to allow for support workers. Ariss Knight died alone in hospital without any family or support workers by her side.[12] The lack of consideration of the impact of the "no-visitor" policy on disabled people resulted in trauma for Knight, her family, and the disabled community. After this event, the Government of British Columbia amended the visitation policies to reflect a need for "special consideration to designated representatives" of disabled people.[13] Despite this amendment, medical staff remained responsible to decide who was essential and who was not, and whether "special considerations" were given.[13] Along with the ableist history of the Canadian healthcare system [14,15], including institutionalization and forced sterilization [16], it seems unlikely that changing the wording of the policy is enough to create substantial change for the disabled community.

Prior to Knight's death, the federal government had established the COVID-19 Disability Advisory Group (CDAG). In fact, the federal government updated their website to include the page regarding the CDAG, on April 10, 2020, just over a week prior to Ariis's death, with the following description:

"The Government of Canada is taking immediate, significant, and decisive action by announcing the establishment of the COVID-19 Disability Advisory Group (CDAG). The CDAG will advise the Minister on the real-time lived experiences of persons with disabilities during this crisis on disability-specific issues, challenges and systemic gaps and on strategies, measures and steps to be taken."[17]

This indicates the federal government had acknowledged, in writing, the challenges disabled people were facing. Yet, the Government of British Columbia had made no considerations for disabled people in emergency situations. These discrepancies between provincial and federal policies due to a lack of communication between varying levels of government is a serious concern and may have made a difference in the case of Ariis Knight.

Months later, in December 2020 at the Health Science's Centre in Winnipeg, Cameron Slimmon was de-

nied a caregiver, despite Shared Health stating that decisions regarding support workers and essential care partners would be made on a case-by-case basis.[18] Slimmon was unable to communicate with hospital staff to adequately express his needs, resulting in him discharging himself from the hospital before his condition had improved. He deemed the vulnerability in his position alone at the hospital to be more dangerous than the medical emergency for which he was being treated.[18] The human rights complaint filed by Slimmon generated pressure for Shared Health to create a written policy, which allowed for "essential care partners" deemed necessary by the hospital.[19] This situation was eerily similar to that of Ariis Knight in British Columbia, however, this event took place months later. It appears that the Manitoba Government had not communicated with, nor observed impacts of similar policies in other provinces and the same mistakes were repeated.

Given that provincial governments are largely responsible for healthcare, there is space for variation in policy from province to province.[20] Shared Health, Manitoba's provincial health organization, had set policies which changed frequently and ultimately left all final decisions about COVID-19 restrictions up to the medical personnel in charge of the unit. Provoked by the human rights dispute by Cameron Slimmons, Shared Health created guidelines for the instances in which the province was under Code Red restrictions.[3,21] People seeking medical attention may have been permitted an "essential care partner", defined as "those providing physical, psychological and emotional support, as deemed important by the patient."[21] In my experience, the determination of essential care partners varied based on which management staff was working that shift; some were more considerate of disabled people, while others immediately rejected support workers.

The procedure went on to state that essential care partner access was exclusive to specific situations and would be supported for patients who "normally have constant care or attendants" or require assistance with "medical history, collateral history, consent and decision making."[21] The guidelines stated that ultimately in these circumstances, consultation with the hospital staff was required to determine if the patient would be granted an essential care partner.[21]

The guidelines set by Shared Health were also largely different than the recommendations by the Federal Government. On the Federal Government website, it was stated that:

"Policies and procedures for hospitals, long-term care homes, COVID-19 Assessment Centres, clinics, family practice, other medical facilities and any organization that provide healthcare and supportive services to those with disabilities should provide permission in their directives on the accompaniment of essential supports at all stages of care within the healthcare environment."[7]

In my experience, staff tended to attempt to find a reason for refusal of a partner, as their role was to uphold the visitation restrictions, which were both

important and necessary to minimize transmission of COVID-19, especially in hospital, where there is an increased risk of severe outcomes for certain patient populations.[22] That being said, in my experience, given that the recommendations and policies left room for interpretation, inconsistent decision making of the staff took place. The Federal Government recommendation was often ignored at our emergency department, as well as in the cases of disabled people attending appointments within the hospital. The Shared Health policy was also often ignored, aside from the line stating that medical staff of the site will have final say in these decisions. It has also been reported that variation between facilities also occurred in the case of a dementia patient.[23] I have been instructed to refuse a care partner for a disabled person who was both deaf and blind, and unable to communicate with medical personnel. A similar case in which a mother was refused to visit her non-verbal son was also reported on early in the pandemic.[24] I have also been instructed to refuse care partners for people amid mental breakdowns, while there has been a suicide attempt in the emergency room washroom and studies have since shown the importance of caregivers to the mental health of patients.[25] There were also instances in which once the patient was denied a care partner, they left the facility rather than being treated. Ultimately, the refusal of support for disabled patients leads to poorer health outcomes[26], demonstrating the dire need of these supports.

Over time, the pandemic phased out of a state of emergency, rules and regulations lessened, and more patients were permitted to obtain their necessary supports. At the time of policy development, we were living through an unprecedented global health emergency. Unfortunately, like many other public health policies developed during our pandemic response, it is impossible to know how many lives were saved through strict visitation policies in hospital. However, we do know that many disabled individuals unduly suffered at the hands of said policies. In my opinion, the "essential care partner" designation was an important component of these policies, and in theory well-defined, but when it came to real life practice, the role faltered and was inconsistently regulated. As stated previously, there were many cases in which the individual safety of disabled patients was compromised, due to rigid and inconsistently enforced policies. As medical professionals, we are well-versed in following procedural policies, which is of great importance, but it is also important to ensure humanity remains in the system when making decisions for all patients, and especially vulnerable ones. Though policymakers are responsible for creating safe procedures, medical professionals also hold a responsibility to advocate for their patients, as outlined by the Royal College of Physicians and Surgeons of Canada under the CanMEDS framework. Looking onward to the next public health emergency, it is important to reflect on our pandemic response, and seeking out the lived-experiences of vulnerable populations is key to consistent and systemic improvement.

