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Cover Art by Laura Kennedy. Read more inside.

HPJ HEALTHY POPULATIONS JOURNAL

Cover Artwork

Sea to Sky

Laura Kennedy
Dalhousie University

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About the Artist

My name is Laura Kennedy. I am a PhD in Health Candidate at Dalhousie University and a Registered Nurse by profession. I grew up in rural Nova Scotia. One of my favourite things about this province is the proximity to the ocean. The rolling waves, sandy shores and coastal trails make me feel at home. This cross-stitch piece, *Sea to Sky,* was a project I completed throughout the COVID-19 pandemic as I stayed at home and felt the world's uncertainty around me. I picked up this craft, that I had not attempted in years, and found comfort in the repetitive movements of threading the floss back and forth between corners. The waves in the piece reminded me of the various places I could still visit while staying close to home. This helped me to appreciate the landscapes nearby. However, the mountains in the piece brought anticipation for future travel and adventures. For generations, a fondness for this craft has been in my family of Scottish origins. Through word-of-mouth stories, I've been told that art often brought my family together, with smaller children writing and acting plays and the adults taking it all in. By reintroducing this craft back into my day-to-day life, I couldn't help but feel connected to my family, both current and past, at a time when I needed it the most.

The author has modified this pattern. The original pattern and name of the pattern is *Sea to Sky* by DianaWattersHandmade (Etsy account).

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Welcome from the Co-Editors-in-Chief and Managing Editor

We are so pleased to welcome readers to the third issue of the *Healthy Populations Journal* (HPJ). HPJ is a student-run, open-access, peer-reviewed journal housed at the Healthy Populations Institute (HPI) at Dalhousie University. Our focus is to highlight student-led population health and health equity research and support new authors in the academic publishing process. Following the publication of our inaugural issue in the Spring of 2021 and second issue in Fall of 2021, we continue to receive positive feedback from readers, reviewers, and researchers about the articles, commentaries, infographics, and artwork we have published. HPJ is so appreciative of the diverse, creative, and intersectional manuscripts submitted by graduate students and the constructive, quality feedback provided by our reviewers.

In this issue we are spotlighting student artwork from Laura Kennedy, a registered nurse and PhD in Health candidate at Dalhousie University. Laura's work and the art of cross-stich is a form of refuge during the COVID-19 pandemic representing the past, present, and future visible in the vast sandy shores and coastal trails that make Nova Scotia home for her. This issue also features a short commentary on *Finding Leisure through Improvisation at Home* during Covid-19 (Tomas). Further, HPJ continues to publish infographics including an infographic about barriers and potential solutions to mental healthcare access for youth refugees and asylum seekers (Barbo) in this Spring issue.

Articles in this issue cover timely, interesting, and important topics such as Mah's commentary and call to advocate for the health of ageing populations around the globe and an evaluation of training materials aimed at increasing confidence of medical students working with lesbian, bisexual, and transgender people diagnosed with cancer (Coulas & Gahagan). Original research featured in this issue present evidence on the connection between perfectionism and mental health in undergraduate students (Kaser et al.), how early childhood educators in Canada might mitigate impacts of Adverse Childhood Experiences (Smith & McIsaac), understanding support-seeking experiences of women in rural Nova Scotia who have been targeted by sexual violence (Heggie et al.), and the reality that gender-diverse people forego accessing healthcare to avoid experiences of discrimination (Middleton & Gahagan).

Several review protocols are in this issue, including a scoping review protocol focusing on conceptualizing and defining how to measure mental health literacy (Coughlan et al.), a scoping review protocol on how exercise programs can meet the needs of people diagnosed with non-curative forms of cancer (Langley et al.), a scoping review on exercise interventions to reduce cognitive impairment in cancer survivors (Jelicic et al.), and an umbrella review protocol on the impacts of exercise training interventions on blood vessel dilation in relation to blood flow (O'Brien et al.).

HPJ would not be possible without support from the Healthy Populations Institute and the guidance from the HPJ Editorial Board Members. We truly hope you enjoy reading volume 2, issue 1.

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Artwork: Focus on leisure and health during the pandemic

Finding leisure through improvisation at home: Self-sustainment during COVID-19

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Abstract

During tumultuous, shaky, and uncertain times such as COVID-19, understandings of and life at home have shifted dramatically, especially amidst lockdown or on-and-off stay-at-home orders. While staying at home made me feel a sense of safety and protection, lockdown was a whole other challenge. Staying at home from morning till dawn, doing the exact same things over and over again, and relying on technology more than ever to fuel my social needs, encompassed my lockdown routine; a routine developed out of desires for normalcy and desperation to feel a sense of stability and so-called productivity. In light of my sanity and survival, I had to make do. I had to improvise. I had to find 'leisure' that worked for me while the world moved cautiously amidst COVID. In the details of everyday pandemic life, I found leisure in improvisation. In some cases such as my lockdown experience, leisure *can* be found in improvisation; not just in one thing or activity per se, but also in a series of pursuits that can help us make do, pass time, keep sane, and even experience temporary bliss and enjoyment amidst an unsteady and unpredictable environment.

Photo caption: Photo (previous page) is a homemade Dalgona coffee in a teacup. At the height of lockdown, making homemade coffee, instead of getting from coffee shops, was a temporary retreat from what I considered 'normal'. Making homemade coffee was an act of improvisation which, despite its unusualness or transitory experience, helped to carry me through the day(s) during the pandemic*.*

The COVID-19 pandemic caused many individuals and families to make alternative arrangements (Vyas & Butakhieo, 2021) within which what was once known as life at *home*, a valuable resource from which many practices and routines of life originate (Tomas, 2022). For many, stay-at-home orders, transitions to work-from-home (Vyas & Butakhieo, 2021), and absence of in-person learning (Azhari & Fajri, 2021) disrupted the *ongoingness* and "everyday atmospheres" within home (Pink & Leder Mackley, 2014, p. 171); consequently de-stabilizing routine practices occurring at home.

Navigating unpredictable circumstances such as living with my family during lockdown, feeling helplessness and disappointment from the dullness of going through the motions of "stay[ing] the blazes home" (April, 2020, para. 2), and adjusting my leisure preferences, were tricky and unsettling. Much like most individuals who jumped on different lockdown bandwagons like baking sourdough bread, creating temporary work-from-home stations, and filming TikTok videos, I entrenched myself into a daily routine consisting of a series of improvised activities that helped me to survive and accept the daily bouts of lockdown. Inspired by my Philippine heritage, I offer reflections on how I used leisure to sustain myself during the pandemic through the frames of *pansamantala* ("temporary" or "for the meantime") and improvisation.

"Pansamantala lang." ("It's only temporary.")*,* as my Filipino elders would say during difficult times as a reminder that suffering or any challenge is temporary, taught me that leisure can be found in improvisation during uncertain times like the pandemic. Meeting with friends over coffee was replaced with virtual coffee dates through FaceTime and with home-brewed, instead of shop-bought coffee. Instead of eating out on special occasions, trying new recipes became a favourite family pastime. My regular gym visits were replaced with following free YouTube fitness videos playing in the family room. And getting ready for school/work was "maintained" by getting dressed for Zoom meetings, as if I were attending them in-person. In the interest of my sanity and survival, I had to make do and improvise–to remind myself that this, too, was *pansamantala.* I had to find leisure in ways that worked for me to sustain myself as the world moved cautiously amidst the pandemic.

Figuring out how to stretch my time by finding meaning and purpose in those improvised daily activities–intentionally engaging in them with care, attention, and gratitude, despite the reminder that they are an improvisation of my so-called 'normal' leisure, taught me to have a greater appreciation for routine activities I not would have otherwise spent moments thinking about prior to the pandemic. While these activities did not *fully* replace my leisure pursuits pre-pandemic, they sustained me; they helped me to keep going despite uncertain circumstances. I didn't do leisure. I found it. I *had* to find leisure by improvising in the details of my everyday life during lockdown. In some cases, such as my lockdown experience, leisure can be found in improvisation, or in a collection of improvisory practices (Pink & Leder Mackley, 2014) taking place within the home to make do, pass time, keep sane, find stability, and experience temporary bliss and enjoyment amidst unsteady and ever-changing times.

Acknowledgements: I would like to thank my PhD supervisor, Dr. Kimberly Lopez, for their support in my pursuit of research interests about home, leisure, and well-being, as taken up by settlers of Philippine descent, which I've drawn from to prepare this manuscript.

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Commentary

Who Is Advocating for the Health of Aging Populations Around the Globe?

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Abstract

The Covid-19 pandemic has exposed the inadequacies of the existing structures in place for the most vulnerable populations; this is especially true for the capacity of healthcare and social systems to care for older adults. There have been global outcries over long-term care systems; yet, who is coordinating the efforts to ensure we are investing in infrastructure to support the health and wellbeing needs of ageing populations? This commentary first situates the health of global ageing populations as an international responsibility, before examining why conventional global health actors have only partially filled this gap. The commentary concludes by calling for a dedicated institution to champion this cause, as global population ageing is unlikely to emerge as a global health priority without an international advocate.

Introduction

The 73rd World Health Assembly declared the years spanning 2020–2030 "the Decade of Healthy Ageing" (World Health Organization [WHO], 2015). Unfortunately, the COVID-19 pandemic has since exposed the inadequacies of the existing structures in place for older adults, especially the capacity of health care systems to care for aging vulnerable populations (The Lancet Healthy Longevity, 2021). On the global health stage, it is unclear who is coordinating the efforts to ensure we are investing in infrastructure to support the health and well-being needs of aging populations. To address this issue, I ask two questions: First, is the health of global aging populations an international or national responsibility? Second, if it is an international responsibility, which global actor or actors claim responsibility for this health issue?

At first glance, a coordinated international network of actors does not appear to be imperative to ensuring healthy global population aging if the health of older adults in one country does not directly influence the health of neighbouring countries. The WHO's 2017 *Global Strategy and Action Plan on Ageing and Health* is a call to action focused mainly on asking Member States to commit to developing their own national evidence-based public health strategies for aging. Guidance for international collaboration is limited to exchanging lessons, conducting research, and collecting information (WHO, 2017).

However, consider this definition of global health: "an area for study, research, and practice that places a priority on improving health and achieving equity in health for all people worldwide" (Koplan et al., 2009, p. 1995). Defining global health in this way puts the emphasis on transnational health issues, determinants, and solutions; it also shapes global health by involving many disciplines within health sciences and beyond (Beaglehole & Bonita, 2010). All these criteria defining a global health issue are met when considering the health of aging populations. First, the diseases of aging, included under the category of non-communicable diseases (NCDs), are not limited to a single condition treated in isolation. NCDs as a whole cause 71% of all global deaths, with the burden of these diseases rising disproportionately in low-middle income countries (WHO, n.d.-a). NCDs are strongly linked to preventable risk factors entrenched in global inequities that transcend national borders. Second, global population aging is a health issue with rapidly changing socio-economic ramifications. Most nation states face "becoming old before becoming rich" (Robinson et al., 2007, p. 18). To illustrate, it took France 142 years to transition from having 10% to 20% of its population over the age of 60 years old; in 2007, China was expected to take 25 years to make the same transition (Robinson et al., 2007) and appears to be on track to do so, given their latest 2020 Census data. Global demographic changes are uncharted territory and require flexibility in delivering health programs across various settings. Therefore, managing the health of aging populations requires a transition from "a find and fix it" model to a coordinated and comprehensive continuum of care (WHO, (n.d.-b), which would benefit from international collaboration as all countries are experiencing these changes simultaneously.

Let us therefore assume that global population aging, defined in this paper as the health of the world's population of older people over the age of 60 years old, is indeed to be considered an international concern; after all, by 2050, 80% of older adults will be living in low-income or middle-income countries, and these nations will have aged populations without high-income resources (Robinson et al., 2007). Aging has historically been neglected by international health agencies. For example, the topic of aging health arose in the international health policy debates on primary health care (PHC) in the 1980s. Lloyd-Sherlock (2002) argues that many tenets of PHC, such as the shift from curative to caring health models and the growing importance of health promotion and community participation, are particularly relevant to the needs of older adults. However, when global organizations prioritized services for mothers and children within PHC to the exclusion of other populations, this further marginalized older people in developing countries who already lacked access to basic health care (Lloyd-Sherlock, 2002). The alienation of aging was further compounded by the World Bank, which evaluated and funded health interventions using disability-adjusted life years with higher values afforded to "productive populations," defined as people between the ages of nine and 55 years old (Lloyd-sherlock, 2002).

Unfortunately, with so many competing interests, health care for older adults has struggled to convey its own significance, and aging populations are lacking an international institution to champion this cause (United Nations Department of Economic and Social Affairs, 2017). The WHO has historically been committed to its priority populations (women and children) and priority health programs (infectious diseases and universal health coverage [UHC]). The health of aging populations can be considered a means for the WHO to achieve UHC rather than a goal in itself, "because without considering the health and social care needs of the ever-increasing numbers of older people, UHC will be impossible to achieve" (WHO, n.d.-c, para 1). Further, the responsibility of global population aging was, until recently, delegated to the Department of Ageing and Life Course within the WHO—a catch-all name that neglected the importance of older populations themselves. Another forerunner to advocate for the health of global populations is the United Nations (UN); it was the first international organization to use its authority to frame global population aging as a health issue through the Vienna and Madrid conferences in 1982 and 2002 (Kendig et al., 2013). The UN could establish an agency to provide leadership for this issue, similar to the founding of the United Nations Children's Fund (UNICEF). Unfortunately, no such agency has been established and the focus on health issues is primarily framed as a means of addressing aging as an economic and development issue (Shiffman & Smith, 2007; UN, 2002). Recent reports by both organizations on aging and aging populations are promising, nonetheless.

The current pandemic has required that governments and policy-makers re-examine their health systems, particularly in relation to older adults as a vulnerable population. While cross-national, regional, and global sharing of research and policy options could result in solutions for common health issues faced by older adults in every country, a barrier is "the absence of an influential global policy community whose principal concern lies with the health and well-being of older people. Whilst many international agencies may have some interest in ageing issues for none is it a high priority" (Lloyd-Sherlock, 2002, p. 200). Shiffman (2009) argues that advocates for issues trying to make it to the top of the global health agenda must "build institutions devoted to their own issues, rather than to leave it to chance that existing global and national institutions are going to select their issues for attention" (p. 611). It is recognized that the role of global health actors in the post-Westphalian era is changing, with historic organizations such as the WHO or UN sharing the policy space with emerging private philanthropists and civil society organizations (CSOs). However, the same problem exists; there are many charities and CSOs involved in global aging, but each concentrates on a different aspect. For example, HelpAge International focuses on aging and development issues in low-middle income countries, the International Association of Gerontology and Geriatrics offers technical expertise in education of geriatric specialists, and the International Federation on Ageing facilitates research and knowledge translation (Kendig et al., 2013; Sidorenko & Mikhailova, 2014). Therefore, global aging populations would benefit from an international advocate, such as UNICEF for children or the Joint United Nations Programme on HIV/AIDS for populations with HIV, who would garner space on the global health agenda, attract resources, and align the interests of states and CSOs. Without governance from a dedicated institution or shared responsibility between multiple global actors in a recognizable coalition, global population aging is unlikely to emerge as a global health priority (Shiffman, 2009). Health issues related to aging populations are not going away any time soon—we must care for older adults now in addition to planning for healthy aging through the life course - it's time for the global health community to decide who will take the lead.

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Research Article

The Prevalence of Perfectionism and Positive Mental Health in Undergraduate Students

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Abstract

The purpose of this cross-sectional survey was to assess the relationship between mental health and perfectionist personality styles within Dalhousie University's undergraduate psychology program (*N* = 191). Positive mental health is characterized by high social, emotional, and psychological functioning in everyday life. Perfectionism has traditionally been studied as a correlate of poor mental health, although relatively recent research has offered a reconceptualization wherein the adaptiveness of perfectionism can support positive mental health. In particular, the perfectionist personality style may be categorized into three types: non-perfectionist, maladaptive perfectionist, and adaptive perfectionist. We classified participants based on their perfectionist personality style and assessed mental health scores across the three perfectionist personality styles. We found that mental health was highest in adaptive perfectionists. Our findings demonstrate that perfectionism can be an adaptive personality style and positively relate to mental health. Our study supports the reconceptualized definition of perfectionism as a potentially adaptive personality style.

Keywords: perfectionism, well-being, mental health continuum, personality, students

Introduction

Perfectionism is typically defined as a pathological personality style that holds negative consequences for well-being (Bieling et al., 2004) and has been coined a destructive quality (Slaney et al., 2001). This traditional concept of perfectionism was derived from clinical research settings and focused on the link between perfectionism and personality or psychological disorders (Birch et al., 2019). By focusing on clinical perfectionism, researchers only measured the maladaptive (unhealthy) qualities of perfectionism (Birch et al., 2019). This past research represents a traditional understanding of perfectionism as a single category personality style where individuals strive to meet extremely high standards (Birch et al., 2019), often leading to low well-being and distress (Bieling et al., 2004). In the last decade, the traditional definition of perfectionism has evolved to a more nuanced understanding of the potential adaptivity of the personality style (Bieling et al., 2004; Birch et al., 2019). The reconceptualized definition of perfectionism includes three types: non-perfectionism, maladaptive perfectionism, and adaptive perfectionism (Rice & Ashby, 2007) and can be measured and determined by the Almost Perfect Scale-Revised (APS-R; Slaney et al., 1996). While in the past, researchers were focused on the maladaptive aspects of perfectionism displayed in their clinical research as a negative influence on well-being (Bieling et al., 2004), more recent studies in non-clinical settings have shown perfectionism can be adaptive and contribute to positive influences on well-being (Rice & Ashby, 2007). The purpose of this cross-sectional survey was to assess mental health across different perfectionist personality styles in undergraduate psychology students.

Literature Review

Maladaptive perfectionism can be understood as "unhealthy" perfectionism (Bieling et al., 2004). In particular, maladaptive perfectionists strive for high standards but do not feel they meet them (Rice & Ashby, 2007), creating discord between personal standard and performance, leading to a failure orientation (Enns et al., 2001; Rice & Ashby, 2007). Adaptive perfectionism can be understood as "healthy" perfectionism (Bieling et al., 2004). Adaptive perfectionists also strive for high standards but are generally satisfied with their efforts or performance (Rice & Ashby, 2007) and are achievement oriented (Enns et al., 2001). With this new understanding of the potential adaptiveness of perfectionism comes a conceptual divide in the literature (Bieling et al., 2004; Birch et al., 2019).

Research on positive mental health (Hone et al., 2014; Keyes et al., 2010) has shown that mental health and mental illness can coincide, meaning that efforts to promote positive mental health and to prevent mental ill health need not happen in isolation. Unlike traditional mental health conceptions that focus on the absence of mental illness, the dual continuum of mental health recognizes that those experiencing mental illness are still capable of experiencing positive mental health (e.g., subjective well-being, positive emotions). According to Keyes's (2002) theory and empirical testing (Keyes, 2005, 2007; Westerhof & Keyes, 2010), it is possible to have positive mental health while also having a mental illness, and likewise, it is possible to have languishing mental health without having a mental illness. This dual-continua model (see Figure 1) is based on the idea that mental health is more than the absence of mental illness, and that they are related but distinct dimensions. This model conceptualizes positive mental health as feelings of happiness and satisfaction with life (emotional well-being), positive individual functioning in terms of self-realization (psychological well-being), and positive societal functioning in terms of being of social value (social well-being). The idea that state of mental health and wellness can encompass dual dimensions has become a central concept of positive mental health (Keyes, 2002, 2007).

With perspectives of mental health as being more than the absence of illness (e.g., the mental health continuum; Keyes, 2002), researchers have been able to provide evidence for an adaptive form of perfectionism where positive mental health is present (Enns et al., 2001; Rice & Ashby, 2007; Slaney et al., 2001). This is especially relevant in research on university students, as they are in an achievement- and success-oriented environment. Enns et al. (2001) studied perfectionism in undergraduate medical students and noted differences between maladaptive and adaptive perfectionism. In particular, the researchers found that adaptive perfectionism in medical students was linked to higher standards and self-reported academic achievement, while maladaptive perfectionism was linked to higher distress and lower well-being (Enns et al., 2001). Rice and Ashby (2007) noted similar qualities in undergraduate university students, with maladaptive perfectionism corresponding to self-imposed high standards and criticism of their work, and

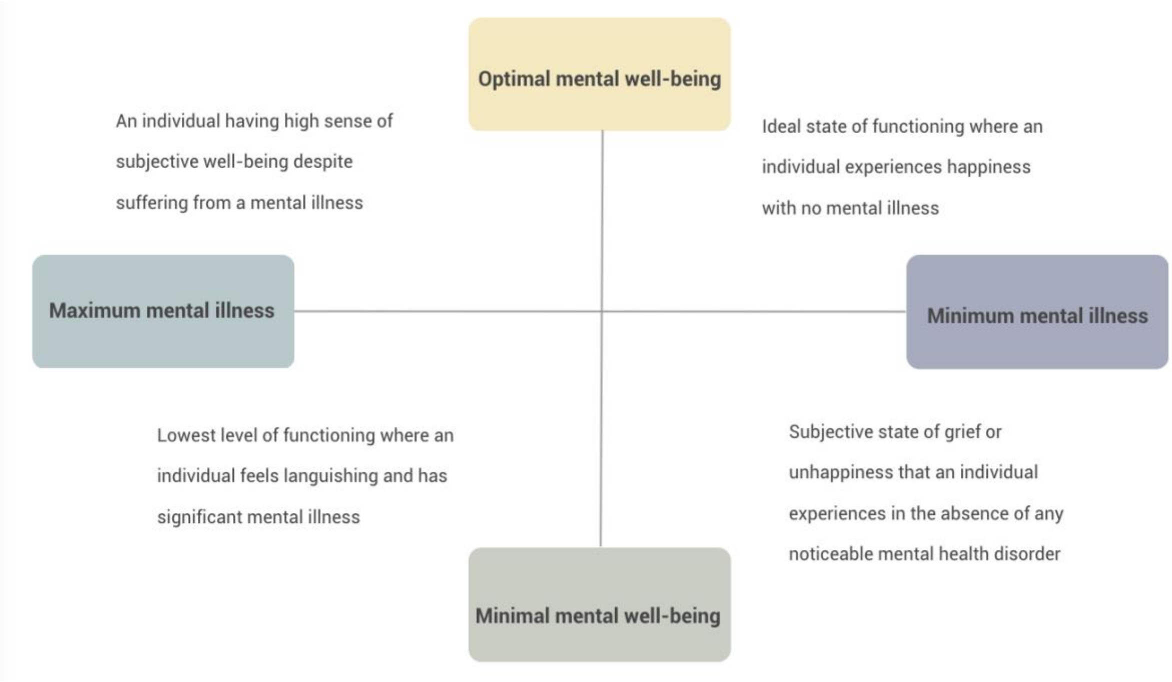

Figure 1

The Dual Continuum of Mental Health
Note. Adapted from "The mental health continuum: From languishing to flourishing in life," by Keyes, (2002).

adaptive perfectionism corresponding to high standards and life satisfaction. These results support the concept of the adaptiveness of perfectionism and that each perfectionist type influences mental health to varying degrees within students.

Past research has explored perfectionism and positive mental health in students separately, sometimes correlating specific aspects of well-being or perfectionism (Chang, 2006; Moate et al., 2019); however, there is very limited research exploring the relationship between the type of perfectionism and positive mental health. In addition, perfectionism and mental health research has typically been explored in more clinical settings where the negative or pathological aspects of perfectionism as a personality style and mental health disorders are the sole focus (Birch et al., 2019). Unlike these clinical studies, our study aims to investigate a mental health promotion perspective on mental health and perfectionism in students, by using scales that encompass the adaptivity of perfectionism and positive mental health as a reflection of student well-being in everyday life.

Objective

The purpose of this study was to reinforce the reconceptualized definition of perfectionism by determining the prevalence of positive mental health (i.e., number of flourishers and average positive mental health score) in perfectionists at a medium-sized university in Atlantic Canada. We used the APS-R developed by Slaney et al. (1996) to categorize individuals based on presence and adaptiveness and the Mental Health Continuum-Short Form (MHC-SF) developed by Keyes (2005) to evaluate mental health levels.

Hypothesis

We expect the average score on the MHC-SF to be higher in adaptive perfectionists than maladaptive perfectionists. As we expect non-perfectionists will, on average, be moderately mentally healthy, we have no hypotheses for non-perfectionists.

Methods

Participants

The sample consisted of undergraduate psychology students (*N* = 191) and was mostly female (87.05%). Participants ranged from 17 to 33 years in age (*M* = 20.71). The sample primarily identified as Caucasian (62.30%) or of African descent (24.08%); a description of participant demographics is in Table 1.

