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Cover art by Pilar Robinson Gonzalez. Read more inside.

About the Cover

Cover Photo: The fall with its bright colours, fresh produce, and seasonal festivities has a documented positive impact on mental health. In addition, many take advantage of the cooler weather to enjoy walking, hiking, and other outdoor activities. Access to public wilderness spaces is therefore beneficial in maintaining both the mental and physical wellbeing of communities.

This photo was taken at Shaw Wilderness Park in Halifax, Nova Scotia, following a summer of extreme drought and bans on outdoor activities in wooded areas. This particularly difficult summer season demonstrated how vulnerable our wilderness areas are, and the support required of our communities to protect them.

During my hike through this area, I saw a diverse array of people and reflected on how the outdoors and nature is for everyone. I am appreciative to have these wild spaces available to me and my community and had missed them over the summer. I also thought about the lands and people around the country who have been impacted by drought and wildfires this year.

This cover art is dedicated to the volunteers, stewards, and advocates who maintain, monitor, and protect the public trails and lands we enjoy.

About the Artist

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About the artist: Pilar is a second-year student at Dalhousie University in the PhD in Health program. Her research is investigating ways to improve access and uptake of the HPV vaccine by Nova Scotian youth

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Welcome from the Co-Editors-in-Chief

We would like to welcome you to volume 5, issue 3 of the *Healthy Populations Journal* (HPJ), a regular issue in our student-run, open-access, peer-reviewed journal. We are pleased to continue to fill a gap in student publishing and offer high quality work from emerging academics and the scholars of tomorrow.

Cover art by Robinson Gonzalez highlights the energy and vitality that a change in seasons can bring while making connections between access to outdoor spaces and well-being, raising awareness on the connections between policy, climate change, and health. Furthering this theme is an exploration of the benefits of dog ownership for mental, physical and social health. Rhéaume-Gagnon & Rhéaume offer a commentary on how having a canine companion can reduce stress and offer tangible health benefits, including spending time outdoors. Gray et al offer an in-depth qualitative description of gaps across systems of health care for youth transitioning from pediatric to adult care concluding how policies and interventions that consider the transition between groups of services are required for optimal health outcomes and experiences receiving care. Continuing across the lifespan, MacIntyre and Numer present a narrative review that demonstrates the ability for public health interventions that go beyond individual level care can support trauma-informed palliative care for older 2SLGBTQ+ people.

A systematic review protocol by Elugbadebo et al. aims at understanding the needs of people with frontotemporal dementia in low- and middle-income countries with an aim of advance knowledge, improving health care outcomes, and promoting equity surrounding access to quality health care for this group. Adapting systematic review methodology to answer hard to get at questions around equity in knowledge mobilization Tse et al. present a protocol for a bibliometric analysis. The aim is examine how terminology in the field of knowledge mobilization is applied, cited, and connected across disciplines, geographies, authors, and journals while producing accessible visual data that highlights patterns related to equity- and/or sovereignty-deserving communities.

HPJ would not be possible without support from the Healthy Populations Institute and the teamwork and guidance from the Editorial Board. Financial support from the Faculties of Health, Medicine, and Dentistry is a testament to Dalhousie's support for student initiatives that we acknowledge and appreciate.

We truly hope you enjoy reading volume 5, issue 3.

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Commentary

The Benefits of Dog Ownership for Mental, Physical, and Social Health

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Abstract

Dog ownership is common in Canada, with approximately 33% of Canadians living with a canine companion. A growing body of scientific evidence suggests that dogs may support human health and well-being across multiple domains. Research has associated dog companionship with improvements in mental, physical, and social health, highlighting a potential role in public health promotion. Mentally, interaction with dogs has been linked to reduced stress and cortisol levels and increased serotonin and dopamine, which may alleviate symptoms of depression, anxiety, and social isolation. Physically, walking and playing with dogs are associated with enhanced cardiovascular health, weight management, and mobility, while also enhancing sleep quality. Socially, dogs serve as social facilitators, fostering social interaction and community engagement. This commentary examines the health benefits of dog companionship through a lifestyle medicine lens. For individuals, it highlights how daily interaction with dogs, whether through ownership or alternative forms of engagement, may support mental, physical, and social well-being. For health care providers, it offers evidence-based insights to guide recommendations around dog-assisted interventions within holistic health strategies. Finally, for public health professionals and policy-makers, it advocates for broader recognition of these benefits in health promotion strategies and recommends inclusive, dog-centred community programs that extend these positive effects beyond ownership alone.

Keywords: dog, mental health, physical health, social health

Introduction

Did you know that 33% of Canadians own a dog? (NielsenIQ, 2016). Dogs and other pets hold a significant place in human life and well-being, serving as more than just companions. Numerous studies have highlighted the positive impact pets, particularly dogs, have on our mental (Purewal et al., 2017), physical (Westgarth et al., 2014), and social health (Carr et al., 2021; Gee et al., 2021). Dogs and other pets can significantly improve cardiovascular health, reduce stress levels, and enhance social interactions (Corliss, 2022). The companionship of a dog not only provides emotional support but also fosters community connections and friendships, enriching our social lives. Additionally, owning a dog encourages regular physical activity, which is a key determinant of health and quality of life, as well as being indicated for the prevention and treatment of various diseases (Cutt et al., 2007). This commentary offers a novel contribution by integrating these known benefits of dog ownership within the framework of lifestyle medicine, an evidence-based approach emphasizing healthy behaviour for preventing and managing chronic diseases (Lianov & Johnson, 2010). We highlight how dog ownership supports stress management, physical activity, and social connection, aligning with the six pillars of lifestyle medicine (Lippman et al., 2024). Importantly, we introduce the concept of a reciprocal, health-promoting relationship between dogs and humans, emphasizing that dogs benefit from healthy, engaged care while enhancing human well-being (Verbeek et al., 2024). Recognizing that dog ownership is not feasible for everyone, we suggest inclusive alternatives, such as community programs and animal-assisted intervention. This commentary aims to provide actionable, evidence-based insights for health care providers and public health leaders, supporting the integration of dog-assisted strategies into clinical practice and community health initiatives

Mental Health Benefits

Owning a dog can significantly enhance mental health by reducing stress levels, as the presence of a dog lowers cortisol and boosts serotonin and dopamine, promoting feelings of well-being (Brooks et al., 2018). This is crucial because high cortisol levels over time are linked to increased cancer risk (Kiecolt-Glaser et al., 2002). Dogs also provide companionship and emotional support, helping to alleviate loneliness and depression (Health benefits of pets, 2024). Therapy dogs are particularly effective in supporting individuals with anxiety, PTSD, and other mental health issues. For instance, a study by Beetz et al. (2012) investigated whether children with insecure-avoidant or disorganized attachment patterns benefit more from the presence of a therapy dog than from a friendly adult or toy during a stressful task. Among 47 boys aged seven to 11 undergoing the Trier Social Stress Test for Children, those in the dog-assisted group showed significantly lower salivary cortisol levels, especially during the recovery period. The findings suggest that therapy dogs provide uniquely effective emotional support for stress regulation, particularly in vulnerable children, reinforcing the value of animal-assisted interventions in educational and therapeutic settings. These benefits are further supported by research from McConnell et al. (2011), who conducted three studies showing that pet owners experienced higher self-esteem, more physical activity, and greater well-being. The researchers found that pets helped fulfill social needs in a way that complemented, rather than replaced, human relationships, and even buffered against the negative effects of social rejection. This suggests that pets, especially dogs, can serve as powerful sources of social support, offering important psychological benefits for individuals dealing with loneliness, social anxiety, or stress-related conditions (McConnell et al., 2011). A study by Matijczak et al. (2024) found that participants who spent time with their dogs after a stressful task experienced increased happiness and reduced anxiety compared to those who did not. The research suggests that interacting with one's pet can serve as an effective strategy to alleviate stress and enhance emotional well-being during challenging situations (Palmer, 2024).

A mixed-methods study of 1,693 adult dog-owners from the United Kingdom (Merkouri et al., 2022) highlights how deep bonds with dogs are associated with enhanced mental well-being and happiness, offering both hedonic and eudaimonic benefits like emotional support during tough times and a renewed sense of purpose. However, the delightful companionship of a dog also brings challenges, as owners may face burdens of responsibility and would benefit from guidance in caring for their dogs and managing problematic behaviors (Merkouri et al., 2022).

Physical Health Benefits

Dogs also promote physical health by encouraging daily exercise through walks, hikes, and playtime, which benefits cardiovascular health, aids in weight management, and improves mobility (Mubanga et al., 2017). For those with cardiovascular diseases, diabetes, or hypertension, low-impact activities such as walking are especially beneficial (Lee et al., 2021; Moghetti et al., 2020). The Canadian Society for Exercise Physiology (CSEP) recommends that adults aged 18–64 years engage in at least 150 minutes of moderate-intensity aerobic physical activity per week (CSEP, n.d.). This activity can be accumulated in bouts of at least 10 minutes and can include brisk walking, cycling, or recreational sports. Achieving this level of activity is associated with reduced risk of heart disease, stroke, type 2 diabetes, and certain cancers, as well as improved mental health and physical function (Warburton et al., 2006). Conversely, insufficient physical activity is linked to increased risk of chronic disease, reduced mobility, and earlier mortality (Lee et al., 2012). Notably, dog ownership provides a sustainable and enjoyable way for adults and potentially children and older adults to integrate activity into daily life (Christian et al., 2013). A scientific statement by Levine et al. (2013) for the American Heart Association found that dog owners were more likely to meet recommended physical activity levels compared to non-owners, which is associated with lower blood pressure and reduced risk of heart disease.

Early exposure to dogs during infancy can strengthen the human immune system and significantly lower the risk of developing allergies and asthma later in life (Ownby et al., 2002). While exposure to dogs can exacerbate asthma symptoms in sensitized individuals, especially those already diagnosed with asthma or severe allergies (Gergen et al., 2018), there is evidence suggesting that controlled and gradual exposure combined with appropriate management strategies, such as improved hygiene practices (e.g., regular dog washing; Hodson et al., 1999), use of air filters and air cleaners (Sublett, 2011), limiting exposure to allergens like dander and in some cases allergen immunotherapy, can help mitigate these risks and may even promote desensitization over time (Chan & Leung, 2018). This is particularly relevant, as it can be emotionally challenging for pet owners to consider separating from their dogs when new or worsening respiratory symptoms emerge. Ultimately, while risks exist, they can often be managed effectively, and the physical, mental, and social health benefits of dog ownership may outweigh these potential drawbacks, especially when tailored intervention and shared decision-making are applied.

As a further benefit, dogs can improve sleep quality by providing a sense of security, leading to more restful and uninterrupted sleep (Patel et al., 2017). This observational study found that people who slept with their dogs in the same room, but not on the bed, often experienced higher sleep efficiency and better overall sleep quality due to the calming presence of their pets. However, allowing the dog to sleep on the bed was associated with reduced sleep efficiency (Patel et al., 2017).

Social Health Benefits

Owning a dog not only enhances mental and physical health but also profoundly impacts social well-being. Dogs act as social catalysts, facilitating interactions between people and fostering a sense of community and belonging (McNicholas & Collis, 2000). Dog owners often find themselves engaging with other pet owners during walks, at dog parks, or in pet-friendly establishments, leading to the formation of new friendships and social networks. A study conducted across four cities in the U.S. and Australia found that pet ownership, especially dog ownership, was significantly associated with higher levels of social capital (Wood et al., 2015, 2017). Dog owners were more likely to meet and connect with people in their neighborhood compared to non-owners and were more likely to trust others and participate in community activities, indicating that dogs can strengthen community bonds (Wood et al., 2017). Beyond community engagement, companion animals can help improve social connection by providing a common topic of conversation and a sense of companionship in social settings, and the presence of a dog can make individuals feel more comfortable and less self-conscious, facilitating smoother social interactions (Wood et al., 2015). Dogs can act as social buffers, reducing feelings of anxiety and stress in social situations (Janssens et al., 2021). Additionally, owning a dog encourages people to be more active in their communities, participating in local events, pet-related activities, and community groups. This increased engagement can foster a sense of belonging and community spirit, as highlighted by Friedmann et al., (2010) who conducted a study examining the role of pet ownership in community engagement. Their research revealed that dog owners reported higher levels of community involvement and satisfaction, attributing this to increased social interactions and feelings of connectedness fostered by regular interactions with other dog owners during walks and neighbourhood activities. The social connections formed through dog ownership can extend into supportive networks that provide emotional and practical assistance, whether through dog walking groups, pet-sitting exchanges, or online communities. Additionally, interacting with other dog owners and the broader community can help strengthen social connection skills and enhance social well-being (Potter et al., 2019). The routine nature of dog walks and park visits provides regular opportunities for positive social interaction, which may be particularly beneficial for older adults or individuals experiencing social isolation. A study by McConnell et al. (2011) investigated the psychological and physical benefits of pet ownership among everyday individuals. Through three studies, the researchers found that pet owners exhibited higher self-esteem, greater physical fitness, and more conscientiousness compared to non-owners. Pets were also shown to fulfill important social needs, complementing human relationships. Notably, thinking about one's pet helped alleviate negative emotions during experiences of social rejection, similar to the comfort provided by thinking about a close friend. These findings suggest that pets can serve as valuable sources of social support, enhancing overall well-being. Pet owners also often exhibit greater empathy and social skills, attributed to their interactions facilitated by their pets (McConnell et al., 2011).

As a further social benefit, dogs can strengthen family bonds by encouraging shared activities such as walking, playing, and caring for the pet, which promotes co-operation, communication, and a sense of responsibility among family members (Rodriges, 2023; Wanser et al., 2020). This helps families connect and spend quality time together, thereby strengthening their relationships. Lastly, dogs can bridge social gaps by bringing together people of diverse backgrounds and demographics who might not otherwise interact. This inclusivity fosters a more diverse and accepting community environment. A review of human-animal interaction research found that pet ownership can facilitate engagement with new people and strengthen community bonds, supporting more inclusive connections across different social groups (McCune et al., 2014). In summary, owning a dog can significantly enhance social health by increasing social interactions, reducing social anxiety, enhancing community engagement, and improving social skills. These benefits extend beyond the individual owner, positively impacting families and communities. Dog ownership fosters social bonds that can lead to a more connected, supportive, and inclusive society. This highlights the integral role dogs play in promoting social well-being.

Mutual Reinforcement and Lifestyle Medicine

Dog ownership not only nurtures mental, physical, and social well-being but also exemplifies the principles of lifestyle medicine. The stress reduction, regular physical activity, and social activities associated with caring for a dog align with the principles of lifestyle medicine's emphasis on healthy behaviours for disease prevention and optimal well-being.

This relationship is reciprocal: both dog and owner encourage each other to maintain a healthier, more active lifestyle, creating a powerful mutual reinforcement that promotes vitality and longevity for both. Recent evidence supports this perspective: a pilot study by Smedberg et al. (2024) demonstrated that eight-week joint outdoor exercise programs for dog owners and their dogs significantly improved the owners' self-reported quality of life and body image acceptance, while also reducing dogs' body condition scores. This highlights the potential of shared physical activity to foster positive health outcomes for both humans and animals, reinforcing the principles of lifestyle medicine and emphasizing the importance of the human-animal bond.

Addressing Barriers and Challenges: Inclusive Alternatives and Support for Dog Owners

While dog ownership can be highly beneficial, it may not be accessible to everyone. Barriers such as housing restrictions, long work hours, financial limitations, allergies, physical or cognitive impairments, or lack of caregiver support can make pet ownership impractical or impossible for some individuals (Applebaum et al., 2020). These challenges can disproportionately affect marginalized groups, including older adults, low-income individuals, and people with disabilities, thereby limiting their access to the benefits of pet companionship (Obradović et al., 2021).

To address these barriers, innovative public health initiatives and community programs focus on promoting interaction with dogs without requiring ownership. Programs like animal-assisted therapy and volunteer-based initiatives provide emotional support, social engagement, and opportunities for physical activity (Wood et al, 2017). For example, community-based programs such as animal-assisted therapy visits in long-term care facilities and community centres demonstrate benefits for mental health and social connection without requiring ownership (Cherniack & Cherniack, 2014).

One notable example in Canada is ElderDog Canada, a national, volunteer-based organization dedicated to supporting older adults in caring for their dogs. Through a network of volunteers, ElderDog assists with dog walking, transportation to veterinary appointments, and temporary dog care during hospitalizations (ElderDog Canada, n.d.). This model not only helps seniors maintain their bond with their pets but also reduces social isolation and prevents pet rehoming. By addressing barriers like limited mobility and financial constraints, ElderDog represents an innovative, equitable approach to fostering well-being through human-animal interaction.

It is important to recognize that not all owners may experience the same benefits equally. Some individuals may face challenges such as the stress of caregiving responsibilities, financial costs, potential health risks like allergies or zoonotic diseases, and even emotional distress if the pet becomes ill or passes away. These challenges can disproportionately affect owners with limited resources or support networks, potentially diminishing the overall benefits of dog ownership.

However, these potential drawbacks can be mitigated through supportive community initiatives, educational resources on responsible pet care, and improved access to veterinary and behavioural services. For instance, community-based programs such as the St. John Ambulance

Therapy Dog Program (St. John Ambulance, n.d.) and Therapeutic Paws of Canada (Therapeutic Paws of Canada, n.d.) offer not only animal-assisted therapy for the broader community but also support and resources for dog owners themselves, helping them manage caregiving challenges.

Conclusion

This commentary highlights the significant impact of dog ownership on mental, physical, and social well-being. Importantly, these benefits align with the core pillars of lifestyle medicine, which emphasize healthy behaviours such as stress management, regular physical activity, and positive social connection to prevent and manage chronic diseases and enhance quality of life.