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Undergraduate medical education post-COVID: enhancing the return to routine

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Abstract

The COVID-19 pandemic has reshaped all aspects of medical education worldwide. Medical schools have adapted in various ways to provide students with an educational experience that is unimpeded by the current pandemic circumstances. The aim of this commentary is to highlight the various modifications that have been made to medical education for pre-clerkship medical students attending the University of Manitoba Max Rady College of Medicine and how those changes can enhance the future of medical education.

Conflict of Interest Statement: The authors declare no conflict of interest.

The COVID-19 pandemic is a global health crisis that has affected all aspects of life including medical education. Most of the published literature with regards to medical education has been focused on observations and analyses during the pandemic, with several Canadian medical schools discussing their efforts to accommodate changes in medical education during these unprecedented circumstances. [1–3] This pandemic led to rapid adaptation and changes to undergraduate medical education curricula and has fostered/augmented online methods of teaching and learning, career development, and other curricular activities online. Despite most Canadian post-secondary institutions are preparing for a complete return to in-person teaching, will the lessons and positive pedagogical outcomes learned during the COVID-19 pandemic be incorporated into undergraduate pre-clerkship medical education?

At the University of Manitoba (U of M) Max Rady College of Medicine, medical students in the preclerkship (also known as pre-clinical) phase of their training became acclimated to a blended learning environment during the COVID-19 pandemic. This included online learning for all whole group learning sessions, tutorials and professional development sessions, while all clinically related sessions and hands-on anatomical gross laboratories remained in-person with proper safety measures for students, faculty and staff. Recent studies in educational fields have shown that a blend mode of curriculum delivery, similar to that adopted by the U of M, has several benefits to both teaching and learning. [4,5] Prior to the COVID-

19 pandemic, Pei and Wu conducted a systematic review demonstrating that online delivery of undergraduate medical education in nine countries, not including Canada, is non-inferior to traditional in-person learning. [6] Additionally, they suggested that a blended learning environment containing both online and offline modalities maximizes student education.

Examinations were also changed to be conducted off campus and online with strict guidelines to minimize any infractions by the test taker. These changes provided advantages to students that would have been absent in the traditional curriculum. Medical students at the U of M have informally self reported feeling less test anxiety and more comfortable in their own test taking environment, which agrees with previous findings. [7] Other benefits to online examinations for students living off campus include saved commute times, reduced travel-related stress (i.e., dealing with weather conditions, traffic and parking). Some disadvantages of off campus and online test taking includes complications due to poor internet connections, false infraction claims, and other unforeseen technological issues. However, with modifications to the technology infrastructure for students, most of these disadvantages can be eliminated to take advantage of the benefits of online testing.

Although some clinical skills components of the curriculum have remained in-person at the U of M, other institutions initially decided to change the method of delivery of these components to online instruction as well. Assessments of the efficacy of complete online de-

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livery of clinical skills required for Objective Structured Clinical Exams (OSCEs) is limited however, learning these skills through online modalities adjunctive to in-person learning has been investigated.[8,9] The advantages are similar to those of online examinations and include increased ease for clinician leaders to participate without the need to commute to campus. However, there are several notable disadvantages with when implementing clinical skill sessions online. Firstly, students may acquire insufficient training in physical examinations with the absence of in-person interactions. It may be more difficult to identify nuances during patient interactions due to camera and microphone quality. Students may also feel ill-prepared in their skills prior to direct patient interactions during their clinical rotations. Holding OSCEs online is another novel method which is currently not well investigated in the literature. Almost all clinical skills are conducted in person as a clinician and how learning clinical skills solely online translates to mastery during clinical years requires further investigation.

The COVID-19 pandemic has caused for unprecedented circumstances which affect every aspect of life including medical education. Current attitudes and previous pedagogical evidence suggest that adaptations arising from this pandemic which may enhance traditional medical curricula based on their utility for students, faculty and staff. More research needs to be conducted to determine which online learning modalities are most efficacious to medical education and how to achieve an optimized balance between online and offline learning. Post-secondary institutions and health science faculties offering medical education may want to continue investing in the improvement of their online learning infrastructures to accommodate the permanent changes in the post-COVID era. This will hopefully contribute to greater learner success in the future.

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The visibility of vitiligo

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Abstract

The world's perception of skin disease has significantly evolved in the last few decades, owing to the greater representation of individuals impacted by visible conditions in society. The shifting mindset towards greater diversity and body positivity in the media has allowed for enhanced awareness of the psychological and physical experiences of individuals living with dermatological disease. This article will explore the heterogeneity of lived experiences with Vitiligo and awareness's role in empowering impacted individuals to feel more comfortable in their skin.

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Individuals with Vitiligo develop depigmented patches of skin, with the face and arms being commonly affected.[1] The estimated global prevalence is between 0.5–2%, with equal rates in males and females and half of all cases developing before age 20.[1–3] The exact prevalence in Canada and Manitoba is assumed to be similar due to the lack of local epidemiological data.

Historically, many societies viewed Vitiligo as a 'curse.'[4,5] Communities in medieval Europe often mistook Vitiligo for leprosy, separating individuals with Vitiligo from the rest of society.[5] As medicine evolved, Vitiligo emerged as a separate entity, now known to be an autoimmune condition affecting melanocytes.[3] Melanocytes are the cells that produce the skin pigment molecule melanin.[6,7] In the pathogenesis of Vitiligo, melanocytes release chemoattractants in response to intracellular stressors.[6] These molecules then guide autoreactive cytotoxic T-cells to the melanocytes' location, eventually leading to localized cell destruction and depigmentation.[6]

Despite an increased understanding of the disease, Vitiligo is still associated with a considerable psychosocial burden, with more than 97% of patients reporting a significant impact on quality of life.[4] The effect on the quality of life includes a substantial increase in comorbid depression and low self-esteem, with more than 92% having experienced stigma due to their Vitiligo.[3,4] Factors associated with the increased psychosocial impact include body surface area (BSA) involvement <25% and genital involvement (depigmented patches of skin develop on external genitalia).[4,8] It is also associated with increased psychosexual dysfunction and stigma.[4,8] Many impacted individuals fear intimate partners will perceive them as having an STI or other infectious disease.[8] A recent study revealed that genital involvement was associated with significant sexual dysfunction in 1541 adults with Vitiligo.[8] Women often experience a greater psychiatric burden as well.[4] One study found over 60% of females and 40% of males with Vitiligo had clinically significant depression.[4]

While many individuals impacted by Vitiligo have experienced distress due to their condition, the nature of this distress differs by skin type.[9] Individuals with darker skin (Fitzpatrick skin types IV–VI)[1] report more significant distress regarding the impact of physical appearance and sense of identity.[9] In comparison, individuals with lighter skin have reported greater concern about developing skin cancer due to the condition.[9] For many persons with darker skin, their physical appearance plays a vital role in their ability to self-identify with a particular ethnic group and not be seen as 'other' by their people.[9,11] This illustrates an important difference in the lived experience of Vitiligo for people with a darker skin type.