Table 1

Demographics of Participants (N = 191)

Variable	*N* (%) or *M*
Sex	
Female	168 (87.96%)
Male	22 (11.52%)
Primary Ethnic Identity	
Caucasian	119 (62.04%)
African descent	46 (24.08%)
Asian	6 (3.14%)
Age	20.71

Measures

APS-R

To evaluate an individual's perfectionist tendencies, we used the APS-R (Slaney et al., 1996), which categorizes individuals' perfectionism based on the conceptualization of perfectionism as adaptive or maladaptive. The APS-R is a 23-question self-report with responses based on a one (strongly disagree) to seven (strongly agree) Likert scale (Rice & Ashby, 2007). To classify perfectionists, the questions are sorted into three subscales: High Standards, Order, and Discrepancy (Slaney et al., 1996). The High Standards subscale measures personal standards and expectations, the Order subscale measures organization, and the Discrepancy subscale measures the negative qualities of perfectionism (Rice & Ashby, 2007). To be considered a perfectionist, individuals must score a 42 or higher on the High Standards section. For perfectionists to be categorized in terms of adaptivity, a Discrepancy score less than 42 indicates adaptive perfectionism and a Discrepancy score greater than 42 indicates maladaptive perfectionism (Rice & Ashby, 2007).

MHC-SF

The MHC-SF (Keyes, 2005) enables two types of measurement for mental health: a score for an individual's level of mental health based on level of psychological, emotional, and social well-being, and classification of mental health into three levels (languishing, moderate, or flourishing). Participants answered 14 questions based on frequency of feelings (Keyes, 2005). The MHC-SF scores on social, emotional, and psychological well-being correspond to a mental health level on the continuum, where high scores generally reflect presence of positive mental health and low scores reflect absence of positive mental health (i.e., languishing). Languishing individuals are identified by low scores (i.e., answering a one or two out of six) on the emotional well-being subscale and low scores on at least half of the questions on the social and psychological well-being subscales (Keyes, 2005). Flourishing individuals are identified by high scores (i.e., a five or six out of six) on each question in the emotional subscale and high scores on at least half of the social and psychological subscale items. Moderately mentally healthy individuals are those who do not fit into languishing or flourishing thresholds. In this study, we focus on the scale score (i.e., average level of mental health) rather than categorizing individuals into mental health levels.

Procedure

This study is part of a larger study on well-being and personality and received ethical approval from the institutional research ethics board. Participants were recruited using

Dalhousie University's undergraduate participant pool platform, wherein any students could register to participate in the study and receive bonus points for an eligible psychology course. Data were collected from participants through a larger online survey that included the APS-R and MHC-SF. Using *R*, we assessed relationships between our continuous data (i.e., overall mental health scores, perfectionism subscale scores, correlation between mental health and perfectionistic standards) and frequency counts of categorical data (i.e., mental health classification, perfectionism type) to understand the relationship between perfectionism and mental health.

Data Analysis Plan

We used the APS-R measure to classify perfectionists; as demonstrated by Rice and Ashby (2007), this scale is an efficient method for classifying perfectionists compared to past studies (e.g., Bieling et al., 2004; Birch et al., 2019) that used both the Frost Multidimensional Perfectionism Scale (Frost et al., 1990) and the Hewitt and Flett Multidimensional Perfectionism Scale (Hewitt & Flett, 1991) to categorize perfectionists. These studies used complex confirmatory factor (Bieling et al., 2004) and cluster analysis (Birch et al., 2019) to group perfectionists, but the calculations used by Rice and Ashby (2007) are a much easier method of classification to understand. We used the mental health continuum to measure the presence of positive mental health (Keyes, 2005). To measure presence of positive mental health, we calculated average scores from the MHC-SF, wherein high scores reflect presence of positive mental health, and low scores reflect absence of positive mental health (Keyes, 2005, 2007). We first assessed the correlation between perfectionism score and mental health score. Due to our interest in assessing differences in mental health (MHC-SF score) across types of perfectionistic individuals (APS-R), we assessed differences in mental health score across perfectionism type.

Results

The majority of individuals were moderately mentally healthy (79%), followed by flourishers (20%), with very few languishers (1%). In terms of perfectionism, the majority of individuals were maladaptive perfectionists (44%), followed by non-perfectionists (42%), with some adaptive perfectionists (14%). Maladaptive perfectionists tended to be moderately mentally healthy (75%) or flourishing (23%; see Table 2). Adaptive perfectionists were nearly entirely moderately mentally healthy (92%). Non-perfectionists were mostly moderately mentally healthy (78%) followed by flourishers (22%).

Overall, participants' APS-R Standards score was lower than the APS-R Discrepancy score. The APS-R Standards score among languishing participants was higher (i.e., higher perfectionistic standards) than in flourishing and moderately mentally healthy participants (see Table 3). Discrepancy scores (i.e., greater discrepancy between standards and performance) were highest among flourishing individuals. Scores on the APS-R Standards subscale was moderately positively correlated with mental health scores, $r = .38$, 95% CI [.17, .56], $p = .0007$. Due to the ranked nature of perfectionism types (i.e., maladaptive perfectionism is objectively unhealthier than adaptive or non-perfectionists), we used a Kruskal-Wallis test as a non-parametric analysis of variance (ANOVA). Mental health significantly differed across perfectionistic personality types, X^2 (2) = 10.01, $p = .007$ (see Table 4). Post-hoc comparisons of mental health scores across perfectionist type showed that the difference was between maladaptive and adaptive perfectionists ($p = .006$).

Discussion

The goal of this study was to reinforce previous research that identified the three types of perfectionism and the understanding that, when classified as adaptive, perfectionism can coincide with positive mental health. We hypothesized that students with an adaptive perfectionistic personality style would have positive mental health, which was supported by the relationship between mental health scores and perfectionism type: mental health was higher in adaptive perfectionists than

Table 2

Prevalence of Mental Health Level by Perfectionism Classification

Mental health	Perfectionism type			
N (%)	Non-perfectionist	Maladaptive	Adaptive	Total
Languishing	0 (0%)	2 (1%)	0 (0%)	2 (1%)
Moderate	63 (33%)	63 (33%)	24 (13%)	150 (79%)
Flourishing	18 (9%)	19 (10%)	2 (1%)	39 (20%)
Total	81 (42%)	84 (44%)	26 (14%)	191

Note. Mental health level classified with the MHC-SF; perfectionism classified with the APS-R; percentages represent column percentages.

Table 3

Average Perfectionism Subscale Scores by Mental Health Level

Perfectionism subscale	*M*		
	Languishing	Moderate	Flourishing
Discrepancy sum	77.00	50.34	59.15
Standards sum	44.50	41.80	41.23

Note. M = average; the Order subscale of APS-R was not included, as it is not used in the perfectionism classification procedure.

Table 4

Average Mental Health Score by Perfectionism Type

MHC-SF	Perfectionism Type			
	Non-perfectionist	Maladaptive	Adaptive	Overall
MHC-SF	49.77 (14.47)	45.10 (12.81)	58.91 (10.29)	47.89 (13.52)

Note. M (sd) presented.

maladaptive perfectionists, and scores on perfectionistic standards and positive mental health were positively correlated.

Mental health in adaptive perfectionists was higher than maladaptive perfectionists, although maladaptive perfectionists did not have significantly higher mental health than non-perfectionists. This suggests that the adaptivity of perfectionism positively relates to mental health. It is not the mere presence of having a perfectionistic personality style that relates to positive mental health, but the adaptivity. These findings are similar to the Birch et al. (2019) study, where researchers determined that adaptive perfectionism encouraged flourishing. Non-perfectionists' mental health was moderate, while maladaptive perfectionists' mental health was the lowest of the three types of perfectionism, suggesting that maladaptive perfectionism negatively relates to mental health or well-being, similar to research by Birch et al.'s (2019) findings, where maladaptive perfectionism was negatively associated with mental health.

Our findings also supported the reconceptualized definition of perfectionism by highlighting the general difference in mental health among types of perfectionism. In particular, maladaptive perfectionism may not always be a detriment to mental health to the point of languishing. Languishing, along with depression, is often associated with significant psychosocial impairment (Keyes, 2002), although many studies measuring mental health distribution show that languishing is fairly uncommon (Keyes, 2005, 2007). Traits associated with maladaptive perfectionism (high concerns, high standards) negatively impact mental health (Bieling et al., 2004); however, these impairments can range in severity and may not always directly result in significant impairment (Rice & Ashby, 2007).

Maladaptive perfectionists had significantly lower average mental health scores compared to the average mental health score of adaptive perfectionists. This demonstrates that perfectionism, when adaptive, can coincide with positive mental health, and supports adaptive perfectionism model and our hypothesis. There was no significant difference between maladaptive and non-perfectionists' average mental health score, suggesting that maladaptive perfectionism may not be "as bad" for mental health as adaptive perfectionism is "good" for mental health.

More generally, the subscale averages of the APS-R for each level of mental health scores (e.g., languishing, moderate, flourishing) supports the adaptive perfectionism model and our hypothesis of a positive relationship between adaptive perfectionism and mental health. Moderately mentally healthy individuals had the lowest scale average and languishing individuals had the highest scale average score, while flourishing individuals had the moderate score. Further, a moderate positive correlation was identified between perfectionism and mental health scores, suggesting that mental health scores and perfectionistic strivings are positively related, providing additional reinforcement of the average scale score findings and support for a positive relationship between adaptive perfectionism and mental health.

Theoretical Implications

The variation in mental health across the three types of perfectionists support our hypothesis that adaptive perfectionists tend to enjoy higher mental health than maladaptive perfectionists. These results are also similar to those of the Rice and Ashby (2007) study on perfectionism and mental health in undergraduates, which found maladaptive perfectionists had low life satisfaction and higher levels of depression and that adaptive perfectionists had higher life satisfaction and very low levels of depression. The study by Birch et al. (2019) also found that maladaptive perfectionism leads to low mental well-being. Taken together, these findings suggest that adaptive perfectionism and positive mental health can coincide.

The theoretical divide in the literature on perfectionism (i.e., whether perfectionism can be adaptive) may be due to the differences between clinical and non-clinical studies

(Bieling et al., 2004; Birch et al., 2019; Rice & Ashby, 2007). For example, experimental research has provided evidence for the adaptiveness of perfectionism (Birch et al., 2019), while clinical research tends to focus on the personality pathology underlying maladaptive perfectionism (Rice et al., 2007). We use the APS-R measure to classify perfectionism as adaptive or maladaptive, and this measure was developed with a non-clinical population (i.e., undergraduate students; Slaney et al., 1996) and with the adaptiveness conceptualization in mind (Slaney et al., 2001). The mere development of this scale as a way to measure adaptivity in perfectionism, provides indirect support to the reconceptualized definition of perfectionism.

Past research measuring positive mental health (Keyes, 2005, 2007) suggests that most of the general population is moderately mentally healthy with fewer languishing and flourishing individuals, which aligns with the distribution of mental health levels in our sample. Moreover, past research on perfectionism suggests that the majority of the population are non-perfectionists with fewer adaptive or maladaptive perfectionists (Slaney et al., 2001), whereas our sample was disproportionately composed of maladaptive perfectionists. There are many factors that may have affected this discrepancy from the norm, including our small sample size or gender disproportion, as past research has shown gender differences in Discrepancy scores on the APS-R (Rice & Ashby, 2007). It is important to note that students are in an environment centred around achievement and may have additional pressure to succeed academically due to the online environment created by COVID-19. Students' achievement-oriented environments may promote excess concern and pressure over academic achievement, and therefore be responsible for a higher percentage of maladaptive perfectionists in our sample.

Limitations and Future Directions

Our study was limited by our focus on a specific demographic—mostly female, Caucasian, undergraduate psychology students. Further, the representativeness of our results for the greater population may not be accurate, as the demographics in the general population are not fully reflected in our sample. A consequence of this may be considered through Chang et al.'s (2004) research on perfectionism and mental health, which compares perfectionism and mental health in Caucasian and African American females and illustrates potential differences related to ethnic origins. In addition, past research evaluating factors of the APS-R found gender impacts scores for the APS-R (Rice & Ashby, 2007). Different demographics could influence the results in ways we cannot see with this limited group.

An additional consideration of our study that may have impacted the reported mental health levels are the various and unexplored situational impacts of COVID-19 on students. The COVID-19 pandemic has introduced an unprecedented environment and experience for university students. All students in this sample were completing school remotely due to COVID-19 restrictions and the transition from in-person to remote learning is undocumented. Due to the abnormality of the pandemic and online learning, students are missing out on normal social and educational interaction which may be paired with other pandemic-related stressors outside of their academics. Lukács (2021) used a questionnaire to measure life changes in Hungarian university students before and after a period of social isolation due to COVID-19 and reported a significant negative impact on university student well-being following social isolation. These findings suggest that social isolation associated with COVID-19 may have negatively impacted university student well-being during data collection, producing decreased mental health scores as a result.

Conclusion

Overall, research on perfectionism and mental health is still ongoing because of the divide in the conceptualization of perfectionism and its effects on mental health (Birch et al., 2019). This study provides evidence for the importance of continued research to develop our understanding of the adaptiveness of perfectionism, a traditionally "unhealthy" personality style, using a health promoting perspective.

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HEALTHY POPULATIONS JOURNAL

Research Article

Adverse Childhood Experiences: Early Childhood Educators' Awareness and Support

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Abstract

Introduction: Adverse childhood experiences (ACEs) refer to prolonged childhood exposure to potentially traumatic events that have lifelong impacts on health and well-being. Early childhood educators (ECEs) can provide supportive environments for children who have experienced, or are currently experiencing, ACEs. This study explored the awareness of ECEs related to ACEs and the assistance they need to create supportive environments for children. **Objectives**: Provide a Canadian context to ACEs and the early childhood education environment, explore awareness of ECEs related to ACEs, and explore the assistance ECEs need to create supportive environments for all children. **Methods**: The three research questions for this study were the following: How aware are ECEs of ACEs? How are ECEs supporting children who have experienced, or are currently experiencing, ACEs? Lastly, how are ECEs supported in supporting children who have experienced, or are currently experiencing, ACEs? Qualitative description, derived from thematic analysis, was used to illustrate the narratives of participants' experiences. Semi-structured interviews were conducted with ECEs (n=9) in Nova Scotia, Canada. Thematic analysis resulted in themes that relate to ECE awareness and support. **Results**: ACE awareness was described as being developed through parent-to-educator communication, observation of child behaviours, and community location. Barriers to awareness included varying comfort levels of parents and stigma around sharing unfavourable experiences that happen in the home. Participants suggested that creating supportive relationships and environments was important for children experiencing ACEs. Additional strategies included professional development opportunities and collaboration with other professionals. **Conclusion/Discussion**: This research identifies areas of support needed to assist ECEs in creating supportive environments for children.

Introduction

Early childhood is a developmental period that influences a child's future health and social emotional development (Irwin et al., 2007). Adverse childhood experiences (ACEs) refer to prolonged childhood exposure to potentially traumatic events that have lifelong impacts (Felitti et al., 1998). ACEs can occur across the child, family, and community ecologies, including child maltreatment (e.g., verbal, physical, or sexual abuse) and family or community stress (e.g., ill or incarcerated family member; death, divorce, or separation of parents; domestic/community violence; or poverty; Blodgett & Lanigan, 2018; Hughes & Tucker, 2018). The toxic stress of ACEs can lead to permanent changes in brain structure and function, and retrospective research demonstrates a link with poor long-term health and social outcomes (Felitti et al., 1998; Fredland et al., 2018; Fuller-Thomson et al., 2016; Hughes et al., 2017; Lee et al., 2016; Poole et al., 2018; Sareen et al., 2013; Thomson & Jaque, 2017; Zarnello, 2018). ACEs demonstrate that future adult health and social outcomes are the product of inequities experienced in early childhood (Srivastav et al., 2020).

With one in three Canadians reporting abuse before the age of 16 (Afifi et al., 2014; Jacobson, 2021), it is important to understand the environmental context that can shape a child's development (Danielson & Saxena, 2019) and help mitigate the impact of ACEs (Merrick et al., 2020; Sege & Harper Browne, 2017). The Bronfenbrenner ecological model provides a valuable framework for understanding child development through their interactions with individuals, groups, and structures within their proximal and distant contexts (Bronfenbrenner, 1977, 1994; Sandberg, 2017). For example, although ACEs can have detrimental impacts on one's development, resiliency can be gained through quality environments and relationships.

Evidence suggests that participating in quality early learning and child care (ELCC) can assist children who have experienced adversity (Sciaraffa et al., 2018), with Mortensen and Barnett (2016) reporting that children facing the most risk for maltreatment typically showed the greatest gains when exposed to high-quality ELCC. The term high-quality ELCC can have different meanings, but a common definition relates to process (engaging materials and activities, positive interactions between adult and child) and structural components (e.g., staff qualifications, adult–child ratio; Bigras et al., 2010). Research suggests that parents often value the emphasis on positive relationships (process quality) between educators, children, and families (Noble et al., 2007; Scopelliti & Musatti, 2013; Sollars, 2020). Unfortunately, children from disadvantaged backgrounds are more likely to experience early childhood trauma and are at increased risk for re-traumatization in communities and schools (Jacobson, 2021; Lew & Xian, 2019; Marryat & Frank, 2019). While early childhood educators (ECEs) working in ELCC have the potential to create physically and emotionally safe environments for children (Sciaraffa et al., 2018; Wertsch, 2005), there is a gap in knowledge about ACEs within this setting.

Although quality ELCC can act as a protective factor against the effects of early childhood trauma (Alat, 2002; Bell et al., 2013; Berson & Baggerly, 2009; Cummings et al., 2017; Little & Maunder, 2021), there is limited Canadian literature related to ACEs and the ELCC environment. Research suggests that many ECEs do not feel prepared to meet the needs of children who have significant social-emotional problems or behavioural difficulties (Kaufman-Parks et al., 2017), yet children who experience ACEs are more likely to experience such concerns. ECEs need a comprehensive understanding of the physiological and psychological mechanisms that underlie children's emotions and behaviours related to being exposed to ACEs (Stormont & Young-Walker, 2017). Educators have expressed stress and frustration when uncertain how to support children with challenging behaviours that might be the result of the child experiencing an ACE, leading to negative adult to child interactions (Chung & Harding, 2009). Understanding the relationship between ACEs and behaviour can help educators be more mindful of their own emotional responses and help them facilitate developmentally-appropriate responses to create a positive child and educator relationship (Cummings et al., 2017; Sciaraffa et al., 2018; Stormont & Young-Walker, 2017).

The purpose of this study was to explore the awareness of ECEs related to ACEs and the assistance they need to create supportive environments for children. An ecological systems framework was used as a lens to interpret the results of the study, providing context to the interactions across systems that influence ECEs related to ACEs.

Methods

This research followed a constructivism/interpretivism approach that considers the social construction of multiple realities as subjective and susceptible to change (Wahyuni, 2012). Using this approach allowed the participants to share their perspectives related to ACEs, employing their own unique and valued reality to give context to the research questions in the study (Wahyuni, 2012). Furthermore, qualitative description enabled a portrayal of participants' experiences by illustrating narratives of those experiences (Willis et al., 2016). Interpreting the various perspectives of other participants allowed for the discovery of common themes, moving beyond what the participant reported and clustering together common ideas from multiple individuals to represent the data (Braun & Clarke, 2006; Willis et al., 2016).

Data Collection

Following the study's ethical approval from the university research ethics board, ELCC directors were sent a recruitment poster using a publicly available provincial directory of ELCC programs. Interested ECEs contacted the researcher by email and, following informed consent, nine participants each took part in an interview (about 45 minutes). Consistent with a qualitative description approach (Bryman, 2012), a semi-structured guide included questions related to their awareness of and received support for ACEs, while also being open to build on participant experiences and expand upon the questions to ensure relevance.

Data Analysis

Interviews were transcribed verbatim, and coding was completed using Nvivo 12 software. The thematic analysis process described by Braun and Clarke (2006) was used, allowing flexibility and usefulness in summarizing key features of the data while generating a thick description that highlights similarities, differences, and unanticipated findings. Each transcript was reviewed, and any identifying information was removed before inputting the transcripts into the software. The primary author familiarized themselves with the data, transcribing the interviews and reviewing the transcripts. The primary author read through the transcripts and created an initial codebook, further naming and defining each code. Verbatim examples from the transcripts were copied into the codebook to further explain the meaning of each code. The two authors discussed the initial codes to further refine emerging codes and search for broader level themes that included collapsing codes together to create bigger, overarching ideas or breaking ideas down to create separate ones. Once the themes were reviewed, they were defined, named, and described through discussion by the authors to ensure representation of participant experiences. Following the identification of themes, Bronfenbrenner's ecological systems theory was used as a framework to support additional interpretation of the study findings.

Results

The ECEs (n=9) worked in a variety of Nova Scotian communities with different ELCC experiences and education. Table 1 below provides demographic information for each participant, paired with a pseudonym that is connected to the following quotes. All participants had an awareness of early childhood trauma, which may have influenced their shared perspectives. The results are presented through three sections: ACE awareness, how ECEs support children, and support for ECEs. Themes within these sections are bolded in each section of the text.

Table 1

Participant Demographics

Location	**Education**	**Years of Experience**	**Pseudonym**
Urban location	Masters level education in Child and Youth	8	Angela
Rural location	Masters level of education	12	Mary
Rural location	Two-year degree	18	Amy
Rural location	Four-year degree	34	Kelly
Urban location	Four-year degree	10	Kelsey
Urban location	Four-year degree	23	Madison
Rural location	Two-year diploma	30	Michelle
Urban location	Two-year diploma	20	Betty
Urban location	Two-year diploma	40	Carolyn

Note. Rural location refers to individuals in towns or municipalities outside the commuting zone of larger urban centres. Urban locations are defined as highly populated areas that have greater access to transportation, etc.