From a mental health perspective, dogs provide invaluable support by reducing stress, alleviating feelings of loneliness, and promoting emotional resilience. Their presence has been linked to increased levels of serotonin and dopamine, contributing to a more positive outlook on life. Physically, dogs encourage an active lifestyle through regular walks and playtime, improving cardiovascular health and aiding in weight management. Moreover, dogs act as social catalysts for connections, bringing people together in parks, in neighbourhoods, and through online platforms, as well as fostering supportive networks that enrich lives and combat feelings of isolation. The presence of dogs in our communities promotes inclusivity and strengthens social bonds, highlighting their unique role in enhancing social well-being.

We also introduce the concept of a reciprocal, health-promoting relationship between dogs and humans, underscoring the mutual benefits of this bond. However, we recognize that not everyone may experience benefits equally. Barriers such as housing restrictions, financial constraints, or physical and cognitive limitations can limit access to dog companionship. To address these challenges, we propose that inclusive alternatives, such as community-based programs and animal-assisted interventions, can provide opportunities for interaction with dogs without requiring ownership, ensuring that more people can access these benefits.

By integrating the known benefits of dog ownership within the framework of lifestyle medicine and highlighting both individual and public health perspectives, this commentary offers a more comprehensive view of how the human-animal bond can promote overall health and well-being. Recognizing and embracing these benefits can lead to a deeper appreciation of our canine companions and their meaningful influence on our daily lives and community health.

Conflict of Interest

The authors declare no potential conflicts of interest for the research, authorship or publication of this article.

Declaration of Ethics

Not applicable. This is a commentary article and does not involve any new studies with human participants or animals.

Author Contributions

ARG wrote the first draft of the manuscript. CR reviewed and revised the manuscript. Both authors approve the final version.

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HEALTHY POPULATIONS JOURNAL

Research Article

Youth and Caregiver Perspectives of Barriers and Facilitators to the Transition From Pediatric to Adult Care: A Qualitative Descriptive Study

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Abstract

Background: Transitions from pediatric to adult care can be a complex process for youth and their caregivers. Exploring barriers and facilitators to transitions from pediatric to adult care is critical to inform the design and implementation of evidence-based interventions to improve transition processes. Previous literature has focused on describing experiences with transition; however, determinants influencing transitions need further exploration. **Objective:** This study explored barriers and facilitators to the transition from pediatric to adult care from youth and caregiver perspectives to inform future intervention design, implementation, and evaluation to support transitions in care. **Methods:** This study used a qualitative descriptive design guided by the COM-B Model of Behaviour. Youth and caregivers of youth in Nova Scotia, Canada, were recruited for semi-structured interviews. Data analysis consisted of directed content analysis, followed by inductive thematic analysis to identify barriers and facilitators of transitioning from pediatric to adult care. **Results:** A total of nine youth and nine caregivers participated in the semi-structured interviews. We identified barriers and facilitators related to the COM-B Model of Behaviour's components of capability, opportunity, and motivation. Main themes from both the youth and caregiver participants relate to developing health literacy for transition processes, shifting roles to increase youth independence, and the importance of health system coordination. **Conclusion:** This project identified intersecting behavioural and contextual determinants related to youth and caregivers' capability, opportunity, and motivation that influence the transition of care process. These findings will be instrumental for designing and adapting interventions and policies to improve youth transitions from pediatric to adult care.

Keywords: behaviour change, transitions in care, pediatric, qualitative research

Introduction

Transitions from pediatric care into the adult care system for youth with complex health care needs is a common yet challenging process (Fegran et al., 2014). This transition for youth who are also experiencing complex health and social care needs often occurs at a pivotal time in their lives. Readiness to transition from a pediatric system to an adult system is individualized and influenced by many factors, including differences between adult and pediatric care models (Hislop et al., 2016). Youth often find shifting from family-centred to patient-centred care challenging due to the increased autonomy that is required in this setting (Li et al., 2024; Toulany et al., 2022). Caregivers (i.e., parents or guardians of youth) are also impacted by the transition from pediatric to adult care. Caregivers have expressed emotions such as grief, sadness, and desperation during the transition period (Edelstein et al., 2017; Ludvigsen et al., 2021; MacNeill et al., 2022; Rafferty & Sullivan, 2017). They often feel their children are transitioning into adult care based on age rather than level of maturity or preparedness, which leaves them feeling reluctant to engage in the transition process (Bratt et al., 2018).

Many barriers are known to hinder transitions in care (Gray et al., 2018; Varty et al., 2020). Interventions are needed to address these known barriers and support transitions from pediatric to adult care. Guidance from the Medical Research Council and National Institute for Health and Care Excellence suggests that interventions are more likely to be effective if conceptual theoretical models are used in the intervention development (National Institute for Health and Care Excellence, 2007; Skivington et al., 2021). For instance, the Behaviour Change Wheel is a systematic, theory-based guide to intervention design based on the principles of the COM-B Model of Behaviour (Michie et al., 2014). This model suggests that for any behaviour to occur there must be a change in one or more of the following: capacity, opportunity, and/or motivation. Michie et al. (2014) describes capacity as physical or psychological ability, opportunity as physical and social factors, and motivation as automatic and reflective processes that influence behaviour. The Behaviour Change Wheel has been used extensively to guide the design of interventions in health services (Craig et al., 2008; Michie et al., 2014).

To date, there has been limited theory-informed analysis of determinants influencing transitions from pediatric to adult care from youth and caregiver perspectives. To ensure successful development and implementation of transition interventions, a pre-implementation assessment of barriers and facilitators is an important first step (Grol & Grimshaw, 2003). The purpose of this study was to identify barriers and facilitators to youth's transition from pediatric to adult care services, from the perspective of youth and caregivers, to inform future intervention design, implementation, and evaluation.

Methods

Design

This study used a qualitative descriptive design involving semi-structured interviews and focus groups to identify youth and caregivers' perspectives on barriers and facilitators to the transition from pediatric to adult care (Lambert & Lambert, 2012). This current study accompanies a previous phase of the research that identified barriers and facilitators to the transition from pediatric to adult care from the perspective of adult and pediatric health care providers (Cassidy et al., 2022).

Setting

This study was conducted in Nova Scotia, Canada, which is home to one tertiary pediatric health centre (hereinafter referred to as the "pediatric health institution") that serves youth from three Maritime provinces. All adult services are under a separate health authority that serves the rest of the province (hereinafter referred to as the "adult health institution").

Integrated Knowledge Translation Approach

This project employed an integrated knowledge translation approach by engaging knowledge users as team members on the research project. Our knowledge users included administrators and health care provider representatives from the pediatric and adult health institutions and the provincial health department, as well as two patient partners who have lived experience transitioning from the pediatric to adult health institution. These team members were involved in different phases of the research process based on interest and capacity, including development of research questions, interview guide development, recruitment, data collection, data analysis, interpretation of findings, knowledge translation planning, and general project management. Further, the co-lead of the research team, JP, is the coordinator for the Transition of Care Committee (TOCC) based at the pediatric health institution. This committee includes youth, caregivers, health care providers, and community partners who have experience or interest in transition and transfer of care processes. Knowledge exchange meetings were held bi-monthly with the TOCC to facilitate two-way dialogue and feedback on different parts of the research project, including interview guide development, recruitment ideas, analysis of study findings, and knowledge translation planning. These meetings were co-facilitated by the two patient partners of the research team.

Theoretical Framework

This study used the Behaviour Change Wheel's COM-B Model of Behaviour to guide our barriers and facilitators assessment (Michie et al., 2014). As described above, the COM-B Model of Behaviour suggests that for a behaviour to occur, there must be a change in a person's capability, opportunity, and/or motivation. This theory-informed approach supports an exploration of all potential determinants of youths' and caregivers' capability, opportunity, and motivation related to transitions from pediatric to adult care (Michie et al., 2014). This model informed the study's interview questions and provided a framework for data analysis.

Participants

Participants were recruited using a stratified purposive sampling strategy with convenience sampling techniques (Palinkas et al., 2015; Teddlie & Yu, 2007). Pediatric patients were eligible to participate if they had experience with a transition in the past three years with one of three conditions of focus: inflammatory bowel disease, diabetes, or juvenile idiopathic arthritis. Caregivers were eligible to participate if they had a child who had gone through transition with one of the three conditions of focus. Youth and caregivers were also eligible if they were currently in the process of going through transition. We aimed to recruit six to 10 participants per focus group, with a goal of completing two youth focus groups and two caregiver focus groups, as outlined by Wilkinson's recommendations for conducting focus groups to uncover rich data for health-related phenomena of interest (Wilkinson, 1998). We applied Guest et al.'s (2006) qualitative sampling criteria (i.e., clarity of data, alignment with research question, variations and contraindications of data) to determine if additional interviews were needed following data analysis.

Materials

We developed a semi-structured interview guide (see Supplemental Materials) based on previous guides sourced from the literature that focused on examining transitions from pediatric to adult care (Grande et al., 2019; Newlove-Delgado et al., 2019; Ödling et al., 2020). The guides were organized based on the COM-B Model of Behaviour, and included questions regarding the participants' capability, opportunity, and motivation around transitioning from pediatric to adult care, as well as additional prompts if clarification of questions was needed (Michie et al., 2014). A draft interview guide was reviewed by seven youths and two caregivers, all of whom are members of the TOCC based at the pediatric health institution, to ensure questions were relevant and terminology was clear. The guides were refined and edited based on their feedback.

Procedure

Care team members from the ambulatory clinics who see patients with inflammatory bowel disease, diabetes, and juvenile idiopathic arthritis identified potential patients and caregivers who met the parameters of inclusion. A care team member provided a letter of information to potential participants containing contact information for the Research Assistant. Additionally, local organizations such as the Crohn's & Colitis Foundation, Arthritis Society Canada, Diabetes Care Program of Nova Scotia, and Brigadoon Village disseminated recruitment posters.

The Research Assistant met with all participants prior to data collection to review consent forms and obtain informed consent. If a participant was unavailable to attend the focus group time, we offered an option to participate in an individual interview. All participants who expressed interest agreed to participate. Consent forms were reviewed again at the beginning of the focus groups and interviews. Each focus group was facilitated by four members of the research team: the principal investigator (Author CEC), who has been trained in using the COM-B Model to conduct behavioural analyses and design interventions; the knowledge translation coordinator (Author JCK), also trained in the COM-B Model; and two knowledge user research partners (Author JP, health system partner; Author AH, youth patient partner). All focus groups and interviews were conducted via Zoom and audio-recorded using Zoom recording features. Focus groups and interviews lasted approximately 45–60 minutes.

Data Analysis

Each focus group and interview was audio-recorded and transcribed verbatim, with all information de-identified. As a pilot, four reviewers (CEC, JCK, RD, AM) reviewed two transcripts (two reviewers each) using Microsoft Word version 15. For each transcript, the primary reviewer used directed content analysis (Hsieh & Shannon, 2005) and a colour coding system to code similar statements into the three COM-B categories (Michie et al., 2014), while the second reviewer used the comment box to point out any discrepancies. Once the four reviewers had independently reviewed the two transcripts, a meeting was held with all reviewers to go through the two transcripts and come to a consensus on any discrepancies identified. Next, preliminary subthemes within the initial coding scheme of the COM-B Model (Michie et al., 2014) were identified using codebook thematic analysis

(Braun & Clarke, 2022). A codebook was developed based on the COM-B categories and affiliated subthemes, consisting of the following: code name, brief definition, full definition, when to use, when not to use, and an example (MacQueen et al., 1998). After development, all research team members reviewed the codebook, provided feedback, and adapted the codebook accordingly.

All transcripts were imported and coded in NVivo Qualitative Software version 12 (https://lumivero.com/products/nvivo/) by two reviewers (CEC, JCK) using the finalized codebook. From there, both reviewers worked together to further inductively examine the coded data to identify barriers and facilitators to the transition from pediatric to adult care. Next, a final list of themes and summaries was developed and reviewed by the research team. The initial findings were presented to the TOCC at the pediatric health institution, and theme refinement was conducted based on their feedback. Finally, to help with the interpretation of the study findings, we conducted a facilitated discussion with the TOCC and asked members what findings were most surprising and what findings were most helpful. Findings are presented in tabular and narrative format with quotes from youth and caregivers using pseudonyms.

Results

A total of 18 participants (youth *n*=9 and caregivers *n*=9) took part in this study. Youth and caregiver participants were independent of one another. Youth participants' ages ranged from 17 to 21 years. Most youth identified as female (*n*=8) and are currently in the transition process (*n*=5). Most caregiver participants identified as female (*n*=7) and as having youth currently undergoing the transition process (*n*=8).

The findings highlight barriers and facilitators to the transition in care from the pediatric to adult system from the perspective of both youth and caregivers. As described in the section to follow, we identified a range of barriers and facilitators across each of the COM-B components: capability (C), opportunity (O), and motivation (M) for youth, followed by caregivers (see Figure 1).

Youth Findings

Youth participants identified a range of barriers and facilitators regarding transitioning from pediatric to adult care including developing health literacy to support the transition process, readiness for independence, and health system coordination (Figure 1 and Table 1). These themes are further broken down into subthemes and categorized based on the COM-B components. Each subtheme will be described below.

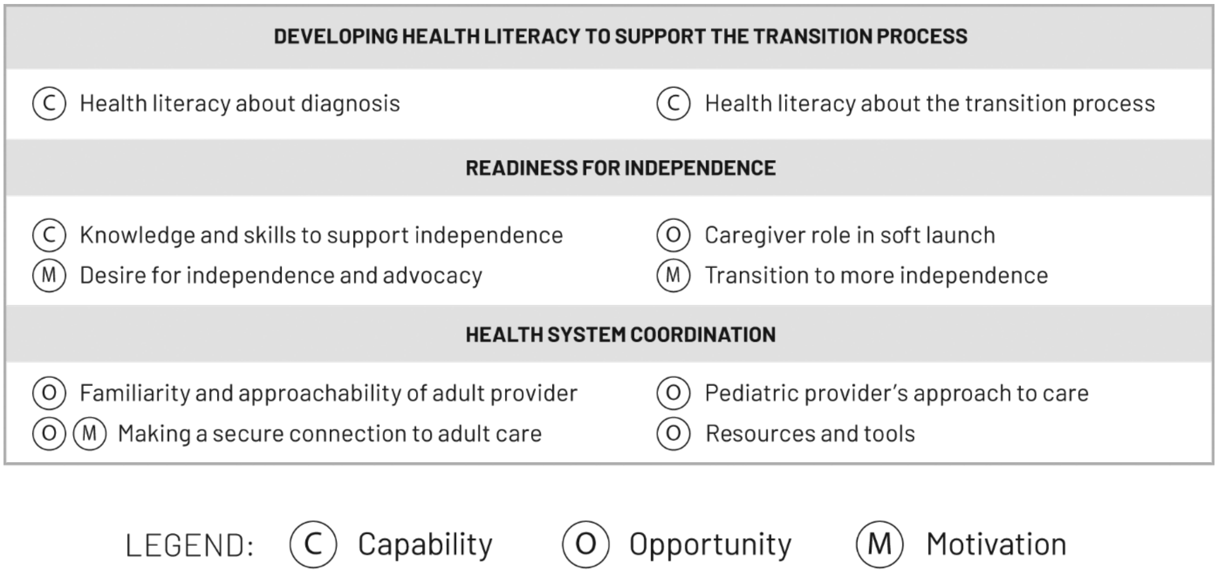
Developing Health Literacy to Support the Transition Process

Youth described needing knowledge related to their health and transition process to facilitate a successful transition. The first subtheme, **health literacy about diagnosis** (a capability), included developing their knowledge on finding, understanding, and using information related to their diagnosis and treatment. The second subtheme, **health literacy about the transition process** (a capability), included developing a specific set of knowledge and skills on finding, understanding, and using information related to their transition process.

Readiness for Independence

Support from caregivers and health care providers helped youth to build their readiness to be independent in their own health care management over time. The first subtheme, **knowledge and skills to support independence** (a capability), was described by participants as the need to learn specific knowledge and skills that would help them be independent in their care and health management.

Figure 1



DEVELOPING HEALTH LITERACY TO SUPPORT THE TRANSITION PROCESS	
Ⓒ Health literacy about diagnosis	Ⓒ Health literacy about the transition process
READINESS FOR INDEPENDENCE	
Ⓒ Knowledge and skills to support independence	Ⓞ Caregiver role in soft launch
Ⓜ Desire for independence and advocacy	Ⓜ Transition to more independence
HEALTH SYSTEM COORDINATION	
Ⓞ Familiarity and approachability of adult provider	Ⓞ Pediatric provider's approach to care
Ⓞ Ⓜ Making a secure connection to adult care	Ⓞ Resources and tools

LEGEND: Ⓒ Capability Ⓞ Opportunity Ⓜ Motivation

The second subtheme, **caregiver role in soft launch** (an opportunity), relates to youth participants highlighting the pivotal role that their caregivers play in their transition. Caregivers facilitated the transition process when they incrementally prepared their child for transition over a period of time. They described this as a "soft launch" that included transferring the responsibility of certain tasks to youth. Some participants described the opposite effect of parents who did not provide this preparation, describing more of a last-minute push right before the transfer point that did not prepare the youth for transition.

The third subtheme, **desire for independence and advocacy** (a motivation), was described by youth as an interest in managing their care; they were motivated by wanting to become more independent.

The final subtheme, **transition to more independence** (a motivation), is what youth described as a parallel transition process that occurs alongside the transition from pediatric to adult care. Youth are simultaneously transitioning away from full dependence upon their parents/caregivers, described as "being babied," to starting to gain independence and advocating for themselves and their own care. It does not appear to be a linear transition, as youth move back and forth between these stages in their growth.