Many patients describe the loss of identity that comes with the depigmenting disorder that often entails questioning self-esteem and self-worth.[12] Women of colour living with Vitiligo often experience a compounded effect leading to more shame from the depigmentation, discrimination in marriage and perceived inadequacy secondary to societal expectations

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[1]Fitzpatrick skin types are categories of skin colour based on an individual's tendency to develop a tan or a burn when exposed to sunlight. Fitzpatrick type I is very fair skin that is most likely to burn, while type VI is dark skin that never burns and is least sensitive to change in response to sunlight. Fitzpatrick skin types I–III are considered lighter skin tones and types IV–VI represent darker skin tones.[10]

of beauty.[3–5,9,12] However, changes in societal beauty standards and increasing awareness of Vitiligo may slowly challenge this negative perception. The last few decades have witnessed an increase in the presence of not-for-profit organizations and social media campaigns that have brought individuals living with Vitiligo to the spotlight.[13–15] This has led to more young people embracing their skin changes from Vitiligo as part of their journey and beauty.[13,16]

A notable example is Canadian model Winnie Harlow, whose modelling career had embraced her Vitiligo as part of her identity despite initially struggling with the condition when she was first diagnosed as a child.[16] Other students bullied Winnie due to her skin looking different.[16] The negative perception from others played a tremendous impact on her mental well-being.[16] She has founded a new skincare brand 'Cay Skin' that celebrates the beauty of Vitiligo.[13,16]

The UK-based Vitiligo Society is an example of a not-for-profit organization established in 1985.[14] This global organization raises awareness through various forms, including Instagram, up-to-date information on disease management for patients and research.[14] The Instagram posts feature many individuals with Vitiligo and capture their daily challenges of living with a visible skin condition.[17] The organization takes a unique and philanthropic stance by selling merchandise, such as dolls with Vitiligo, that recognize the skin condition and provide funding for the organization and research efforts.[14] The organization also offers parents' school support packs' that contains information for schools to create supportive environments for kids with Vitiligo and allow them to feel seen by the world around them.[14] Physicians can also refer patients to these resources to connect with others experiencing the same changes.

Most of the adequately conducted research is not accessible to the general public or people living with Vitiligo because publications are written for a scientific audience with access through paid subscription libraries. These organizations act as bridges that make research accessible and allow individuals with the disease to understand their condition better and connect to others. Providing information to people living with Vitiligo empowers and assists individuals in explaining misconceptions about their disease.

The Vitiligo Society, the Vitiligo Research Foundation and other organizations are especially active on June 25th for World Vitiligo Day.[14,16,18] Global celebrations of this day reach millions across the globe with the hashtag #worldvitiligoday, in similar ways as other health-promoting hashtags such as #worldmentalhealthday.[15,18] These awareness campaigns have recently increased outreach to more ethnically diverse populations.[15,18] These populations have a greater proportion of people with richer skin tones who experience a greater impact on their sense of identity and physical appearance.[15,18] World Vitiligo Day has a significant online presence that functions as a platform for people living with the condition to share their stories and be seen with the 'flaws' on their skin.[19] The awareness through organizations and social media has allowed for a narrative of change and greater acceptance of the condition for individuals impacted by Vitiligo. Individuals with the condition are no longer afraid to post online images of themselves without covering up their skin.[17,19]

Acceptance of Vitiligo as part of one's identity has led some people to choose not to pursue any disease-altering treatment and instead focus on loving the body that they have.[13,16,19] Common treatments for Vitiligo include steroid creams and light therapy that aim to pigment existing patches and slow down disease progression.[20] Most treatments for Vitiligo seek to conceal the depigmentation as much as possible.[20] The choice not to pursue therapy is an important decision that highlights an essential change in an individual's perception of the condition. This change has considerable consequences for the clinical setting and highlights that clinicians should not make assumptions about an individual's therapy goals.

Individuals living with the disease have given various TED talks over the past few years, highlighting everyone's unique journey.[21,22] Speakers have spoken about how embracing their Vitiligo as part of who they are and not something to be ashamed of has been liberating.[21,22] These platforms have allowed individuals living with Vitiligo to define their journey rather than medicine or outdated preconceptions. The sharing of these stories is essential for young people who are newly diagnosed with Vitiligo.

In summary, every individual's experience with the condition is as unique as the Vitiligo pattern on their skin. While many people living with it have unfortunately experienced distress and discrimination, the changing landscape of what society defines as beautiful allows for greater visibility and acceptance on both a personal and societal level. The emergence of advocacy organizations and social media awareness empowers individuals living with Vitiligo to share their stories as people with visible skin disease.

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Insights from the cutting edge: an interview on corneal neurotization and ophthalmic surgical innovation

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Abstract

This article explores the field of ophthalmic surgical innovation through an in-depth interview on corneal neurotization, a groundbreaking procedure aimed at restoring corneal sensation in patients suffering from neurotrophic keratopathy. The discussion offers insights into the technical details and challenges of performing this novel surgery, which is being conducted for the first time in Manitoba. By speaking with a ophthalmic surgeon at the forefront of this technique, the article examines the goals, surgical steps, and expected outcomes of corneal neurotization. The interview also delves into the surgeon's reflections on preparing for and executing novel procedures, highlighting the emotional and intellectual preparations required, the collaborative efforts with the plastic surgery team, and the adaptations made in response to intraoperative challenges. The conversation provides a unique perspective on the importance of lifelong learning, adaptability, and continuous innovation in surgical practice, offering valuable lessons for medical students, trainees, and professionals eager to embrace novel challenges in their careers.