ACE Awareness

Participants reflected on the ways in which life in rural communities, parent and educator communication, and observation of child behaviour influenced their awareness of ACEs. While discussing their centre's ***community***, participants mentioned they felt this community increased their awareness of a child's early life experiences. One participant stated the following:

> *Because we're a small community, we probably know more than we want to know. Yeah and because we're a small community and because you know, I watch the staff take the time to get to know the parents … but families share quite a bit and being in a small community even if the family's not sharin', you see it and you know everything.* (Mary)

Participants in rural areas spoke to their strong sense of community, which made it easier to develop genuine and trusting relationships and create a safe place for families to be comfortable discussing their home life. One participant commented on this:

> *You know, we have rules against Facebook, things like that—but we know our families and our families know us. We*

> *have parents who came to this centre as kids and now their kids go here, so, we have those relationships built and they trust us with stuff, you know? I may be walking down the street and so and so might tell me "so and so passed" or "so and so did this," so it's definitely natural to have that open communication when you're a close, close community.* (Madison)

ECE and family communication was often focused on general events before and after ELCC during drop-off and pick-up times (e.g., "How was your morning?"). Communication seemed to be influenced by the varying comfort level and individual preferences of families. Although participants often respected these boundaries, they found it more difficult to understand a child's behaviours when unaware of their experiences. Some participants felt this might be related to stigma around certain behaviours and experiences. One participant discussed this:

> *And it's stuff that could've—yeah, it's just been kind of gradually, and I don't know if that comes from the parents not having all the info … or not wanting us to maybe peg their child you know what I mean by that? Because there's a lot of stigma that goes with that stuff too, right?* (Kelly)

Participants also spoke about how ***children expressed their experiences through play.*** A few participants discussed how watching children's play made them aware of adverse early experiences. Often, participants indicated that they suspected a child was experiencing an adverse event at home because of the behaviours displayed at the centre. Participants spoke about the difficulty of not knowing the best practices to use or how to navigate the situation, as certain expressions through play may have been a result of home experiences. One participant commented on this:

> *Most often I see a teacher taking a child over there so the other children can't hear what happened or in play what are they talking about with one another? "Daddy hit Mummy," "we don't have food in our house," "I have to go to Nanny's house," like we're hearing that but then they're taking that trauma and putting it on another child because then that child goes home and tells Mummy "so and so told me that their daddy hit them, will my daddy hit you?" or whatever, so it's a full circle.* (Carolyn)

How ECEs Support Children

Participants reflected on how creating ***supportive relationships and environments*** for children is crucial, especially for those with ACEs. For example, some participants described the importance of *consistent routines and clear expectations in the ELCC environment, which could also foster relationship building. One participant stated the following:*

> *I think that structure is really important too for children that have experienced trauma and that is something that we definitely provide here and consistency like we're very—we try to be as consistent as we can across the staff … we try and like diminish that stress as much as we can 'cause I think that's a really—a really big one for a lot of kids now, stress and anxiety.* (Kelsey)

In addition to safe environments for children, creating safe environments for families was also seen as crucial. Participants discussed how they created welcoming environments for both children and families, making sure families felt comfortable with them and the centre. Examples included incorporating family photos throughout the ELCC space and maintaining ongoing communication. However, participants also discussed difficulties in creating positive relationships with children who may have experienced ACEs that impacted their trust. One participant spoke about this:

> *Initially, I found they would—they would test more, you know, try to push you away … it's almost like they're testing like you know okay, you know for the abandonment, attachment type of thing you know it's like "Are you gonna go? Let's see what I can do to make you go and if*

> *you're not gonna go then okay you're here," so.* (Michelle)

When asked about what steps were taken when challenges were encountered, ECEs discussed the importance of showing care. Ultimately, letting children know they were valued and supported was described as one of the most important components of forming supportive relationships. One participant stated the following:

> *But I feel like always—always the first one is like you have to give tremendous love to this child no matter what, that's number one because this child now doesn't really trust anybody, he doesn't like anybody, right? So I think yeah whenever I get those like behaviour I don't really know what's happening sometimes right? And some behaviours are really tough right? And—and I try to yeah I try to focus on that first.* (Betty)

Support for ECEs

Participants also discussed public perception of their profession and how that affected their capacity to support children with ACEs. One participant commented on this:

> *It becomes tricky because it's like we can only do so much too we can only try and develop those connections with families, try to ask them for meetings as many times as we can, but if they're not willing to do it then what do we do? And sometimes just unfortunately in our profession we're not always seen as professionals so sometimes just having that other person—hey this person specializes in this.* (Angela)

Participants also discussed the additional resources they needed to enable their work with children and families within their community. The majority of participants identified a ***lack of training and resources*** to support children experiencing ACEs. In terms of the supports needed, the majority of participants described a limit in number of opportunities for professional development related to ACEs. Without support, participants felt limited in how they could support families. One participant stated the following:

> *I think it's simply more intentional training and maybe it's required training. You know if the child maybe doesn't have a diagnosis but you know they have some trauma or they're having behaviour then they can have some extra supports within the classroom. It would just be beneficial for everyone to have that consistent training on best practice for trauma, because even when they're little even when there's not something going on they're gonna build those tools for when the trauma kinda comes up or having their words to ask for help or having words to say "I'm really frustrated" yeah and then more workshops as we already talked about there's definitely more of an awareness kinda coming out but there needs to be more training.* (Carolyn)

Participants also mentioned the need for specific training in the field of trauma and ACEs to support the ELCC profession. One participant shared their thoughts on this:

> *So, here's the best example when a child loses a parent, whether it be, we had a child recently lose her mum to cancer, we don't have the proper training to be able to know what to say to the child so we're on the phone calling people to say "okay well what do we say," … cause we're looking at a lot of different mental health situations, so what do we as teachers tell the kids, sometimes it's honestly you kinda just try and ignore it and hope that it goes away because I don't know what to do.* (Amy)

In addition to professional development, participants discussed how they were often unsure where to go for support and needed additional resources to support children and families. Participants described how they often looked to other professions for support, such as psychologists or social workers. Participants referred to these professions as "experts," saying that knowing whom to call was something they needed when supporting children with ACEs. Participants assumed that these professions dealt with trauma more frequently, suggesting that working together and communicating with these individuals would offer more insight into navigating best practices. One participant shared the following:

> *I would be happy to meet those experts, so that, they could help us, those kinds of traumas or situations and what kind of things you can do or you can support family or child, so there will be more supports and experts other than ECEs I mean we are the front lines but once like we are—we can see there [is] something going on in this family then we want to have somebody working on those as a team right?* (Michelle)

Supporting the ECEs who themselves may have experienced an ACE was also discussed by a few participants. One participant gave the following comments:

> *We also have to understand that our staff have once been children our staff have gone through things and what happens when you get that little boy or girl that's looking in that teacher's eyes and saying "my mum hit me" that staff may have a flashback but then hey, she knows she can pick the phone up, make that phone call to child protection but then it's left at that, nobody's coming back to say "hey we took care of little _____ [child's name] she's okay, things are going to be okay, Mum's getting the help that she needs," none of that is there, so.* (Amy)

Discussion

In this study, ECEs described their awareness of ACEs, stating that they often became aware due to parent and educator communication, observation of child behaviours, or community location, as well as discussing barriers to this awareness such as stigma and varying comfort levels of parents. Creating supportive ELCC environments and building relationships with parents and children were identified as important in supporting children with ACEs. ECEs in this study felt that additional resources were needed to assist them in supporting children , including professional development opportunities and greater collaboration with or access to other professionals. Bronfenbrenner's ecological systems theory offers a lens through which to discuss these results in relation to previous literature. An adapted visual representation of the ecological model with results from this research is presented in Figure 1. The arrows in the diagram reflect the interrelationships within and across the multiple levels.

Participants in this research described how two of the main ways to support children experiencing ACEs were through supportive relationships and ELCC environments. The results of this research suggest that it might be difficult to form relationships with children who may have experienced ACEs. Previous research states that children who experience ACEs are more likely to have insecure attachments (Sciaraffa et al., 2018). Our results are supported by previous research that has found that children with insecure attachments have difficulty trying to form supportive relationships with other adults (i.e., educators and other caregivers; Bretherton, 1995; Sciaraffa et al., 2018). Participants further stated that they became aware of ACEs through a child's behaviours or through their play. Previous research supports the notion that children often re-enact their previous experiences (Scheeringa, 2011). Play is a child's natural medium for self-expression through which they can express their feelings, thoughts, fears, and conflicts, as well as develop self-awareness and self-esteem (Cooper, 2000). Supporting children through therapeutic play could be a beneficial way to support children with ACEs. Creating training opportunities across the province to help support educators with this type of play could be another strategy to further support both educator and child.

The home (a microsystem), along with an ELCC setting (another microsystem), are influential environments that support the development and growth of young children.

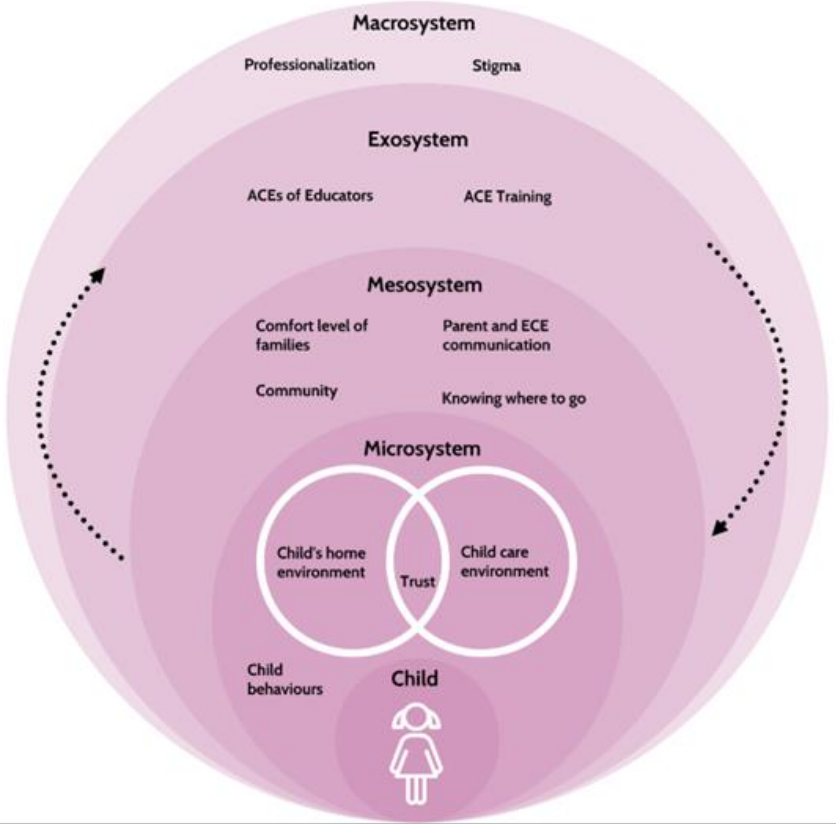

Figure 1

Study of Results Based on Bronfenbrenner's Ecological Systems Theory.

Ideally, both environments would be a supportive space for children; however, if a child experiences an ACE, an ECE may be the only dependable and safe relationship in a child's life (Sciaraffa et al., 2018). If a child develops a secure attachment with an educator, this relationship can serve as a protective factor against unfavourable experiences or behaviours that may result in the home or due to a previous insecure attachment (Mortensen & Barnett, 2016; Sciaraffa et al., 2018). Participants in this study reflected that other ways to support children experiencing ACEs included consistent routines and clear expectations. Previous literature supports this finding, stating that important components for coping with adversity are safe environments, predicable routines, and exposure to interesting and stimulating activities (Bakken et al., 2017; Campbell-Barr, 2017; Gomez, 2016; Sciaraffa et al., 2018). Evidence supports that participating in quality ELCC can assist children who have experienced adversity (Sciaraffa et al., 2018). ECEs play an important role in the early education and development of children. Skilled, attentive caregivers can help a child feel physically and emotionally safe (Sciaraffa et al., 2018; Wertsch, 2005). Insufficient spaces, lack of transportation, low subsidy rates, and financial constraints are barriers to accessing ELCC in Nova Scotia (Government of Nova Scotia, 2016). Making ELCC affordable, accessible, inclusive, and culturally relevant can help more Nova Scotian families access quality ELCC, offering developmental benefits to both children and society (Archambault et al., 2020; Government of Nova Scotia, 2016).

Although it is important to create relationships and environments that are supportive for children, this study also suggests that it is equally important to create these relationships and safe environments with families (a mesosystem interaction). In this study, participants indicated that they tried to develop relationships with families that made them feel comfortable, welcomed, and valued, which helped encourage increased communication about potential adverse experiences at home. In particular, participants from rural communities felt this might have been easier because individuals knew each other. This corresponds with previous research that suggests that parents who feel welcome in the ELCC space are more likely to feel their input and perspectives are valued, making them more likely to be involved and co-operative within the centre (Sciaraffa et al., 2018). However, parental stigma was found to be a barrier in this study that obstructed communication and relationship building with parents (a macrosystem interaction).

Previous research suggests that the social processes of stigmatization and discrimination can have complex and devastating effects on the health and welfare of families and communities, and thus on the environments in which children live and grow (Nayar et al., 2014). Perceptions of stigma can negatively impact parents' engagement in their children's education, leading them to feel a sense of powerlessness (Wilson & McGuire, 2021). Some research suggests that parents with children who display behaviours that educators find difficult in a classroom have more conflict with their child's teacher, the parents explaining that they have often felt criticized or blamed for such behaviour (Broomhead, 2013; Gwernan-Jones et al., 2015), and this consequently leads to an unhealthy parent-teacher relationship. There is limited research on how ECEs can limit the feelings of parental stigma of ACEs, but previous research looking at African refugee parent and teacher relationships suggests that creating caring, respectful, and culturally sensitive communication can foster positive refugee parent-teacher relationships. Employing a multi-dimensional approach that incorporates extra time, resources, and community support could create the potential for supportive teacher and parent relationships, especially for those families who experience inequity (Tadesse, 2014). ELCC and families could work together to increase the amount of effective communication needed to support children. However, this will continue to be a challenge, as parental stigma continues to be a large factor. Receiving training or professional development around this topic could help educators feel more comfortable approaching situations that may be influencing the child. This could also help ECEs learn strategies for making families feel more comfortable discussing previous experiences.

In this study, educators reflected on their work not being viewed as professional (a macrosystem interaction). Research suggests that ECEs often devalue their own professional identity, which may be due to a lack of confidence around what is perceived as professional (Harwood et al., 2013). Devaluing their work may also be due to societal opinions regarding ELCC (Harwood et al., 2013). Educators in this study often labelled other occupations such as psychologists and social workers as "professionals." Educators further stated that they would like to collaborate with these professionals in order to receive the information they need. The knowledge, expertise, and responsiveness to a child's needs that ECEs have cannot be underestimated; however, ECEs continue to experience low pay, lower training levels, and poorer status than other occupations who work with children (Murray, 2018). Although a team and interdisciplinary effort would be helpful, if educators are more adequately supported, they may not always have to reach out to others for support. Additionally, interdisciplinary efforts need to include all-around trust and support for all professions involved (Hall & Weaver, 2001). Therefore, in order for an interdisciplinary approach to work, mutual respect among all professions involved would be necessary, which may be a challenge due to general opinions regarding the ECE profession. With such mutual respect, creating a collaborative approach within ELCC may assist ECEs in supporting children experiencing ACEs. Creating partnerships with local social workers, psychologists, and others would be beneficial in order to combine a wide array of knowledge among multiple professions.

The majority of participants in this study said that they would like to see more opportunities to learn about ACEs and how to support children through specific training on trauma-informed care (an exosystem interaction). Although limited in Canada, American research suggests the usefulness of creating trauma-informed or trauma-sensitive spaces for children in both school and early childhood settings (Alat, 2002; Cummings et al., 2017; Fredrickson, 2019). Recent literature adds that training on attachment-aware and trauma-informed approaches can act as a buffer or protective factor against professional burnout (Little & Maunder, 2021). As stated above, children from disadvantaged backgrounds are more likely to experience early trauma, causing educational and community spaces to become inequitable spaces (Reyes et al., 2013). Building trauma-informed services can inform, complement, and support inclusive and equity-based practices for diverse populations (Bilias-Lolis et al., 2017; Dorado et al., 2016). Shifts toward trauma-informed practices create responsive and compassionate learning environments for all children, including those who have experienced inequities through trauma or past experiences (Bilias-Lolis et al., 2017). At an exosystem level, ACEs could become a priority across ECE training institutions and in professional development opportunities across the province. It may be beneficial to require mandatory, reflective training on ACEs for ECEs working in ELCC, so that all staff have the same base knowledge needed to support children as well as themselves. Additionally, specific training for creating trauma-sensitive ELCC environments is needed. Besides professional development and module training, a course surrounding ACEs and early childhood trauma could be added into the curriculum of diploma and degree-level early childhood educator programs. This course could provide future ECEs with a base-level understanding before they begin their practice.

In this research, participants discussed the importance of acknowledging the fact that some ECEs themselves have experienced ACEs, making it difficult to support children. Previous research in related fields, such as schools, suggests that teachers can be vulnerable to secondary stress due to their supportive role with students and potential exposure to students' experiences with traumas, violence, disasters, or crisis (Hydon et al., 2015). Mandatory training opportunities, such as workshops and seminars around the importance of self-care, could help support early childhood educators within the field.

Strengths and Limitations

Nine participants took part in this study through a semi-structured interview process that provided an opportunity to gather unique narrative experiences of participants (Braun & Clarke, 2006). Additional research to extend the diversity of participants would deepen our understanding of the experiences of ECEs. Further, gaining insight from families would help to extend the results of this study and identify the possible collaboration that could occur to support children with ACEs at the mesosystem level. In order to mitigate these limitations, the codes and themes were represented through the participants' thoughts and experiences, meaning that the codes and themes were closely related to what the participants expressed in the interviews. The researcher maintained an audit trail throughout the data collection and analysis process, which included reflections from the researcher after interviews, during the coding and theming process and throughout the overall research process.

Conclusion

There is limited research using ECEs' voices to describe their awareness and perceived support related to ACEs. As discussed by Bronfenbrenner (1991), for a child to display resiliency, they need at least one adult who cares deeply for them and provides support. This research begins to fill the knowledge gap related to ACEs and the ELCC environment to address health equities experienced by children. ECEs described their awareness of ACEs, developing this awareness from parent and educator communication, observation of child behaviours, and community location, as well as discussing barriers to this awareness such as stigma and varying comfort levels of parents. Participants suggested that creating supportive relationships and environments was important when supporting children. Additionally, participants suggested that factors such as increased interdisciplinary collaboration and professional development opportunities would help support them. It is further suggested that various levels of mandatory, reflective training and a more accessible ELCC system across Nova Scotia will help support children with ACEs. This research also promotes the important and valuable role of ECEs, supporting the notion that they, along with additional professionals, have the capacity to support children experiencing ACEs to build more equitable and supportive early childhood systems.

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Research Article

Accessing Sexualized Violence Services and Supports for Women in Rural Nova Scotia: A Qualitative Study

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Abstract

Introduction: Both rural and urban women who experience sexualized violence can face significant barriers to accessing services and supports, including fear of victim blaming, stigma, and re-traumatization. To date, there is a paucity of research that specifically examines the experiences of women accessing sexualized violence services and supports in rural places and the unique or additional barriers they may face. **Objectives:** The purpose of this qualitative study was to understand the experiences of women living in rural Nova Scotia who accessed services or supports after experiencing sexualized violence. **Methods:** Participants were recruited through community organizations and social media. Interviews were conducted with nine women in Fall 2019. Data were analyzed using feminist-thematic analysis. **Results:** Findings indicate that the women shared experiences of navigating a fragmented system of services and supports, and many reported harmful experiences with the justice system and formal health care system. Some women also experienced positive experiences with community-based services. Enhancing community-based services is recommended as one key strategy for improving access to sexualized violence services and supports in rural communities.

Keywords: sexualized violence, health care, women's health, sexual health, qualitative

Introduction

It is estimated that one in three adult Canadian women will experience some form of sexualized violence in their lifetime (Cotter & Savage, 2019). Sexualized violence is a broad term used to describe any physical or psychological violence that is carried out through sexual means (Jewkes et al., 2002). Although it is known that women may experience barriers to accessing sexualized violence services, relatively little is known specifically about the experiences of women living in rural areas and their potentially unique experiences when accessing sexualized violence services and supports (Wuerch et al., 2019). Sexualized violence services and supports include, but are not limited to, sexual assault nurse examiners, sexual assault centres, mental health professionals, victim services, police, residential support (e.g., transition houses), and peer support (Break the Silence NS, n.d.-a).

Rural areas may lack the breadth of formal services available in urban areas (Garasia & Dobbs, 2019; Wilson et al., 2020). In this study, a formal service was defined as a service that is funded and mandated to provide resources. In a rural area, this might include hospitals, clinics, women's centres, and other related community-based organizations. An informal support was defined as existing outside of formal supports and could include friends, family, informal women's groups, and online communities. The services that exist in rural places may be over-burdened in efforts to service a large geographical area and may come at a greater travel and/or time cost to women. Women in both urban and rural places may also fear being seen when they access sexualized violence-related services; this fear may be exacerbated in rural communities, as these communities are small and often close-knit. This qualitative study aimed to explore the experience of women living in rural communities in Nova Scotia accessing formal services or informal supports after experiencing sexualized violence. There is relatively little literature on the experiences of women living in rural communities accessing sexualized violence services or supports. The perspective of women living in rural places is valuable and needed to inform service and support provision in rural contexts, as these women may experience accessing services differently than women in urban communities.

Background

Existing research has shown that women who experience sexualized violence can face significant barriers to accessing both formal services (e.g., hospital-based services, community organizations) and informal supports (e.g., friends and family; O'Dwyer et al., 2019; Sualp et al., 2021). These barriers may include fear of victim blaming, stigma, and a re-triggering or traumatic experience (Gravelin et al., 2019; Milesi et al., 2020; Ullman, 2010).

Rural areas are generally defined as communities smaller than, and significantly distant from, larger urban communities (Lutfiyya et al., 2012). In Canada, communities with a population of less than 1,000 and outside of major population centres (e.g., towns) are rural (Statistics Canada, 2015). In general, there are fewer services in rural places than urban centres, and transportation is often a major barrier to accessing rural services (Peek-Asa et al., 2011; Smith et al., 2008). There are also fewer primary and secondary health care services in rural communities, with communities often having a limited number of hospitals, clinics, and/or family physicians (Shah et al., 2020; Youngson et al., 2021).

There is a growing body of evidence on the experiences of women in rural areas who are experiencing intimate partner violence (IPV), with IPV defined as "violent offences that occur between current and former partners who may or may not live together … ranging from emotional and financial abuse to physical and sexual assault" (Cotter, 2021, p. 4). Barriers to accessing IPV services in rural areas include a general lack of services (Edwards, 2015; Youngson et al., 2021), a lack of trust in existing services (Anderson et al., 2014), and a slow emergency response time in crisis situations (Moffitt et al., 2020). IPV and sexualized violence intersect (Jaffray, 2021), but there are differences in the service needs of women experiencing sexualized violence and/or IPV. IPV services typically include risk assessment, risk management, safety planning, and emergency housing (Jeffrey et al., 2019). In contrast, sexualized violence services typically include an immediate medical response and/or treatment from a sexual assault nurse examiner or other professional, along with long-term mental health supports (University of Kentucky Centre for Research on Violence Against Women, 2011). There is less known about the experiences of rural women accessing sexualized violence services specifically. Existing literature has identified poor transportation availability, limited community resources, lack of knowledge about services, and a lack of anonymity as main barriers to accessing sexualized violence services (Averill et al., 2007; Carter-Snell et al., 2020; Logan et al., 2005).

Study Context

This study was conducted in Nova Scotia, where 43% of the population currently lives in rural areas, compared to the national average of 19% (Statistics Canada, 2018). Nova Scotia has a total population of 923,598, with approximately 51% of the population identifying as women (Statistics Canada, 2019). With an aging population, out-migration of youth, and overall economic insecurity, rural communities in Nova Scotia are experiencing declines in infrastructure and service provision, including health care services. Many emergency departments in rural areas are operating at reduced hours (Province of Nova Scotia, 2019). In general, Nova Scotia is experiencing a family physician shortage; this is exacerbated in rural communities, as family physicians are concentrated in Halifax, the capital city and largest urban centre in the province (Doctors Nova Scotia, 2018). In 2016, Nova Scotia had the highest prevalence of low-income households among all provinces in Canada (Statistics Canada, 2017), with rural areas in Nova Scotia reporting higher rates of low-income households than Halifax (Statistics Canada, 2020). A lack of public transportation in rural Nova Scotia impedes access to critical services (Canada Without Poverty, 2015).

Historically, many rural communities in Nova Scotia have been dependent on resource extraction-based economies (e.g., coal, steel, fishing; Gibson et al., 2015). While some rural communities continue to benefit from these industries, they directly employ fewer people (Gibson et al., 2015). As industries have waned or ceased completely, rural communities in Nova Scotia are navigating job loss and/or new low-pay work and the need to diversify economies. Given that poverty and economic precarity increase women's likelihood of experiencing sexual violence (Gurr et al., 2008), the economic situation of many communities in the province may mean increased risk for many women (Women's Action Coalition of Nova Scotia, n.d.).

There are currently only three sexual assault centres in Nova Scotia, the largest and most urban of which announced in 2019 that it would temporarily stop accepting new clients due to capacity constraints (Bethune, 2019). Break the Silence, a provincial government-funded sexualized violence prevention initiative, maintains a map of services related to sexualized violence as part of the provincial sexualized violence strategy (Break the Silence, n.d.-b). However, this map includes generalized services such as all local RCMP detachments and family services offices, making it challenging to accurately assess the number and type of services related to sexualized violence across the province.

Methodology

Study Design

This qualitative study was rooted in critical feminist theory. Rhode (1990) defines the shared "commitments" of critical feminist theorists as the following: centring gender in analysis, describing experiences in a way that corresponds to women's experiences, and identifying change necessary for greater gender equality/equity. It is important to put the voices of women who have experienced sexualized violence first and foremost as the experts of their needs and wants, a role that may have been denied to them throughout various service and support interactions. The methodology of this study aims to reflect this by elevating the voices of women living in rural places.

To be included in the study, participants must have accessed or attempted to access a service or support in a rural area after any experience of sexualized violence in the previous two years. Participants were recruited via information sharing at nine women's centres and nine transition houses in rural areas across Nova Scotia, and on social media by sharing information about the study on Facebook, Twitter, and Instagram. Participants were given $20 to thank them for their time.

Sample

Nine participants were recruited and interviewed for this study. Research on the suggested minimum sample needed for qualitative thematic analysis varies (Braun & Clarke, 2012). Guest et al. (2006) suggest that conducting up to 12 interviews is ideal, although themes can be present with as few as six. Boddy (2016) argues that sample sizes as low as one can be justified by the context of the research. For this exploratory study, the goal was to speak to a small number of women (eight to 10) about their experiences.

Participants ranged in age from 21–50 years old and represented seven different geographical counties within Nova Scotia. We did not specifically ask about such demographic characteristics as race and sexual orientation, but some participants disclosed demographic information during the interview as it related to their experience of accessing services and supports.

Data Collection

The lead researcher conducted all interviews in Fall 2019 and Winter 2020. Participants were given the option of an in-person or telephone interview, and interviews were audio-recorded with the consent of the participants. Interviews lasted 30–45 minutes. We designed open-ended questions and probes to encourage participants to speak to the experience of accessing services and supports in rural Nova Scotia, and to generate discussion with respect to what services and supports are needed. Questions asked about what formal services and informal supports participants accessed, what they would have liked to access, and what recommendations they had for services and supports. This study was approved by the Dalhousie University Research Ethics Board.

Due to the sensitive nature of the interview questions, procedures were put in place in the event of the participant needing support post interview. A list of resources and community supports was distributed at the end of each interview to participants who wanted the resource. A guidebook to researching violence against women (Ellsberg & Heise, 2005) was referred to throughout the data collection process to ensure maximum participant safety. The lead researcher also completed the Nova Scotia Sexual Violence Strategy training on Supporting Survivors of Sexual Violence. This prepared the researcher to better listen and respond to any participants' disclosures of sexualized violence. The interview guide did not ask about the experience of sexualized violence, only the experience of accessing services and supports.