Health System Coordination

For youth, ideal health system coordination of the transition experience is a fluid process involving positive relationships with both pediatric and adult health care providers. The first subtheme, **familiarity and approachability of adult provider** (an opportunity), describes how several youth participants had the opportunity to meet their adult care provider before they were transferred from pediatric care provider at transition clinics (clinics where pediatric and adult providers meet together with youth to discuss transfer). Pre-transfer meetings were a critical facilitator to a positive transition, as it helped youth become comfortable with adult care providers.

The second subtheme, **pediatric provider's approach to care** (an opportunity), relates to the youth's experience with the pediatric provider's approach to transition, which can be a facilitator or barrier to transition. Participants noted that pediatric providers hinder the transition process when they talk about adult care in a negative light. This can create anxiety and fear of what is to come. Contrarily, pediatric providers can be key facilitators and supporters of transition when they consider it to be a continuum of care and ensure successful attachment after the transfer point.

The third subtheme is **making a secure connection to adult care** (an opportunity and motivation). Youth described a successful transition to be a seamless, fluid process where key players from both pediatric and adult care systems are involved. One participant used the analogy of tracking a package to ensure the youth is sent, tracked to ensure they reached adult care, and then followed-up with to ensure they were received.

The final subtheme relates to **resources and tools** (an opportunity) to support the transition process. Youth participants described a variety of different tools they have used to support the transition process, including written documents and digital applications. Others described potential tools that would facilitate the process, the majority of which focused on virtual methods to document transition-related information.

Table 1

Youth Perspectives on Barriers and Facilitators to the Transition from Pediatric to Adult Care

Themes	Sub Themes	Quotes
Developing Health Literacy to Support the Transition Process	Health literacy about diagnosis (C)	"I could tell immediately that the level of education, the level of insight that I was supposed to have regarding my own care, and specifically the continuation of care, right, not just the acute setting, but the chronic nature of it, you know, all of those became very apparent to me like personally at the age of 15 when I was first introduced to the adult health care system."—Isabella, Youth Participant
	Health literacy about the transition process (C)	
Readiness for Independence	Knowledge and skills to support independence (C)	"I wanted to be way more independent, way more adult. In the rheumatology clinic, they actually like taught me how to do my own like medication injections. So that was like actually a good thing that I got out of it." —Anthony, Youth Participant
	Caregiver role in soft launch (O)	"It was kind of one day he was just like hands off. And looking back, I wish it would have been more of like a soft launch, kind of, instead of just, lighting it all on fire… But ideally it would be like a soft launch, they're there to support you if you are having like troubles with it. And not like hard shoving you, like 'figure it out on your own, idiot,' kind of thing." —Kaheela, Youth Participant

Themes	Sub Themes	Quotes
	Desire for independence and advocacy (M)	“I was going to add that like I find personally that was one good thing about adult care, is I felt like I was listened to a lot more often. Like the things I was saying was taken a bit more seriously. Because I feel like obviously with pediatric care, kids just say things to say things. But like whenever I was saying something, I was like saying it to be taken seriously. And it wasn’t. So that's why I feel like I actually like adult care a bit more.”—Isabella, Youth Participant
	Transition to more independence (M)	“It was really quite sudden. Like I didn’t expect that to happen. And I was quite… We kind of had a good thing going there at the [pediatric health institution], and then it was like all of a sudden, here you go, you’re out in the world on your own, and you have to just figure this out.” —Jade, Youth Participant
Health System Coordination	Familiarity and approachability of adult provider (O)	“But in like a real world, if this could happen, meet the doctors, meet my nurse, and know their faces and be comfortable around them. And then they will warn me of like what I should be responsible with. And then we could make a plan of what’s going to happen when I see them. But I mean I know I’m an adult, and it would kind of be like last minute, but I just like structure.”—Kaheela, Youth Participant
	Pediatric provider’s approach to care (O)	“You know what I mean? Like that was like everyone was like, ‘Oh, stay in pediatrics as long as you can because adult care sucks,’ kind of thing. And that needs to like go out the window because there was definitely stress that came just because everyone made it such a big deal. And it wasn’t as big of a deal as everyone made it out to be… My doctors when I was at pediatric [were saying it]. It was like you know when you’re in high school, and they’re like, ‘Your profs in university won’t care,’ it was like that.

Themes	Sub Themes	Quotes
		Like the same idea. I remember that." —Ben, Youth Participant
	Making a secure connection to adult care (O, M)	"But the second part of what would make a good transition, I look at it as if somebody was sending off a package, they checked to see if the package landed and the people receiving it had received their package, and it was all good. It was landed, it was in the right hands, and it was everything was okay."—Aya, Youth Participant
	Resources and tools (O)	"I really wish there was a checklist. Because, yeah, that would be very helpful… I think like leading up to that transition, there should be a checklist to make sure like you have all the information you need, you know how to do this or that or… Yeah, just to make sure that you're ready."—Hana, Youth Participant

Note. C = Capability, O = Opportunity, M = Motivation

Caregiver Findings

Caregiver participants identified a range of barriers and facilitators regarding their youth transitioning from pediatric to adult care including their supporting role in their youth's health literacy, changing responsibilities and supporting greater independence, and health system coordination (Figure 2 and Table 2). These themes are further broken down into subthemes and categorized based on the COM-B components. Each subtheme will be described below.

Supporting Role in Youth's Health Literacy

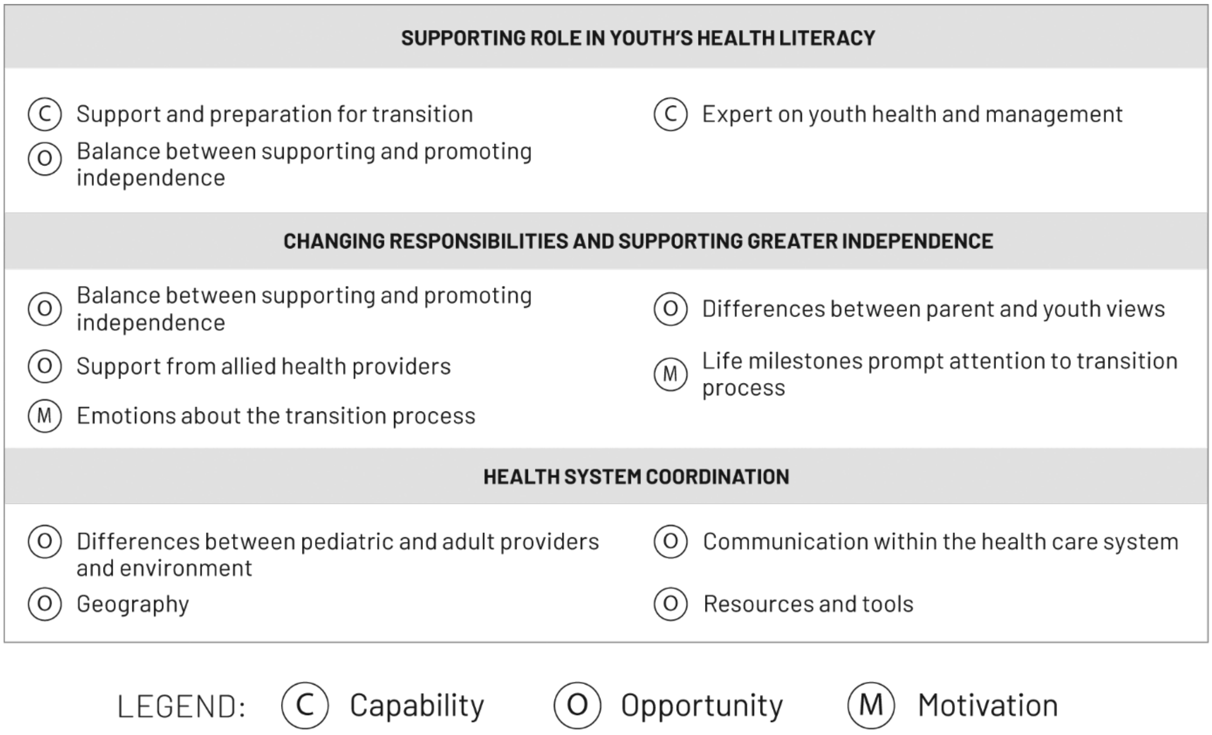
Caregivers helped facilitate the development of youth health literacy by preparing their children for transition through support and education. The first subtheme, support and preparation for transition (a capability), relates to the learnings and teachings facilitated by caregivers to prepare youth for transition at an early age. Early preparation and slow progression to begin transition was identified as a facilitator to supporting a successful transition.

The second subtheme, expert on youth health and management (a capability), is described as the knowledge caregivers possess of what has occurred throughout the history of their child's condition, from symptom onset and diagnosis and throughout their health history. Caregivers often helped with medical management of care such as helping to pick up prescriptions, scheduling meetings, or getting other material items.

The final subtheme, balance between supporting and promoting independence (a capability), relates to caregivers navigating the question of how to provide enough space for promoting independence and self-management while remaining a consistent support throughout transition. Caregivers expressed that they are constantly navigating the shifting balance of power between their youth and themselves.

Figure 2

Caregiver Perspectives on Barriers and Facilitators to the Transition From Pediatric to Adult Care



SUPPORTING ROLE IN YOUTH'S HEALTH LITERACY

- Ⓒ Support and preparation for transition
- Ⓞ Balance between supporting and promoting independence
- Ⓒ Expert on youth health and management

CHANGING RESPONSIBILITIES AND SUPPORTING GREATER INDEPENDENCE

- Ⓞ Balance between supporting and promoting independence
- Ⓞ Support from allied health providers
- Ⓜ Emotions about the transition process
- Ⓞ Differences between parent and youth views
- Ⓜ Life milestones prompt attention to transition process

HEALTH SYSTEM COORDINATION

- Ⓞ Differences between pediatric and adult providers and environment
- Ⓞ Geography
- Ⓞ Communication within the health care system
- Ⓞ Resources and tools

LEGEND: Ⓒ Capability Ⓞ Opportunity Ⓜ Motivation

Changing Responsibilities and Supporting Greater Independence

Caregivers described a shift of responsibilities to respond to changes in youths' needs for both independence and support. The first subtheme, balance between supporting and promoting independence (an opportunity), relates to the relational aspects of finding balance.

The second subtheme is related to the differences between parent and youth views (an opportunity). Some caregivers reported differing views on managing the health condition and transition and the need for compromise on the approach to care planning to support youth's needs.

The third subtheme, support from allied health providers (an opportunity), relates to how caregivers described allied health care providers, such as occupational therapists, physiotherapists, social workers, and psychologists as facilitators for youth in transition. Participants noted barriers to transition when allied health care providers were not part of adult care teams moving forward.

The fourth subtheme, life milestones prompt attention to transition process (a motivation), was described as a facilitator because overlapping milestone moments can prompt parents to become aware of the upcoming transition in care. Caregivers described these moments as birthdays, graduation, or the transition to post-secondary education/employment/programming.

The fifth subtheme, emotions about the transition process (a motivation), relates to the wide range of emotions that caregivers experience during the process of transition. Caregivers worry about their child being their own advocate and being able to communicate for themselves, and they also fear the unknown in the adult system regarding coordination and treatment. Contrarily, caregivers shared that they experienced a positive outlook for their children when there was a good relationship with the health care provider and experience with the adult health care system.

Health system Coordination

Caregivers described a range of barriers and facilitators related to health system coordination, which are reported here with four subthemes.

First, caregivers reported **differences between pediatric and adult providers and environment** (an opportunity) related to wait times, communication, and scheduling. Caregivers shared their experiences with the lack of follow-up in the adult system, and the lack of a key contact person. Participants attributed this to potential differences in priorities between adult and pediatric health care systems.

The second subtheme, **communication within the health care system** (an opportunity), relates to the communication styles and approaches used by the health system throughout the transition period. Caregivers shared that there was often a lack of communication between the different areas of the health system. The pediatric and the adult care systems communicated in different ways, which proved to be a barrier in navigating the transition process. According to caregivers, in the pediatric system there was intentional coordination embedded in conversations among different care providers, but the same was not seen among adult care services.

The third subtheme, **geography** (an opportunity), relates to the accessibility of the health care system. Caregivers described barriers to accessing services in rural settings, especially when systems do not communicate with one another (e.g., emergency care and primary care). Caregivers expressed significant challenges when seeking care for their child in adult settings, as they did not have access to their health care documents because the electronic health records are not integrated across the province or different health care settings.

The final subtheme focused on the **resources and tools** (an opportunity) caregivers had to support the transition process. Caregivers shared their preference for resources that were readily available and promoted in pediatric settings. Further, caregivers shared how technology and mobile apps are advancing and helping with self-management and medical care for their children.

Table 2

Caregiver Perspectives on Barriers and Facilitators to the Transition From Pediatric to Adult Care

Themes	Sub Themes	Quotes
Supporting Role in Youth's Health Literacy	Support and preparation for transition (C)	"But they are trying to make the child more independent, I think, too, and take control of the disease. And so it's good. But I think it's important to recognize that, too, that as a parent, you have to do that. But the child, too. You know, you have to teach the child to transition to be an adult, basically, I guess."—Lina, Caregiver Participant
	Expert on youth health and management (C)	"… in some ways I think from my experience, I'm more in tune. I know the diabetic terms and technology more than he does. So I'm thinking, well, when [son] transitions, is he going to transition and get an

Themes	Sub Themes	Quotes
		endocrinologist, or is he going to end up with a GP who may not have the knowledge and expertise that, you know, he needs? And that kind of is in the back of my mind."—Monica, Caregiver Participant "I still order the supplies and all that stuff. And it's like in my head, my plan is he's got to start transitioning, you know, to learn that, too." —Wendy, Caregiver Participant
	Balance between supporting and promoting independence (O)	"I mean that's hard because it's hard as parents to let go of that involvement as well. Not that you're not still involved when they're young adults, but you have to coach them and support them in a different way. So I think it was important for both of us that she had those opportunities, that we both felt confident, right. It really helped with her confidence. And she can… She is quite good at navigating and speaking for herself, I will say." —Andrew, Caregiver Participant
Changing Responsibilities and Supporting Greater Independence	Balance between supporting and promoting independence (O)	"I wanted to show him that we're there to support him, but also give him the right level of independence. So it's right from the get-go and this challenge of what does that look like when an 11-year-old really wants to kind of be independent in a lot of ways, and suddenly he couldn't be. So, yeah, right away." – Wendy, Caregiver Participant
	Differences between parent and youth views (O)	"…Supporting patient goals, I would say that was one of the other key things with our experience at the [pediatric health institution]. Was that many times… It clearly sometimes wasn't my goal. What

Themes	Sub Themes	Quotes
		was important was that they supported [daughter]'s goals, right, in a way that, you know, she always felt supported, that her goals were first and foremost of what everybody was working towards, right…" — Vera, Caregiver Participant
	Support from allied health providers (O)	"So tying it all together for him, the psychology team was crucial. And he still reaches out and wants to talk to them sometimes even about just other social things as well, maybe not even pertaining to his disease." – Nissa, Caregiver Participant
	Life milestones prompt attention to transition process (M)	"So then all of a sudden he started applying for universities and started getting a few acceptance letters, and trying to figure all that out. And then it was like, oh, wait a minute, he's not only going off to university, but now he's also going off to not the [pediatric health institution]. So what is that going to look like? How is that going to work out?" —Mona, Caregiver Participant
	Emotions about the transition process (M)	"So they have started at the last appointment kind of talking to her about that. And she is very independent, but she has some learning disabilities as well. So I do worry about her managing her appointments, and talking to doctors on her own, and those kinds of things. That part worries me." —Nissa, Caregiver Participant
Health System Coordination	Differences between pediatric and adult providers and environment (O)	"One of the biggest, I think, differences is that in the pediatric care, there is such regular follow-up. That adult health care is typically much more issue-related. You get seen for issues. As opposed to pediatrics, there's just this

Themes	Sub Themes	Quotes
		continuous system of contact with your pediatric care providers…" —Joan, Caregiver Participant
	Communication within the health care system (O)	"And it's like to me that kind of made him a little more independent at his appointment because he was in front of the screen and I was in the other room kind of just listening. And he went through it with his endocrinologist. And it's like, wow, cool, like he did well. And I think, you know, in a way it's like the Zoom and this… If there's a positive thing to COVID, it was that." —Lina, Caregiver Participant
	Geography (O)	"And, you know, with us being an hour out of the [city centre], too, the systems don't talk. So we go into emerg or we go into outpatients or we go somewhere else, even the family doctor, they can't look up the same things as easy." —Malika, Caregiver Participant
	Resources and tools (O)	"It's the team at the [pediatric institution] tends to pick up on when other resources are required or could be useful. You know, like psychology or pain clinics or just those other specialty services in general. And we don't have to source them so much on our own. They're almost just there and being provided as needed." —Monica, Caregiver Participant

Discussion

This study identified barriers and facilitators to the transition from pediatric to adult care from the perspectives of youth and caregivers using the COM-B Model of Behaviour (Michie et al., 2014). This study contributes to a growing body of evidence on transitions of care by providing important insights into the behavioural and contextual aspects of transition from the youth and caregiver perspective. Our analysis highlights important determinants related to youth and caregiver capability, opportunity, and motivation that future interventions and programs should target.

Capability

Youth and caregiver participants identified the need for specific knowledge and skills related to managing their health and navigating the transition process. Similar findings are highlighted in the literature. Gray and colleagues' (2018) systematic review identified knowledge as a common cited barrier in the transition process. Previous studies have designed, implemented, and evaluated youth transition programs aimed at improving health literacy to support transition (Huang et al., 2007; Melita et al., 2019; Varty et al., 2020). For example, Melita and colleagues (2019) introduced a program based on cognitive behavioural techniques and reported improved transition outcomes, including increased self-management skills. However, many of these interventions lack caregiver involvement (Melita et al., 2019). Participants in our study highlighted that caregivers have the expertise in their youth's health care throughout pediatric care and need to transfer that expertise to their youth during the transition to adult care. Future design of transition educational interventions should consider caregiver involvement alongside youth to (a) facilitate sharing of caregivers' expertise and (b) develop programs tailored specifically to caregivers' knowledge needs.