Keywords: Corneal Neurotization, Ophthalmology, Surgical Innovation

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Preamble

Clerkship is a time in a medical trainee's career that is filled with new experiences and coinciding reflection. For myself, this period has elicited a great respect for the knowledge and skills possessed by my mentors and other healthcare professionals who surround me daily. This experience has cultivated an appreciation akin to the Dunning-Kruger curve; an understanding of the extensive learning and experience that is required to achieve a remotely similar level of proficiency.[1] Although this experience was daunting at first, a new revelation has brought me comfort by knowing that those whom I admire around me have also traversed this rite of passage. They were once medical students and learners who diligently honed their skills, bridging the chasm of knowledge and experience they had encountered. Through these shared experiences we are bound by a common thread in the medical community.

Clinical experience has also provided insight into another lesson that learning does not end upon graduation from medical school. The physician's pledge is an oath made upon the inauguration of a medical trainee to signify their commitment to practicing medicine.[2]

Moreover, it establishes an understanding that learning and curiosity are continually pursued throughout a physician's lifetime. In the context of clinical medicine, this translates to a physician's dedication to continually better oneself through evolving and adapting medical knowledge and skills.

Perhaps no medical field illustrates the perpetual quest for knowledge and mastery of skills better than surgery, where practitioners must constantly evolve to offer care that is to the highest standard of medical treatment. In this ever-advancing field, the breakthrough of novel surgical techniques has created massive changes in regard to patient care.[3]

Ophthalmology is one such surgical specialty in which innovation is at the forefront of patient care. Over the past few decades, the specialty has seen massive advances, such as in the treatment of retinal diseases and cataract surgery, which now can be performed in minutes. The pioneering of novel surgical techniques and technology such as phacoemulsification has had a significant impact on reducing wait times and accelerating visual recovery for patients undergoing ophthalmic surgery which ultimately illustrates how innovation profoundly enhances care.[4]

Oculoplastics, a subspecialty of ophthalmology, has

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also seen radical advancement. Of recent developments, a novel procedure called corneal neurotization has become revolutionary for treating corneal anesthesia. I had the unique opportunity to speak with a surgeon at the cutting edge of this innovative procedure, set to perform Manitoba's first corneal neurotization surgery. Our following conversation explores not only the technical details and challenges of performing the groundbreaking surgery but also offers a personal glimpse into valuable lessons on adapting and embracing novel situations in medicine.

The following interview was conducted on April 15, 2024. It has been lightly edited for clarity and length.

Interview Part One:

Thank you so much for taking the time to speak with us today. To start, could you please describe what the goals of corneal neurotization are?

"It is a pleasure to speak to you today. Corneal neurotization is a procedure aimed at restoring corneal sensation in patients with corneal ulcers due to lack of sensation. This is called neurotrophic keratopathy and it can be from various etiologies such as herpetic keratitis, surgical trauma, diabetes, or congenital insensitivity.[5] In each of these pathologies, the corneal nerve becomes nonfunctional. For the patient tomorrow the most likely etiology is HSV but there could be various factors at play. When corneal sensation is lost this can cause a lot of problems. Similar to how a diabetic foot loses sensation - a very protective mechanism is lost. The loss of corneal sensitivity is not just a matter of diminished sensation; the nerves are also important to the cornea because they provide nutritional support by releasing paracrine neurotrophic factors.5 Without this support you can have recurrent corneal erosions and ulcers, poor wound healing, and vision-threatening complications (figure 1, 2). With this procedure, our goal is to reestablish the sensation to the cornea, which also promotes natural processes. The sensation will hopefully recover because the infraorbital nerve provides new nerve growth into the patient's eye via the nerve graft."

Could you please give a brief description of what the surgery entails?

"There are several steps to this surgery.[6] We start by harvesting an autologous nerve graft (figure 3). For tomorrow's surgery, we're planning on using the sural nerve which runs down the back of the calf and the ankle. The sural nerve is the most commonly used graft for nerve reconstruction and is chosen because it is easily accessible and most patients are not bothered by the resultant minor sensory deficits on the distal lower leg and dorsum of the foot. We'll isolate this and remove a piece (figure 4). We'll use this nerve piece to be the new nerve conduit to the cornea. While the sural nerve graft is being harvested, I'll dissect into the inferior orbital space to isolate the infraorbital nerve,

taking off a small piece of bone from the orbital floor to expose the nerve. The nerve graft will be tunneled from the inferior orbit into the superficial layers of the eye (figure 5). We'll then create an anastomosis with sutures to connect one end of the graft to the infraorbital nerve and the other end to the eye. After the graft is securely connected to the infraorbital nerve, the final portion of the surgery is to separate the other end of the graft into fascicles and attach them to the corneal limbus (figure 6). The nerve fascicles are then covered with conjunctiva."

How long after surgery would you expect sensation and healing to return to the cornea?

"The healing phase will take time. The nerves have to recover, and I expect this to take at least 6 months.[7] I'll see the patient in my office and monitor for signs of nerve regeneration and improvement of corneal sensation."

What specific steps do you take the night before surgery to make sure you're mentally and physically prepared?

"The evening before a surgery, I like to make sure I'm mentally and physically prepared. First, I make sure to get a good night's sleep; it helps for maintaining focus during surgery. I also think it's important to review the surgery steps, especially if it involves anatomy I haven't worked with for a while. I find that mentally visualizing the entire process helps with preparation. I also review any notes I may have written in pre-op and earlier clinics regarding the patient. There's often long wait times for surgery so there can be a significant gap between my initial consultation with the patient and the day of the procedure. Refreshing my memory on their specific case makes surprises less likely when we're in the operating room."

I find the OR environment to be intense at times. Are there any routines you do in the OR to alleviate stress?

"I have a couple of things that I like to do to stay relaxed. Playing music I enjoy helps me stay calm. Having familiar, relaxing tunes can help to ground yourself. I prefer something relaxing and fun to create a calm atmosphere without being too loud or fast. If I anticipate a long surgery ahead, I'll take time to stretch beforehand to prevent cramping. I'll be in the OR beforehand as well doing small things like adjusting the temperature for comfort if anesthesia allows. Also ensuring all equipment, like the microscope, loops, and headlight, are set to my preferences and review all the equipment that I'll need with the nurses. I try to minimize in-surgery adjustments as much as I can. I also try to position myself to be ergonomically comfortable during surgery and to avoid awkward body positions, especially for longer cases."