Data Analysis

Data were analyzed for key themes using Braun and Clarke's (2006) six-step process for inductive thematic analysis. Thematic analysis is a theoretically flexible method for analyzing data, allowing it to be used in a variety of contexts and with a variety of theoretical frameworks (Braun & Clarke, 2006). A feminist approach to data analysis acknowledges that pure objectivity in analysis is both impossible and undesirable (Gatenby & Humphries, 2000), and reflection on researcher positionality is necessary (Burgess-Proctor, 2015; Philip & Bell, 2017). All members of the research team identify as women living in urban areas, and acknowledged that their positionality impacts data interpretation.

Key Findings

Participants spoke about their experiences attempting to access and/or accessing a variety of formal services, including both individual and group counselling, primary care, and hospital-based services. Informal supports, including peer support and family and friends, were also discussed by participants. We identified four key themes: (a) Context of accessing services and supports, (b) Navigating formal services and associated burdens, (c) What women wanted to access, and (d) What women accessed. See Table 1.

Theme 1: Context of Accessing Services and Supports

Living in a Rural Community

Living in a rural community had various influences on participants' ability to access both formal services and informal supports. They spoke about confidentiality concerns, a pervasive culture of silence around sexualized

Table 1
Summary of Themes and Subthemes

Theme	Subthemes
1: Context of accessing services and supports	Living in a rural community Narratives surrounding sexualized violence in a rural place
2: Navigating formal services and associated burdens	Navigation Burdens of navigation
3: What women wanted to access	Long-term, trauma-informed mental health services Peer support Education
4: What women accessed	Justice system services Health system services Community-based services Informal supports

violence in rural communities, and a lack of anonymity. One participant described the anxiety-ridden experience of accessing a counselling service in her community:

> *I would always be nervous when I was going in. I'd be nervous about bumping into somebody I knew if I was leaving. I'd have to really make sure I looked like I wasn't crying. I would be embarrassed if someone were to see me.* (P8)

Living in a rural area also made the process of navigating services and supports difficult in a practical sense. Often there were few formal services available, or none at all; several women stated plainly that there were no services (including general health care services) to access in their community. Several participants reported that while there were general health care services, there were no specialized options (e.g., trauma therapy, support groups), and some services had limited hours.

In contrast, other participants did report that living in a rural place *facilitated* access. For example, one participant believed that knowing the service providers in her rural area helped her to obtain appointments. Another woman expressed appreciation for living in a tight-knit community of strong women who provided support by helping her access services when her car stopped working:

> *I had car trouble. Every single one of them [women in community] emailed to say, can I give you a ride? Just to have community like that and to be around a group of women was so meaningful.* (P9)

Narratives Surrounding Sexualized Violence in a Rural Place

Women also spoke about dominant narratives that influenced their ability to access services and supports, including terminology, pervasive ideas about who perpetrates sexualized violence, the question of what is considered to be a legitimate experience of sexualized violence, and community stigma. Several women reported that while services typically used the term "sexualized violence," they did not feel that term accurately described their experiences and instead used a variety of terms to describe their own experiences, including "a non-consensual experience" and "sexual assault." Several women said they felt guilty about using services that they believed were for women who had experienced sexualized *violence* because they perceived their experience to be less overtly violent, and therefore not a legitimate experience of sexualized violence. As one woman explained:

> *I had a hard time feeling like I was entitled to any of the resources that were around. Because it's always about sexualized violence and that wasn't exactly how I would have labelled my own*

> *experience. And part of it was that I still felt a little guilty around the level of severity of my incident and I felt that there were a lot of other women that were more deserving of those resources. I think I just carried that guilt and didn't want to seek out the resources that I needed because of that.* (P6)

Some of the participants reported that narratives about sexualized violence perpetuated in the media prevented them from feeling comfortable accessing formal services. Negative perceptions of survivors of sexualized violence in the media interacted with a culture of silence toward sexualized violence in their rural communities. Several participants reported that coverage of high-profile celebrity perpetrators of violence discouraged them from accessing services. Hearing how people in their communities blamed the victims, they assumed they would not be believed if they disclosed their own experience. For example, one participant described how media coverage of Jian Ghomeshi, a prominent Canadian celebrity charged with sexual assault in 2014 (and eventually acquitted), impacted her:

> *When I had been dealing with all this stuff, Jian Ghomeshi was happening. The micro-aggressions I would hear would be like "trigger warning" or "Oh, I just got raped by that exam…" I hear that, it was just like someone stabbed me in the chest. It was so painful.* (P8)

Theme 2: Navigating Formal Services and Associated Burdens

Navigation

Every woman spoke about the difficulty they experienced in identifying what services they could possibly access, and then navigating access to the service. In general, the participants knew little about what services were available after an experience of sexualized violence. To seek information, many participants contacted general health services (e.g., a walk-in clinic) to ask what services were available in their communities, and found that health professionals were also unaware of what services were available. All participants felt that staff at these services were not aware of other services in the community and were not equipped to help them. Participants expressed feelings of helplessness that they had taken a (sometimes daunting) step to seek help and were, ultimately, offered nothing. This is exemplified in one woman's experience at a walk-in clinic where she asked the physician who or what services she could contact to get help. The physician suggested she pay out-of-pocket for a private therapist to obtain timely support, even though there was a free, trauma-informed sexualized violence therapy service in her community. The physician was not aware of this service. The participant described her negative experience:

> *The doctor had no idea of what was going on. He was just kind of helpless. He basically recommended me to the public mental health services. He was like you're going to have to wait forever. And then he recommended me to a private therapist. But there was no mention of [community-based organization].* (P9)

Burdens of Navigation

In the process of navigating services, women described being required to retell the story of their trauma repeatedly, which they found to be re-traumatizing and distressing. In some cases, the expectation that they would have to retell a traumatic event repeatedly was what prevented them from trying to access a service. They often felt passed around by different service providers. According to one participant, "I don't really want to be passed around and I don't really want to have to inform and retell the story of every past trauma I've had to every human being I encounter" (P6).

In addition to the emotional stress of navigating services, participants reported that they experienced time, transportation, and economic burdens. All women reported experiencing significant wait times to receive formal services, ranging from three weeks to a year. Some women were so discouraged when they were informed about a wait-list that they chose to pay out of pocket for private services. In cases where there was not a service to access within their local community, having access to transportation to travel to other communities was necessary. Most communities in rural Nova Scotia have no public transportation.

Participants reported additional economic burdens associated with the process of navigating services. Seeking safety, one woman moved away from the person who assaulted her. She felt that there should be more housing supports integrated into other services. Another woman had to leave her employment because she had experienced sexualized violence in the workplace. She reported that service providers seemed ill-equipped to help her access both sexualized violence services and assistance with leaving her job and receiving income support.

Theme 3: What Women Wanted to Access Long-Term, Trauma-Informed Mental Health Services

All participants stated that the service they most wanted to access was long-term, one-on-one mental health support that was specific to sexual trauma or, at the very least, utilizing a trauma-informed approach. Participants wanted services to take less of a "one size fits all" approach and provide more collaborative and individualized options, and wanted services to have a flexible timeline (e.g., not a maximum of six sessions). Some rural places have a limited number of specialized mental health professionals, or even none at all, impeding the women from having choices between different approaches. Participants wanted to be able to choose a therapeutic approach and provider that worked for them, rather than having to make do with whatever they could access.

Peer Support

All the participants reported wanting to access peer support. The term "peer support" was not explicitly defined by participants, but they spoke about wanting support from people with shared experiences of sexualized violence, who were not close friends or family.

Women said they felt alone and isolated living in a rural place and that connecting with other women in the community would have been helpful. Although women could access informal support through family and friends, they reported wanting to access a formalized peer support, where peers might have some training and could connect them to other formal services if needed. In general, women felt that peers with similar experiences would be understanding and would be able to validate their experiences of sexualized violence. As one participant described:

> *I think it's a great idea to have a peer who has experienced these issues. They live it everyday … I think that people would feel comfortable and that they're not alone and these people can relate to them, they've gone through similar situations in their lives. I would trust somebody more with lived experience than without. One hundred percent.* (P5)

Education

Several women wanted more education on consent and sexualized violence. This is not necessarily something they wanted to access *after* experiencing sexualized violence; in most cases, the participants would have liked to learn about consent as youth. Several women reported that it took them a long time after experiencing sexualized violence to process and understand the violation, and having education on these and similar issues could have shortened that process and allowed them to start seeking services sooner. As one woman explains, "We didn't get educated on consent in high school and I didn't know until my counsellor gave me a sheet on it that silence is not consent" (P2).

Theme 4: What Women Accessed Justice System Services

Several women reported negative and harmful interactions with the police and/or justice system. For example, one woman went to the police immediately after the experience of violence. She requested a female officer and was denied, which she stated made her feel unsafe and uncomfortable. She felt that the officer who took her statement doubted her and implied that she was lying. She was not offered any health or support services by anyone in the police department. She describes her traumatic experience as follows:

> *They didn't give me any information. They didn't even tell me about the sexual assault centre. They treated me like they didn't even care what I had to say. And that was awful. I hope another woman does not have to go through that. It is re-traumatizing. It makes you feel worse. It's really, really hard to get help in the first place. When you feel like you're just being treated like you're nothing it's not a fun feeling. Or they don't believe you. It feels like nobody really cares. And what happened to you was brutal and wrong and against the law*. (P3)

Health System Services

Many participants also described experiencing negative and harmful attitudes from staff and providers when accessing formal health services. They reported that the therapists to whom they were referred were not able to provide adequate support for dealing with their experience(s) of sexualized violence, due to both attitude and a perceived lack of experience with clients who had experienced sexualized violence. Women reported feeling blamed and judged by health professionals for what had happened to them. They felt that although the therapists and counsellors were trained to treat trauma, they seemed uncomfortable and inexperienced with discussing and treating trauma stemming from sexualized violence. One participant describes feeling treated in a dismissive manner:

> *I told him about [experience of violence] and I think almost exactly after I told him what happened he received a phone call and proceeded to answer it. That would happen quite often in our appointments. He was okay with the family trauma stuff that I was talking to him about. But when I tried to talk to him about the sexual violence it was awful.* (P6)

Community-Based Services

Several participants reported mainly positive experiences with community-based, non-profit organizations with an explicit aim to support women, such as women's centres and sexual assault centres. They attributed this to the attitudes of the staff, including trauma therapists, nurses, and non-clinical support workers. Women described staff attitudes as non-judgmental, supportive, friendly, and kind, and felt that community-based services were "easy" to access. Some women found community-based services to be straightforward about what services they offered, what services they did *not* provide, and approximate wait times. Women also found that the physical environment of a women's centre was comfortable and made them feel less fearful of disclosing and discussing sexualized violence, compared to the environment of a hospital. Women who had accessed services at women's centres reported that the explicitly feminist mission and values of the centres made them comfortable because they could anticipate that the staff and providers would respond to their experiences in a supportive and validating way. Many participants explicitly praised their local women's centre staff and suggested that there should be more funding for the centres, a testament to the value they see in these community organizations.

Informal Supports

All women reported relying on friends and/or family in some capacity. In most cases, they found friends and family were able to provide support. However, relying on friends and family for support was complex. The ability of friends and family to provide support was limited by their experiences and biases, their capacity to provide support, and by the participants' own desire to protect their family and friends. Women felt hesitant telling some family and friends about their experiences of sexualized violence because they did not want to burden or worry them. This was especially true with respect to participants' parents. Women also reported that they found participating in activities such as advocacy, volunteering, activism, yoga, and spirituality provided them with informal types of support. Despite these informal supports providing some help, participants felt they were not adequate supports on their own and reported that they still wanted access to some type of formal service.

Discussion

The purpose of this qualitative study was to understand the experiences of women living in rural Nova Scotia who accessed services or supports after experiencing sexualized violence. Women attempted to access a range of both formal services and informal supports. Generally, women wanted to access formal mental health services, through community-based organizations. Participants faced a number of barriers to accessing services and supports, most of which are consistent with those found in the existing literature, such as a fear of victim blaming, lack of awareness of services, and anonymity concerns (Averill et al., 2007; Carter-Snell et al., 2020; Logan et al., 2005). Our study adds to this literature by highlighting the role of narratives around sexualized violence in a rural place, the difference in experiences between community not-for-profit services and non-community-based services (e.g., public health care system), and the challenges of navigating some services.

Societal and Rural Context

Women's access to services was influenced by the realities of living in small, rural communities and by societal narratives about sexualized violence such as what "counts" as sexualized violence. Pervasive ideas about what is and is not sexualized violence have been referred to as the "rape myth." Heath et al. (2013) described the elements of the "classic rape" or "rape myth" as including "abduction, the perpetrator being a stranger, severe force, and serious injury" (p. 1066). Whatley (1996) found that the general public is more likely to see the "classic rape" as a crime, and more likely to ascribe blame and responsibility to victims who experience sexualized violence outside of the "classic rape." However, all widely available statistics on sexualized violence point to perpetrators most often being known to the victim, unlike the "classic rape." In our study, women reported discomfort with the terminology of sexualized violence. Some felt undeserving of services and contrasted their experiences of violence to other "more severe" experiences. This suggests that internalization or acceptance of the "classic rape" myth impacts women's service use.

Women also reported a pervasive culture of silence surrounding sexualized violence in their rural communities. While the #MeToo movement broadly increased awareness of sexualized violence (O'Neil et al., 2018), such awareness-focused campaigns may not always translate well in rural contexts. The public declaration of having experienced sexualized violence intrinsic to #MeToo (intended to destigmatize and engender solidarity) may not always be an option in a small community if women have concerns about confidentiality, and less reliable internet access may also influence participation in digital-based movements (Rotenberg & Cotter, 2018). Access to early education about consent and sexual health may also be lacking. In Nova Scotia, the provincial sexual education curriculum currently does not include any discussion of consent, and the curriculum on prevention of gender-based violence is not comprehensive, according to Action Canada's *The State of Sex-Ed in Canada* report (Action Canada for Sexual Health and Rights, 2020). Participants reported lacking a basic understanding of consent and power dynamics, which led them to blame themselves for not asserting themselves in the situation and to avoid seeking services or supports. Access to more comprehensive early sexual education could help to dismantle the pervasive culture of silence that women described.

Formal Services

Existing literature on formal services tends to focus on the experiences of women accessing hospitals and/or reporting to police (O'Dwyer et al., 2019). There is a relative lack of research examining community-based services (e.g., non-profit organizations with a mission to serve women and/or survivors of violence). One study (Campbell et al., 2001) did find that women reported "healing" and positive experiences with both community-based services and mental health professionals. The women we interviewed did not report *consistently* positive experiences with mental health professionals. They only reported positive experiences with mental health professionals who were based in a community organization, such as trauma therapists working at a women's centre. Women also reported positive experiences with non-clinical staff at community organizations, such as the administrative staff. This suggests that community-based services remove or mitigate some of the barriers commonly experienced by women accessing formal services by virtue of their trauma-informed approach to service delivery. The principles of a trauma-informed approach are safety, transparency and trustworthiness, choice, collaboration and mutuality, and empowerment. While non-community-based services may employ a trauma-informed approach, there are aspects of the current health care system in Nova Scotia that prevent it from fully adopting a holistic, collaborative, and trauma-informed approach, such as non-open-ended session duration (e.g., six sessions maximum; Rubin, 2008).

All community-based services accessed by the participants appeared to have an explicitly feminist mission and/or value statement that recognizes women as experts of their own lives and centres clients' experiences and wishes (Women's Centres Connect, n.d.). Participants did not report experiencing stigma, victim blaming, or a fear of re-triggering or traumatic experience with respect to accessing community-based services. They reported the opposite: they felt validated and heard, and indicated that they did not experience fear or anxiety accessing the service because they could anticipate a positive reaction from staff.

Fragmented Services

Challenges in accessing formal services were highlighted by all participants in our study. Every woman interviewed expressed a desire or need to access a range of health and social services, including mental health counselling, medical attention, peer support, police, justice system, education, housing support, and employment supports. Women found navigating a fragmented service system distressing, re-traumatizing, and economically taxing, and shared experiences of health professionals having little-to-no ability to assist them in accessing other resources. They felt they bore alone the emotional toll and economic costs of navigating a fragmented health care and social support system.

Existing literature has identified fragmented services as a barrier to accessing services and supports for women who have experienced sexualized violence (Gregory et al., 2021; Logan et al., 2004). In Canada, where the fragmentation of health and social services is a growing issue, researchers and clinicians have called for action on integration of services (Misra et al., 2020; Ravenscroft, 2005). In the absence of high-level service integration, health navigation or "patient navigation" programs can mitigate the impacts of a fragmented system, such as lack of awareness of services, logistical barriers (e.g., transportation), and difficulty negotiating/maintaining relationships with providers (Carter et al., 2018; Dohan & Schrag, 2005). In a scoping review of 34 papers that included a navigation program involving both the health care system and community-based services, Carter et al. (2018) found no examples of navigation programs for survivors of sexualized violence. This study highlights the need for some form of navigation support.

Peer Support

There is limited discussion in the existing literature about peer support for women who have experienced sexualized violence. Although other fields, such as mental health and addictions, have adopted peer support programs (Tracy & Wallace, 2016), there appear to be few established programs in the field of sexualized violence. A number of women in our study wanted to access peer support, but they also felt that the value of peer support is limited by lack of capacity to refer to clinical/professional services (e.g., referrals, prescriptions, diagnosis).

Strengths and Limitations

Study participants were diverse in age and spoke to a variety of services and supports. There are, nevertheless, several limitations to this study including the fact that beyond diversity in age, diversity among participants may be limited, as we did not collect socio-demographic information beyond age. In Nova Scotia, racialized women have reported feeling unwelcome and unheard in “mainstream” spaces for survivors of violence, including community-based services (Creating Communities of Care, n.d.). Our study also does not speak to the experiences of trans and nonbinary populations, who face both a greater risk of experiencing sexualized violence (Jaffray, 2020) and additional barriers to accessing services (Du Mont et al., 2020; Sualp et al., 2021). Future research should explore the service access experiences of diverse and marginalized populations.

Recommendations

Based on our findings, we can make several recommendations to improve access to sexualized violence services and supports in rural places.

Practice

Invest in community-based services. A meaningful investment in community-based services could help improve access in rural places by increasing capacity for community-based organizations to support more clients and/or provide mobile/outreach services to women.

Research

Explore peer support and patient navigation programs. Peers can provide safe and validating support that women cannot access through a professional who may lack lived experience. Women in our study suggested that peer support should be “formalized” so they could be referred to other services. A peer support program delivered in partnership with a formal service or with a trained facilitator might be ideal. A patient navigation program may also be useful for women living in rural places who face a highly fragmented system and unique challenges to accessing services, such as extensive travel. More research is needed to understand how women in rural places would want to access peer support and/or patient navigation programs.

Education

Continue to challenge stigma and shift narratives surrounding sexualized violence. Women’s ability to access services was impacted by stigma and dominant narratives. Women made several suggestions to address this, including education on consent and sexualized violence starting at an early age and increased community dialogue on sexualized violence. This education and dialogue must consider the local, rural context of the community to be relevant and effective.

Conclusion

This study aimed to explore and understand the experiences of women accessing sexualized violence services and supports in rural communities in Nova Scotia. Women navigated a fractured and complex health and social support system, influenced by both their local community context and broader discourses surrounding sexualized violence. Although women reported several barriers to accessing services and supports, women also reported positive experiences with community-based organizations and presented a few suggestions to provide collaborative and trauma-informed care in their communities. The data were collected prior to the COVID-19 pandemic, which has amplified existing barriers and created new barriers to access for women experiencing sexualized violence. There is strong global evidence that COVID-19 has driven increases in gendered violence (Bettinger-Lopez & Bro, 2020; Canadian Women’s Foundation, 2020; John et al., 2020; UN Women, 2020). During lockdown measures, people experiencing violence may not be able to connect safely and confidentially to services while confined to their homes (Evans et al., 2020). Beyond lockdowns, evidence suggests that the economic crisis spurred by COVID-19 will continue to drive increased gendered violence (Sharma & Borah, 2020). This study highlighted a need to meaningfully invest in community-based services in rural communities to support women who have experienced violence, and this need may be increasingly urgent given the COVID-19 pandemic.

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HPJ HEALTHY POPULATIONS JOURNAL

Research Article

Forgone Health Care: A Secondary Analysis of Survey Data on the Experiences of a Sample of Transgender and Nonbinary Nova Scotians

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Abstract

Introduction: International research has identified that transgender and nonbinary populations experience high rates of discrimination, stigma, and negative health care experiences (Clark et al., 2018; Costa et al., 2018; Ercan Sahin et al., 2020). Collectively, these experiences can lead to forgone health care, defined as patients not accessing necessary health care due to many barriers, which can negatively impact health outcomes (House of Commons Canada, 2019). **Objective:** This study focuses on examining challenges in accessing gender-affirming health care among a sample of transgender and nonbinary Nova Scotians, and explores how these experiences may contribute to forgone health care. **Methods:** This research utilized secondary data analysis of a subset of data from an existing province-wide online survey of transgender and nonbinary Nova Scotians. The methodology of this study utilizes thematic analysis of closed-ended and open-ended survey response categories. The socio-ecological model was used as the conceptual framework to describe the various levels of influence contributing to transgender and nonbinary people forgoing health care. **Results:** Three main themes emerged from the data. Fear of discrimination leading to decreased quality of care, poor availability of transgender- and nonbinary-specific health services, and perceived or actual low levels of cultural competency among health care providers. **Conclusion/Discussion:** These factors contributed to forgone health care within this population, to which we respond with a number of recommendations to improve patient-provider interactions. Specifically, we recommend additional resources and training for health care providers and trainees to improve their cultural competency in providing gender-affirming care.

Introduction

Although Canada has a long-standing history as a signatory for the World Health Organization's declarations on health care access as a human right, as well as a reputation on the world stage for being a leader in health equity, challenges remain in meeting the needs of LGBTQIA2 populations. There is a long history of this community self-advocating and fighting for their rights, with same-sex marriage legalized only in 2005 and the recent banning of conversion therapy occurring nationally in 2022 (Aiello, 2022; Eichler, 2021). This history of advocacy is recognized in a 2019 report on LGBTQIA2 health from the Canadian House of Commons Standing Committee on Health, which identified challenges facing LGBTQIA2 people and culminated in the development of recommendations for provinces and territories to act on (House of Commons Canada, 2019). A key recommendation was the need for uniform coverage across the country for gender-affirming health care (House of Commons Canada, 2019). According to the World Health Organization, gender-affirming health care is defined as "social, psychological, behavioural or medical … interventions designed to support and affirm an individual's gender identity" (World Health Organization, Regional Office for Europe, n.d., para 9). Although the federal government has acknowledged the need for appropriate, consistent, and gender-affirming health care for LGBTQIA2 Canadians, the reality is a fragmented health care system with variable health care access for LGBTQIA2 people across the country.

Access to gender-affirming health care and care in a gender-inclusive space, which facilitates health care usage, is necessary for transgender and nonbinary populations to maintain optimal health and well-being (Clark et al., 2018; Colpitts & Gahagan, 2016; Edkins et al., 2016; Gahagan & Subirana-Malaret, 2018). Transgender and nonbinary populations are defined as those whose "sex assigned at birth does not completely align with their current gender identity" (Price-Feeney et al., 2020, p. 264).

However, there are concerns regarding how sex and gender are conceptualized within health research and how this may inaccurately represent health inequities and access (Gahagan et al., 2015). For example, in research, transgender and nonbinary populations may be grouped together with the larger LGBTQIA2 community, but this larger community may have differences in challenges to accessing health care. LGBTQIA2 is an acronym for lesbian, gay, bisexual, transgender, queer and/or questioning, intersex, asexual, and Two Spirit. There is ongoing debate among academics on the most appropriate acronym to use, but this study will consistently use LGBTQIA2, while recognizing there may be considerable differences within subsets of this population.

In Canada, existing data indicate that transgender and nonbinary individuals have worse health outcomes in general when compared to the general population and other subsets of the LGBTQIA2 community (Abramovich et al., 2020; Giblon & Bauer, 2017; Veale et al., 2017). Such disparities may be associated with unique barriers to health care, including fear of—or actual experiences of—discrimination and stigmatization, the feeling that health care workers would not be educated to address their needs, and cost barriers to gender-affirming treatments (Abramovich et al., 2020; Clark et al., 2018; Colpitts & Gahagan, 2016; Edkins et al., 2016; Gahagan & Subirana-Malaret, 2018; Harbin et al., 2012; Kenagy, 2005; Lee et al., 2021; Socías et al., 2014; Whitehead et al., 2016). These barriers may lead to what is referred to as forgone health care, which is generally characterized as patients not accessing health care despite a need to do so (Clark et al., 2018; House of Commons Canada, 2019).