Opportunity

Previous research supports the involvement of caregivers in the transition process (Gray et al., 2018; Jivanjee et al., 2009; Varty et al., 2020). Caregivers provide a wealth of knowledge and support for youth, acting as an essential resource to support youth in a successful transition (Bratt et al., 2018; Varty et al., 2020). Before the transition begins, caregivers are often managing the youth's care (Bratt et al., 2018). During the transition, the caregiver's role evolves into that of a facilitator. By ensuring continued involvement throughout this process, caregivers support successful transition (Bratt et al., 2018). This should include their role in a "soft launch" that recognizes milestones to initiate the transition process early.

Relationships among youth, caregivers, and health care providers were identified as a critical barrier and/or facilitator to the transition process. Youth have often built trusting and well-established relationships with their pediatric care providers, leading to hesitancy in transitioning to comparatively unknown adult care (Mbalinda et al., 2020). Youth participants in our study illustrated how easy it can be for providers to influence the transition experience with their approach, both positively and negatively. Supporting transitions of care is a trust-building exercise; our findings reiterate previous research on the need for providers to earn trust among youth and caregivers to support the transition process (Bollegala & Nguyen, 2015).

Our previous qualitative study on health care providers' experiences with the transition from pediatric to adult care also identified relationship building as a key facilitator to the transition process (Cassidy et al., 2022). This relationship shift can be challenging, especially if youth and caregiver views are not aligned. Moving forward, providers may benefit from understanding the different emotions involved for both youth and caregiver, helping families to understand these natural points of conflict and helping caregivers focus on their broader goals for their youth's transition into adulthood. Further, providers should continue to collaborate with caregivers with stronger understanding of the shifting role of the caregiver to a facilitator during the transition process. Supporting this shift in responsibility may help caregivers empower youth to engage in conversations about their health care.

Motivation

Our study findings highlight the interconnections between social opportunity- and motivation-related barriers and facilitators. Many youth participants described a desire to manage their own care; they were motivated and wanted to become more independent. Previous studies have shown that youth are motivated by the desire for independence and moving away from having an "outsider" feeling as adolescents in a pediatric care setting (Varty et al., 2020). Much of the literature describes the transition from pediatric to adult care in a negative, challenging context (Fegran et al., 2014; Tuchman et al., 2008; Varty et al., 2020). Similarly, our youth participants described difficult conversations they had with providers and caregivers. However, they also highlighted the excitement and positive aspects of transition; these tap into youth's motivation, including optimism and beliefs about the future. Some research has found that youth report the transition from pediatric to adult care services to be a natural next step in their care: Youth may be apprehensive but also excited for transition and the prospect of becoming more independent decision-makers in their own care (Varty et al., 2020). This is a significant and unexpected shift from caregivers' and health care providers' traditional perspective of the transition process being clouded in negative feelings of anxiety, fear, and youth's uncertainty and lack of preparation (Varty et al., 2020). Incorporating the youth's perspective is important to showcase excitement that comes along with transitions. A culture shift is needed to transform our thinking of transition and design new interventions to support youth to leverage the positive and exciting elements of the process that come with taking those next steps in their health care journey.

Implications

This study has important implications for designing, implementing, and evaluating interventions to support the transition from pediatric to adult care. We used the COM-B Model of Behaviour to explore factors influencing transitions from pediatric to adult care from the perspective of youth and caregivers. By describing barriers and facilitators in behavioural and contextual terms, this theory-informed approach will inform the design of tailored interventions (Michie et al., 2014). Future research may continue to use the Behaviour Change Wheel to help with the design of new interventions to support transition of care that tap into the capability-, opportunity-, and motivation-related barriers and facilitators described in this study.

This study's focus on identifying barriers and facilitators to transition in care that could inform effective intervention design will be valuable for youth, caregivers, health care providers, and organizations aimed at improving the transition from pediatric to adult care. In our local context, the Transition of Care Committee (TOCC) identified this research as a significant priority for their work. They were a close research partner in our integrated knowledge translation approach, and the goals and objectives of the research project align well with the committee's mandate, as they are responsible for informing practice and guiding program development to support the transition from pediatric to adult care. The TOCC can use these findings to ensure transition interventions address the identified barriers and leverage the facilitators to transition of care. Similar transition groups or health care providers may find similar utility in the study findings to guide their practice and to design programs or interventions that address barriers and leverage facilitators in their local context.

This work also illustrates important implications for researchers and transition-of-care evaluation research. To date, the focus has been on youth health, knowledge and self-efficacy outcomes (e.g., A1C laboratory testing, self-efficacy, self-management), and health system resource use outcomes (e.g., emergency department visits, paramedic use, and hospitalization records; Mackie et al., 2014; Sequeira et al., 2015). Recent knowledge synthesis efforts have identified patient-centred quality indicators for the transition from pediatric to adult care, including education, continuity of care, satisfaction, and self-management (Bailey et al., 2022). Given our unexpected findings on youth's motivation for transitioning to adult care, there is an opportunity to expand on these patient-centred outcomes and identify motivation-based indicators. Future evaluation research should start to measure these patient-reported experience outcomes alongside more traditional health system outcomes.

Limitations

study findings should be considered with the following limitations. This sample included participants from similar demographic characteristics, including gender and race. Thus, our findings may not be representative and transferable to many youth and caregivers experiencing transitions from pediatric to adult care. This study would have benefitted from a more explicit health equity lens in the research team composition and study design, including recruitment, data collection, and data analysis methods, to provide a more diverse perspective on youth and caregiver experiences with transitioning from pediatric to adult care. Our study describes barriers and facilitators to the transition of care from pediatric to adult care; however, it could be strengthened with a subsequent study aimed at understanding the impact of health equity on the transition of care process and outcomes. This could include tailored recruitment efforts to a diverse sample of participants that is more representative of our local community, interview guide questions and probes that use an intersectionality-enhanced behaviour change framework, and a health equity framework for analysis (Etherington et al., 2020).

Conclusion

This qualitative descriptive study identified barriers and facilitators to support the transition from pediatric to adult care from the perspective of youth and caregivers. We used the COM-B Model of Behaviour to guide our data collection and analysis methods and identified intersecting behavioural and contextual determinants related to youth and caregivers' capability, opportunity, and motivation that influence the transition of care process. Moving forward, transition-in-care interventions should be multi-component and tailored to (a) support youth and caregivers' preparation for the transition process, (b) leverage the relational influences among youth and caregivers to facilitate the transition process, and (c) address the barriers to system-level coordination to ensure a secure attachment of youth in the adult care system. Overall, these findings contribute to a growing body of literature that can be used to guide transition-in-care intervention design, implementation, evaluation, and sustainability while improving outcomes for youth, caregivers, health care providers, and the health system as a whole.

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Conflict of Interest

Authors state no conflict of interest.

Declaration of Ethics

The authors received ethics approval from the IWK Health and Nova Scotia Health Research Ethics Boards (Approval #1026111).

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HEALTHY POPULATIONS JOURNAL

Research Article

Non-Clinical Interventions to Reduce Inequities in Palliative Care for 2SLGBTQ+ People: A Narrative Review

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Abstract

Introduction: People who identify as Two-Spirit, lesbian, gay, bisexual, transgender, and/or queer (2SLGBTQ+) experience health disparities across the lifespan, including at end of life. Recently there has been recognition of the value of health promotion approaches to palliative care that address the social and structural determinants of a good death. Current reviews on 2SLGBTQ+ palliative care are primarily framed through a clinical, patient-provider level lens. **Purpose:** To understand how implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people are described in the literature. **Methods:** A narrative review was conducted adhering to a systematic procedure. Six relevant databases were searched, and 1,547 records were screened by two independent reviewers. To be eligible for inclusion, studies had to describe one or more implemented and evaluated non-clinical intervention that addressed at least one inequity or barrier to palliative care for 2SLGBTQ+ people. Charted data was analyzed using inductive content analysis. The socio-ecological model (SEM) was used to critically examine findings. **Results:** Six studies were included for review. Examples of non-clinical interventions across various settings and multiple socio-ecological levels were noted. We identified four overarching themes to describe how non-clinical interventions reduce inequities in palliative care for 2SLGBTQ+ people. **Conclusion:** This review revealed gaps in interventions at organizational, community, and public policy levels. Future research should map efforts specific to the Canadian context and empower 2SLGBTQ+ communities to evaluate and report on the interventions they lead. A trauma-informed intersectional approach should be used in the design of interventions with and for 2SLGBTQ+ community members.

Keywords: 2SLGBTQ+, palliative care, end-of-life care, interventions, inequities

Introduction

People who identify as Two-Spirit, lesbian, gay, bisexual, transgender, and/or queer, plus others who identify with sexual and gender diversity (2SLGBTQ+), experience health disparities across the lifespan, including at the end of life. Minority stress negatively impacts 2SLGBTQ+ people's health, life expectancy, and health-risk behaviours (Hajek et al., 2023; Lick et al., 2013; Meyer, 2003). Minority stressors range from distal experiences such as discrimination to proximal experiences such as concealing identity or internalizing and anticipating stigma (Meyer, 2003). Each 2SLGBTQ+ population experiences distinct and layered forms of minority stress. Additionally, 2SLGBTQ+ populations face a greater risk for certain advanced cancers as well as other serious health conditions. A review by Quinn et al. (2015) identified seven cancer sites that may disproportionately affect 2SLGBTQ+ populations, including anal, colorectal, lung, breast, cervical, endometrial, and prostate cancers. 2SLGBTQ+ people experience significant barriers to cancer screening (Haviland et al., 2021). As such, many do not receive timely intervention and are more likely to be diagnosed with advanced illness (Quinn et al., 2015). In addition to cancer, alcohol and tobacco use (Schuler et al., 2018) and risk of cardiovascular disease (Caceres et al., 2022) are also higher among 2SLGBTQ+ people. For example, older sexual minority women are more likely to have arthritis, asthma, a heart attack, a stroke, multiple chronic conditions, and poor general health compared to the general population (Fredriksen-Goldsen et al., 2017). More than ever, given an aging population and disproportionate health risk, 2SLGBTQ+ people need access to quality palliative care (Javier, 2021; Stinchcombe et al., 2017; Wilson et al., 2021).

Palliative care is a type of care that maintains the dignity and quality of life of people with life-limiting illnesses by relieving physical, psychological, social, and spiritual suffering (World Health Organization [WHO], 2020). The WHO estimates that each year 56.8 million people globally need palliative care. 2SLGBTQ+ people access palliative care services late or not at all because of anticipated or actual discrimination (Haviland et al., 2021; Maingi et al., 2018; van Klinken & van Leeuwenhoek, 2023). Recent reviews on palliative care highlight 2SLGBTQ+ people's concerns around identity disclosure, legal protections, discrimination or mistreatment from providers, insufficient provider knowledge, and respect for chosen families (Haviland et al., 2021; Maingi et al., 2018). Many 2SLGBTQ+ people, particularly transgender and gender diverse people, are not confident they will be treated with dignity and respect as they lose their autonomy and functional independence at end of life (Rosa et al., 2023). 2SLGBTQ+ people's willingness to disclose their identity or access palliative care is further threatened as they are targets of rhetoric, violence, and policies from the "anti-gender movement" (Tunney, 2024). There remains an imbalance between 2SLGBTQ+ people's disproportionate need for palliative care and the complex array of barriers to palliative care they face.

Numerous recommendations have been published on how to improve palliative care for 2SLGBTQ+ people (e.g., Cloyes et al., 2018; Javier, 2021; Maingi et al., 2018; van Klinken & van Leeuwenhoek, 2023). These recommendations largely stem from clinical domains like oncology nursing (Cloyes et al., 2018; van Klinken & van Leeuwenhoek, 2023), palliative medicine (Lintott et al., 2022), or geriatric medicine (Stinchcombe et al., 2017). There appear to be no reviews on the implementation of recommendations in practice, except for one review by Robinson and Matamoros (2024) with findings restricted to interventions applied at the patient-provider level. There is a need to examine measured outcomes and impacts of interventions to understand whether and how they affect inequities in palliative care for 2SLGBTQ+ people (Cloyes & Candrian, 2021; Robinson & Matamoros, 2024). Creating meaningful and sustainable improvements in palliative care requires confronting the role of organizational, community, and policy dimensions in generating and maintaining disparities.

The value of health promotion approaches to palliative care that address social and structural determinants of a good death have been increasingly recognized since the seminal work of Allan Kellehear in 1999 (Kellehear, 2020; Sirianni, 2020). A good death occurs when individuals are enabled to die the way they want to, which requires the right care and support systems (Krikorian et al., 2020). Palliative care has been criticized for being too embedded in the mainstream health care system and for isolating serious illness, death, and dying as personal problems (Kellehear, 1999; Rosenberg & Yates, 2010; Sawyer et al., 2021). Health-promoting palliative care de-professionalizes palliative care, promoting it as a collective duty across sectors and communities (Kellehear, 1999). This has been recognized as a model that "promotes optimal health even in the presence of incurable disease" (Rosenberg & Yates, 2010, p. 206). Health promotion approaches have been named as a promising solution for issues of access, cost, and equity in palliative care (Sirianni, 2020).

Health promotion approaches to palliative care represent a category of non-clinical interventions that extend beyond patient-provider encounters to reduce inequities in care (Chen et al., 2018). These interventions could include cultural humility training, online tools, or a health care bill of rights (Canadian Virtual Hospice, n.d.; Maingi et al., 2015; Rhoten et al., 2022). While improvement in the clinical delivery of palliative care to 2SLGBTQ+ patients is critical, it is necessary to examine available non-clinical interventions to ensure access to a good death for all 2SLGBTQ+ people facing life-limiting illness. The purpose of our narrative review is to understand what is known in existing literature about implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people.

Methods

We conducted a narrative review to answer the following question: How does the literature describe implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people? Three objectives were outlined to address the research question: (a) to explore what and how non-clinical interventions reduce inequities in palliative care for 2SLGBTQ+ people, (b) to critically examine implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people through a socio-ecological lens, and (c) to identify gaps in the existing literature as it relates to non-clinical interventions regarding palliative care for 2SLGBTQ+ people.

Given the emerging state of the literature on palliative care for 2SLGBTQ+ people, a narrative review is most suitable for this research. This review method was chosen to establish an overview of the literature on palliative care for 2SLGBTQ+ people. Narrative review methodology is useful for comprehensive appraisal of previously published studies and current knowledge gaps (Ferrari, 2015). Narrative reviews allow researchers to present a rich summary of what is known on a topic, along with interpretation and critique (Greenhalgh et al., 2018). The quality and rigour of narrative reviews may be enhanced by borrowing from elements of systematic review methodologies designed to reduce bias in study selection (Ferrari, 2015).

Search Strategy

We completed systematic searches of the following databases in June 2024: PubMed, Embase, Sociological Abstracts, Academic Search Premier, Gender Studies Database, and CINAHL. We consulted a health science librarian to develop the search strategy and examined the concept map used by Robinson and Matamoros (2024) in their review. Keywords and synonyms (Table 1) were searched using AND/OR operators. The unique search strategies for each database can be found in Appendix A. Reference lists of selected articles were scanned to identify additional studies.

Table 1

Keywords and Synonyms for Search Strategy

Population: "2SLGBTQ+ people"	Key Concept: "Palliative care"
LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*'	'End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill'

Inclusion and Exclusion Criteria

There was no restriction on publication date, country, or population age. Only studies in English were included, due to time and resource constraints that prohibited access to translation. Published full-text journal articles were considered for inclusion if they described one or more implemented and evaluated non-clinical intervention that addressed at least one inequity or barrier to palliative care or a related subdomain (e.g., hospice or end-of-life care) for 2SLGBTQ+ people. We defined "non-clinical intervention" as any intervention that does not focus on an individual health care provider and patient encounter in the clinical environment (Chen et al., 2018). Health promotion approaches and initiatives were considered within the scope of "non-clinical interventions."