How do you counsel or prepare a patient who is nervous on the day of performing a novel surgery?

"It's important to be honest with patients. Even though this is my first time performing this surgery, these are steps that I am familiar with and parts I've done before in other surgeries. I've found that a patient's nervousness often stems from uncertainty about what to expect. I take the time to walk them through the process: explaining the surgery in detail, its duration, what sensations they might experience afterward, including any discomfort, and the expected timeline for discharge from the hospital. Acknowledging that the patient's anxiety before surgery is natural is also important. I assure them that our OR team will make their experience as comfortable as possible. Sometimes we provide medication to help ease their anxiety ahead of the procedure."

What emotions and feelings do you have before doing a surgery/procedure for the first time?

"Facing a surgery for the first time always brings a complex mix of emotions. Tomorrow's procedure is different because I'll be working with a plastic surgeon which is different from my usual solo surgeries. She'll handle the leg part to harvest the graft and also anastomose the graft to the infraorbital nerve, and I'll focus on the eye. There's a sense of excitement since this will be the first time this procedure is performed in Manitoba with collaboration between two specialties – Ophthalmology and Plastic Surgery. I'm eager to see the results, especially in terms of restoring sensation and healing. There's still some anxiety due to the novelty of the procedure. It's important to strike a balance between humility and confidence. While the new experience introduces some nervousness, my confidence is rooted in the skills I've developed over years in surgery. This gives me a solid foundation to lean on."

Interview Part Two:

Six weeks after the surgery, I had the opportunity to speak with the surgeon again, this time focusing on the lessons he'd learned and his reflections on the case.

"I am very pleased with how it went. I expected a learning curve, but I thought it went well, considering it was the first time we performed this procedure. With the help of the Plastic Surgery team, we completed the case successfully and without any problems. Post-operatively, everything seems to be progressing as expected; the corneal ulcer has healed, and it looks very promising for the return of corneal sensation (figure 7). Overall, the eye appears much healthier compared to before the surgery. The patient is also very happy. When I last saw her, she mentioned feeling some improvement in how the eye felt. She stated that there was some tingling on her left cheek and I reassured her that this will improve with time. We still need to wait a few months—six months or more—to know the final results and see if corneal sensation has markedly improved."

Were there any unexpected challenges or surprises during the surgery? If so, how did you address this?

"Initially, I was hesitant about exposing the infraorbital nerve, particularly about exposing the nerve to the necessary degree without causing excessive bleeding or damage that could result in lasting facial sensation impairment. Fortunately, that part ultimately turned out well but did require extra caution. Suturing the sural nerve graft to the infraorbital nerve was another area of concern, but it went smoothly with the assistance of the Plastic Surgery team (figure 8). It was immensely helpful to have a nerve plastic surgeon accustomed to this type of work, and I enjoyed the teamwork as this is not something I often get to do."

What modifications to your technique or approach would you make when performing this surgery again in the future?

"I thought the length of the sural nerve graft was very long, and we didn't actually need the entirety of it. Because it was the first time we did it, we decided to err on the side of caution rather than risk not having enough. In terms of technique, instead of making a conjunctival incision close to the limbus, I would make the incision further back and tunnel the graft further under the conjunctiva so that the nerve fascicles lay closer to the cornea and were well-covered."

Reflecting on the process of learning this new procedure, what advice would you give to medical students and young doctors about embracing new challenges and evolving their practice?

"I would advise them to learn the basics first before learning new techniques. It's essential to master your fundamental skills before moving on to advanced procedures. I would not suggest learning too many new procedures at the start of one's career. Once these foundational skills are mastered, you can then branch out, focus on improving, and evolve new skills. You can do this by being curious and proactive: attend meetings, read journals and textbooks, watch surgical videos online, and talk to other surgeons. Asking to observe new techniques is also a great way to learn. Through this approach, you will build new techniques upon the solid base of fundamentals you've already established."
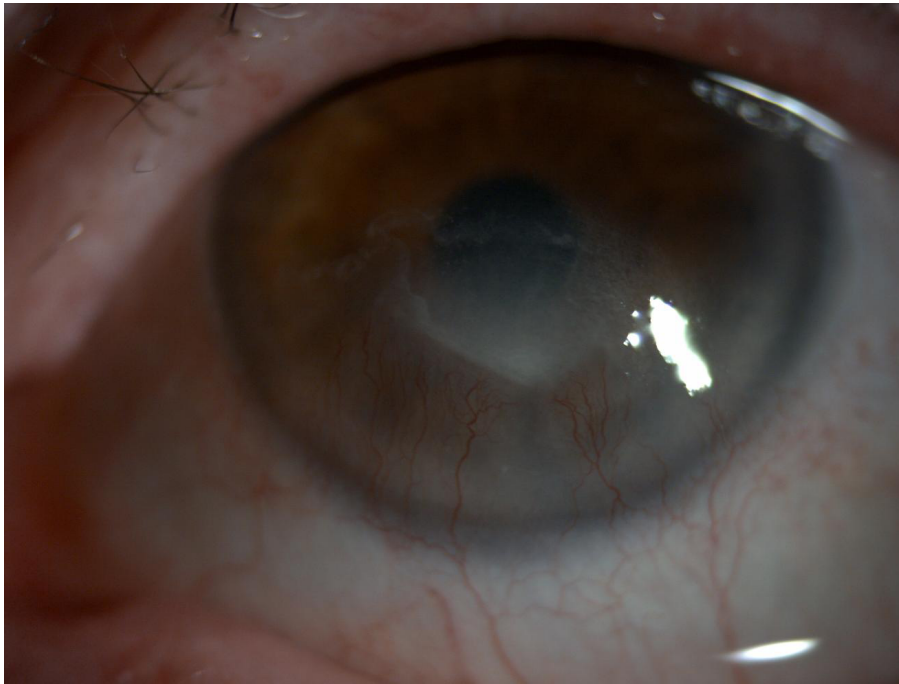
Figure 4. Chronic non-healing corneal ulcer of the candidate patient imaged with slit lamp microscopy. Adequate corneal sensation is required for healing of the ulcer.

Figure 5. Non-healing chronic neurotrophic corneal ulcer stained with fluorescein dye.