Evidence suggests that health care providers may not have the knowledge or skills needed to specifically address the unique health care needs of these populations in an affirming manner (Harbin at al., 2012; Lee at al., 2021; Gahagan & Subirana-Malaret, 2018). Transgender and nonbinary individuals have expressed concerns they will not receive accurate and appropriate medical advice from their primary health care providers, which can lead to their forgoing health care (Colpitts & Gahagan, 2016; Socías et al., 2014). Furthermore, research on transgender individuals has demonstrated that comfort with their family physicians is positively correlated with better general and mental health outcomes, while levels of discomfort have been associated with forgoing health care, which can lead to poorer health outcomes (Clark et al., 2018). Taken together, these two points mean that level of comfort and confidence in health care providers impacts the likelihood of transgender and nonbinary people accessing health care.

Research examining forgone health care within transgender and nonbinary populations in the Canadian context is needed to recognize the specific barriers contributing to this health inequity, as well as to provide interventions. This is particularly pressing, given Canada's publicly funded health care system and longstanding commitment to health equity (Colpitts & Gahagan, 2016; Gahagan & Subirana-Malaret, 2018; Harbin et al., 2012).

This research offers a secondary data analysis of an existing data set, which is the first of its kind within the Nova Scotian context aimed at advancing our understanding of how transgender and nonbinary populations access health care (Colpitts & Gahagan, 2016; Gahagan & Colpitts, 2017; Gahagan & Subirana-Malaret, 2018). Currently, individuals residing in Nova Scotia seeking specific types of gender-affirming surgery must travel to Quebec (Nova Scotia Health Library Services, n.d.), creating barriers that may lead to forgone health care and the potential loss of follow-up back in Nova Scotia. Furthermore, local health care practitioners may not be culturally competent with regard to transgender and nonbinary patients (Hadland et al., 2016; Klein & Nakhai, 2016; Margolies & Brown, 2019). Cultural competence is defined as "cultural knowledge, welcoming attitudes towards diverse populations, and skills in communicating with people from different groups" (Margolies & Brown, 2019, p. 38). If cultural competence is poor regarding transgender and nonbinary individuals, an extra barrier to care accessibility is created.

In addition to concerns that health care providers may lack cultural competence in relation to transgender and nonbinary health care, current medical students often lack LGBTQIA2-specific training in their curricula, which may further contribute to an overall lack of affirming health care providers (Arthur et al., 2021; Click et al., 2020; Greene et al., 2018). For example, health care providers who practise with an assumption that every patient is cisgender (identifies with their assigned gender at birth) can harm patients, and there is evidence to suggest medical students must receive further training to best address this population's health needs in a safe, gender-affirming, and culturally competent manner (Arthur et al., 2021; Click et al., 2020; Greene et al., 2018; Lee et al., 2021).

Methods

Guiding Framework

The socio-ecological model (SEM), developed by Urie Bronfenbrenner, provides the conceptual framework to contextualize the survey responses (Kilanowski, 2017). Examining the contributions and interactions between individual-, community-, and policy-level factors allows us to gain an understanding of forgone health care among transgender and nonbinary populations in Nova Scotia. The SEM has been used in research to describe the influence of stigma and discrimination on health outcomes for transgender and nonbinary populations (Johns et al., 2018). Further, the SEM provides a useful conceptual framework in analyzing questions related to levels of influence, ranging from macro-level consideration (such as primary health care access) through to micro-level issues (such as comfort with primary care providers and perceived competency of primary care providers on trans-specific needs; Do & Nguyen, 2020; Johns et al., 2018; King et al., 2020; Lacombe-Duncan et al., 2021).

Participants

The inclusion criteria for this research study is based on the original study design: (a) individuals who self-identify as transgender or nonbinary, (b) live in Nova Scotia, (c) are eighteen years or older, and (d) have the ability to complete survey questions in English. Participants were voluntarily recruited through prideHealth's social media to complete the survey. prideHealth is an organization that offers support for LGBTQIA2 communities within the Halifax Regional Municipality of Nova

Scotia and aims to improve access to primary health services (Nova Scotia Health Authority, n.d.). After being presented with the study information/consent form, participants selected "I consent" on the first survey page on the online platform Opinio before beginning the survey, indicating they had read and agreed to participate. Data collected through Opinio is stored on servers managed by Dalhousie University.

Study Design

The survey gathered data about key health issues facing transgender and nonbinary Nova Scotians, including self-rated health measures, social support, demographic questions, whether they had a primary health care provider, which health region they lived in, what they regarded as their key health priorities, and what was missing from their health care needs. Questions related to forgone health care among transgender and nonbinary populations were selected for the secondary data analysis and inform the results presented in this paper.

The online survey questions included both closed-ended and open-ended response categories. There were 238 partially completed surveys and 109 fully completed surveys included in our data set, all of which were included in analysis to obtain a larger sample size more representative of the population. Thematic analysis was used to organize open-ended questions with supplemental descriptive statistics from demographic data, in an effort to examine the experiences of transgender and nonbinary people contributing to forgone health care (Braun & Clarke, 2012; Johns et al., 2018). The process of thematic analysis included sensing themes, recognizing themes consistently, developing codes, and interpreting themes in the context of socio-ecological model (Boyatzis, 1998). Analysis was completed by both authors. Ethics approval through the Dalhousie University research ethics board was obtained (REB # 2021-5590) prior to utilization of existing data.

Results

Health Care Usage

Access to health care, including regular health care checkups, is noted in the literature as an important contributing factor to health outcomes across the life course. In relation to this issue, when asked "When was the last time you went in for a routine checkup?" the majority of participants (55%) reported having had a routine checkup within the past 12 months. Participants reported that the most common reasons for the checkup were a blood pressure check (65%), a mental health screening (40%), and STI screening (31%).

When asked "How often have you sought primary health care services for your own personal health concerns in the past 12 months?" many participants (42%) reported seeking primary health care services between two and five times in the past 12 months. Other studies have shown a higher uptake of primary health care services in transgender individuals compared to their cisgender counterparts, but this is thought to be due to individuals actively medically transitioning and the frequent appointments of this process (Abramovich et al., 2020).

In terms of using health-related programs or services in their community in the past 12 months, the most frequently utilized service indicated was walk-in clinics (63%), followed by emergency departments (44%) and sexual health centres (36%).

Access to health care can be stymied by lack of proximity to prevention programs, and it may be noted that most health care resources in Nova Scotia are located in or close to Halifax (Veugelers et al., 2003). When asked "In which of the nine former district health authorities do you generally access health services at present?" the majority (68%) stated they access health services within Capital Health/IWK, which is located in the Halifax Regional Municipality. Respondents were also asked whether they access health care services in a different former district health authority than the one they currently live in, and why. Those who reported accessing care in other areas of Nova Scotia described a lack of transgender- or nonbinary-specific health services in their local communities, and the need to "access transition-related services in Halifax." Participants also described a cycle of being misgendered after reminding local health care providers, and one participant felt their health concerns were "not being taken seriously."

Access to Primary Care Provider and Satisfaction Level

Although there are approximately 8% of Nova Scotians currently without a primary health care provider (Grant, 2021), we found that the majority of participants (80%) reported that they currently have a primary health care provider or doctor. For those who reported "no" to this question, the majority of those participants (71%) identified a lack of primary health care providers or doctors accepting new patients in their community as a reason for not having a primary health care provider or doctor. In addition, many participants (43%) also identified a lack of LGBTQIA2-friendly or affirming primary health care providers or doctors in their community as a reason for not having a primary health care provider. The lack of LGBTQIA2-friendly primary health care providers could help explain our findings of a large proportion of participants accessing walk-in clinics to receive health care. In terms of the level of overall satisfaction with their primary health care provider or family doctor, approximately one third (32%) of respondents reported being "satisfied."

Disclosing Identities

Disclosure of one's gender identity and/or gender expression can be impacted by stigmatization, and we found that, in terms of comfort in discussing issues of gender identity/gender expression with their primary health care provider or family doctor, the responses varied. A five-point Likert scale was used, with the following response categories: very uncomfortable, somewhat uncomfortable, uncertain, somewhat comfortable, and comfortable. The greatest frequency (33%) was "somewhat uncomfortable" in discussing gender identity/gender expression with their primary health care provider or family doctor.

Without disclosure of one's transgender identity, individuals may have difficulty gauging the cultural competency of their provider. When asked "Are you 'out' to your primary health care provider or family doctor?" the majority of participants (72%) responded yes. In addition, among those participants (20%) who are not "out" to their primary health care provider, it was indicated they did "not feel as though it would be safe and could possibly jeopardize the quality of care [they] receive," and that their "provider ignores [their] transness." Furthermore, a participant noted gendered language is used "in the appointment process and I don't feel safe outing myself as non-binary yet."

Participants were asked "How trans friendly is your primary health care provider or family doctor?" A five-point Likert scale was used with response categories of the following: very trans friendly, somewhat trans friendly, uncertain, somewhat trans unfriendly, and not at all trans friendly. The highest proportion of participants were "uncertain" of how trans friendly their primary health care provider or family doctor was, at 38%.

Health Care Provider Familiarity with Transgender and Nonbinary Health

When asked "How would you describe your primary health care provider or family doctor's knowledge of health issues specific to gender identity/expression?" 34% of participants were uncertain about their provider's knowledge of these health issues.

Trust within the physician-patient relationship is paramount in patient-centred care. With respect to the extent to which participants trust their primary health care provider or family doctor to provide the best health and wellness care possible for them, only 31% of participants reported trusting their primary health care provider or doctor completely.

When asked "In general, how would you describe the inclusiveness of health care service environments in Nova Scotia for LGBTQ populations?" 32% of participants responded that they were uncertain of the inclusiveness of health care service environments in Nova Scotia.

In terms of having had a negative health care experience(s) in Nova Scotia in the last five years related to their orientation/behaviours or gender identity/expression, the majority of participants (70%) indicated a negative health experience(s).

In describing what made the experience(s) negative, participants identified various reasons, with the most frequent being the following: health care providers making assumptions about participants' gender identity/gender expression (65%), medical intake forms using heteronormative or cisnormative language (65%), and the health care providers not being knowledgeable about health issues specific to participants' gender identity/gender expression (60%). Other reasons cited by participants included "refused to acknowledge my identity in anyway [sic]," "switch family doctor to avoid discrimination/ignorance," "being deadnamed regularly causing me much dysphoria," and "chosen name not used consistently by providers."

Conversely, when asked "Have you had a positive health care experience(s) in Nova Scotia in the last five years related to your orientation/behaviours or gender identity/expression?" the majority of participants (75%) had had a positive health care experience.

In terms of what made this experience positive, the majority of participants (90%) indicated that an LBGTQIA2-friendly health care provider (90%), an inclusive environment (70%), and comfort discussing sexual orientation/behaviours with the health service provider (67%) were key contributors to a positive experience.

When asked to rate key factors that are important to improving LGBTQIA2 health care experiences in Nova Scotia, the following were highly rated:

- making health service environments more inclusive and welcoming by posting signs and posters that reflect my gender identity,
- removing heteronormative and cisnormative language from medical intake forms,
- having patient advocates to assist transgender populations in navigating health care systems,
- education and/or training for health service providers on transgender- and nonbinary-specific health concerns,
- training health service providers how to be more transgender-friendly in their service provision, and
- advocacy and education for trans populations regarding their rights related to health care.

Specifically, participants noted it is "very important" to have education and/or training for health service providers on transgender- and nonbinary-specific health concerns (90%), training for health service providers on how to be more trans friendly in their service provision (86%), and advocacy and education for trans populations regarding their rights related to health care (76%).

Theme 1: Fear of Discrimination and Decreased Quality of Care

The first theme identified is fear of discrimination and decreased quality of care, originating from the finding that a notable portion of participants (40%) indicated their negative health care experiences were due to discrimination based on their LGBTQIA2 identity. In the open-ended responses, a participant noted that they had to "switch family doctors to avoid discrimination/ignorance" and that there was a culture of "transphobia in [rural] County." Considering these experiences, it is unsurprising that 20% of participants were not "out" to their primary health care providers, with participants indicating they feel it could "possibly jeopardize the quality of care," and they "don't feel safe outing myself as non-binary yet," so to receive "proper treatment … have to lie about my gender presentation." At the individual level, this fear of discrimination may prevent transgender and nonbinary individuals from sharing their identity with their health care provider or accessing health care services.

Theme 2: Poor Availability of Transgender/Nonbinary-Specific Health Services

The second theme identified is poor availability of transgender/nonbinary-specific health services. Specifically, the reasons for accessing health care services in a different former district health authority include accessing "transition related services in Halifax, due to unavailability of these services locally" and "no trans health services exist in [rural] County." Participants noted travel from their local communities to Halifax for gender-affirming care, citing the Halifax Sexual Health Centre as their "only option" and that Halifax offers "more knowledgeable [providers] for trans people you wouldn't find in the [rural location]." The survey data suggests that varying degrees of access within Nova Scotia to transgender- and nonbinary-specific health services is creating barriers to health care.

Theme 3: Perceived or Actual Poor Cultural Competency of Health Care Providers

The third theme identified is perceived or actual poor cultural competency of health care providers. Participants' responses varied in their perceptions of their health care provider's knowledge of health issues specific to their gender identity/gender expression, with 34% being uncertain of their provider's knowledge level. Only 31% of participants reported trusting their primary health care provider completely to provide the best health and wellness care. The SEM can help situate this at the interpersonal level, where participants have varied confidence in their provider's ability to address their specific health needs. Most participants (90%) reported it was "very important" that providers have education and/or training on the specific health concerns of transgender and nonbinary populations. This suggests there may be a discrepancy in the perceived competency of providers regarding transgender and nonbinary health needs, and highlights how strongly participants feel it is necessary for providers to have such knowledge. This points to larger systemic issues at the institutional level with medical education, with evidence from other studies suggesting that medical students do not feel their training is preparing them to adequately address the health needs of their transgender and nonbinary patients (Arthur et al., 2021; Click et al., 2020). A consequence of these issues is transgender and nonbinary populations forgoing necessary health care, which in turn may lead to poorer health outcomes overall.

Discussion

These results provide insight into the health care experiences of transgender and nonbinary populations in Nova Scotia. Three major themes emerged: fear of discrimination and decreased quality of care, poor availability of transgender- and nonbinary-specific health services, and perceived or actual poor cultural competency of health care providers.

Participants repeatedly expressed fear of discrimination and decreased quality of care, which may prevent individuals from accessing health care. This aligns with previous research that found uptake of cervical cancer screening by transgender men was influenced by their health care provider's acceptance of their gender identity (Semlyen & Kunasegaran, 2016). If transgender and nonbinary individuals fear discrimination, they may forgo needed health care and consequently have worse health outcomes.

Poor availability of transgender- and nonbinary-specific health services was an emerging theme among participants. This lack of access to specific services means transgender and nonbinary individuals in Nova Scotia may go without appropriate supports for social and medical transitioning.

Perceived or actual poor cultural competency of health care providers was a prevalent theme in analysis. If providers are not culturally competent in regard to transgender and nonbinary populations, individuals may feel they will not receive adequate care and instead choose to forgo health care. A seemingly obvious solution would be to increase cultural competency training for health care providers. However, the evidence has shown mixed results in increasing the quality of care and comfort level of providers to service provision after cultural competency training (Raffoul & Lin, 2015). This suggests individual-level interventions, such as cultural competency training for individual health care providers, will be ineffective at targeting systemic change. Research must be completed on how to effectively improve cultural competency on a systems-wide level, in order to best address the needs of transgender and nonbinary participants.

A limitation of this study is the exclusion of participants under the age of eighteen. Transgender and nonbinary adolescents may experience unique health care challenges specific to their age group that lead to forgone health care that were not examined in this study. This is an underexamined area that warrants further research.

Conclusion

This Nova Scotia-based study is the first to explore transgender and nonbinary health experiences in relation to forgone health care and to offer concrete recommendations on addressing the noted gaps as identified from the participants' responses.

The findings from this study can be useful in advancing our understanding of how to address key shortcomings in meeting the unique health concerns facing transgender and nonbinary populations in Nova Scotia. The key themes identified from the survey data have provided guidance for the following recommendations to improve transgender and nonbinary Nova Scotians' experience accessing health care, with an eye to reducing forgone health care and improving health outcomes:

1. Complete further research to uncover the most effective methods of increasing provider cultural competency relating to transgender and nonbinary patients.
2. Include perspectives of transgender and nonbinary people under the age of 18 regarding health care access concerns.
3. Expand categories of demographic data to include transgender and nonbinary populations during provincial health care data collection to gain a better understanding of health indicators for these populations.
4. Further research and action should explore policy-level changes, to allocate greater provincial health care funding for transgender- and nonbinary-specific health services and health navigation programs, such as prideHealth, to improve access across all communities in Nova Scotia.

As noted in this research, and despite Canada's long-standing commitment to health equity, more needs to be done to better meet the unique health care issues and health disparities facing transgender and nonbinary populations. Further, as Canada begins to mobilize on the key recommendations from the House of Commons Canada report, this may provide an opportunity for Nova Scotia to leverage resources and support in addressing these disparities. However, in order to mobilize for change at the various levels of influence, as noted in the SEM, more attention needs to be paid to the needed structural changes, including how we train the next generation of health care providers to be more gender-affirming and how we mobilize the equitable provision of health care in Nova Scotia. Until we more fully address these various levels of influence on health care access, we will continue to see worse health outcomes among transgender and nonbinary Nova Scotians.

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Research Article

An Evaluation of Cancer's Margins Training Videos and Their Impact on Medical Students' Self-Rated Confidence in Working with Lesbian, Bisexual, and Transgender (LBT) Patients with Breast and Gynecological Cancers

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Abstract

Lesbian, bisexual, and transgender (LBT) patients with breast and gynecological cancers face unique challenges and barriers to accessing LBT-affirming health care. Physician attitudes and knowledge around working with LBT patients contribute to these challenges and barriers. Despite this, there is very limited LBT-specific education in the medical curriculum. Cancer's Margins (https://www.lgbtcancer.ca/) is a national project funded by the Canadian Institutes of Health Research. Through the Cancer's Margins project, a series of first-person videos were developed that can serve as additional training content for medical students for working with LBT patients with what has been traditionally termed "women's cancers." The focus is on LBT individuals specifically, rather than the broader 2SLGBTQA+ community, because of the anatomy involved with breast and gynecological cancers. This project serves to evaluate the impact of the Cancer's Margins videos on the self-reported confidence of Dalhousie University medical students in working with these populations. Medical students were invited to participate in a two-part online survey using a 38-item survey that explored self-rated confidence before and after watching the Cancer's Margins videos. There were four open-ended questions for feedback on the videos to help assess overall self-rated impact. Ultimately, 23 surveys were either fully or partially completed. Overall attitudes toward LBT patients were positive, but overall confidence was variable. There was an average increase of 8% in overall group self-rated confidence after watching the Cancer's Margins videos. Incorporating training for working with LBT patients into the medical school curriculum could increase quality of care and break down barriers in access to care for LBT populations. The Cancer's Margins training videos can be an effective resource for medical students for increasing self-reported confidence.

Introduction

Lesbian, bisexual, and transgender (LBT) patients face unique challenges and barriers when seeking health care. For example, when compared with heterosexual and cisgender peers from the same socioeconomic class, LBT patients are less likely to be able to access appropriate health care, and this barrier to access may exacerbate or create health disparities between LBT and non-LBT patients (Obedin-Maliver et al., 2011). Transgender patients in particular face additional and unique barriers to accessing safe and affirming health care (Kamen et al., 2019). Reisner et al. (2016) defined affirming health care as "health care that holistically attends to transgender people's physical, mental, and social health needs and well-being while respectfully affirming their gender identity" (p. S238), which should be applied to all aspects of health care, not just gender-affirming therapies. Discrimination, inequality in health care quality, and poor patient-physician relationships may stem from inadequate, or complete lack of, education for physicians for working with LBT populations (Schreiber et al., 2021).

Previous research suggests that discrimination in health care plays a role in cancer screening for LBT patients. For example, a previous study found that lesbians are more likely to avoid preventative cancer screening such as mammography or cervical cancer screening due to the fear of discrimination (McKay, 2011; Sabin et al., 2015). Once diagnosed with cancer, LBT patients are left with more than just the challenge of coping with their new diagnosis—LBT patients must also decide whether, when, and how to disclose their sexual orientation and/or gender identity to their physician (Kamen et al., 2019; Katz, 2009). The risks of disclosing, or not disclosing, sexual orientation and/or gender identity may be informed by perceptions and/or actual negative health experiences of mistreatment by physicians and other health care providers (Alpert et al., 2017; Durso & Meyer, 2013; Kamen et al., 2019). These risks may be the consequence of physicians' potential lack of knowledge or implicit and/or explicit negative attitudes toward LBT patients. In addition, negative attitudes held by physicians may result in compromised ability to care for LBT patients, hostile patient-physician relationships, and the inability for LBT patients to safely disclose important health information (Parameshwaran et al., 2017). For patients with "women's cancers," such as cancer of the breast, ovaries, and/or uterus, it is especially important to have an affirming support network because of the heteronormative and cisnormative approaches that are currently used for cancer screening and treatment (Gahagan et al., 2021). For LBT patients with women's cancers, these support networks may not look the same as those of non-LBT patients. For example, LBT patients are more likely to have support networks comprising friends and current and/or former partners, due to past rejection or non-acceptance from their biological family (Grossman et al., 2000; Kamen et al., 2019; Kamen et al., 2015). Unfortunately, there is a lack of training for oncologists that focuses on LBT-specific health care (Pratt-Chapman et al., 2021; Wheldon et al., 2018).

Compared to heterosexual women, lesbian, bisexual, and queer women are at increased risk for breast and cervical cancers due to decreased screening rates resulting from a poor patient-physician relationship or increased patient discomfort (Quinn et al., 2015). In addition, they may be regarded as being less at risk for the human papillomavirus infection that most often causes cervical cancer, due to higher rates of nulliparity among this population (Institute of Medicine, 2011; Quinn et al., 2015; Zaritsky & Dibble, 2010). The research on transgender cancer risk is lacking, but transgender patients are more likely to experience discrimination, stigma, and lack of access to safe and affirming health care, which may lead to avoidance of screening tests (Bauer et al., 2009) and potentially increase their risk of delayed diagnosis of cancer.

The negative impact on LBT populations caused by lack of specific physician education and training is clear. However, what is less clear is why medical education is still lacking an adequate focus on LBT health. Despite the

Association of American Medical Colleges recommending that medical school education include training on providing exceptional care to LBT patients, addressing needs specific to LBT patients, and improving communication skills regarding sexual orientation and gender identity, the median reported hours dedicated to LBT education in medical schools in Canada and the United States was only five hours throughout the entire medical education program (Obedin-Maliver et al., 2011). Sanchez et al. (2006) found that third- and fourth-year medical students with more exposure to LBT patients had more positive attitudes toward sexual minority patients, were more likely to take a sexual history, were more likely to screen for sexual orientation, and were more likely to demonstrate greater overall knowledge of LBT health. This suggests that introducing medical students to LBT patients and related curriculum during their training may improve the implicit and explicit biases that are currently detrimental to LBT patients' health care access and quality. Education for physicians and student physicians is crucial, because a lack of training on the needs of LBT patients places the onus on the LBT patients to teach their physicians to care for them and puts them at risk for experiencing suboptimal care and discrimination (Poteat et al., 2013; Pratt-Chapman et al., 2021).

McLeroy et al. (1988) expanded on an ecological model for health promotion, focusing on five levels that influence health behaviour: intrapersonal factors, interpersonal processes and primary groups, institutional factors, community factors, and public policy. Ecological models assume that there are multiple levels of influence to behaviour, and that these levels interact with and reinforce one another; this suggests the potential for intervention strategies at each of these five levels of influence (Golden & Earp, 2012). Incorporation of specific LBT training into medical school curriculum with the goal of improving health outcomes for the LBT population would be an intrapersonal level of intervention because it is aiming to change the knowledge, beliefs, and skills of individuals, with the individuals in this case being future physicians (Golden & Earp, 2012).

Cancer's Margins is a national research project funded by the Canadian Institutes of Health Research that has developed a series of first-person videos that explore sexual and gender diversity and experiences with cancer within the LBT population (https://www.lgbtcancer.ca/). The Cancer's Margins videos can serve as additional training content for medical students to supplement the limited content that they receive throughout their curriculum. However, the videos on the Cancer's Margins website have not yet been evaluated for their impact on health care professionals in relation to their self-rated confidence when working with LBT patients in general, or when working with LBT patients with breast and gynecological cancers. The goal of this project is to evaluate the impact of the Cancer's Margins training videos on medical students' self-rated confidence around working with LBT patients.