Study Selection

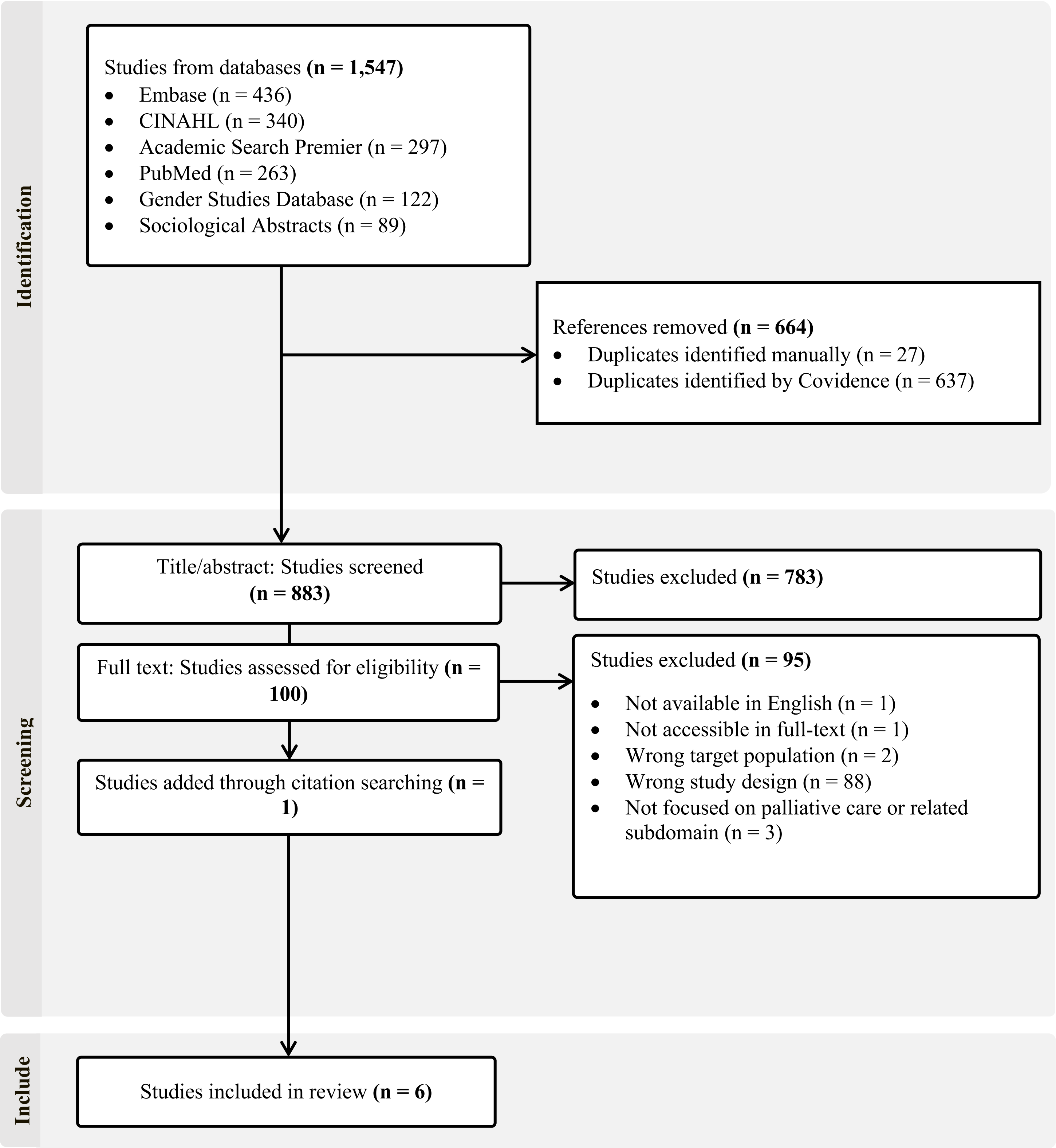
Our search strategy identified 1,547 records. We imported all records into Covidence (https://www.covidence.org/), where 637 duplicates were removed automatically and 27 were removed manually. Clear inclusion and exclusion criteria were developed (Appendix B). Titles and abstracts were screened independently by two reviewers against the inclusion/exclusion criteria. One hundred records were included for full-text review by two independent reviewers. Five studies were deemed eligible for inclusion in the review, and one additional study was identified through citation searching. A flow chart of the study selection process for this study is outlined in Figure 1.

Data Extraction and Synthesis

A comprehensive data charting form was developed by the research team to extract information relevant to the research question. Author, publication year, country of study, study population, study design, data collection method(s), study objective(s), intervention description, type of intervention, location/setting of intervention, target 2SLGBTQ+ population(s), inequities/barriers targeted, and key findings were charted in Microsoft Excel. Author GM extracted all data independently. We used descriptive statistics to describe study characteristics, and we used inductive content analysis (ICA) to thematically analyze the data. ICA has been identified as a method of qualitative content analysis well-suited for health-related research, particularly when the aim is to provide an answer relevant to policy or practice (Vears & Gillam, 2022). ICA involves five inductive stages in which qualitative text content is iteratively coded into categories or sub-categories (Vears & Gillam, 2022). After becoming familiar with the studies through reading and charting data, GM highlighted terms in the Microsoft Excel chart relevant to the research question. Highlighted terms were used to generate codes. Codes were then analyzed and organized into broad categories and sub-categories. Herein these categories are referred to as themes. Themes were debriefed with Author MN.

Figure 1

Flow Chart of Study Selection Process



In accordance with Vears and Gillam (2022), a theoretical framework was used to aid in the interpretation of the themes. McLeroy et al.'s (1988) socio-ecological model (SEM) includes intrapersonal, interpersonal, organizational, community, and public policy levels. The SEM is used in health promotion to emphasize how effective interventions must move beyond individually oriented behaviour change (McLeroy et al., 1988; Stokols, 1996). The SEM provided a strong framework for us to critically examine findings and identify gaps in the literature.

Results

Study Characteristics

We identified six studies in the final review. Publication dates ranged from 2013 to 2022. Two studies were conducted in Canada, and the other four were conducted in Ireland, Nepal, the United Kingdom, and the United States, respectively. Most studies used mixed methods and conducted questionnaires (n=5; 83%) and semi-structured interviews or focus groups (n=4; 66%). Two studies (33%) had a quasi-experimental design with pre-post-test evaluation. Table 2 outlines the types of interventions and target populations reported in the studies. While all (n=6) interventions aimed to impact palliative care for adults, two (33%) were tailored to older adults, and one (16%) was tailored to young men of colour who have sex with men living with HIV. The interventions evaluated in the studies include interdisciplinary provider training sessions (n=3; 50%); a volunteer community-based network of 2SLGBTQ+ older adults (n=1; 16%); a care and support centre (n=1; 16%); and a web-based platform for LGBT older adults (n=1; 16%). Half (n=3; 50%) of the interventions targeted multidisciplinary providers and the other half (n=3; 50%) targeted sexual and gender minorities. An overview of the characteristics of the six studies can be found in Appendix C.

Table 2

Overview of Types of Interventions and Target Populations

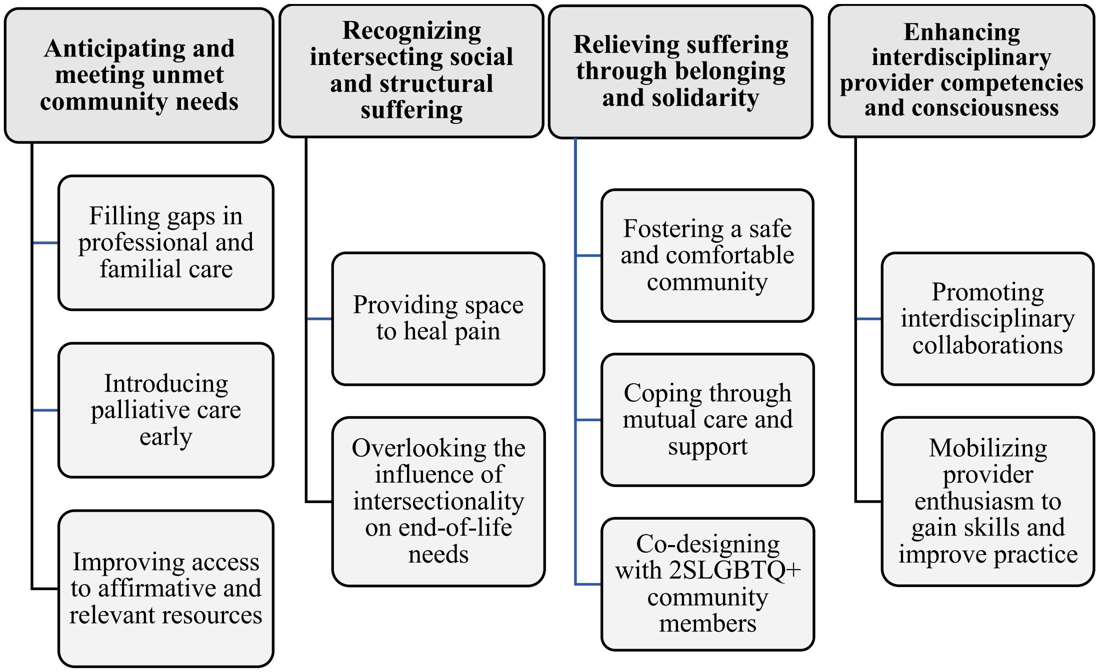
Author(s), Publication year	**Type of Intervention**	**Target Population**
Alexander et al., (2021)	Training on the early use of the palliative approach to care. All staff received 4-hour quarterly in-service workshops over 18 months, and a sub-group received 1–2-hour training sessions over a 5-month period	Multidisciplinary providers at HIV outpatient clinics
Baskaran & Hauser, (2022)	Palliative care and support centre organized by a non-profit organization.	LGBTQI+ people with terminal or chronic illnesses
Beringer et al., (2017)	Web-based platform including resource inventory on end-of-life care and planning	LGBT older adults
Chidiac et al., (2021)	1.5-hour one-time training session	Multidisciplinary providers at four hospices
Grassau et al., (2021)	Volunteer community-based network focused on promoting affirming and safe care and community connection	LGBTQ2S+ older adults and allies

Author(s), Publication year	Type of Intervention	Target Population
Reygan & D'Alton, (2013)	50-minute one-time training session	Multidisciplinary providers at two hospitals and two hospices

Through ICA, several themes and sub-themes were revealed. These themes reflect gaps in the existing literature and explore what and how non-clinical interventions reduce inequities in palliative care for 2SLGBTQ+ people. The four main themes include (a) anticipating and meeting unmet community needs, (b) recognizing intersecting social and structural suffering, (c) relieving suffering through belonging and solidarity, and (d) enhancing interdisciplinary provider competencies and consciousness. Figure 2 outlines the themes and sub-themes.

Figure 2

Themes and Sub-themes



Theme 1: Anticipating and Meeting Unmet Community Needs

The first theme pertains to how non-clinical interventions are developed in response to unmet 2SLGBTQ+ community needs.

Filling Gaps in Professional and Familial Care

It was evident in our review that non-clinical interventions fill gaps in practical, social, and emotional support generated from relying on the health care system and families of origin to meet the needs of 2SLGBTQ+ people with life-limiting illness. Baskaran and Hauser (2022) described how, in the care-and-support centre they evaluated, oftentimes family would be absent for patients' final moments, requiring staff to fill the void of caregiving and emotional support. While loneliness and alienation from support can be exacerbated at the end of life, Grassau et al. (2021) reported simultaneous experiences of "families of choice" stepping forward to provide informal caregiving. In 2SLGBTQ+ communities, the term "chosen family" is used to describe family-like groups of close friends, as opposed to legal or biological family members, who serve as essential social supports (Weston, 1991). Grassau et al. (2021) warn that informal caregiving should not be relied on to compensate for the failure of the health care system to care for people of non-cisgender or non-heterosexual identities.

Introducing Palliative Care Early

Multiple (n=4) of the interventions in our review involved either providing early access to palliative care (Alexander et al., 2021; Baskaran & Hauser, 2022) or introducing the concept of palliative care early on in the face of life-limiting illness (Beringer et al., 2017; Grassau et al., 2021). Alexander et al. (2021) found that 2SLGBTQ+ palliative care training enabled interdisciplinary staff to integrate palliative approaches into chronic disease management for young men of colour who have sex with men living with HIV. The palliative care centre in Baskaran and Hauser's (2022) study supported 2SLGBTQ+ people living with terminal and chronic illnesses, including predominantly those with HIV/AIDS. Beringer et al. (2017) and Grassau et al. (2021) reported on how workshops, film nights, panel discussions, or web-based platforms can encourage 2SLGBTQ+ older adults to engage in end-of-life planning and spark proactive conversations about end-of-life and aging.

Improving Access to Affirmative and Relevant Resources

Some (n=2) of the interventions in our review enabled 2SLGBTQ+ people to access information, booklets, posters, and videos that mirrored their identities and needs (Baskaran & Hauser, 2022; Beringer et al., 2017). For example, on the web-based platform evaluated by Beringer et al. (2017), videos were posted on topics like going back into the closet (i.e., concealing 2SLGBTQ+ identity) at the end of life. Beringer et al. (2017) found that an online inventory can be useful for 2SLGBTQ+ people to be confident accessing end-of-life planning and care resources that have been screened for genuine 2SLGBTQ+ friendliness. In the community network evaluated by Grassau et al. (2021), older 2SLGBTQ+ adults accessed resources for themselves and volunteered in long-term care, home care, community services, and seniors' centres to deliver sessions on frailty, chronic illness, and end of life for 2SLGBTQ+ people.

Theme 2: Recognizing Intersecting Social and Structural Suffering

This theme underscores the importance of recognizing intersecting social and structural causes of suffering as symptoms that should be attended to for 2SLGBTQ+ people with life-limiting illness.

Providing Space to Heal Pain

Many (n=3) studies described ways in which the non-clinical intervention attended to the impact of past and present trauma on suffering at end of life (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). Grassau et al. (2021) reported that a trauma-informed intervention allows 2SLGBTQ+ people to work through the effects of past trauma—like abuse, the HIV pandemic, and rejection from family of origin—on their current state of illness. Baskaran and Hauser (2022) described how a care-and-support centre treated experiences of systemic discrimination and oppression as social and structural causes of pain. One of the mechanisms for healing this pain was empowering 2SLGBTQ+ people receiving palliative care to engage in 2SLGBTQ+ advocacy efforts (Baskaran & Hauser, 2022). Beringer et al. (2017) described how a web-based platform for end-of-life planning and care was extended to respond to unique health care, housing, psychological, spiritual, and social concerns for 2SLGBTQ+ people.

Overlooking the Influence of Intersectionality of End-of-life Needs

Almost all (n=5) of the interventions in our review framed 2SLGBTQ+ people as a monolithic group (Baskaran & Hauser, 2022; Beringer et al., 2017; Chidiac et al., 2021; Grassau et al., 2021; Reygan & D'Alton, 2013). Chidiac et al. (2021) noted that one drawback to short or one-time training is the lack of ability to convey to providers the intersectionality and diversity present among 2SLGBTQ+ people. In Baskaran and Hauser's (2022) evaluation of a care-and-support centre, participants expressed a wish that staff would affirm the uniqueness of their individual identities, rather than treating them based on reductionist perceptions about who a "2SLGBTQ+ person" is. Participants in Grassau et al.'s (2021) study suggested that older gay men may be more likely to engage in opportunities for social connection than explicit emotion sharing (e.g., discussion group). The training program evaluated by Alexander et al. (2021) considered intersectionality between incarceration, mental illness, homelessness, employment, religion/spirituality, and social network for young men who have sex with men with HIV.

Theme 3: Reliving Suffering Through Belonging and Solidarity

This theme illuminates how non-clinical interventions can relieve suffering at the end-of-life for 2SLGBTQ+ people, specifically by fostering environments of belonging and solidarity.

Fostering a Safe and Comfortable Community

Whether online or in-person, the interventions described by Baskaran and Hauser (2022), Beringer et al. (2017), and Grassau et al. (2021) created a space for people to build community based on common needs, fears, and challenges at the end of life. Baskaran & Hauser's (2022) evaluation of a care-and-support centre revealed that new friendships were forged among fellow community members, which fostered a sense of support that was described as "therapeutic." Almost all providers and administrators at the care-and-support centre evaluated by Baskaran and Hauser (2022) identified as 2SLGBTQ+. In the community network evaluated by Grassau et al. (2021), consistent programs like discussion groups were identified as important for forming bonds and trust among members. Beringer et al. (2017) found that a web-based platform for end-of-life planning and care with signs of 2SLGBTQ+-friendliness (e.g., rainbow flags) and moderated interactive discussion boards can foster a supportive community for 2SLGBTQ+ older adults.

Coping Through Mutual Care and Support

A bi-directional process of both giving and receiving care was illustrated in three of the studies in our review (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). In their study of a care-and-support centre, Baskaran and Hauser (2022) described how 2SLGBTQ+ patients provided peer-to-peer support by staffing a hotline for rural 2SLGBTQ+ community members to call with questions about their sexual orientation or gender identity. In the web-based platform evaluated by Beringer et al. (2017), 2SLGBTQ+ older adults showed a desire to extend support to others by sharing links on social media to 2SLGBTQ+-friendly end-of-life planning and care resources. Grassau et al. (2021) emphasized that while volunteer community-based networks aid in preserving self-determination for 2SLGBTQ+ people at end of life, upholding this type of informal caregiving is tiring work that should be reinforced by formal and professional support.

Co-designing with 2SLBTQ+ Community Members

The majority of studies (n=5) reported on the involvement of 2SLGBTQ+ community members not just as recipients, but as active collaborators in the interventions (Alexander et al., 2021; Beringer et al., 2017; Chidiac et al., 2021; Grassau et al., 2021; Reygan & D'Alton, 2013). The community network described by Grassau et al. (2021) showed that palliative care interventions can draw on community development principles by designing initiatives with and for community members. Beringer et al. (2017) conducted town halls, focus groups, and an engagement process with 2SLGBTQ+ people to gather input for a web-based platform. In the training program evaluated by Reygan and D'Alton (2013), a 2SLGBTQ+-identified facilitator with lived and professional expertise was engaged. 2SLGBTQ+ people served as advisors to inform the design and implementation of the training programs evaluated by Alexander et al. (2021) and Chidiac et al. (2021). Chidiac et al. (2021) found that 2SLGBTQ+ people's participation on the project team was vital to ensure providers and leaders engaged with the 2SLGBTQ+ population and considered their needs.

Theme 4: Enhancing Interdisciplinary Provider Competencies and Consciousness

This theme relates to the impact of training programs as a non-clinical intervention to reduce inequities in palliative care for 2SLGBTQ+ people.

Promoting Interdisciplinary Collaborations

In all the studies that evaluated training as an intervention (n=3), staff from multiple disciplines participated (Alexander et al., 2021; Chidiac et al., 2021; Reygan & D'Alton, 2013). Alexander et al. (2021) described interdisciplinary team involvement as an essential component of delivering quality palliative care. The programs evaluated by Chidiac et al. (2021) and Reygan and D'Alton (2013) both comprised a presentation and interactive discussion. These were developed and adapted for providers/staff from diverse disciplines and intended to establish a foundation of collective awareness of the issues and needs of 2SLGBTQ+ people in the context of a life-limiting illness. The programs involved nurses, chaplains, physiotherapists, occupational therapists, health care assistants, doctors, counsellors or therapists, and social workers (Chidiac et al. 2021; Reygan & D'Alton, 2013).