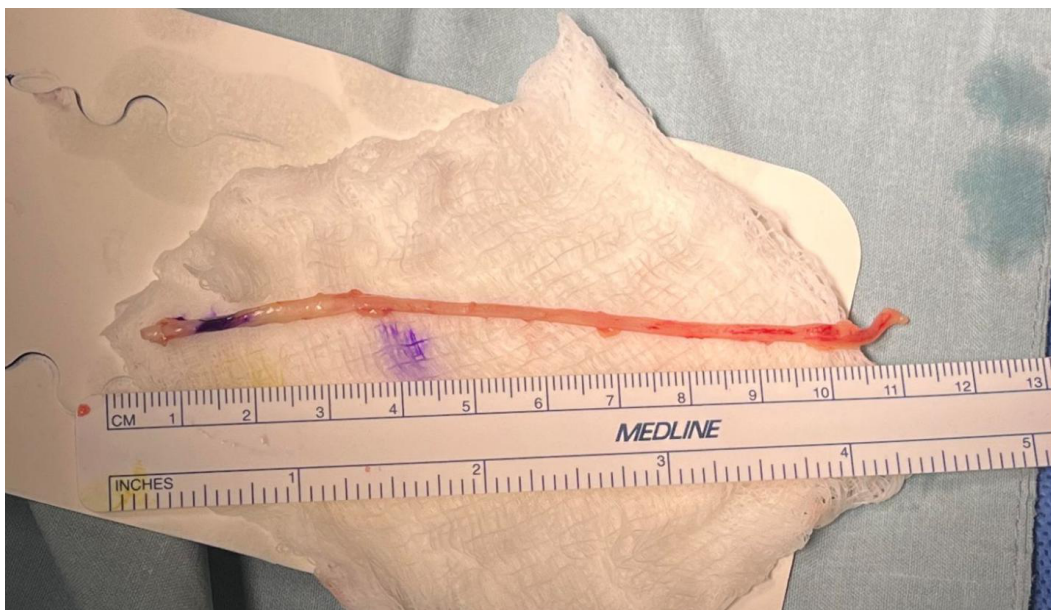**Figure 6.** Exposure of the sural nerve on the posterior-lateral leg.

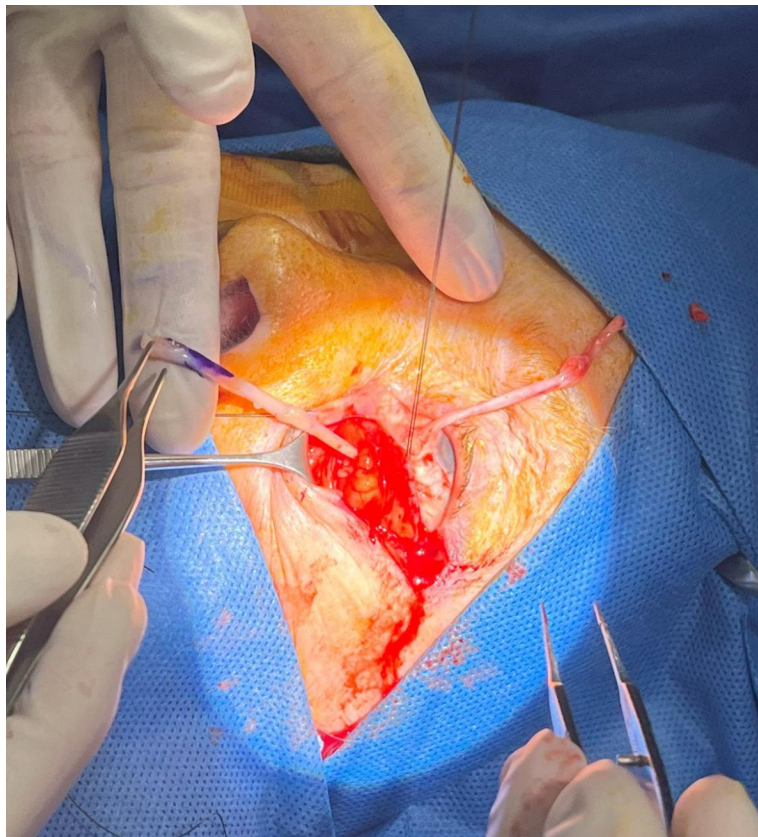**Figure 7.** Isolated sural nerve graft.

Figure 8. Sural nerve graft tunneled subconjunctivally from the inferior orbital space into the subconjunctival space of the patient's eye.
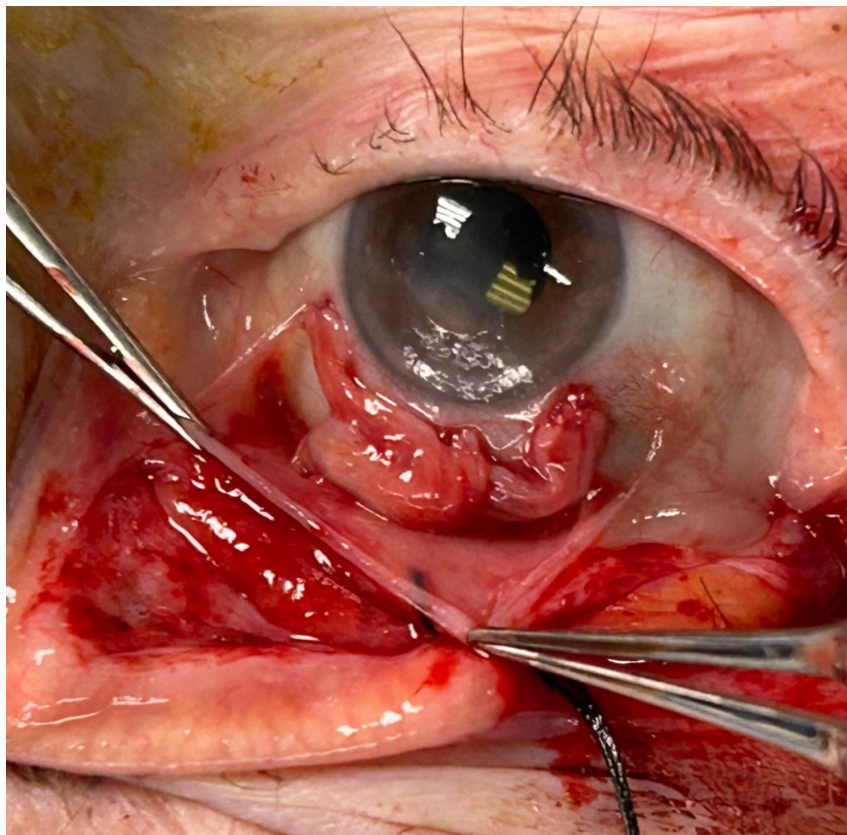