Methods

An anonymous online two-part survey was created using the Opinio survey platform. Part One of the survey consisted of five demographic questions, nine specially devised questions, and six questions adapted from Parameshwaran et al. (2017). Ten of these questions ask students to rate their confidence in a variety of scenarios on a five-point Likert scale from "very unconfident" to "very confident" (1–5). For example, "How confident would you feel performing a physical examination on an LBT patient?" The remaining five questions ask students to rate how much they agree with a given statement on a five-point Likert scale from "strongly disagree" to "strongly agree" (1–5). For example, "If given the choice, I would prefer not to work with LBT patients." Part Two of the survey consisted of four questions regarding which of the Cancer's Margins videos were watched and the students' opinions of them, along with 14 of the same questions asked in Part One of the survey.

The invitation to participate in the survey was distributed via email in June 2021 to medical students in all four years at Dalhousie Medical School. The survey was open for four weeks. Students completed Part One of the survey, which included a demographic survey and 15 questions that collected information on self-rated baseline confidence for working with LBT patients. The participants were then invited to the Cancer's Margins website to watch videos in one or more content areas of their choosing, such as "Healthcare Provider Communication" or "Sexuality and Cancer." Participants then returned to complete Part Two of the survey. Completion of Part One of the survey, watching the Cancer's Margins videos, and completion of Part Two of the survey were all completed in one sitting.

Data analysis was conducted on the 11 fully completed surveys. Data analysis included only the calculation of descriptive statistics (mean, median, and mode) for each question on Part One and Part Two of the survey. The descriptive statistics were used to compare responses to questions that were on both parts of the survey to see if there was a difference between how participants responded to the survey questions before and after watching the Cancer's Margins videos. Open-ended questions were collected to assess whether participants found the Cancer's Margins videos to be a useful resource, which videos were the most impactful, and whether there was a desire to learn more. Minor qualitative analysis was conducted on the open responses to identify common themes in the responses.

Results

Of the 469 medical students who were invited to participate in the study, 23 students responded to the survey (4.9% uptake), and 11 of those students fully completed the survey. Most participants who partially completed the survey stopped after Part One of the survey. Data analysis was conducted on the 11 fully completed surveys that included only descriptive statistics and, where available, open-ended responses. The majority of participants had just completed their first year of medical school (n=7), and the remainder had just completed their second year of medical school (n=4). There were no participants from third or fourth year. Well over half (63.6%) of participants were between the ages of 20 and 24, 81.8% self-identified as female, and 63.6% self-identified as heterosexual (Table 1).

As indicated in the survey data responses, participants were neither confident nor unconfident about clarifying unfamiliar sexual or gender terms used by patients (Table 2). Participants reported being confident in their ability to take a social history from an LBT patient but reported being neither confident nor unconfident taking a sexual history from an LBT patient. Participants were overall unconfident in deciding which ward a transgender patient should be admitted to and were unconfident about knowing where to find LBT-specific health services in their area. Participants were similarly neither confident nor unconfident in talking to patients about their breast or gynecological cancer regardless of whether the patients were cisgender, heterosexual, lesbian or bisexual, or transgender or nonbinary. However, 90.9% of participants reported feeling confident in asking for a patient's preferred pronouns during a medical history.

Overall, 63.6% of participants agreed that they had received specific training on LBT health issues, and 100% agreed that LBT patients may have different experiences with breast and gynecological cancers than their non-LBT counterparts (see Table 2). The majority of participants (72.7%) strongly disagreed that they would prefer not to work with LBT patients, and strongly agreed that they would like to receive specific training for working with the LBT population (72.7%). Participants either agreed (45.5%) or strongly agreed (54.5%) that specific training for working with LBT patients is required in order to effectively serve these patients.

On the Cancer's Margins website, participants had the option to watch videos in one or more content areas of their choosing. The two most frequently watched content areas were "Trans*, Gender and Cancer" (n=7) and "Healthcare Provider Communication" (n=7).

Table 1

Demographic Characteristics of Participants (n=11)

Training Completed	Year 1 = 7 Year 2 = 4 Year 3 = 0 Year 4 = 0
Sex	Male = 2 Female = 9
Sexuality	Straight = 7 Lesbian = 0 Gay = 0 Bisexual = 2 Queer = 1 Questioning = 0 Something else = 1 Prefer not to say = 0
Age	20–24 = 7 25–29 = 2 30–34 = 1 35–39 = 1
Highest Level of Education Prior to Starting Medical School	Bachelor of Science = 7 Bachelor of Arts = 0 Masters = 1 PhD = 1 Other Bachelor's Degree = 2

The least watched content area was "Feeling Cancer" (n=1), followed by "Cancer Support Networks" (n=2) and "Cancer, Survivorship and Mortality" (n=2). Most of the participants (81.8%) watched videos in more than one content area. The mean number of content areas watched by participants was 3.3, and the mode was two.

Across all of the average self-reported confidence scores for the group (n=11) on a scale from one to five, there was an average increase of 8% after watching the Cancer's Margins training videos (Table 2). The greatest increase in self-reported confidence was for finding information about LBT-specific health services in the participant's area, with the average self-reported confidence score for the group on a scale from one to five increasing by 0.77 (15.4%) from 2.63 to 3.4. There was also an increase in participants' self-rated agreement that LBT patients may have a different experience with breast and gynecological cancer of 0.36 (7.2%) after watching the Cancer's Margins training videos. There was no change in participants' desires to work with LBT patients after watching the videos, with participants strongly disagreeing with the statement "If given the choice, I would prefer not to work with LBT patients." There was, however, a change in participants' self-rated interest in receiving specific training in relation to working with LBT patients, decreasing by 0.19 (3.8%). After watching the videos, there was a slight increase of 0.09 (1.8%) for participants' self-reported agreement that specific training for working with LBT patients is required to effectively serve these patients.

Most participants (90.9%) agreed that they had learned something about LBT experiences with cancer from watching the Cancer's Margins videos, while one participant neither agreed nor disagreed. Most of the participants (81.8%) agreed that the Cancer's Margins training videos changed the way they think about LBT patients, while two participants disagreed and one participant neither agreed nor disagreed. All the participants either agreed (45.5%) or strongly agreed (54.5%) that the videos on the Cancer's Margins website are a valuable resource.

In addition to the five-point Likert scales, participants were asked four open-ended questions designed to assess the specific impact of the Cancer's Margins training videos. When asked which of the videos impacted them the most in terms of their professional development, some participants (n=3) stated that they were impacted the most by the video titled "The Neither Story," because it showed the importance of being sensitive and accepting to patients, and because it showed that cancer treatment has the potential to be gender affirming (i.e., using necessary cancer surgeries to obtain desired bodily characteristics without the typical associated monetary cost; in this case

Table 2

Survey Data (n=11)

Please rate your level of confidence from "very unconfident" to "very confident"	Part One: Mean, Median (Q1–Q3), and Mode	Part Two: Mean, Median (Q1–Q3), and Mode
How confident do you feel clarifying unfamiliar sexual or gender terms used by patients?	Mean = 3.27 Median (Q1–Q3) = 3 (3–4) Mode = 3	3.63 4 (3–4) 4
How confident do you feel taking a social history from an LBT patient?	3.54 4 (3–4) 4	3.72 4 (3–4) 4
How confident do you feel taking a sexual history from an LBT patient?	3.09 3 (3–3) 3	3.63 4 (3–4) 4
How confident do you feel deciding in which ward (i.e., male ward/female ward) a transgender patient should be admitted?	3.09 3 (2–4) 2	3.45 4 (3–4) 4
How confident do you feel knowing where to look in order to find information about LBT-specific health services in your area?	2.63 2 (2–4) 2, 4	3.4 4 (3–4 4
How confident would you feel performing a physical examination on an LBT patient?	3.27 3 (3–4) 3	3.45 4 (3–4) 4
How confident would you feel speaking with a heterosexual cisgender female patient about her breast or gynecological cancer?	3.27 3 (2–4) 4	3.72 4 (3–4) 3
How confident would you feel speaking with a lesbian or bisexual female patient about their breast or gynecological cancer?	3.36 3 (3–4) 3, 4	3. 72 4 (3–4) 3
How confident would you feel speaking with a transmasculine or nonbinary patient about their breast or gynecological cancer?	2.91 3 (2–4) 2, 3	3.36 3 (3–4) 3, 4
How confident would you feel asking for a patient's preferred pronouns during a medical history?	4.1 4 (4–4) 4	4.36 4 (4–5) 4, 5

Please rate your level of agreement from “strongly disagree” to “strongly agree”	Part One: Mean, Median (Q1–Q3), and Mode	Part Two: Mean, Median (Q1–Q3), and Mode
I have received specific training on LBT health issues.	Mean = 3.45 Median (Q1–Q3) = 4 (3–4) Mode = 4	N/A, this question was only asked in Part One of the survey
LBT patients may have a different experience with breast and gynecological cancers.	4.27 4 (4–5) 4	4.63 5 (4–5) 5
If given the choice, I would prefer not to work with LBT patients.	1.27 1 (1–2) 1	1.27 1 (1–2) 1
I would like to receive specific training for working with LBT patients.	4.73 5 (4–5) 5	4.54 5 (4–5) 5
Specific training for working with LBT patients is required in order to effectively serve these patients.	4.54 5 (4–5) 5	4.63 5 (4–5) 5

it was “free bottom surgery”). Two participants stated that they were positively impacted by hearing stories of cancer and cancer treatment being told through an LBT lens in general, and two participants wrote about the importance of considering the whole patient, including the sexuality aspect. One participant said, “patients’ sex lives are important to them and we are not truly achieving patient-centered care if we are not addressing this as well, especially in situations where treatment can impact one’s sexuality.”

When asked what further information they would like to know that wasn’t included in the Cancer’s Margins videos, two participants stated a need for hands-on or clinical experience, and two participants expressed a desire to learn more about transgender health specifically. All participants that answered the open-ended question about the usefulness of the training videos (n=7) stated that they think the videos are very useful because of the importance of hearing the voices of LBT patients. Some participants stated that the LBT community is underrepresented in medical school education, and that hearing first-person stories about LBT experiences with cancer and other conditions may help students recognize their own cisgender and heteronormative biases when working with LBT patients. When asked for feedback on the Cancer’s Margins videos, some participants expressed the need for closed captioning in both English and French so that every video can be watched by both English and French speakers.

Discussion

Similar to other recent research related to LBT-specific training (Arthur et al., 2021; Lee et al., 2020; Parameshwaran et al., 2017; Wahlen et al., 2020), we found that medical students overall had a baseline positive attitude toward LBT patients. At baseline, participants in this study either disagreed (27.3%) or strongly disagreed (72.7%) with the statement “If given the choice, I would prefer not to work with LBT patients” and showed a desire to receive specific training for working with LBT patients (27.3% agreed, 72.7% strongly agreed). It is uncertain whether this baseline acceptance and positive attitudes among medical students are due to previous education on LBT health or if it is societal. Although the attitudes were overall positive, the self-reported confidence for working with LBT patients was variable. There was no obvious difference between participants in different years of study.

Other recent studies (Arthur et al., 2021; Lee et al., 2020; Obedin-Maliver et al., 2011; Parameshwaran et al., 2017) have found that LBT training was lacking in the medical curricula, but 63.6% of participants in this study agreed that they had received specific training in LBT health issues. There was no assessment in this project of whether the participants felt that the LBT-specific training they received was adequate, or whether it was through the medical education curricula or from previous degrees or other sources.

The highest level of baseline confidence across participants was related to asking for preferred pronouns, and the lowest level of baseline confidence across participants was related to knowing where to look to find information about LBT-specific health services. The average low level of confidence in knowing where to find LBT-specific health services is consistent with the results from the same question in the studies conducted by Arthur et al. (2021) and Parameshwaran et al. (2017). The high level of confidence in asking for preferred pronouns is promising when considering the suggestion made by Kamen et al. (2019) that cancer care providers, and ultimately providers in general, "ask about and use patients' correct names and pronouns" (p. 2530).

When asked about which of the videos impacted them the most, 27.3% of participants named "The Neither Story" with reference to the fact that some cancer treatments have the potential to be gender affirming—for example, with chest surgery after breast cancer or "bottom surgery" after ovarian, uterine, or cervical cancer. One of the suggestions by Kamen et al. (2019) for cancer care providers was to "provide transition-related surgeries and hormone therapy when relevant and possible in the context of cancer care" (p. 2528). Introducing medical students to first-person stories like "The Neither Story" may start the conversation that is necessary to making gender-affirming surgery and therapies a normal part of cancer treatment for LBT patients with breast and gynecological cancers who desire such therapies/surgeries.

There are a number of limitations to this study. The first and most significant limitation is the small sample size. Because only 11 surveys were fully completed and included in data analysis, which amounts to only 2.3% of medical students at Dalhousie, the data is not representative of the population at this medical school. Second, all participants are from a single university, so the results are not representative of students at other medical schools across Canada. Third, all participants who fully completed the survey had just finished their first or second year, so there is no data included from students in their clinical years. It is likely that students further along in their medical training have more confidence with clinical encounters in general, and it is more likely that they have had exposure to working with LBT patients simply because they have more exposure to working with patients. It is possible that students who chose to participate in this study already have more positive attitudes about LBT individuals than those who did not participate. The research was conducted by one of their peers, so although the survey was anonymous there is a possibility that responses were skewed. The majority of participants who partially completed the survey stopped before Part Two, which is at the point that they were invited to watch the videos on the Cancer's Margins website. There are several potential reasons for this, with some possibilities being the following: time commitment too great, videos not interesting to the student, or issues with returning to the survey after completing watching the videos. Another limitation is that the demographic survey did not include race or ethnicity. Sex, not gender, was on the demographic survey, which may have discouraged individuals who do not identify as male or female from participating despite the option to opt out of self-identifying as male or female.

It is clear from the literature that physician attitudes and knowledge are a barrier for LBT patients to access the quality health care that they deserve. The data from this study suggests that medical students want to learn more about LBT-specific health care so that they can make patients feel safe and heard and provide them with the care that they need. More investigation should be done into the amount and quality of LBT-specific education being received by medical students across Canada, based on the students' opinions and perspectives. The response to the Cancer's Margins videos' quality and usefulness as a source of education were overall positive. It could be beneficial for medical students to be exposed to the Cancer's Margins training videos during their education, in addition to hands-on clinical encounters with members of the LBT community.

Conclusion

Variation in confidence for working with LBT patients was identified, with deficits seen in a few key areas. Despite the variation in self-reported confidence, participants had positive attitudes about working with LBT patients and had a desire to learn more about how to better serve this population. Incorporating LBT-specific training during the medical school curriculum could serve to break down the barriers for this population to access quality health care, and based on the responses from this survey the Cancer's Margins training videos would be a welcome and effective resource for medical students. Particular attention should be directed toward teaching students about transgender health care and how to locate LBT-specific health services.

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HPJ HEALTHY POPULATIONS JOURNAL

Research Protocol

Clarifying the Concept of Mental Health Literacy: Protocol for a Scoping Review

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Abstract

This scoping review will chart the peer-reviewed literature to clarify the concept of mental health literacy (MHL) and how it can be measured. MHL is an emerging area of study within mental health promotion, as programming and policy efforts devoted to promoting mental health emerge. Enhancing MHL in the general population is a strategy for promoting mental health by reducing stigma and empowering individuals to recognize, interpret, and understand their mental health, and know when to seek help for themselves and others. Despite the positive outcomes associated with MHL, conceptualization varies in scope, purpose, process, and outcome; there is little consensus of what "counts" as MHL. A clearly defined conceptualization of MHL is needed to support research, programming, and policy in mental health promotion. Papers on the theoretical and conceptual principles underlying MHL and primary studies documenting MHL initiatives and methods will be included. A scoping literature search will be performed following the search protocol for scoping reviews by JBI to identify all relevant literature on MHL. Searches will be conducted in five scientific databases; there will be no time limit imposed, although all sources must be written in English or French. Identifying the conceptualization and measurement of MHL in research that is guiding mental health interventions will provide conceptual clarity, ultimately advancing knowledge of mental health literacy.

Introduction

Mental health literacy (MHL) was introduced four decades ago as "knowledge and beliefs about mental disorders which aid their recognition, management, or prevention" (Jorm et al., 1997, p. 182). The general public's ability to access, understand, and use information in order to promote their health may lead to positive outcomes as a means of facilitating early intervention (Jorm et al., 1997). Building a mental health literate society can be considered an upstream approach to public mental health. For example, when teachers, parents, and peers recognize the early indications of mental health challenges and distress, know about the best types of help available, and also know how to access these supports, they are mental health literate and can facilitate appropriate help-seeking (Kelly et al., 2007). An early survey on MHL in Australia suggested that most people are unable to correctly label a disorder or illness portrayed in a depression or schizophrenia vignette (Jorm et al., 2006), and while this has improved over the following decade (Kelly et al., 2007), as knowledge of mental health develops via research, the room for laypersons' knowledge to improve also grows.

Mental health literacy has since evolved (Kutcher et al., 2016) to include knowledge that benefits the mental health of others, such as the following:

- knowledge of disorder prevention strategies
- recognition of developing mental disorders
- knowledge and beliefs about causes
- knowledge and beliefs about self-help
- knowledge and beliefs about professional help
- attitudes that facilitate recognition and help-seeking
- knowledge of how to seek mental health information
- cognitive organization of MHL

In a report for the Canadian Alliance on Mental Illness and Mental Health, Bourget and Chenier (2007) emphasized the mental health promotion relevance of MHL and added social skills and capacities that support mental health promotion to their conceptualization for policy purposes. More recently, MHL has included reducing stigma and promoting self-help strategies and help-seeking efficacy (Jorm, 2012).

On average, Canadian adults tend to show adequate MHL, but vary in personal help-seeking preferences (e.g., self-management) across age groups (Marcus et al., 2012). Successful interventions and initiatives to promote MHL have been primarily in school settings, focused on improving the MHL of teachers and other supporters of adolescent mental health (Kutcher & Wei, 2014; Kutcher et al., 2015). Other interventions include population-wide and individual training on mental health first aid, which is loosely based on physical first aid and has been shown to contribute to positive health outcomes (Jorm et al., 2006). There is little evidence as to what components of a program work when educating young people or adults about mental health (Kelly et al., 2007), which is of concern, considering that public MHL can reduce barriers to public acceptance of evidence-based mental health care (Jorm, 2000). For example, some initiatives focus on population-wide blanket approaches, with little consideration for developmentally-appropriate, settings-based context. Other initiatives focus on a targeted approach, such as educating the public in neighbourhoods with high mental disorder incidence (Wolff et al., 1999). Another approach is to involve mental health experts in a media campaign to reduce stigma and provide publicly available educational tools (Nairn, 1999). Improving MHL is an important step in integrated care, where mental health supports and services are not siloed from other health care. For example, a consequence of poor MHL is that the burden of mental health prevention and promotion would largely be on professionals, which increases their workload and patients' wait times and ultimately poorly affects the mental health care system (Kelly et al., 2007).

The original conceptualization of MHL was based on the positive outcomes accrued from the general public's ability to gain access to, understand, and use information in order to promote their mental health via an upstream approach (i.e., early intervention/prevention; Jorm et al., 1997). As the field of public mental health has grown, increasing MHL in educators, parents, and health professionals has become a priority. Given the positive outcomes (Brijnath et al., 2016; Jorm, 2012; Kelly et al., 2007; Kutcher & Wei, 2014; Kutcher et al., 2015) associated with mental health literacy, best practices for promoting mental health literacy are still unclear. As our interest is in clarifying the concept of MHL and how it is measured, and as early writings of MHL frame it as a tool for promoting mental health in the general public, we seek to chart the evidence base for mental health literacy in the general population.

Exploring the evidence base for community MHL may also serve as a foundation for future evidence reviews for specific populations (e.g., students and educators).

Charting the literature on mental health literacy will provide the data from which we will systematically analyze the concept of mental health literacy. Overall, conceptual clarity will help advance the study and application of mental health literacy.

Mental health literacy is an emerging tool within community mental health promotion, yet it remains unclear what "counts" as MHL. Components related to MHL have been previously reviewed, including measurement (Brijnath et al., 2016; Furnham & Hamid, 2014; O'Connor et al., 2014; Wei et al., 2015), levels of MHL in non-Western countries (Furnham & Hamid, 2014), web-based and in-person interventions (Brijnath et al., 2016; Wei et al., 2015; Yamaguchi et al., 2020), and MHL in relation to eating disorders (Bullivant et al., 2020). Notably, these efforts are varied in scope and nature, and lack consensus across theoretical background, best practices, and alignment with programming resources. Moreover, in the six years since the most recent conceptual review, there have been 13,300 papers published that refer to the concept of MHL. However, without a comprehensive conceptualization of MHL, the utility of this work is limited and provides mixed and inconclusive results. The current review aims to fill this gap by developing a cohesive conceptualization of MHL and its measurements and encompasses the broad spectrum of MHL topics rather than focusing on specific aspects of the subject matter.

A first step is taking stock of the landscape of the evidence base and identifying how it has been defined, measured, and utilized in mental health promotion. To analyze the concept of MHL, we will scope the peer-reviewed literature documenting the concept, measurement, and theory of MHL.

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* was conducted on June 28, 2021, and no current or in-progress scoping reviews or systematic reviews on the topic were identified.

Review Questions

RQ 1: How is MHL empirically conceptualized in research on community samples?
Sub-question 1: How has MHL been defined in empirical research in research on community samples?
Sub-question 2: What is the prevailing theoretical framework of MHL in empirical research in research on community samples?

RQ 2: How is mental health literacy empirically measured in research on community samples?
Sub-question 1: What characterizes studies that use vignettes to measure MHL?
Sub-question 2: What characterizes studies that use scales to measure MHL?

Inclusion Criteria

Participants

This review will consider studies that explore MHL in the general population (i.e., community representation, rather than students or health professionals). Sources will include those not limited by demographic characteristics, such as age, sex, or disorder type.

Concept

This review will consider studies that explore MHL, including its conceptual underpinnings, theoretical background, and measurement methods.

Context

This review will consider all primary studies that describe, measure, utilize, or evaluate the concept of MHL within the general population, such as community samples.

Types of Sources

This scoping review will consider all primary studies for inclusion, including quantitative, qualitative, and mixed methods study designs that empirically measure MHL.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2020).

Search Strategy

The search strategy will aim to locate published primary studies and conceptual and theoretical papers. An initial limited search of MEDLINE (PubMed) and PsycInfo (EBSCO) was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a full search strategy for PubMed, CINAHL, MEDLINE, ERIC, and PsycInfo in consultation with a librarian (see Appendix A). The search strategy, including all identified keywords and index terms, will be adapted for each included information source. The reference lists of articles written by the pioneer of MHL (Jorm) will be hand searched for additional papers.

Articles published in English and in French will be included, with no time limit. The consulting librarian suggested databases to be searched, including PsycInfo (EBSCO), MEDLINE (PubMed), ERIC (as MHL is a psychoeducational concept), and CINAHL.

Study/Source of Evidence Selection

Following the search, all identified records will be collated and uploaded into Mendeley (www.mendeley.com) and duplicates removed. Following a pilot test, titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant papers will be retrieved in full, and their citation details imported into Covidence (www.covidence.org). The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full-text papers that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) flow diagram (Tricco et al., 2018).

Data Extraction

Data will be extracted from papers included in the scoping review by two independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the conceptual and theoretical development of MHL, the evidence base or theoretical background that MHL-promoting programs are informed by, the methods and measures that the program has been evaluated with, and the outcome of the program implementation. A draft extraction tool is provided (see Appendix B). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included paper. Modifications will be detailed in the full scoping review. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data Analysis and Presentation

The data extracted from relevant published literature will be displayed to include the author and year of publication, type of source, conceptual and theoretical background, measurement, intervention content, population(s), materials used, and documented outcomes. Data extracted from included papers will be presented in a tabular form, and the table will report key findings relevant to the review question. Data will be synthesized based on complexity of concept used and will then be classified into themes using content analysis. A narrative summary will accompany the tabulated data and will describe how the results relate to the review objective and question.

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Appendix A

Search Strategies

Table A1
Initial Search Strategy

Search	Query	Records retrieved
#1	“mental health literacy”	310

Note. PubMed, PsycInfo, and SCOPUS. Initial search conducted June 28, 2021. Limited to English.

Table A2
Final Search Strategy

	Query	Search Details	PubMed	PsycInfo	CINAHL	ERIC
3	#1 AND #2	("mental health"[Title/Abstract] OR "mental hygiene"[Title/Abstract] OR ("mental health"[Subject] OR "mental hygiene"[Subject])) AND ("literacy"[Title/Abstract] OR "illiteracy"[Title/Abstract] OR "illiterate"[Title/Abstract] OR "literate"[Title/Abstract])	1,897	1,969	164	163
2	(literacy[Title/Abstract] OR illiteracy[Title/Abstract] OR illiterate[Title/Abstract] OR literate[Title/Abstract]) OR (literacy[Subject] OR illiteracy[Subject] OR illiterate[Subject] OR literate[Subject])	“literacy”[Title/Abstract] OR “illiteracy”[Title/Abstract] OR “illiterate”[Title/Abstract] OR “literate”[Title/Abstract]	31,111	40,672	4,852	214
1	(“mental health”[Title/Abstract] OR “mental hygiene”[Title/Abstract]) OR (“mental health”[Subject] OR “mental hygiene”[Subject])	“mental health”[Title/Abstract] OR “mental hygiene”[Title/Abstract] OR “mental health”[Subject] OR “mental hygiene”[Subject]	188,597	251,192	19,814	10,518

Note. Databases: PubMed, CINAHL, MEDLINE, ERIC, and PsycInfo. Searched January 10, 2022. Limited to English and French, with no time limit.