Mobilizing Provider Enthusiasm to Gain Skills and Improve Practice

The impetus for most training programs was a lack of resources and education available to providers to develop the necessary skills and awareness to provide 2SLGBTQ+-inclusive palliative care (Chidiac et al., 2021; Reygan & D'Alton, 2013). Training programs enhanced providers' knowledge about 2SLGBTQ+ issues and needs, their confidence to provide palliative care for 2SLGBTQ+ patients, and their comfort using 2SLGBTQ+-related terminology and language (Chidiac et al., 2021; Reygan & D'Alton, 2013). Alexander et al. (2021) reported that training about the palliative care approach enabled those working in related fields, like HIV management, to incorporate cross-disciplinary skills to improve their practice. Chidiac et al. (2021) found training to be an essential approach to counter negative provider attitudes and assumptions about 2SLGBTQ+ patients. In the programs evaluated by Chidiac et al. (2021) and Reygan and D'Alton (2013), participants reported the training as useful for their practice and indicated that they would be interested in further training and would recommend it to colleagues.

Discussion

This narrative review reveals what is known about implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people. After a systematic search and screening process, six studies were included. We employed the socio-ecological model (SEM) as a lens to critically examine the findings according to the research question and objectives.

Examining Results Through a Socio-Ecological Lens

McLeroy et al.'s (1988) SEM emphasizes that interventions must not focus solely on individually oriented behaviour change but should also target intrapersonal, interpersonal, organizational, community, and public policy levels. Interventions can span multiple interrelated SEM levels.

Intrapersonal

This level of the SEM refers to changing individual characteristics, such as knowledge, behaviours, attitudes, and skills (McLeroy et al., 1988). All (n=6) studies in our review involved interventions at this level. Half (n=3) of the studies focused on interdisciplinary provider training (Alexander et al., 2021; Chidiac et al., 2021; Reygan & D'Alton, 2013). Half (n=3) of the studies addressed the lack of practical end-of-life resources for 2SLGBTQ+ people (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). Though intrapersonal interventions can be "criticized as superficial because they do not change structural forces that give rise to stigma," they are still valuable and oftentimes easier to implement (Cook et al., 2014, p. 103). Our review found that intrapersonal interventions can be useful to increase providers' understanding of and sensitivity toward 2SLGBTQ+ patients and to support 2SLGBTQ+ people in navigating inequities in end-of-life planning and care.

Interpersonal

This level of the SEM suggests that interpersonal relationships are an important source of social resources that mediate life stress and influence overall well-being (McLeroy et al., 1988). Three studies in our review revealed examples of harnessing existing social relationships and building up support networks to restore 2SLGBTQ+ people's self-determination over their palliative care experiences (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). These interventions fill gaps in end-of-life care to care for more than the physical causes of suffering. Support networks create a reciprocal process of giving and receiving practical and emotional support. However, findings from Grassau et al. (2021) cautioned that it is not sustainable to rely on volunteer support networks in the absence of progress at systematic and structural levels, such as in the health and social care systems.

Organizational

This level of the SEM underscores the importance of organizational context for the scale and spread of non-clinical interventions. Non-clinical interventions require substantial human and financial investments to be sustained and are often incompatible with the goals and norms of health organizations (McLeroy et al., 1988). Our review found that most (n=5) non-clinical interventions regarding palliative care for 2SLGBTQ+ people did not target the organizational level. However, Baskaran and Hauser (2022) describe a palliative care centre funded and staffed by a 2SLGBTQ+ non-profit organization. Our review showed that training at organizations like hospices can contribute to a culture of understanding and interest in improving care for 2SLGBTQ+ patients (Chidiac et al., 2021; Reygan & D'Alton, 2013). This organizational culture shift could in turn spark the implementation of other 2SLGBTQ+-specific interventions.

Community

This level of SEM refers to partnerships among informal networks, institutions, and organizations (McLeroy et al., 1988). Our review found no examples of interventions regarding palliative care for 2SLGBTQ+ people that target the community level. Some (n=3) interventions fostered a sense of community through support networks, but these largely functioned in isolation from organizations and institutions and did not engage beyond 2SLGBTQ+ people, their caregivers, and allies (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). Our review highlighted the importance of institutions and organizations to develop interventions with and for 2SLGBTQ+ communities (Alexander et al., 2021; Beringer et al., 2017; Chidiac et al., 2021; Grassau et al., 2021; Reygan & D'Alton, 2013).

Public Policy

This level of SEM refers to the power of public policy, procedures, and laws (McLeroy et al., 1988). Evident in our review is the lack of implemented and evaluated interventions at the policy level regarding palliative care for 2SLGBTQ+ people. Baskaran and Hauser's (2022) study provided a glimpse into how interventions could empower 2SLGBTQ+ patients to engage in advocacy efforts. Strong governmental or organizational policy is necessary to support the institutionalization of interventions and to address underlying social and structural drivers of inequities in palliative care for 2SLGBTQ+ people.

Gaps in Non-Clinical Interventions

There is a need for more interventions outside the clinical environment and patient-provider interaction. Our review found a substantial lack of implementation and evaluation of interventions regarding palliative care for 2SLGBTQ+ people. Without evaluation, it is difficult to assess whether recommended programs, policies, and practices are feasible, sustainable, and acceptable and whether they reduce the barriers and inequities 2SLGBTQ+ people face in palliative care. There are many factors that may contribute to interventions not being reported on or evaluated. This includes limited community organization resources and access to research expertise, a lack of dedicated funding and support for knowledge mobilization, and systemic marginalization of 2SLGBTQ+ populations in research.

Existing interventions fail to recognize the intersection of distinct social categories of identity (e.g., race, Indigeneity, socio-economic status, age, ability) across and between 2SLGBTQ+ populations. The literature echoes this finding, highlighting a need for interventions tailored to transgender and gender nonconforming people, as well as Two-Spirit, Black, and other 2SLGBTQ+ people of colour (De Jong et al., 2024; Robinson & Matamoros, 2024). Training interventions could be perceived as inauthentic and reductionist by 2SLGBTQ+ populations if they are done in the absence of organizational change (De Jong et al., 2024). Our review highlighted a gap in interventions at the organizational, community, and public policy levels. Addressing this gap is critical, as the power of intrapersonal and interpersonal interventions to tackle inequities could be stifled by deeply rooted social and structural factors.

Strengths and Limitations

To our knowledge, this is the first review study to provide an overview of existing implemented and evaluated non-clinical interventions for palliative care for 2SLGBTQ+ people. Our study is novel in its application of the SEM to map how existing interventions address inequities in palliative care for 2SLGBTQ+ people. The rigour and quality of this narrative review is enhanced by the systematic procedure that was established a priori to select and analyze studies (Ferrari, 2015; Rumrill & Fitzgerald, 2001). Screening was conducted by two independent reviewers. Our review examines the types, barriers, and benefits of interventions, and therefore does not conclude about the effectiveness of them. Critical and quality appraisal of the included studies was not within the scope of this review. As only journal articles published in English were eligible for inclusion, studies published in other languages or other relevant literature could have been excluded. Work done by communities and organizations that may not be evaluated or reported in published literature could have been missed. As the studies in our review span a vast array of countries and cultures, not all interventions or findings may be transferrable to the socio-cultural and health system context of Canada.

Implications

This narrative review contributes to the inquiry into what and how interventions reduce inequities in palliative care for 2SLGBTQ+ people. Our review features literature about interventions that have been implemented in various settings and forms and across multiple socio-ecological levels. Our findings provide insight that could assist health administrators, researchers, and policy-makers in their efforts to reduce barriers to palliative care for the over one million people who identify as 2SLGBTQ+ in Canada (Statistics Canada, 2022). The information presented in this study could set the stage for future research on interventions for other equity-deserving groups who face disparities in palliative care (Bassah et al., 2024; Bowers et al., 2022). By focusing on interventions beyond the clinical environment and patient-provider interaction, our review contributes to the health-promoting palliative care field and applies a new lens in response to the need to improve palliative care for 2SLGBTQ+ people (Rosenberg & Yates, 2010; Sirianni, 2020). Our review elucidates how interventions that address social and structural dimensions of care promote access to a good death for 2SLGBTQ+ people facing life-limiting illness. The identified interventions model how palliative care can be de-professionalized to empower 2SLGBTQ+ patients and their communities to have ownership over their death and dying.

Recommendations for Future Policy, Practice, and Research

Canada-specific research, such as a grey literature review, is vital given inadequate national palliative care capacity that will likely exacerbate gaps in care for 2SLGBTQ+ people (Canadian Cancer Society, 2023). Future evaluative research could benefit from employing the SEM to assess, across multiple levels, if and how interventions improve palliative care for 2SLGBTQ+ people. Strengthening the evidence base on the outcomes of these interventions could support long-term human and financial investment. 2SLGBTQ+ people should be engaged in priority-setting, design, delivery, and evaluation of interventions. It is critical to ensure community groups and organizations have access to the knowledge and tools to report on the interventions they lead. For example, freely accessible evaluation guides have been developed to empower Compassionate Communities to evaluate the impact of their initiatives (Pallium Canada, 2025). Further, community groups and organizations can face barriers to reporting their work, as many journals still privilege academic and clinical research. There is a need to reframe what is considered valid research to ensure the impactful work and lived expertise of communities is disseminated broadly.

Employing a trauma-informed intersectional approach would ensure the impacts of distinct social categories of identity on end-of-life experiences are considered in intervention design, implementation, and evaluation (Shimmin et al., 2017). Health authorities, long-term care facilities, and hospices could review health equity frameworks and inclusion policies to ensure they contain best practices for 2SLGBTQ+-inclusive care. These organizations could modify and implement non-clinical interventions presented in our review. Providers and administrators may also refer to existing resources, anchored in evidence and lived expertise, to better serve 2SLGBTQ+ communities at end-of-life (Acquaviva, 2023; Canadian Virtual Hospice, n.d.; National Hospice and Palliative Care Organization, 2021).

Conclusion

Our review found six studies that reported on the implementation and evaluation of non-clinical interventions regarding palliative care for 2SLGBTQ+ people. Interventions that address social and structural determinants of inequities in palliative care for 2SLGBTQ+ people promote access to a good death. There is a gap in interventions at the organizational, community, and public policy levels. Future research should map efforts specific to the Canadian context and employ the SEM to evaluate implemented interventions. Future interventions should be designed and implemented using a trauma-informed intersectional approach and by centring 2SLGBTQ+ community members' distinct identities, needs, strengths, and lived expertise.

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Declaration of Ethics

Ethics application is not required for this study.

Conflict of Interest

The authors have no conflicts of interest relevant to this article to disclose.

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Author Contribution

GM conceptualized and designed the review, led the search and screening, led data extraction and interpretation, and drafted the initial manuscript. MN supervised the study and critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted.

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Appendix A

Database Search Strategies

PubMed	("Palliative Care"[MeSH Terms] OR "Terminal Care"[MeSH Terms] OR ("end of life care"[Title/Abstract] OR "Palliative Care"[Title/Abstract] OR "supportive care"[Title/Abstract] OR "palliat*"[Title/Abstract] OR "hospice"[Title/Abstract] OR "home palliative care"[Title/Abstract] OR "Terminal Care"[Title/Abstract] OR "terminally ill"[Title/Abstract])) AND ("lgbt*"[Title/Abstract] OR "queer"[Title/Abstract] OR "gay"[Title/Abstract] OR "lesbian"[Title/Abstract] OR "transgender"[Title/Abstract] OR "bisexual"[Title/Abstract] OR "two spirit"[Title/Abstract] OR "homosex*"[Title/Abstract] OR "gender minorit*"[Title/Abstract] OR "sexual minorit*"[Title/Abstract] OR "Sexual and Gender Minorities"[MeSH Terms])
CINAHL	S1 TI (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) OR AB (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) S2 (MH "LGBTQ+ Persons+") OR (MH "Asexuality") OR (MH "Bisexuality") OR (MH "Homosexuality") OR (MH "Questioning Persons") OR (MH "Gender Identity") S3 TI (‘End-of-life care’ OR ‘palliative care’ OR ‘supportive care’ OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) OR AB (‘End-of-life care’ OR ‘palliative care’ OR ‘supportive care’ OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) S4 (MH "Terminally Ill Patients") OR (MH "Hospice Patients") OR (MH "Palliative Care") OR (MH "Hospice Care") OR (MH "Terminal Care") S5 = S1 OR S2 S6 = S3 OR S4 S7 = S5 AND S6
Academic Search Premier and Gender Studies Database	S1 TI (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) OR AB (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) S2 SU (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) S3 TI (‘End-of-life care’ OR ‘palliative care’ OR ‘supportive care’ OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) OR AB (‘End-of-life care’ OR ‘palliative care’ OR ‘supportive care’ OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) S4 SU (‘End-of-life care’ OR ‘palliative care’ OR 'supportive care' OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) S5 = S1 OR S2

	S6 = S3 OR S4 S7 = S5 AND S6
Sociological Abstracts	S1 title(LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) OR abstract(LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) S2 title(‘End-of-life care’ OR ‘palliative care’ OR ‘supportive care’ OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) OR abstract(‘End-of-life care’ OR ‘palliative care’ OR ‘supportive care’ OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) S3 mainsubject(LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR ‘two-spirit’ OR homosex* OR ‘gender minorit*’ OR ‘sexual minorit*’) S4 mainsubject(‘End-of-life care’ OR ‘palliative care’ OR ‘supportive care’ OR palliat* OR hospice OR ‘home palliative care’ OR ‘terminal care’ OR ‘terminally ill’) S5 = S1 OR S3 S6 = S2 OR S4 S7 = S5 AND S6
Embase	S1 'palliative therapy'/exp OR 'terminal care'/exp OR 'terminally ill patient'/exp S2 lgb*:ti,ab OR queer:ti,ab OR gay:ti,ab OR lesbian:ti,ab OR transgender:ti,ab OR bisexual:ti,ab OR 'two-spirit':ti,ab OR homosex*:ti,ab OR 'gender minorit*':ti,ab OR 'sexual minorit*':ti,ab S3 'end-of-life care':ti,ab OR 'palliative care':ti,ab OR 'supportive care':ti,ab OR palliat*:ti,ab OR hospice:ti,ab OR 'home palliative care':ti,ab OR 'terminal care':ti,ab OR 'terminally ill':ti,ab S4 'lgbtqia+ people'/exp S5 = S1 OR S3 S6 = S2 OR S4 S7 = S5 AND S6

Appendix B

Inclusion and Exclusion Criteria

Inclusion	Exclusion
• Published in English • Published journal articles • Full-text accessibility • All countries and locations • All ages • 2SLGBTQ+ population(s) • Directly focused on palliative care or a related subdomain • Describes one or more non-clinical intervention regarding palliative care for 2SLGBTQ+ people • The non-clinical intervention addresses at least one inequity or barrier to palliative care for 2SLGBTQ+ people or subpopulation • The non-clinical intervention has been implemented and evaluated	• Not published in English • Grey literature, media articles, conference abstracts, protocols, books, book chapters, commentaries, and editorials. • Studies that are not available in full-text • Non-2SLGBTQ+ people as target population • Studies that are not focused on palliative care or a related subdomain • Studies that describe a clinical intervention (i.e., patient-provider level) • Studies where the described non-clinical intervention does not directly address an inequity or barrier to palliative care for 2SLGBTQ+ people or subpopulation • Studies that describe an intervention that has not yet been implemented or evaluated.

Appendix C

Overview of Study Characteristics

Author(s), Publication Year	Country	Design	Study Population(s)
Alexander et al., (2021)	United States	*Mixed methods, quasi-experimental:* combined the use of pre-post-test questionnaire, interviews, and longitudinal chart reviews.	• HIV-positive young men aged 18–35 years who have sex with men (yMSM) (n=197) Multidisciplinary providers
Baskaran & Hauser, (2022)	Nepal	*Mixed methods:* combined the use of questionnaire with semi-structured interviews.	• LGBTQI+ patients (n=8) • Multidisciplinary providers (n=5) • Family/community members (n=2) • Administrators (n=14)
Beringer et al., (2017)	Canada	*Mixed methods:* Phase 1 consisted of a series of focus groups to inform the design of a web-based platform. Phase 2 involved a town-hall meeting to solicit feedback about the platform. Next, platform traffic was monitored, and user feedback was also collected from social media and emails.	• LGBT older adults • Community organizations • Health care providers
Chidiac et al., (2021)	United Kingdom	*Quantitative, quasi-experimental:* pre-post-test questionnaire.	• Palliative care multidisciplinary providers (n=145)
Grassau et al., (2021)	Canada	*Mixed methods:* combined the use of semi-structured focus groups and demographic questionnaire.	• 2SLGBTQ+ Ottawa Senior Pride Network members (n=9)
Reygan & D'Alton, (2013)	Ireland	*Mixed methods:* combined the use of questionnaire and interviews.	• Oncological and palliative care multidisciplinary providers (n=201)

HPJ HEALTHY POPULATIONS JOURNAL

Review Protocol

Prevalence and Incidence of Frontotemporal Dementia in Low- and Middle-Income Countries: A Systematic Review Protocol

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Abstract

Background: In many low- and middle-income countries (LMICs), the incidence of frontotemporal dementia (FTD) appears to be rising, yet insufficient epidemiological data and subsequent under-reporting obscure its true impact. This gap in knowledge undermines efforts to secure the resources needed for comprehensive FTD care and also complicates the development of targeted public health strategies in these regions. **Objective:** To examine the incidence and prevalence of FTD in low- and middle-income countries and explore how methodological and contextual factors (e.g., diagnostic criteria, health system infrastructure, and under-reporting) influence the accuracy of these estimates and the development of effective public health responses. **Methods**: We developed this protocol using the PRISMA-P (Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols) guidelines. Our plan is to perform a thorough search of the following electronic databases: MEDLINE, Embase, CINAHL, Google Scholar, PsycInfo, and Global Index Medicus (WHO), covering all records from their inception through January 31, 2025. Additional studies will be identified through reference lists of relevant full-text articles. Two independent reviewers will complete initial screening, data extraction, and bias assessment using the Joanna Briggs Institute critical appraisal tools for cohort and analytical cross-sectional research. Studies that are homogeneous will be subjected to meta-analysis; any that are not will be discussed through a narrative summary. **Expected Results:** Help illuminate the true impact of FTD in LMICs, provide guidance for more effective policies, and lay a solid foundation for future research that improves diagnosis, treatment, and outcomes. **Relevance**: This review will advance our knowledge, improve health care outcomes, and promote equity in addressing FTD in LMICs.