Figure 9. Graft separated into three nerve fascicles and attached to the subconjunctival limbus area of the eye with sutures. The other end of the graft is attached to the infraorbital nerve.
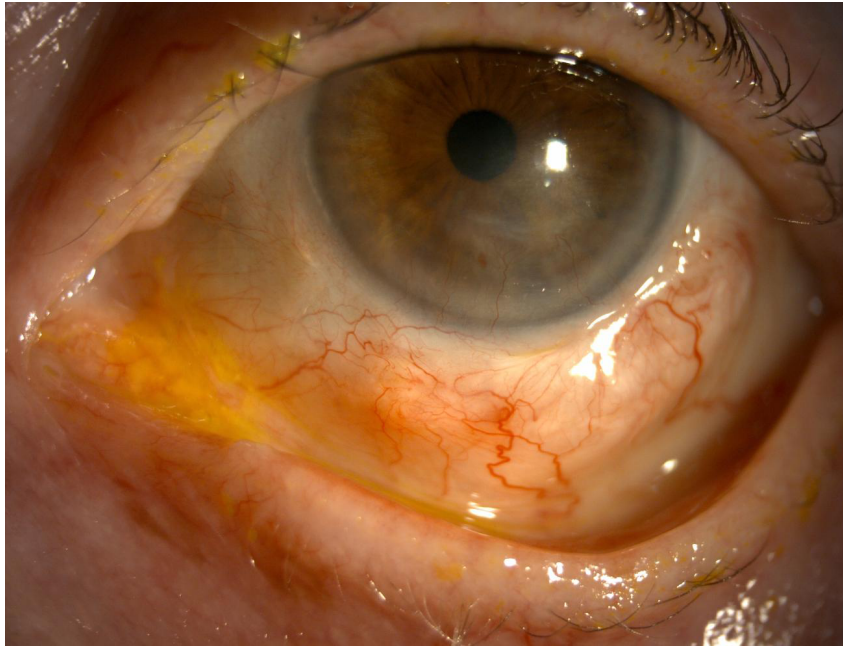
Figure 10. Slit lamp microscopy six weeks postoperatively shows a healed corneal ulcer and subconjunctival nerve graft inferiorly.

Figure 11. Two surgical teams perform corneal neurotization surgery. The Ophthalmology team at the patient's head isolates and exposes the infraorbital nerve while the Plastic Surgery team harvests the sural nerve graft.

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On sensitivity: a medical student and an artist reflect on the impact of a late ADHD diagnosis

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Abstract

In this piece, a medical student and an artist explore the impact of a late attention-deficit/hyperactivity disorder (ADHD) diagnosis through an interview. ADHD often manifests differently in females compared to males. The traditional diagnostic criteria, developed from studies predominantly involving boys, under represents symptoms seen more in females such as internalized distress and emotional sensitivity. Singer-songwriter Mackie Friesen received their diagnosis later in life at age 26, but struggled throughout childhood with undiagnosed ADHD and its impact on self-perception. Existing diagnostic tools lack inclusive and sensitive diagnostic criteria that acknowledge the diverse expressions of ADHD. Rather than identifying and treating the negative aspects of the disorder, diagnosis should focus on recognizing and harnessing positive traits such as emotional intelligence and creativity. Societal and cultural factors influence inaccuracies in diagnoses in all medical fields. This analysis invites physicians to refine diagnostic criteria to better capture the varied presentations of ADHD, and allow for a more holistic and empathetic approach to mental health.

Keywords: ADHD, bias, trauma-informed, psychiatry, interview

Conflict of Interest Statement: None to declare.

Introduction

Attention-Deficit/Hyperactivity Disorder (ADHD) can present differently in men and women. There are two general subtypes of the disorder based on symptom constellation: hyperactive – which is more common in males – and inattentive, which is more common in females. The typical picture of ADHD is an inattentive, distractible child that is disruptive in the elementary classroom. This profile was based on research performed decades ago, primarily on young boys.1 Females demonstrate lower self-reported ratings of classic ADHD sequelae, such as hyperactivity and externalized impulsivity.[1] Females instead tend to internalize their distress, leading to low self-esteem and inattention as characteristic symptoms.[1] For this reason, many female diagnoses are missed until adulthood. I met one such case at a party a few years ago. Mackie Friesen (she/they), also known by their stage name Snackie, opened up to me about the experience of receiving an ADHD diagnosis at age 26. Between their artistic background and my scientific one, we had many theories on what inefficiencies were at play in their delayed diagnosis. They had thoughts on how society and culture played into the issue, whereas my mind went to the clinical realm of interviews and inventories (standardized sets of questions to measure symptoms of mental disorders).[2] I decided to conduct an interview of my own to better understand her experience. What follows is the interview and analysis it informed.

Tell me about how you arrived at a diagnosis.

MACKIE: "About a year and a half ago I came to the end of a six-year relationship, and then had a rebound that didn't end well. That's what happened before I hit rock bottom – or what I've seen called the 'dark night of the soul.' I remember this moment of complete surrender where I was crying on the floor in Child's pose. I remember thinking to myself 'I don't really want to live like this. Something bigger is going on than this relationship that just ended. I need to get help.' I talked to my family doctor and they started me on antidepressants and anti-anxiety medication. They also suggested an online CBT course. It was 10 modules, online chat counselling and journaling exercises. I started paying more attention to behaviours and logging my moods throughout day.

"During this time a friend of mine was diagnosed with ADHD. She told me about her experience and sent me Instagram pages made by and for people with ADHD – flipping through them I was like, check, check,

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check, this is me. I did a lot of my own research before approaching my doctor about it. I definitely felt a lot of impostor syndrome, but luckily my doctor was receptive in getting me the support I needed."

What kind of kid were you in grade school?

MACKIE: "I was a daydreamer. One hundred percent."