Appendix B

Data Extraction Instrument

Study citation	MHL definition	Country	Theoretical background	Sample size	Measurement of MHL	Key findings/ conclusion

HEALTHY POPULATIONS JOURNAL

Research Protocol

Characterizing Non-Curative Cancer Patients' Preferences, Barriers, and Facilitators to Engaging in Exercise Programs: A Scoping Review Protocol

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Abstract

Objective: The objective of this scoping review is to understand the existing knowledge on non-curative cancer patients' preferences, barriers, and facilitators to engaging in an exercise program, as well as strategies for practitioners to increase the uptake of exercise programs for non-curative cancer patients. **Introduction**: Early palliative interventions for patients with non-curative cancers have been shown to have positive effects on an individual's quality of life. A common objective of early palliative interventions is to enhance quality of life, enable symptom management, and improve mental health. Although not a specific component of early palliative care, tailored exercise programs have the similar goal of enhancing quality of life in non-curative cancer patients. **Inclusion criteria**: This review will consider sources that include non-curative cancer patients and their needs and experiences regarding participation in exercise programs. Qualitative, quantitative, mixed methods, and grey literature will be searched. **Methods**: This scoping review will be conducted in accordance with JBI methodology. Databases to be searched from their respective inception to September 9, 2021, include CINAHL, MEDLINE, Embase, Scopus, SPORTDiscus, and PsycInfo. A comprehensive search strategy was developed in accordance with JBI methodology to retrieve relevant sources. Two independent reviewers will screen titles and abstracts as well as full texts of relevant sources. The results of the search and the study inclusion process will be reported in full in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) flow diagram. Data will be extracted by two independent reviewers and then mapped onto the Behaviour Change Wheel. The results will be presented narratively, using appropriate tables and figures. **Conclusion**: This review will map key barriers, facilitators, and preferences to partaking in exercise programs for individuals with non-curative cancer. This will aid in informing priorities for subsequent implementation studies.

Introduction

The number of cancer survivors has steadily increased over the past several decades and is projected to increase by as much as 31% in the next 10 years (National Cancer Institute, 2020). Owing to improved treatment, the number of those living with a non-curative disease is also on the rise (Stegmann et al., 2021). Non-curative cancer entails a cancer that cannot be treated through chemotherapy or radiation, and treatments are targeted toward symptom relief. Current palliative chemotherapy for some cancer patients includes targeted immunotherapies to prolong an individual's life but will not cure them of cancer. As well, individuals who have uncontrolled pain from bone metastases should receive radiation to control pain; however, their therapy is not curative. For those individuals who bear a non-curative diagnosis, improving quality of life and symptom management (World Health Organization, 2021) becomes of particular importance. Most individuals with non-curative cancer encounter vastly different challenges compared to those who are placed on traditional treatment paths. This includes but is not limited to psychological distress, lack of social connectivity, and loss of physical function (Brown et al., 2006; Jassim et al., 2015; Oldervoll et al., 2005; Porock et al., 2000; Prue et al., 2006; Stegmann et al., 2021). In this review protocol, the term non-curative cancer will be used synonymously with palliative cancer, terminal cancer, advanced stage cancer, and metastatic cancer. A palliative approach to care entails identifying and supporting individuals early in their illness trajectory, with the objective of enhancing quality of life, enabling symptom management, and improving mental health. These are of the utmost importance when working with individuals diagnosed with non-curative cancers (World Health Organization, 2021). It is part of the overall philosophy of palliative care to provide active holistic care for individuals across all ages with severe health-related suffering (Sawatzky et al., 2016).

Recent medical and technological advancements have extended the life of cancer patients, resulting in a greater number of individuals living longer with a non-curative diagnosis and progressive functional deterioration (Chui et al., 2009; Kamal et al., 2011; Oechsle et al., 2011). An individual's ability to engage in activities of daily living is often substantially diminished and is frequently cited as one of the most distressing concerns (Neo et al., 2017). Tailored exercise interventions early in disease trajectory have been shown to help mitigate loss of physical function, lessen fatigue and symptom burden, and foster enhanced quality of life in palliative cancer patients (Twomey et al., 2018; Uster et al., 2018). Although not a specific component of early palliative care, tailored exercise programs have the similar goal of enhancing quality of life. Utilizing gentle exercise has been shown to have a positive effect on individuals with non-curative cancer (Oh et al., 2014). However, due to both a lack of knowledge of benefits and limited access to tailored exercise programs for individuals with non-curative diagnoses, only 34% of those with advanced disease meet physical activity (PA) guidelines (Knowlton et al., 2020). Efforts are needed to clearly understand these barriers and facilitators to engaging in PA in this sub-population of cancer patients to support the implementation of effective interventions into standardized cancer care.

Regrettably, the uptake and implementation of exercise into standard practice in non-curative cancer care continues to be limited. A high proportion of non-curative cancer patients (63%) are willing to participate in a structured exercise program, and 54% of ·

non-curative cancer patients have successfully completed an exercise program, even though they are terminally ill (Oldervoll et al., 2005). A better understanding of the preferences, barriers, and facilitators to program uptake is important when designing interventions for this sub- population, and it is important to increase patient access to physical activity across the cancer continuum. Implementation researchers recommend using a theory-based approach to identify barriers and facilitators to uptake and then tailor interventions. Accordingly, conducting a theory-based analysis of patient preferences, barriers, and facilitators to exercise uptake in non-curative cancer patients helps to understand the relationship between these factors and the mechanisms by which they influence behaviour (Michie et al., 2014). Studies have found that the use of theory-based approaches to intervention design can lead to more successful implementation and intervention success (Craig et al., 2013). As such, adopting a systematic, theory-informed approach will help to (a) identify the preferences, barriers, and facilitators to exercise uptake in this population at multiple levels (e.g., individual, social, cultural, political) and (b) design implementation strategies to acknowledge patient preferences, overcome barriers, and enhance facilitators to exercise uptake.

Many implementation theories and frameworks exist to provide systematic guidance for designing, implementing, and evaluating interventions aimed at changing behaviour. The Behaviour Change Wheel (BCW) is a synthesis of 19 existing behaviour change frameworks that offers a comprehensive and systematic guide to intervention design (Michie et al., 2014). The BCW includes an analysis of the nature of the behaviour, the mechanisms that need to be addressed in order to create behaviour change, and the interventions and policies required to change those mechanisms (Michie et al., 2014). The BCW uses the COM-B model, which proposes that one needs Capability (C), Opportunity (O), and Motivation (M) to perform a Behaviour (-B; Michie et al., 2014). We have selected the BCW over other implementation models, theories, and frameworks such as the Consolidated Framework for Implementation Research (CFIR; Damschroder et al., 2009) or the Promoting Action on Research Implementation in Health Services (PARIHS) framework (Rycroft-Malone, 2004) because of the BCW's core focus on mapping behavioural change barriers and facilitators to targeted, evidence-based behavioural change strategies. The BCW's behavioural analysis is an important first step in designing and implementing theory-informed interventions. To our knowledge, this type of behavioural analysis has not been conducted in the context of exercise adoption in non-curative cancer patients.

For the purposes of this review, non-curative cancer patients will encompass those individuals living with cancer and not on curative-intent treatment. That is, their anti-cancer treatment is intended to optimize symptom management, improve quality of life, and/or slow tumour progression as opposed to cure.

The objective of this scoping review is to identify, characterize, and map the existing knowledge on non-curative cancer patients' preferences, barriers, and facilitators to engaging in an exercise program. A scoping review will be conducted, as it is exploratory in nature and will aid in identifying and analyzing knowledge gaps, scope, and volume of the current literature, as well as mapping current evidence. A scoping review will also serve to inform questions for subsequent systematic reviews. A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* was conducted, and no current or underway scoping or systematic reviews on the topic were identified. Findings from this review will inform the design of behavioural interventions to support non-curative cancer patients in increasing exercise uptake.

Review Question

The questions driving this review are the following:

1. What are non-curative cancer patients' preferences, barriers, and facilitators to participating in exercise programs, and how do these preferences, barriers, and facilitators map onto the COM-B?
2. What exercise interventions currently exist for non-curative cancer patients?

Inclusion Criteria

Participants

This review will consider literature that includes non-curative cancer patients (incurable cancer, palliative cancer, terminal cancer, advanced cancer, and metastatic cancer) as participants. This review will exclude pediatric and adolescent patients with non-curative cancer (<18 years of age) or individuals who are considered in remission or cancer survivors. Excluding childhood cancers is due to the vast difference in experiences for pediatric and adolescent cancer patients compared to adults (Zebrack, 2008).

Concept

This review will consider literature that explores patient preferences, perceived barriers, and facilitators for non-curative cancer patients to participate in exercise programs. Exercise will be defined as planned, structured, and purposeful PA (Caspersen et al., 1985), and will include—but is not limited to—walking programs, strength training and mixed exercise programs, and any other form of purposeful PA. Preferences will be defined as "the fact of liking or wanting one thing more than another" (Cambridge University Press, n.d.-c), a facilitator will be defined as "someone [or something] who helps to make something happen, or makes it easier" (Cambridge University Press, n.d.-b), and a barrier will be defined as "something that prevents something else from happening or makes it more difficult" (Cambridge University Press, n.d.-a).

Context

This review will consider studies located in all care settings, including hospital, community, primary care, and ambulatory care settings. This review will exclude studies that are based in long-term care or hospice settings, as the focus is on a population that has >6 months to live. Studies will not have a geographical limit.

Types of Sources

This scoping review will consider both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, pre-post studies, and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports, and descriptive cross-sectional studies for inclusion.

Qualitative studies that focus on qualitative data including—but not limited to—designs such as phenomenology, grounded theory, ethnography, qualitative description, action research, and feminist research will also be considered. Text and opinion papers will also be considered for inclusion in this scoping review.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2020). There were no patients or public involvement in the design, conduct, reporting, or dissemination plans of this research.

Search Strategy

The search strategy will aim to locate both published and unpublished studies. An initial limited search of MEDLINE and CINAHL was undertaken to identify articles on the topic. The words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a full search strategy for CINAHL, MEDLINE, Embase, Scopus, SPORTDiscus, and PsycInfo (see Appendix A). The search strategy, including all identified keywords and index terms, will be adapted for each included database and/or information source. A health librarian (SM) was consulted throughout the search strategy conception. The reference list of all included sources of evidence will be screened for additional studies, as well as backward and forward searching. Only studies published in English will be included. There will be no date range for this review, in order to explore trends across time.

Information Sources

The databases to be searched include MEDLINE, CINAHL, Embase, Scopus, SPORTDiscus, and PsycInfo. Sources of unpublished studies and grey literature to be searched include ProQuest Dissertations & Theses Global and the first 10 pages of Google Scholar. We will also search for grey literature using the Canadian Agency for Drugs and Technologies in Health (CADTH) grey literature checklist *Grey Matters: A Practical Tool for Searching Health-Related Grey Literature* (CADTH, 2019). In addition, relevant organizational, governmental, and health care association websites will be searched including—but not limited to—Canadian Cancer Society, American Cancer Society, National Cancer Society, Cancer Research UK, National Health Institute, National Cancer Institute, Public Health Agency of Canada, Government of Canada websites, and provincial health authority websites.

Study/Source of Evidence Selection

Following the search, all identified citations will be collated and uploaded into Covidence (a citation management platform) and duplicates removed. Following a pilot test of 50 included articles, titles and abstracts will then be screened by two or more independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant sources will be retrieved in full, and their citation details imported into Covidence. The full text of selected citations will be assessed in detail against the inclusion criteria by two or more independent reviewers. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with an additional reviewer. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) flow diagram (Tricco et al., 2018).

Data Extraction

Data will be extracted from papers included in the scoping review by two or more independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the participants, concept, context, study methods, and key findings relevant to the review questions. Before data extraction begins, two independent reviewers will pilot the data extraction tool for five articles, and they will discuss any additional information needed to be extracted.

A draft extraction form is provided (see Appendix B). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review. Any disagreements that arise between the reviewers will be resolved through discussion, or with an additional reviewer. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Data Analysis and Presentation

Data on preferences, barriers, and facilitators will be analyzed using the BCW as a coding guide. First, we will conduct a behavioural analysis of non-curative cancer patients, preferences, barriers, and facilitators to participation in exercise programs. Preferences, barriers, and facilitators will be extracted as reported by the study authors and then categorized into the six subcomponents of the BCW's COM-B model of behaviour (psychological capability, physical capability, social opportunity, physical opportunity, automatic motivation, and reflective motivations; Michie et al., 2014). Two reviewers will conduct the data classification using a pre-defined coding manual based on definitions and guidance from the BCW. Any discrepancies will be resolved by consensus or with a third reviewer. Final BCW categorizations will be reviewed and discussed with the entire research team. Given the focus of this scoping review on mapping existing literature, we will not be explicitly performing a risk of bias assessment.

The PRISMA-ScR (Tricco et al., 2018) reporting guideline will be followed for this scoping review. Study findings will be reported using the PRISMA-ScR (Tricco et al., 2018), as well as the PRISMA 2020 guidelines (Page et al., 2021). The extracted data will be presented in tabular form that aligns with the review objectives and questions. In addition to the tables, a graphic image will be created of the preferences, barriers, facilitators, and strategies found in the included studies. A narrative summary will accompany these presentations and will describe how the findings relate to the review's objectives and sub-questions. Results will be classified under main conceptual categories: study characteristics (including country or origin, study population, study setting, design), outcome measures, barriers, facilitators, strategies/interventions, reported key findings, and implications.

Conclusion

This review will map key barriers, facilitators, and preferences to partaking in exercise programs for individuals with non-curative cancer. In doing so, this review will identify behavioural strategies to systematically reduce patient barriers and address participant capability, opportunity, and motivation regarding exercise programming and will also inform priorities for future implementation studies.

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Conflicts of Interest

There is no conflict of interest in this project.

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Appendix A

Search Strategy

1	((cancer* or neoplas* or leukemia* or leukaemia* or tumor* or tumour* or lymphoma*) adj3 (advanced or metast* or "life limiting" or "non curative" or terminal or palliative or incurable))
2	(Exercise or "resistance training" or aerobic* or "motor activity" or "exercise therapy" or "physical activity" or training)
3	(Barrier* or attitude* or preference* or adher* or complian* or persist*)
4	Exp terminal care/ or exp terminally ill/ or exp palliative care/
5	Exp Exercise/
6	"attitude or health personnel"/ or attitude to death/ or attitude to health/ or "treatment and compliance"/ or patient compliance/ or patient dropouts/ or patient participation/ or patient satisfaction/
7	2 or 5
8	3 or 6
9	Exp Neoplasms/
10	4 and 9
11	1 or 10
12	7 and 8 and 11

Appendix B

Data Extraction Instrument

Author	Title	Country	Year	Definition of non-curative cancer	Barriers	Facilitators	Preferences	Strategies	Intervention Details	Key Findings	Implications	Limitations

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Research Protocol

Characterising Pragmatic Exercise Interventions to Reduce Cognitive Impairment in Cancer Survivors: A Scoping Review Protocol

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Abstract

Objective: The objective of this scoping review is to identify the characteristics of pragmatic exercise interventions aimed at reducing cognitive impairment in cancer survivors, and their effectiveness in reducing this impairment and maintaining high adherence. **Introduction:** Cognitive impairment (CI) is a particularly troublesome side effect of cancer treatment that has been suggested to decrease following exercise interventions. Most existing research consists of randomized control trials, which often lack external validity. Pragmatic interventions fill this gap. However, some pragmatic trials that provide real-world evidence struggle to maintain strong participant adherence. Thus, examining characteristics of pragmatic interventions with high levels of adherence may be beneficial in improving overall adherence in future pragmatic trials on this topic. **Inclusion criteria:** This review will examine literature with cancer survivors who are partaking in pragmatic exercise programs. Specifically, literature exploring the effects of pragmatic exercise interventions in decreasing cancer survivors' CI will be examined, with no limits to intervention frequency, intensity, time, or type. "Cancer survivor" will be defined as any individual with a cancer diagnosis, at any point along the survivorship continuum. **Methods:** A comprehensive search strategy was developed in accordance with JBI methodology to retrieve relevant sources. Databases to be reviewed from inception to present will include CINAHL, MEDLINE, Embase, SPORTDiscus, Scopus, and PsycInfo. Two independent screeners will examine titles and abstracts as well as full texts of relevant sources. The results of the search and the study inclusion process will be reported in full in a Preferred Reporting

Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) flow diagram. The results will be presented narratively, using appropriate tables and figures.

Keywords: physical activity, chemobrain, cognitive dysfunction, community-based

Introduction

Cancer is a malignant disease in which mutated cells proliferate independently, invade surrounding tissues, and metastasize throughout the body, and it is the leading cause of death in Canadians (Statistics Canada, 2018). Largely due to a growing aging population, the number of individuals diagnosed with cancer is on the rise. Responsible for 30% of all deaths nationwide, 45% and 43% of Canadian men and women, respectively, will be diagnosed with cancer at one point over their lifetime (Canadian Cancer Statistics Advisory Committee, 2019). However, due to progress in detection and treatment technology, survival rates are increasing. Since 1988, survival rates for men and women with cancer have increased by 35% and 20%, respectively (Canadian Cancer Statistics Advisory Committee, 2019). With parallel increases in both diagnoses and survival, more survivors are facing the long-term side effects associated with cancer and its treatments than ever before—effects that have been found to significantly hinder their quality of life (Boykoff et al., 2009; Frost et al., 2000; Holzner et al., 2001; Mitchell & Turton, 2011; Schmidt et al., 2016; Selamat et al., 2014). Of these side effects, cognitive impairment (CI), colloquially referred to as "chemobrain" or "brain fog," is particularly troublesome.

CI refers to any declines in perceived or objectively measured cognitive functioning including, but not limited to, deficits in attention, executive function, concentration, memory, processing, spatial and task processing speeds, and cognitive fatigue (Joly et al., 2015; Mitchell & Turton, 2011; Schmidt et al., 2016; Selamat et al., 2014). Empirically, it has been suggested that chemotherapy directly induces CI in survivors, citing cases in testicular, colorectal, prostate, and breast cancers (Buffart et al., 2015; Joly et al., 2015). In addition to cognitive deficits, CI also impacts survivors' psychosocial well-being and is often reported as a survivor's most troublesome symptom, resulting in declines in quality of life and daily functioning, as well as social and professional drawbacks (Boykoff et al., 2009; Frost et al., 2000; Holzner et al., 2001; Saarto et al., 2012; Schmidt et al., 2015). In those living with CI, there is often a perceived inability to perform tasks that had been appraised as simple prior to receiving chemotherapy, such as those related to survivors' occupations, contributing to a lost sense of identity (Henderson et al., 2019). This detrimental undermining of identity has been linked to reduced confidence, doubts regarding returning to work, and difficulties with social interaction (Henderson et al., 2019).

In managing and reducing CI symptoms, research has found considerable success in developing exercise as a promising intervention (Campbell et al., 2020; Myers et al., 2018). Aerobic, resistance, and mixed modal exercise interventions have each demonstrated positive effects on CI in survivors, when examining both cognitive functioning as a whole as well as cognitive fatigue specifically (Campbell et al., 2020; Hacker et al., 2011; Schneider et al., 2007). This variety in effective intervention style provides survivors with flexibility in terms of program design that can lead to the attainment of personal fitness goals as well as CI symptom improvements. Interestingly, exercise interventions have been suggested to reduce CI acutely as well, diminishing time commitments required by survivors to draw benefits (Salerno et al., 2019).

While some survivors will require acute psychosocial support, supportive lifestyle interventions such as exercise may be viewed by survivors as less stigmatizing than discussing mental health issues, while still offering substantial mental health benefits. Moreover, resources allocated to psychosocial programs are frequently not adequate to provide services beyond the needs of patients currently receiving therapy or who have acute mental health needs (Recklitis & Syrjala, 2017). Similarly, access to psychosocial oncology care providers may be limited to those survivors living in close proximity to major cancer centres. Community group-based exercise programming can increase access to complementary mental health care and may offer benefits beyond those of psychotherapy alone. Literature also suggests that there are benefits to conjunctive exercise and psychotherapy interventions (Courneya et al., 2003). Breast and prostate cancer survivors have credited these forms of interventions with creating mutual aid and trust while helping with self-identity and returning to normalcy (Martin et al., 2015).

While there is encouraging research evaluating exercise interventions' effectiveness in diminishing survivors' CI, it has been found that adherence levels are critical limitations to these studies. In a recent systematic review conducted by Campbell et al. (2020), over 25% of randomized control trials examined had low intervention adherence, taking away from the review's promising finding that exercise had beneficial effects on survivors' CI. Low adherence levels hinder the ability to draw practical and accurate interpretations from these studies. Thus, achieving high adherence levels is critical in determining the efficacy of exercise interventions, making it advantageous to determine the qualities of interventions that maintained high subject participation. Recognizing trends emerging from this body of interventional research could provide researchers with valuable intervention designs to improve adherence and decrease attrition.

Most studies examining exercise's effect on survivors' CI follow randomized control trial designs in which participants and programs are extensively controlled. While randomized control trials are deemed the gold standard for determining causal relationships, the addition of real-world evidence in this field would be beneficial in developing knowledge regarding applications of exercise interventions to a broader and more diverse population of cancer survivors. Real-world evidence is often gathered from pragmatic trials—studies designed to assess interventions in environments that mimic real-world routine clinical practice conditions (Patsopoulos, 2011). Pragmatic exercise trials may feature loose inclusion criteria, individualized interventions, or self-directed programming (Cuesta-Vargas et al., 2011; Treweek & Zwarenstein, 2009).

The objective of this scoping review is to identify the characteristics of effective pragmatic trials that have examined the impact of exercise interventions on cancer survivors' CI. Specifically, the frequencies, intensities, times, and types of these exercise interventions that maintained consistently high participant involvement will be analyzed for any similarities and trends. Attention will also be given to those specific studies that found positive effects of exercise on decreasing symptoms of CI. A scoping review method was chosen to capture studies that incorporated a variety of designs, which will allow reviewers to investigate this topic using a heterogeneous data set of previously published literature. A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* was conducted, and no current or underway systematic reviews or scoping reviews on the topic were identified. Findings from this review will provide researchers, health care professionals, and allied health care providers with practical guidance on improving intervention adherence and effectiveness in reducing CI.

Review Questions

The questions to be addressed in this review are the following:

1. What were the frequencies, intensities, times, and types of pragmatic exercise interventions that led to a positive effect on CI in survivors? How do they compare to those interventions that did not show such effects?

2. What are the frequencies, intensities, times, and types of pragmatic trials that had high adherence levels?

Inclusion Criteria

Participants

This review will examine literature with adult cancer survivors as participants. Cancer survivorship involves the well-being and health of those living with cancer, beginning at the time of diagnosis through to the end of life (National Cancer Institute, n.d.). For the purposes of this review, the term "adult cancer survivor" will apply to any adult (over 18 years of age) having received a cancer diagnosis, at any point along the cancer continuum (diagnosis through to palliation).

Concept

This review will consider literature exploring the effects of pragmatic exercise interventions in decreasing cancer survivors' CI. Exercise will be defined as structured, planned, and purposeful physical activity (Caspersen et al., 1985). All types of exercise interventions, including aerobic, resistance, meditative movement (e.g., yoga, tai chi), and multimodal interventions of any frequency and duration will be examined. Adherence will be defined as the degree to which participants follow agreed-upon exercise plans.

Context

This review will examine studies with no limits related to geographic location or care setting. Studies must include an element of "real world" to be considered, and this includes pragmatic trials or studies run in communities by qualified health care professionals and/or trained fitness professionals.

Types of Sources

This scoping review will consider various study designs including non-randomized controlled trials, pre-post studies, and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports, and descriptive cross-sectional studies for inclusion.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2020). There was no patient or public involvement in the design, conduct, reporting, or dissemination plans of this research.

Search Strategy

The search strategy will aim to locate both published and unpublished studies. An initial limited search of MEDLINE and CINAHL will identify articles on the topic. The words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles will be used to develop a full search strategy for CINAHL, MEDLINE, Embase, Scopus, SPORTDiscus, and PsycInfo (see Appendix A). The search strategy, including all identified keywords and index terms, will be adapted for each included database and/or information source. The reference list of all included sources of evidence will be screened for additional studies. Only studies published in English will be included. There will be no date range for this review, in order to explore trends across time.