Protocol Registration: This protocol has been registered in PROSPERO (CRD42023473937).

Keywords: frontotemporal dementia, older adults, low- and middle-income countries

Background

Frontotemporal dementia (FTD) is a neurodegenerative disorder marked by the progressive deterioration of the frontal and temporal lobes of the brain, leading to notable changes in personality, language, and behavioural patterns (Bang et al., 2015). Although it is the second most common form of early-onset dementia, FTD remains under-recognized, particularly in low- and middle-income countries (LMICs), but it is gradually gaining attention (George-Carey et al., 2012; Hogan et al., 2016). These regions face unique health care challenges, including limited access to diagnostic tools, underdeveloped health care infrastructure, and a lack of trained specialists (Duthey, 2013). Consequently, the true burden of FTD in these populations is likely under-reported, leading to gaps in understanding both its prevalence and incidence.

While research on FTD has gained momentum in high-income countries, there exists a notable gap in our understanding of its prevalence and incidence in LMICs. The underestimation of FTD in LMICs represents a significant public health concern. The absence of accurate data exacerbates existing limitations of health care resources and delays the implementation of effective diagnostic and therapeutic strategies. Furthermore, the growing elderly population in these regions amplifies the need for a critical examination of neurodegenerative diseases. With a shifting demographic landscape, it is imperative to take stock of how literatures have described the burden of FTD, as early detection and intervention could mitigate its profound personal and societal impacts. LMICs are characterized by rich cultural and genetic diversity (Campbell & Tishkoff, 2008; Fatumo et al., 2022). The presentation and progression of frontotemporal dementia (FTD) are not uniform across populations, highlighting the need for a more contextually-informed approach to understanding its prevalence and incidence in diverse cultural settings (Akinyemi et al., 2022; George-Carey et al., 2012). In many LMICs, neurological disorders are frequently underdiagnosed, a reality made worse by deeply ingrained cultural stigmas and systemic barriers to health care access (George-Carey et al., 2012). The absence of reliable epidemiological data not only distorts our perception of FTD's true burden but also limits the development of effective public health responses. A critical examination of FTD prevalence and incidence in these contexts is therefore essential—not only to address under-reporting but to advocate for more robust diagnostic frameworks and equitable health care interventions.

With the population aging in LMICs and a consequent increase in incidence of dementia, there is currently a drive for more studies on dementia in these regions (Akinyemi et al., 2019; Akinyemi et al., 2022). Despite FTD being nearly as prevalent as Alzheimer's disease, research—particularly clinical trials—continues to overwhelmingly focus on the latter. This imbalance reflects a broader issue: the systemic neglect of less conventional dementias, particularly in LMICs, where health care resources are already stretched thin. Given that resource allocation in LMICs must be evidence-based, the lack of robust epidemiological data on FTD results in its persistent under-recognition and underfunding. This systematic review examines the prevalence and incidence of FTD in these regions, exposing the methodological, diagnostic, and structural barriers that obscure FTD's true impact. Uniquely, this review challenges the current research and policy paradigms, advocating for a more equitable distribution of resources and a recalibration of dementia research priorities in LMICs. This review seeks to catalyze informed policy reforms and drive urgent investments in research, diagnosis, and care for people living with FTD, which has remained largely invisible in global health discourse.

Research Question

1. What is the reported incidence and prevalence of frontotemporal dementia in low- and middle-income countries, and how do methodological and contextual factors (e.g., diagnostic criteria, health system infrastructure, and under-reporting) influence the accuracy of these estimates and the development of effective public health responses?

Methods

Protocol and Registration

This protocol has been developed in accordance with the PRISMA-P (Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols) guidelines (Moher et al., 2015) and follows the recommendations set out by the Meta-analysis of Observational Studies in Epidemiology guidelines. It has been registered with the International Prospective Register of Systematic Reviews (PROSPERO) under the reference CRD42023473937. Any amendments made to the protocol will be documented and reported alongside the final systematic review findings.

Systematic Review and Team Members

The lead investigators (OE, CO, and OO) will oversee the review process, including developing research questions, designing search strategies, screening articles, extracting and analyzing data, and preparing the manuscript. Content expertise will be provided by OO and CO. Two reviewers will independently screen article titles and abstracts, while OO and CO will conduct full-text screening and data extraction. A subject librarian specializing in systematic reviews will design and execute search strategies across relevant databases. OE, CO, and OO will synthesize the literature using systematic methods. Statistical analysis, including meta-analysis, will be conducted by CO and OO. This protocol follows the PRISMA-P guidelines, with a PRISMA-P checklist provided in an additional file. Any protocol modifications will be documented and published with the review results.

Eligibility Criteria

This study will review human studies that meet the following criteria (Table 1) using the PICO framework (Participants, Interventions, Comparators, and Outcomes). It will be restricted to studies conducted in the English language from database inception up to January 31, 2025.

Information Sources

The electronic searches will be conducted using MEDLINE, Embase, CINAHL, Google Scholar, PsycInfo, and Global Index Medicus (WHO). This search will be streamlined to focus on LMICs and studies conducted from inception to January 31st, 2025.

Search

The search terms were determined through consultations with the librarian, a geriatrician, a content expert, and review authors OO and CO. We have already conducted a string-search that was first developed for MEDLINE (Appendix A) and will be adapted for the other five databases. These search strings will combine terms related to frontotemporal dementia and its prevalence and incidence in LMICs. Boolean operators will be utilized. Keywords selected will include all possible combinations of terms reflecting the following:

Table 1

Eligibility Criteria for Systematic Review

Population	**Included**: ● Elderly person as defined by WHO: aged 60 and above ● Research articles in the English language ● Original research articles focusing on frontotemporal dementia (FTD) in low- and middle-income countries (LMICs) ● Only primary sources will be used, to avoid bias and inaccurate data ● Articles published from inception to January 31st, 2025 **Exclusion**: ● Studies not available in the English language ● Studies conducted on people below 60 years of age
Outcome	**Main Outcome:** Incidence and prevalence of FTD **Secondary Outcome:** ● Risk factors associated with FTD ● Incidence and prevalence of subtypes of FTD

Prevalence

(Prevalence* OR frequency* OR incidence*) AND

Frontotemporal dementia

('Frontotemporal dementia' OR 'frontotemporal degeneration' OR 'frontal lobe dementia' OR 'Picks disease' OR 'Primary progress aphasia') AND

LMIC's

(developing countr* OR developing nation? OR developing population? OR developing world OR less developed countr* OR less developed nation? OR less developed population? OR less developed world OR lesser developed countr* under developed nation? OR underserved world OR under served countr* OR under served population? OR under served world OR deprived countr* OR deprived nation? OR poor countr* OR poor nation? OR poor population? OR poor world OR poorer countr* OR poorer nation? OR poorer population? OR poorer world OR developing econom* OR less developed econom* OR lesser developed econom* OR under developed econom* OR underdeveloped econom* OR middle income econom* OR low income econom* OR lower income econom* OR low gdp OR low gnp OR low gross domestic OR low gross national OR lower gdp OR lower gnp OR emerging economies OR emerging nation?**)**

Sources of Evidence

Data Management

The outcomes of the conducted database search will be transferred to Zotero 6.0, a citation manager. Subsequently, duplicates will be systematically eliminated. Following the deduplication process, the identified articles will be exported to Rayyan, a web-based systematic review management tool. Covidence will be utilized for screening of titles, abstracts, and full texts. The results of this screening process, categorizing both included and excluded articles, will be exported and organized to facilitate the generation of the PRISMA flow chart.

Data Screening

The eligibility screening will take place in two stages: a review of titles and abstracts, followed by a full-text assessment. At each stage, two reviewers (OO and OC) will work independently to ensure a thorough evaluation. To refine the process, we will carry out a pilot screening where both reviewers will independently assess the first 50 articles, compare their findings, and resolve any discrepancies. The results of their screenings will be compared and reconciled to enhance inter-reviewer agreement before proceeding to the full-text screening phase. This step will help establish consistency between reviewers before proceeding with the full screening process.

Data Extraction Process

Data extraction will be independently carried out by OO and OC and supervised by OE using a standardized data extraction form set up on a Microsoft Excel spreadsheet (Appendix B). In cases of conflicts during either the screening or data extraction stages, the third review author, OE, will intervene to resolve discrepancies. Following the methodological guidelines of Lipsey and Wilson (2000) and Khaliq et al. (2022), relevant information will be extracted from each study.

Data Items and Outcomes

Data items and outcomes will include citation details such as the first author, year, and country of publication, as well as study design (cohort, case-control, cross-sectional, or longitudinal study), geographic location of study, status as LMIC (based on World Bank designation), the sample characteristics, method of assessment/diagnostic criteria for FTD and its subtypes, and percentage of FTD and risk factors studied/associated with FTD.

Risk of Bias Assessment

Risk of bias assessments at the study level will be completed independently by the two reviewers (OO and OC). The quality of the studies included in this review will be evaluated using the Joanna Briggs Institute (JBI) critical appraisal tools for cohort and analytical cross-sectional studies (Moola et al., 2015). These tools are widely used for assessing observational studies due to their clear instructions and structured approach (Khaliq et al., 2022). Two reviewers will independently assess each study, and if there are any disagreements, a third reviewer will step in to help resolve them.

Data Synthesis

Narrative Synthesis

A qualitative synthesis will be used to summarize the results of all included studies. Studies will be grouped based on risk factors, and sub-types of frontotemporal dementia will be compared between studies.

Meta-analysis

The meta-analysis will be conducted using the Comprehensive Meta-Analysis (CMA, Version 4) software (Borenstein, 2022). To measure the overall effect, Fisher's z-transformed correlation coefficient will be used, reported alongside its 95% confidence interval and *p* value. In cases where multiple effect sizes are reported from the same population, the average effect size will be included in the analysis (Nielsen et al., 2020). For studies with independent subgroups, each subgroup will be treated as a separate sample. CMA software applies inverse variance weighting to combine studies, ensuring a more precise overall estimate. A forest plot will be generated to visualize the results, while a funnel plot will be used to assess potential publication bias. The prevalence of frontotemporal dementia will be assessed, and a meta-analysis will be performed. We will calculate pooled prevalence and 95% confidence intervals using a random effects model for all included studies and those at low risk of bias. We will assess heterogeneity with a p value < 0.05 considered as significant. We will also report findings following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2015).

Confidence in cumulative evidence

The summary of evidence will be assessed using GRADE (Schünemann, et al., 2013). The source of evidence and bias due to study limitations and reporting will be considered in the cumulative evidence.

Discussion and Potential Impacts

This review on the prevalence and incidence of frontotemporal dementia (FTD) in low- and middle-income countries (LMICs) is the first of its kind. This systematic review is expected to highlight variations in the prevalence and incidence of FTD across LMICs. Gaining a clearer understanding of the true burden of FTD could facilitate earlier diagnosis, improve differentiation from other dementias, and support more tailored management strategies, ultimately enhancing patient outcomes and quality of life (Akinyemi et al., 2022; Elugbadebo et al., 2021). An evidence-based approach to addressing FTD would allow for more effective resource allocation, including the training of health care professionals, the development of reliable diagnostic tools, and the establishment of specialized care programmes for those affected by the condition.

A systematic review will identify critical gaps in current diagnostic criteria, health care access, and reporting systems within LMICs. Addressing these gaps would ensure that FTD cases are recognized and recorded more effectively, contributing to improved data quality for future research and health care planning. Identifying the scarcity of reliable data on FTD in LMICs could also stimulate future research initiatives. This would encourage collaborative, multi-disciplinary research to better understand the disease and its impact, focusing on specific socio-cultural and economic challenges faced in LMICs (Adebusoye et al., 2020; Oyinlola, 2024). Informed policy and resource allocation are crucial outcomes that can guide policy-makers in LMICs. Furthermore, the review's findings will help address the global imbalance in dementia care and research. With its focus on low- and middle-income countries where resources are often constrained, this review highlights the need for international collaboration and funding, ensuring that care and research efforts are more equitably supported across varying socio-economic contexts.

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Conflict of Interest

The authors declare no conflicts of interest.

Declaration of Ethics

Ethics application is not required for this study.

Author Contributions

OE: Conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, software, supervision, validation, visualization, writing – original draft and review/editing.

CO: Conceptualization, data curation, formal analysis, investigation, methodology, resources, software, writing – original draft and review/editing.

OO: Data curation, formal analysis, investigation, methodology, resources, software, writing – original draft and review/editing.

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Appendices

Appendix A – MEDLINE Search String

Ovid MEDLINE(R) ALL <1946 to September 09, 2024>		
1	(Prevalence* or frequency* or incidence*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	908890
2	('Frontotemporal dementia' or 'frontotemporal degeneration' or 'frontal lobe dementia' or 'Picks disease' or 'Primary progress aphasia').mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	11907
3	1 and 2	1112
4	(older adult* or old* or aging or age* or old age or elder* or geriatric* or gerontolog* or senior* or frail*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	14398546
5	3 and 4	826
6	(developing countr* or developing nation? or developing population? Or developing world or less developed countr* or less developed nation? Or less developed population? or less developed world or lesser developed countr* under developed nation? or underserved world or under served countr* or under served population? or under served world or deprived countr* or deprived nation? or poor countr* or poor nation? or poor population? or poor world or poorer countr* or poorer nation? or poorer population? or poorer world or developing econom* or less developed econom* or lesser developed econom* or under developed econom* or underdeveloped econom* or middle income econom* or low income econom* or lower income econom* or low gdp or low gnp or low gross domestic or low gross national or lower gdp or lower gnp or emerging economies or emerging nation?).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	164905

Appendix B – Data Extraction Sheet

Date:	
Reviewers' details:	
Article title	
Year of publication	
First author's name	
Countries	
Research questions/objectives	
Theoretical framework	
Study design	
Methodology (qualitative or quantitative)	
Location of the study (community, hospital or nursing home, or home)	
Sample size	
Method of assessment/diagnostic criteria used	
Percentage of FTD reported	
Risk factors studied/associated with FTD	
Inferential statistics	
p value	
Other key findings noticed from the article	
Reflections of the reviewers	

HPJ HEALTHY POPULATIONS JOURNAL

Review Protocol

Knowledge Mobilization in Research With Equity- and/or Sovereignty-Deserving Communities: A Bibliometric Analysis Protocol

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Abstract

Introduction: Knowledge mobilization (K*)—a term encompassing activities such as synthesis, dissemination, exchange, and application of knowledge—is discussed and cited across disciplines, particularly in research addressing equity- and/or sovereignty-deserving communities. Despite increasing calls for applied research, significant gaps remain between knowledge generation and its outcomes. Community-based participatory research (CBPR) aims to narrow this gap, especially in contexts marked by historical and systemic exclusion. **Objectives and Methods**: The objectives of this bibliometric analysis are to examine how K* terminology is applied, cited, and connected across disciplines, geographies, authors, and journals, and to produce accessible visual data that highlights patterns related to equity- and/or sovereignty-deserving communities. Adhering to established bibliometric methods, we will use Covidence to pre-screen records, export relevant records for a search within the Web of Science Core Collection to generate data, and then analyze and visualize citation and authorship trends and keyword occurrences using Excel, VOSviewer, and Gephi. **Results and Discussion**: The findings will reveal the frequently used K* terms, their citation patterns, and how they cluster across disciplines, geographies, authors, and journals. Network visualizations will highlight influential citations, recurring keywords such as equity and community engagement, and thematic intersections with research involving equity- and/or sovereignty-deserving communities. The bibliometric analysis will contribute critical insights into how K* is framed and interacts with equity- and/or sovereignty-deserving communities within the literature. **Conclusion**: Our protocol serves as a replicable guide for future bibliometric analyses in this area. By leveraging systematic searching protocols and the rigour of bibliometrics, we can create data visualizations to map influence, reveal hidden connections, and present complex knowledge landscapes in ways that are both analytically robust and accessible to diverse audiences, including equity- and/or sovereignty-deserving communities.

Keywords: knowledge translation, knowledge mobilization, implementation science, review, community-based research, equity

Introduction

Many disciplines have mechanisms to bridge the gap between the production of academic knowledge and action, policy, and/or practice. While there may be multiple terminologies to describe this process, most involve some form of synthesis, dissemination, transfer, and exchange (Turin et al., 2020). Terms such as *knowledge translation*, *knowledge mobilization*, and *knowledge transfer and exchange* are examples of widely utilized English terms in academia (Azimi et al., 2015). Without consistent nomenclature or metadata across disparate disciplines, examining the gap between knowledge production and its translation into action is fraught with difficulty. Throughout this paper, we have adopted the term *K**, which Shaxson et al. (2012) used to encompass the various terminology associated with knowledge translation and knowledge mobilization.