Were you rambunctious, a bit of a trouble-maker?

MACKIE: "I wasn't, no."

So not the typical image that comes to mind of a child with ADHD, bouncing off the walls.

MACKIE: "Definitely not. I do have this one memory from grade 8 where I was doodling during class and the teacher made me stop so I would pay attention. But really, I was paying way more attention when I was doodling because I was under-stimulated. So as soon as I was told to stop [doodling], I'd start daydreaming and miss way more of the lecture. I ended up doing a lot of my learning at home."

What would have been different if you had been diagnosed earlier?

MACKIE: "I think I really would have benefitted from one-on-one assistance, or special ed. Not that I did poorly in school – I'm from a small town and both of my parents worked at my school, so there was a lot of pressure to do well – and I did. But the burden really fell on me to do it on my own outside of class. The classroom wasn't a very safe space for me. One time I asked a question in math class and the teacher's response was 'Maybe you have to go back to kindergarten.' In her mind, since I was grouped with all the other kids, the only reason for me to miss something was not paying attention or being a "bad kid." After things like that happening over and over again, I learned to internalize a lot.

"I think the bigger picture here is the impact not knowing this about myself had on how I viewed myself. It's been a lot of un-learning and re-training my brain to not resort to negative-self talk and fight-or-flight in the face of every 'threat.'"

How do you think your diagnosis affects you as a musician?

MACKIE: "I really don't think it impacts that part of my life negatively at all. One component to [my] ADHD is hyper-sensitivity to stimuli like sounds and physical sensations that cause distraction and overwhelm. On the other hand, it makes me more sensitive to things that others aren't, which is a very beautiful thing to have as a creative person. Being hypersensitive extends beyond the physical senses. It makes me more sensitive to the feeling in a room, the feelings of others. It's what makes me more intuitive and empathetic. Allowing myself to lean into those skills has made it so much easier for me to channel creative energy. Hav-

ing a diagnosis has allowed me to embrace those parts of myself that help me be more creative because I'm learning to let go of the things that block me and give me fear. Having ADHD doesn't impact my creativity at all in a bad way. But the way that I've learned to look at myself has. "A good example is if I'm constantly thinking about how I'm going to be perceived while trying to create. Wondering 'are people going to like this song' – focusing on all the wrong things... Thinking that I'm "too much" or having a sensitivity to rejection means that I overthink everything, I want to be a perfectionist. I can't tell you how many videos I have on my phone that I recorded but never posted because they weren't good enough in my mind. When in reality, probably no one would have noticed any of the mistakes that I'm perceiving. I have 2 full albums recorded that I still haven't released."

Tell me more about how ADHD can get in the way of things.

MACKIE: "The ability to hyper-fixate on things can go either way, depending on your trauma-informed brain. If I'm allowing negative thought patterns to perpetuate, the ADHD tendencies come out in a really bad way.

"I know that if I can focus too much on negative things and that can block me from creativity, I can also focus on positive things and that can open up the door for me to access this part of me that allows me to be creative. And that's something I can use as a tool to process my own stuff and be present in that moment to fully experience what I'm feeling. I can use that sensitivity to feel something in that moment and give it as a gift through music."

What would you like practitioners in psychiatry to know?

MACKIE: "There seems to be a really strong focus on the negative, and I'm not sure there has to be. ADHD seems to be regarded as something that needs to be fixed. Maybe my brain isn't what needs to be fixed, but all these norms of what a learner, worker, a person should be – is."

In a clinical context, sensitivity has a different meaning. It refers to the ability of a diagnostic test to accurately identify cases in which the target disease is present.[3] However, there is typically a trade-off between this ability to identify every patient who has the illness, while accurately excluding those who don't (known as a test's specificity[3]). This sensitivity-specificity trade-off has long inconvenienced both clinicians and researchers. Thus, physicians typically use several tools to evaluate different aspects of the suspected disease before making a diagnosis, such as finding x on physical exam, along with laboratory result y, and imaging sign z. Standalone confirmatory tests – so-called "gold-standards" – do exist but are often too invasive or expensive to be used routinely. In practice, absolute diagnostic certainty is generally not the goal.

Instead, clinicians need to establish that the comparative risk of treating the patient is less than that of not initiating treatment, regardless of disease presence. This is one of the first concepts we were taught in clinical reasoning, yet has taken the longest to sink in. I remember being concerned about how uncommon certainty is in medicine; that black and white scenarios are hugely outnumbered by the many, many shades of grey. Since western medicine is so firmly rooted in empirical science, I expected confirmatory tests to be much more prevalent in practice than they are. Physicians are trained to identify underlying causes of problems and – hopefully – fixing them. It's hard for medical professionals to imagine diseases or disorders as anything other than what Mackie said: something in need of fixing. Psychiatry is a unique sub-field of medicine in that its baseline for patients isn't defined by objective physiological measurements. It remains the only specialty where diagnoses are – at least to the extent of my knowledge – entirely clinical. Pathology is defined by a pattern of cognition that causes "significant distress or impairment,"[4] usually secondary to a symptom deemed "atypical." In Mackie's case, "distress and impairment" was skillfully concealed as a child. She internalized her symptoms and they manifested differently later in life. The gender bias in psychiatric research built insensitive diagnostic inventories,[1] which fail to capture this picture of a patient with ADHD. This is the ultimate cause of the delayed diagnosis and years of inadequate psychological support.

So, what can we do about it?

Until a gold standard biological marker is discovered for ADHD, we can start by attempting to eliminate the gender bias in psychiatry. This can be done by researching expressions of disease of people of all genders and expanding diagnostic criteria accordingly. Adding to this effort in any field of medicine is not the 21st-century clinician's aspiration, it is their responsibility. I also appreciated Mackie's question of why diagnostic criteria focus on negative aspects of disease. It would be interesting to investigate the diagnostic power of items on inventories that capture positive aspects of "disorders." Based on what Mackie shared, I'm curious about an inventory item for ADHD that would assess for emotional intelligence or creativity. Though I'm still wrestling to understand the logic that underpins much of clinical reasoning, my takeaway is this: perhaps sensitivity is underappreciated – not just in diagnostics, but as a trait itself.

Snackie's most recent single "Could It Be" (2023) is available on major streaming platforms.

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