Information Sources

The databases to be searched include MEDLINE, CINAHL, Embase, Scopus, SPORTDiscus, and PsycInfo. Sources of unpublished studies and grey literature to be searched include ProQuest Dissertations and Theses Global and the first 10 pages of Google Scholar. We will also search for grey literature using the Canadian Agency for Drugs and Technologies in Health (CADTH) grey literature checklist *Grey Matters: A Practical Tool for Searching Health-Related Grey Literature* (CADTH, 2019).

Study/Source of Evidence Selection

Following the search, all identified citations will be collated and uploaded into Covidence (a citation management platform) and duplicates removed. Following a pilot test of 50 included articles, titles and abstracts will then be screened by two or more independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant sources will be retrieved in full, and their citation details imported into the JBI System for the Unified Management, Assessment, and Review of Information (Piper, 2019). The full text of selected citations will be assessed in detail against the inclusion criteria by two or more independent reviewers. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with review performed by a third reviewer. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) flow diagram (Tricco et al., 2018).

Data Extraction

Data will be extracted from papers included in the scoping review by two or more independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the participants (age, diagnosis, stage, and treatment), concept, context, study methods, and key findings relevant to the review questions. CI outcomes, measured both objectively and subjectively, will be extracted, including—but not limited to—working and spatial memory, verbal fluency, task switching, cognitive fatigue, and cognitive functioning pertaining to quality of life. There will be no constraints regarding which CI outcomes will be included. Before data extraction begins, two independent reviewers will pilot the data extraction tool for five of the same articles, and they will discuss any additional information needed to be extracted.

A draft extraction form is provided (see Appendix B). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review. Any disagreements that arise between the reviewers will be resolved through discussion, or with the input of a third reviewer. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Data Analysis and Presentation

Data regarding frequency, intensity, time, and type of physical activity will be extracted for the relevant studies' exercise interventions. When evaluating adherence, a graded approach will be used. Studies will be categorized as having either low (≤33%), mediocre (34-66%), or high (≥67%) adherence levels when comparing the number of participants who started the intervention to the number of those who completed it. Any discrepancies will be resolved by consensus or with a third reviewer. Final categorizations will be reviewed and discussed with the entire research team.

Given the focus of this scoping review on mapping existing literature, Tomlin and Borgetto's (2011) classification of research pyramid will be used to assess the level of evidence. This pyramid breaks down articles into four separate categories (descriptive, experimental, outcomes, and qualitative research) to evaluate the level of evidence of studies included from different study designs. Each category describes four levels of evidence from most to least rigorous. Descriptive research is divided into Level 1: Systematic reviews of related descriptive studies; Level 2: Association, correlational studies; Level 3: Multiple-case studies (series), normative studies, descriptive surveys; and Level 4: Individual case studies. Experimental research is divided into Level 1: Meta-analyses of related experimental studies, Level 2: Individual (blinded) randomized controlled trials, Level 3: Controlled clinical trials, and Level 4: Single-subject studies. Outcome research is divided into Level 1: Meta-analyses of related outcomes studies; Level 2: Pre-existing group comparisons with covariate analysis; Level 3: Case-control studies, pre-existing group comparisons; and

Level 4: One-group pre-post studies. Finally qualitative research is divided into Level 1: Meta-synthesis of related qualitative studies; Level 2: Group qualitative studies with more rigor ([a] Prolonged engagement with participants, [b] Triangulation of data [multiple sources], [c] Confirmation of data analysis and interpretation [peer and member checking]); Level 3: Group qualitative studies with less rigor (a, b, c); and Level 4: Qualitative studies with a single informant.

The PRISMA-ScR reporting guideline will be followed for this scoping review (Tricco et al., 2018). The extracted data will be presented in tabular form that aligns with the review objectives and questions. In addition to the tables, a graphic image will be created of the frequency, intensity, time, and type of exercise interventions found in the included studies. A narrative summary will accompany these presentations and will describe how the findings relate to the review's objectives and sub-questions. Results will be classified under main conceptual categories: study characteristics (including country or origin, study population, study setting, design), outcome measures, key findings, and implications.

Funding

No funding was provided for this project.

Conflicts of Interest

There is no conflict of interest in this project.

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Appendix A

Search Strategy

Database	Search Terms	Results
MEDLINE (Ovid)	#1 exp Cognition/ #2 exp cognition disorders/ or exp cognitive dysfunction/ #3 exp Memory/ #4 (cognitive* adj2 (function* or dysfunction* or impair*)).ti,ab. #5 (memor* or remember*).ti,ab. #6 ("chemo brain" or "chemo fog" or chemobrain).ti,ab. #7 Executive Function/ #8 Prefrontal Cortex/ #9 Hippocampus/ #10 Brain/ #11 Attention/ #12 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 #13 exp Antineoplastic Agents/ #14 Cancer Survivors/ #15 exp Neoplasms/ #16 exp Antibiotics, Antineoplastic/ #17 exp Doxorubicin/ #18 exp Fluorouracil/ #19 exp antineoplastic protocols/ or exp chemotherapy, adjuvant/ or exp consolidation chemotherapy/ or exp induction chemotherapy/ or exp maintenance chemotherapy/ #20 Neoadjuvant Therapy/ #21 (chemotherapy or cancer* or neoplas* or leukemia* or leukaemia* or lymphoma* or metasta*).ti,ab. #22 #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 #23 exp Exercise/ or exp Exercise Therapy/ #24 exp Yoga/ #25 Qigong/ #26 exp Exercise Movement Techniques/ #27 (pilates or "tai chi" or "tai ji" or qigong or yoga or aerobic* or exercise or "resistance training" or "weight training" or workout* or swim*).ti,ab. #28 #23 or #24 or #25 or #26 or #27 #29 #12 and #22 and #28	979

Appendix B

Data Extraction Instrument

Author		Cancer treatment(s)	
Title		Pragmatic Elements	
Country		Intervention Frequency	
Year		Intervention Intensity	
Study Aim		Intervention Time	
Study Design		Intervention Type	
Inclusion Criteria		CI Measure	
Exclusion Criteria		Adherence	
Number of Participants		Key Findings	
Cancer type		Implications	
Cancer stage		Limitations	

HPJ HEALTHY POPULATIONS JOURNAL

Research Protocol

The Impact of Exercise Training Interventions on Flow-Mediated Dilation: An Umbrella Review Protocol

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Abstract

Introduction. (Cardio)vascular diseases are among the top causes of death in Western societies. The impact of exercise training interventions to improve endothelial-dependent, flow-mediated dilation (FMD) responses has been reviewed extensively. These reviews may differ in their inclusion criteria, exercise type, exercise mode, exercise intensity, specific research questions, and conclusions. Comparing and contrasting these reviews will assist with the determination of optimal exercise programs across healthy and clinical populations. **Objectives.** We will conduct an umbrella review (or review of reviews) on systematic reviews and meta-analyses that examined the impact of exercise training interventions on peripheral artery FMD. The impact of exercise training design, population or artery studied, FMD methodology, and quality of reviews will be explored. **Methods.** A database search will be conducted in Scopus, Embase, MEDLINE, CINAHL, and Academic Search Premier for systematic reviews and meta-analyses on exercise training and FMD. All reviews must be conducted in adults (≥18 years). No limitation will be placed on the population (disease status, sex, etc.) or type of exercise training. Study quality will be determined using the JBI critical appraisal checklist for systematic reviews. Two independent screeners will examine titles, abstracts, and full texts of relevant sources and conduct the quality assessments. The results will be presented narratively and in a tabular format to align with the review objectives. **Conclusion.** This umbrella review may provide insight into the optimal training program to improve arterial health and act as an agent of change for modifying existing community exercise programs or clinical rehabilitation programs.

Introduction

Peripheral artery diseases are characterized by a narrowing or blockage of peripheral arteries, which impairs blood flow to tissues and drastically increases the risk of experiencing an adverse cardiovascular event (Howell et al., 1989). Dysfunction of the vascular endothelium is an initial stage in the etiology of peripheral artery diseases (Brevetti et al., 2003). Endothelial-dependent vasodilatory function can be non-invasively determined using high-resolution ultrasound via the flow-mediated dilation (FMD) technique. This peripheral arterial assessment quantifies the increase in lumen diameter following a transient hyperemia, induced by a brief period of distal ischemia (Celermajer et al., 1992). A larger relative FMD response (i.e., greater percent increase from baseline) is indicative of a "healthier" artery.

The brachial FMD response is primarily nitric oxide-mediated (Green et al., 2014), strongly correlated to coronary artery function (Broxterman et al., 2019), and predictive of cardiovascular disease risk (Yeboah et al., 2009). Heterogeneous FMD responses exist between upper- and lower-limb arteries (O'Brien et al., 2019; Thijssen et al., 2008), with lower-limb arteries being the most common site of atherosclerosis development (Debasso et al., 2004; Lowry et al., 2018). Lower-limb arteries are directly involved in supplying active tissues when engaging in traditional lower body modes of aerobic exercise (e.g., running and cycling). As such, investigating the impact of these aerobic exercise interventions on endothelial-dependent vasodilation may provide insight into pragmatic strategies for improving cardiovascular health.

Previous systematic reviews and meta-analyses have focused on comparing the impact of resistance versus aerobic exercise programs (Ashor et al., 2015) and moderate-intensity continuous versus high-intensity interval training (Ramos et al., 2015) on vascular function. Furthermore, the impact of exercise training on peripheral artery endothelial function has attracted the interest of numerous researchers and practitioners hoping to improve cardiovascular health through lifestyle behaviours (O'Brien et al., 2020; Rakobowchuk et al., 2008; Sales et al., 2020; Sawyer et al., 2016). Such studies incorporated varied exercise training programs, populations, arteries of interest, and other methodological characteristics (e.g., cuff position or inflation pressure for FMD, inclusion of a control group, etc.). Accordingly, there have been several systematic reviews examining exercise training and endothelial function, which vary in the studies included and provide inconsistent evidence as to whether exercise training augments FMD (Ashor et al., 2015; Early et al., 2017; Ramos et al., 2015) or not (Campbell et al., 2019). Systematic reviews and meta-analyses provide a high level of evidence but conflicting reviews, or multiple reviews on a single topic, make it challenging to discern the true impact of an intervention on health outcomes.

Umbrella reviews (or a review of reviews) summarize, compare, and contrast existing systematic reviews and meta-analyses (Fusar-Poli & Radua, 2018). Umbrella reviews are among the highest level of evidence synthesis (Aromataris et al., 2015). There is variability in how exercise training interventions are implemented (frequency, intensity, type, time; Marriott et al., 2021), populations of interest, and how/where FMD was conducted (Thijssen et al., 2019). Given this, along with the inconsistent findings among previous reviews (Ashor et al., 2015; Campbell et al., 2019; Early et al., 2017; Ramos et al., 2015), an overview of existing reviews and meta-analyses could provide high-level evidence into the impact of exercise on endothelial function. This may confirm that there is not a "one size fits all" approach for every population, artery, and/or exercise training intervention.

Research Question

By performing an umbrella review of existing systematic reviews and meta-analyses on the topic, we will answer the following question: What is the impact of exercise training on FMD? We will explore whether differences exist between the training characteristics, population of interest, arteries of interest, individual review inclusion/exclusion criteria, and study quality of the reviews.

Methods

Inclusion and Exclusion Criteria

Population

Only review studies examining adults (all participants' age: ≥18 years) or results presented separately for adults-only will be included. No restriction will be placed on participants' health status.

Intervention

Any exercise training intervention. No restriction in the length, type, or frequency of the exercise training was implemented. As the focus is on exercise training, reviews on the acute response to exercise (single session) will be excluded. No restriction will be placed on study design (e.g., not exclusive to reviews of randomized controlled trials only), the date of publication, or the language of publication (i.e., non-English). If needed, a language interpreter will be utilized to translate the publication to English. Conducting a meta-analysis is not a requirement of inclusion but will be extracted if presented.

Comparator

No comparator is required. Systematic reviews that examine single interventions without or with a comparator group (e.g., non-exercise controls, usual care, other exercise intervention, etc.) will be included.

Outcome

Systematic reviews that do not utilize FMD as an outcome variable will be excluded. We will include reviews regardless of the artery investigated but will explore the potential impact of artery location on FMD outcomes in response to exercise training.

Study Design

To be included, studies must conduct a systematic review and/or meta-analysis on the impact of exercise training on FMD. Studies published as editorials, opinions, non-systematic reviews (e.g., narrative review, scoping reviews, integrative reviews, rapid reviews), or conference abstracts will be excluded.

Search Strategy

The proposed review will be conducted in accordance with the JBI methodology for umbrella reviews (Aromataris et al., 2020). The search strategy was developed in conjunction with authors who have previous experience conducting exercise training interventions and the FMD technique (Bray et al., 2020; O'Brien et al., 2018, 2019, 2020). The specific search terms are presented in Appendix A along with an example search strategy developed for PubMed (MEDLINE). Database searches will be conducted from inception using Scopus (Elsevier), Embase (Elsevier), PubMed (MEDLINE), CINAHL (EBSCO), and Academic Search Premier (EBSCO) databases. PROSPERO, the JBI Systematic Review Register, and the Cochrane Database of Systemic Reviews were searched in February of 2022 to ensure no other researchers were conducting a study of a similar nature.

Study Screening Process

Following the literature search, article citations will be downloaded to an online research management system (Mendeley) and duplicates removed. Remaining references will be exported to systematic review software for screening (Covidence). The titles and abstracts of citations will be separately screened by two reviewers who will identify potential articles for inclusion. The full text of apparently relevant articles will be obtained and screened by the same two reviewers. If a consensus cannot be reached between the two reviewers regarding inclusion, a third reviewer will serve as the arbiter. The reference lists of included articles will be hand-searched for potentially relevant articles.

Study Quality Assessment

The quality of each included review will be assessed via the JBI critical appraisal tool for evaluating systematic reviews (Aromataris et al., 2015). The tool was developed by the JBI umbrella review methodology working group, and scores each question as met, not met, unclear, or not applicable (Aromataris et al., 2015). The specific 10 questions are presented in Appendix B. Identical to the article screening process, quality assessment will be independently completed by two reviewers. For inconsistencies regarding their quality assessment decisions, a senior third reviewer will be consulted to make a final decision. Reviews will not be excluded based on their quality (out of 10).

Data Extraction

For included reviews, the characteristics of the studies/participants included, as well as the exercise training characteristics, FMD protocols/measures, and meta-analysis results will be extracted. A data extraction template that includes each of the specific variables of interest is provided in Appendix C. All data extraction will be separately conducted by two reviewers using the Data Extraction option in Covidence. The data extraction tool will be piloted on three studies by two reviewers and may be modified, depending on whether additional relevant information is gained from this pilot. Any changes or additional variables extracted will be described in the dissemination of results. If required, authors will be contacted for additional information. Data may be extracted from figures using WebPlotDigitizer (V.3, 2020; Available from https://automeris.io/WebPlotDigitizer), which has demonstrated strong validity (Drevon et al., 2017). All meta-analyses outcomes may use unique effect size metrics but will be converted into a Cohen's d effect size and standardized mean differences (Fusar-Poli & Radua, 2018).

Data Analysis and Preparation

A reporting guideline is currently in development for umbrella reviews, but is not yet released (Preferred Reporting Items for Overviews of Reviews [PRIOR]; Pollock et al., 2019). If the PRIOR guideline is released before completion of the present study, it will be followed. If not, we will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement (Page et al., 2021) and the PRISMA literature search extension (PRISMA-S; Rethlefsen et al., 2021). A sensitivity analysis will be conducted on systematic reviews that exhibit higher study quality versus lower study quality (based on median split). Secondary outcomes include exploring results across exercise training principles (frequency, intensity, type, time, volume, progression), participant health status, sex, race, artery examined, unique inclusion/exclusion criteria, quality of studies included in each review, and inclusion of a meta-analysis.

Given that a 1% absolute increase in relative brachial artery FMD is associated with a ~13% relative risk reduction in experiencing an adverse cardiovascular event (Inaba et al., 2010), a 1% standardized mean difference will be considered clinically significant a priori for studies examining the brachial artery. Such thresholds do not exist for relative FMD changes in other arteries (e.g., popliteal, radial, etc.), and therefore will be based on thresholds of Cohen's d, with very small = <0.2, small = 0.2–0.5, medium = 0.5–0.8, and large = >0.8 (Cohen, 1992). Cohen's d will still be determined for brachial FMD.

The screening results will be presented visually via a PRISMA flow diagram with reasons presented for full-text exclusions. Our primary results will be presented in tables and potentially summarized using a graphic figure and/or infographic of main findings.

Potential Implications

The information gained from the umbrella review may provide insight into the optimal exercise training program for endothelial function and, consequently, into the improvement of cardiovascular health. As with all umbrella reviews, our study can only report on what researchers have systematically reviewed and/or meta-analyzed. There may be instances when a potentially impactful factor could influence results (e.g., biological sex), but if few studies have evaluated that factor, the level of evidence the umbrella review can provide on this potentially impactful variable is limited. Amalgamating systematic reviews will provide a current description of what is known regarding the impact of exercise training on endothelial function assessed using FMD, which may provide insight into future areas of investigation to advance our knowledge on therapeutic approaches to improving cardiovascular health. For example, findings may be applied to the design of community exercise programs and/or prompt changes to existing programs (e.g., cardiac rehabilitation) to enhance cardiovascular function in prevention, pre-habilitation, and rehabilitation settings.

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Appendix A

Search Strategy and Example Search Results

Search	Terms	Results
1.	"Aerobic"[All Fields] OR "Resistance"[All Fields] OR "Resistance Intervention"[All Fields] OR "Strength training"[All Fields] OR "Physical exercise"[All Fields] OR "High-intensity exercise"[All Fields] OR "Exercise training"[All Fields] OR "Aerobic training"[All Fields] OR "Physical activity training"[All Fields] OR "Yoga"[All Fields] OR "Tai-Chi"[All Fields] OR "Flexibility Training"[All Fields] OR "Balance Training"[All Fields] OR "Weightlifting"[All Fields] OR "Vigorous Exercise"[All Fields]	1,114,620
2.	("Flow-mediated dilation"[All Fields] OR "Endothelial function"[All Fields] OR "FMD"[All Fields] OR "Endothelial-dependent dilation"[All Fields] OR "Shear-mediated dilation"[All Fields]) NOT "Cerebral"[All Fields]	25,328
3.	"Review"[All Fields] OR "Meta-analysis"[All Fields]	3,779,350
4.	1 AND 2 AND 3	730

Note. The search strategy will be adapted for each database as needed. A test of this search strategy on February 2, 2022, yielded 730 results using PubMed only, indicating a reasonable number of citations to screen using this database.

Appendix B

JBI Critical Appraisal Tool for Evaluating Systematic Reviews

1.	Is the review question clearly and explicitly stated?
2.	Were the inclusion criteria appropriate for the review question?
3.	Was the search strategy appropriate?
4.	Were the sources and resources used to search for studies adequate?
5.	Were the criteria for appraising studies appropriate?
6.	Was critical appraisal conducted by two or more reviewers independently?
7.	Were the methods used to combine studies appropriate?
8.	Was the likelihood of publication bias assessed?
9.	Were recommendations for policy and/or practice supported by the reported data?
10.	Were the specific directive for new research appropriate?

Appendix C

Data Extraction Template

Variable
General Characteristics
Author Last Name & Year
Title
Country
Number of Databases Searched
Date Searched and Date Range
Number of Studies Included
Names of Each Study Included in Review
Number of Participants (Males/Females)
Population of Interest
Inclusion/Exclusion Criteria
Pre-registered Review (Yes/No)
Author Funding
Review Study General Exercise Training Characteristics
Frequency
Intensity
Type
Time
Volume
Progression
Ultrasound Measures
Artery of Interest
General Relative FMD Outcomes (if no meta-analyses)
General Absolute FMD Outcomes (if no meta-analyses)
General Normalized FMD Outcomes (if no meta-analyses)
General Baseline Diameter Outcomes (if no meta-analyses)
FMD protocol (if provided)
Study Quality Tool
Average Study Quality
Key Systematic Review Findings
Meta-Analyses
FMD Results (with units of effect size)
Normalized FMD Results (with units of effect size)
Baseline Artery Diameter Results (with units of effect size)
Comparator (e.g., control group, moderate intensity training)
Heterogeneity
Potential Biases (e.g., funnel plot)
Sensitivity Analyses

Note. FMD: flow-mediated dilation.

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Infographic

Barriers and potential solutions to mental healthcare access for youth refugees and asylum seekers

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Abstract

Globally, over 82.4 million people were forcibly displaced in 2020, about 42% (35 million) of which are children and youth. Youth, aged 15 to 24, are highly susceptible to mental health difficulties, particularly those who are refugees and asylum seekers. Serious post-traumatic stress disorder, depression, and anxiety symptoms have been seen in youth refugees and asylum seekers months after they have resettled in their host countries. Yet, they encounter numerous barriers to accessing mental health support. This infographic illustrates the preliminary findings of an integrative review conducted to determine the barriers to mental health access of youth refugees and asylum seekers as well as the potential solutions to these barriers. CINAHL, PubMed, PsycINFO, EMBASE, Web of Science, ProQuest Dissertations & Theses Global, and other relevant organizations' websites were searched for published and unpublished articles. Data from eligible articles were extracted and analyzed through thematic analysis. Findings from this review have the potential to inform future research, policy, and practice.

Barriers and Potential Solutions
to mental healthcare access for youth refugees and asylum seekers

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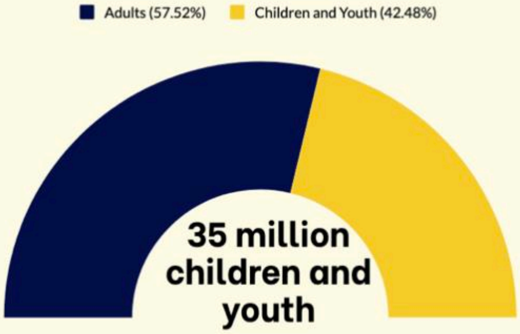
In 2021, over 84 million people worldwide
were forced to leave their homes and countries due to conflicts, human rights violations, and natural disasters



Youth refugees and asylum seekers[1]
have a higher risk of mental health difficulties

- **post-traumatic stress disorder**
- **anxiety**
- **depression**

[1] The term 'youth' is commonly defined as individuals between the age of 15 to 24 years old.
While a refugee is "someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted" and an asylum seeker is a person who is in the process of claiming refugee status
(Bersaglio et al., 2015; Kadir et al., 2019; Mohamed & Thomas, 2017; Papadopoulos & Shea, 2018; United Nations High Commissioner for Refugees, 2010, 2021)

Youth refugees and asylum seekers encounter numerous barriers to accessing mental health support

Cultural barriers

There is a variability in healthcare providers' cultural competence. Some might have not received the appropriate training.

Difficulty navigating healthcare system

All countries have diverse healthcare systems. Refugee and asylum seeker youth do not necessarily know in advance which country will be hosting them; hence, they are unable to learn the host country's healthcare system a head of time.

Language barriers

Youth generally do not speak the same language as health providers in host countries.

Stigma

Certain communities have negative beliefs towards mental health conditions, which may impede their help-seeking behaviours.

Financial costs

Services and medications are at times only partially or completely covered by public healthcare.

Discrimination

Attitudes of xenophobia[2] and racism towards refugees and asylum seekers persist, particularly during the COVID-19 pandemic.

Other resettlement stressors

Fear that seeking mental health support might have legal ramifications and affect their migration/citizenship requests.

Distrust of services

Youth might be originating from countries where their governments are dishonest, making them wary about government-funded healthcare systems.

2. Xenophobia represents the fear, hatred, or hostility towards outsiders, foreigners, or non-native born individuals within a given population (Arya et al., 2021, Baak et al., 2020; Cheng et al., 2015; Colucci et al., 2014; Kadir et al., 2019; Marshall et al., 2016; Yakushko, 2018)

Potential Solutions to access barriers

Mandatory cultural competency training

All healthcare providers and allied staff should undergo mandatory cultural competency training on an ongoing basis.

Available interpreters

Interpreters are valuable to communicating with refugees and asylum seekers who do not speak the host country's language, but providers must be cautious about confidentiality concerns.

Designated healthcare navigators

Navigators may serve as the first point of care for youth for whom they can build a therapeutic relationship with, enabling them to ask their questions concerning mental health and associated services.

Enhance mental health literacy

Courses on health, mental health, and healthcare services must be integrated into youth's school curriculum and public service announcements.

Increase funding and subsidizes

Implementation of programs that are tailored to youth refugees' and asylum seekers' financial needs and healthcare expenses.

More research and knowledge translation

Increased research on youth mental health service is required to better understand the barriers and facilitators to access.

(Arya et al., 2021; Colucci et al., 2014; Marshall et al., 2016; United Nations Network on Migration, 2022)

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