In the Canadian context, federal research funding agencies predominantly use two terms and definitions for the process in which research knowledge is disseminated and used. The Social Sciences and Humanities Research Council of Canada (2025) uses the term knowledge mobilization to mean “an umbrella term encompassing a wide range of activities related to the production and use of research results, including knowledge synthesis, dissemination, transfer, exchange, and co-creation or co-production by researchers and knowledge users” (para 4). The Canadian Institutes of Health Research (CIHR; 2012) uses knowledge translation and further distinguishes the terms *integrated knowledge translation* (IKT) and *end-of-grant knowledge translation* to describe the temporal commitments to engaging with knowledge users, rightsholders, and interest holders. CIHR defines knowledge translation as “a dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge” (CIHR, 2012, p. 1). Both definitions share similar concepts, especially the involvement of knowledge users throughout the research process.

Knowledge-with-Action Gap

While research institutions are increasingly encouraging applied research that involves research users, there remains a gap between the generation of research knowledge—mainly through academia—and the use/uptake of said knowledge. Arguably, non-academic communities are largely motivated to invest time and resources, including human resources, into research that offers valuable K* commitments and benefits back to their own communities. For research intended to have “real world” applications and relevance, research plans and grant applications require naming K* priorities, initiatives, and expected outcomes. That said, the level of community/public (“knowledge users”) engagement, leadership, and governance within research is highly varied and under-reported in academic literature (Nguyen et al., 2020).

A general disconnect between knowledge-user K* needs and research training, practices, and grants (e.g., timeframes, finance administration) has been written about by scholars; however, there is often little description about K* processes and outcomes within peer-reviewed literature on individual studies (Grimshaw et al., 2012; Morton Ninomiya et al., 2022; Turin et al., 2023). Grimshaw et al. (2012) posited that knowledge generated from research has not been successfully turned into health practices and policies. Turin et al. (2020) have suggested that the gap between research findings and application is due to the socio-cultural, organizational, and economic contexts that play a major underlying role during the research and mobilization process. On the other hand, Merga (2021) pointed out that academics may not be prepared to do K* work, or if they are, their already-large workload leaves them with little capacity to do so. Similarly, academics may see no motivational benefit to facilitate K* work that does not advance their own career (Fischman et al., 2018; Sharp et al., 2022). Such disconnections impact community members' perceptions of and investment in research.

Community-Based Participatory Research

Community-based participatory research (CBPR) approaches claim to shift research paradigms in ways that help increase the value and utility of K* in the research process (Jull et al., 2017). Minkler and Wallerstein's (2003) definition of CBPR includes an aim to improve community health through the combination of research and action (e.g., K*). CBPR is especially important pertaining to research intended to improve the health and well-being of people who are structurally and systematically excluded or discriminated against, referred herein as *equity- and/or sovereignty-deserving communities,* which include but are not limited to Indigenous communities, settled racialized diasporas, sexual orientation and gender identity/expression minority communities, people with disabilities, and people experiencing houselessness, poverty, and/or substance use (Heller et al., 2024; Public Health Association of Canada, 2001). The term "equity- and/or sovereignty-deserving" affirms the inherent rights of communities to justice, dignity, self-determination, and full participation in society.

Traditional research within Eurocentric knowledge systems have been marked by a power imbalance between the researcher and the researched, whereas collaborative and collective research approaches that flatten power hierarchies are often credited as coming from Indigenous and tribal ways of knowing and doing (Christensen, 2012; Ferreira & Gendron, 2011; Wallerstein & Duran, 2018). Christensen (2012) and Morton Ninomiya et al. (2020) have shown the usefulness of CBPR in engaging respectful and culturally appropriate research methods to ensure that research knowledge positively impacts Indigenous communities. K* is what makes research matter. To address equity- and/or sovereignty-deserving communities, one can argue that it is only ethical to ensure community-driven K* needs and priorities are reflected in K* in CBPR. Despite increased pushes to fund research that promises to inform practices, policies, and decisions through K* efforts, K* is often conceptually and institutionally limited by researchers' and funders' understandings of K* possibilities.

Bibliometric Analysis

Bibliometric analysis is a method of statistically analyzing large volumes of data (Donthu et al., 2021). This analysis provides a quantitative metric of relationships between an author's work and how it is read and used as a reference in another author's work (Donthu et al., 2021). Its availability and usefulness across multiple disciplines have significantly contributed to its popularity. Application and software programs such as VOSviewer and Gephi allow for rich data visualization that can recognize trends and make sense of unstructured data.

Using bibliometric analysis, researchers can see how the diffusion of knowledge is moving through a particular field and represent it visually to better understand publication relationships

(Donthu et al., 2021). These relationships in data can also be quantified and statistically described to extract meaningful information such as the strength of the associations. This method will be instrumental when seeking to understand why and how often the K* gap exists across and within different research disciplines. Additionally, inferences about how the K* gap has evolved over time can be made, allowing for a more macro-level approach (Öztürk et al., 2024). Finally, predictions regarding this gap's future direction can be made with statistical tools such as Microsoft Excel**.**

Objective

Disconnections between knowledge and action, especially in research with equity- and/or sovereignty-deserving communities, often mirror systemic oppressions and colonization (Israel et al., 2019; Smith, 2012; Stern, 2019; Tuck & Yang, 2012; Wallerstein et al., 2017). Through a bibliometric analysis, we will identify patterns and observe how (a) K* terminology is used and cited, (b) K* is associated with disciplines, geographies, authors, and journals, and (c) it is influenced by specific authors and citations. Another key objective is to produce easy-to-understand visual data that offers important insights, which will shape future in-depth studies that can further interrogate unexplained phenomena revealed by the bibliometric analysis. Together, we will shine a light on K* commitments that claim to serve equity- and/or sovereignty-deserving communities. The bibliometric analysis will answer the following research questions:

1. Since 2010, which terms capturing the general concept of knowledge mobilization (K*) are being used and cited across disciplines and geographies over time?
2. What connections can be made between K* terms and disciplines, authors, journals, and geographies?
3. What citations seem to be most influential around K* terms?
4. What are frequent keyword co-occurrences for common K* terms?

Methods

Our bibliometric analysis draws partially on methods described by Donthu et al. (2021) and van Nunen et al. (2018). The data sources for bibliometric analyses and data visualization programs vary from one study to the next. We describe in the forthcoming sections how we will collect, screen, analyze, and report on our bibliometric analysis. This protocol has been registered with Open Science Framework (https://osf.io/43e8k).

Search Strategy and Terms

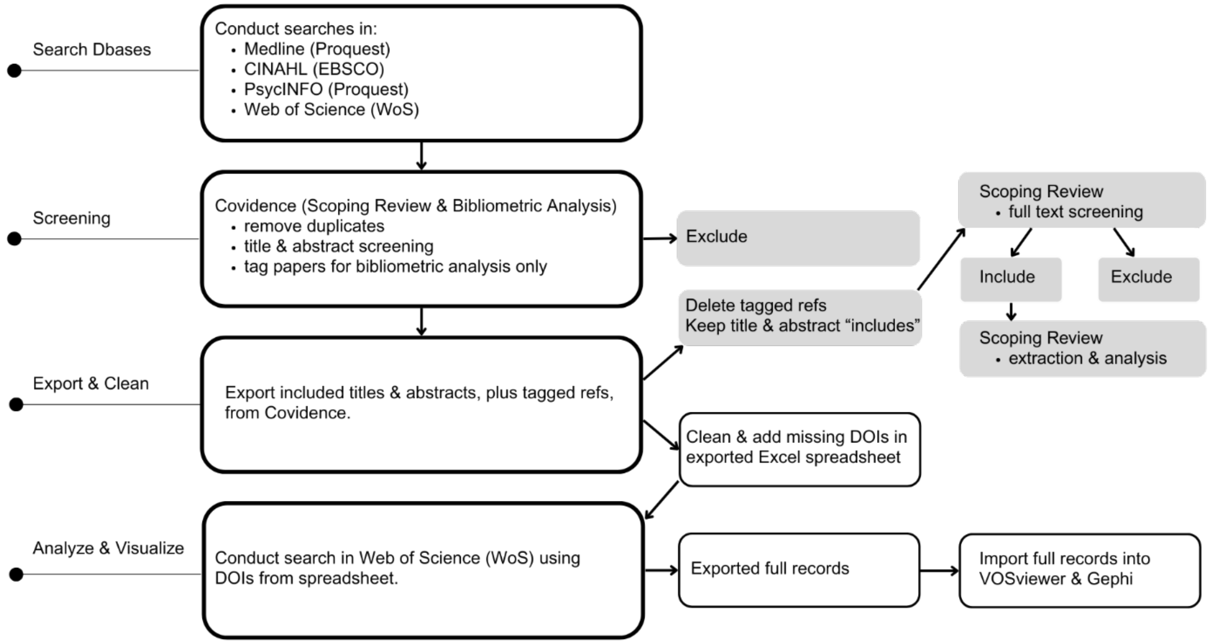
This bibliometric analysis is being conducted in tandem with a scoping review (Barhouche et al., 2025) on the same topic. A search strategy (see Supplementary File 1) was developed with the support of two academic librarians. This search strategy was finalized in MEDLINE (ProQuest) and subsequently translated for PsycInfo (ProQuest), CINAHL (EBSCO), and the Web of Science Core Collection (Clarivate). The search strategy emphasized four central concepts—vulnerable populations, community-based research, K*, and health and well-being—drawing on terminology from previous published approaches (Campbell, 2020, 2022; Cooper et al., 2014; Woodford et al., 2020) and excluding outdated or problematic terms to ensure the search was as inclusive as possible.

An initial search was conducted in June 2024, and the results were imported into Covidence for deduplication and title and abstract screening. An updated search will be conducted in late 2025. The inclusion criteria at the title and abstract phase of the scoping review and bibliometric analysis are the same, except that the scoping review will include only primary research papers, excluding reviews and discussion papers. For the bibliometric analysis, we want to include all relevant review and discussion papers, so we are "tagging" them in Covidence before excluding them in the scoping review. References for sources included at the title and abstract screening for the scoping review, plus tagged and excluded review and discussion papers, will be exported from Covidence as an Excel file.

In the Excel file, we will fill in any missing DOIs before running a search in the Web of Science Core Collection using DOIs only. We chose the Web of Science Core Collection over other databases because it covers a wide range of disciplines, includes key studies from different fields, and offers reliable export options with full record data and fewer duplicates, helping reduce errors in the final analysis and visualizations. Figure 1 visually outlines the workflow of the bibliometric analysis in relation to the concurrent scoping review study.

Figure 1

Overview of Data Management for the Bibliometric Analysis and Scoping Review



Note. Shaded boxes indicate additional steps needed only for the concurrent scoping review study.

Inclusion and Exclusion Criteria

Eligible literature in the bibliometric analysis will include peer-reviewed papers (conceptual, theoretical, quantitative, qualitative), reports, books, commentaries, theses/dissertations, reviews, and discussion papers that mention K* in the title, abstract, or keywords. Because international discourse and explicit interest in K* in health and wellness research accelerated around 2010, this review will include studies from 2010 onward. During this period, influential frameworks, new funding streams, and specialized journals and communities of practice emerged, making 2010 a logical starting point to capture contemporary understandings, terminology, and applications of these concepts while minimizing the influence of outdated or less-developed discourse (CIHR, 2010; Conklin et al., 2011; Networks of Centres of Excellence of Canada, 2016; Wilson et al., 2010). Only papers that are about equity- and/or sovereignty-deserving communities will be included. We define equity-seeking, deserving, or denied groups as people who are structurally, systemically, and socially marginalized or excluded by dominant power structures and who have inherent human rights to self-determination, including Indigenous Peoples; refugees, newcomers, and asylum seekers; racialized diasporas; Two-Spirit, lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and others whose identities fall outside heteronormative or cis-normative communities (2S/LGBTQIA+); people with mental health conditions, disabilities, and/or chronic illnesses; and older adults (Heller et al., 2024; Public Health Association of Canada, 2001). The inclusion and exclusion criteria and their rationale are listed in Table 1.

Table 1

Inclusion and Exclusion Criteria for Bibliometric Analysis of Knowledge Mobilization Terminology

Inclusion Criteria	Exclusion Criteria	Rationale
Printed in English.	Printed in languages other than English.	English is the only shared fluent language of the research team.
Published in 2010 or later.	Published before 2010 or older.	We want the most up-to-date articles, especially considering the rapid changes in K* literature. We are interested in seeing how it has developed in the past 15 years. Google trends show consistent usage in search terms from 2010 and beyond.
Uses specific terminology to describe K* in their paper.	Papers that do not use a specific term(s) to refer to K* initiatives, even if they describe elements of K* (e.g., implementation science; translational science).	We are interested in terms that people use to name and describe K* initiatives they facilitate.
The study addresses or supports something that aims to improve well-being for equity- and/or sovereignty-deserving communities.	Studies focused on capitalistic endeavours for monetary gain and power or focused on communities that are not equity- and/or sovereignty-deserving.	We are interested only in K* efforts in studies that aim to improve forms of well-being for communities who do not have equitable access to health and well-being.

Note. K* = knowledge mobilization.

Screening

As described in the search strategy section above, we screened search results from Web of Science (Clarivate), MEDLINE (ProQuest), CINAHL (EBSCO), and PsycInfo (ProQuest) in Covidence. To ensure high inter-rater reliability, researchers screened 25 randomly selected records based on titles and abstracts. If agreement was below 75%, we would have discussed and refined the inclusion and exclusion criteria before independently screening an additional five records. However, the threshold was reached upon first try. Titles and abstracts are being independently screened by two researchers. Based on the title and abstract, if one researcher thinks the record meets the inclusion criteria and the other does not, papers will be put in a “conflict” list. Each item in the conflict list will be resolved with a conversation between the two researchers, and, if consensus cannot be reached, the record will be included for full-text screening. Relevant records will be exported from Covidence with DOIs—missing DOIs manually added—and the finalized list of DOIs will be searched in Web of

Science. Full records and cited references will then be exported as a RIS file for further analysis in (a) Excel after passing through a citation manager, and (b) VOSviewer and Gephi, where data will also be visualized (Donthu et al., 2021).

Data Analysis and Visualization

In Excel, we will have all author names, author affiliations, publication date, article titles, journal names, DOIs, abstracts, and keywords. We will report on the following: (a) number of unique authors who have contributed, (b) number of unique institutions (of first author), (c) number of countries (based on affiliation of first author), (d) number of journals in which the articles were published, (e) total number of articles published per year, (f) leading contributing authors, (g) total numbers of citations of articles per year, (h) average citations per year, (i) most popular keywords and terms used in titles that link to equity- and/or sovereignty-deserving communities and K* concepts, and (j) clusters of citations around topics and geographies (Donthu et al., 2021; Zhu et al., 2020). Metrics reported in the bibliometric analysis will form a snapshot that informs us of the landscape of the literature in knowledge translation, as well as a baseline for future research to compare against. The extraction table (Table 2) lists which data will be analyzed in Excel, VOSviewer, or Gephi to answer specific questions.

Table 2

Bibliometric Extraction Table for Analysis of Knowledge Mobilization Terminology

Category	Description / Purpose	Data Source / Tool	Aligned Research Question(s)
Record ID	Unique ID for tracking each publication	Web of Science export	Supports internal data management across all questions
Title	Title of the article	Web of Science	Q1 (term usage); Q4 (title keyword trends related to K* and equity)
Authors (Full List)	All listed authors, comma-separated	Web of Science	Q2 (co-authorship patterns, disciplinary spread); Q3 (identify influential authors)
First Author	Name of the first author	Web of Science	Q2 (author-level analysis); Q3 (identify leading contributors)
Author Affiliations	All author affiliations	Web of Science	Q2 (institutional collaboration analysis); Q3
First Author Institution	Institution of first author (used to count unique institutions)	Web of Science	Q2 (institutional influence by geography); Q3
First Author Country	Country of first author's affiliation	Web of Science	Q1 (geographic distribution of K* terms); Q2
Year of Publication	Track publication and citation trends per year	Web of Science	Q1 (temporal trends); Q3 (citation growth over time)

Category	**Description / Purpose**	**Data Source / Tool**	**Aligned Research Question(s)**
Journal Name	Journal in which the article was published	Web of Science	Q2 (disciplinary reach of K*); Q3 (journal influence)
DOI	Digital Object Identifier	Web of Science	Supports traceability and citation checking
Abstract	Abstract text for keyword and contextual analysis	Web of Science	Q1, Q2, Q4 (contextual use of K* and equity-related terms)
Author Keywords	Provided by authors	Web of Science	Q1, Q2, Q4 (identify co-occurrence of K* with equity-related terms)
Keywords Plus	Keywords generated from references	Web of Science	Q1, Q4 (additional term frequency for co-occurrence analysis)
K Term Present? (Y/N)*	Manual flag if article uses a K* term (e.g., KM, KT, implementation science)	Manual in Excel	Q1 (K* terminology identification across the dataset)
K Term Used (Text)*	Specific K* term(s) used in the article	Manual or keyword match	Q1 (granular understanding of term variation by geography/discipline)
Equity/Sovereignty Term Present? (Y/N)	Manual flag for equity or sovereignty-deserving group terms	Manual in Excel	Q4 (detecting thematic linkages between K* and equity- and/or sovereignty-deserving group terms)
Equity/Sovereignty Keywords	Specific keywords related to equity, justice, Indigenous research, etc.	Manual or keyword match	Q4 (used in thematic mapping, clustering of values-based or critical research)
Discipline / Field	Assigned or inferred discipline based on journal or author info	Manual coding / automated	Q1, Q2 (term usage across disciplines; clustering of disciplinary affiliations)
Total Citations (All Years)	Total number of citations for the article	Web of Science	Q3 (identify influential works)
Citations This Year	Annual citation count	Web of Science	Q3 (current relevance of articles)
Average Citations Per Year	(Total Citations ÷ Years since publication)	Derived in Excel	Q3 (relative influence over time)
Co-occurrence Cluster (Keywords)	Thematic groupings of recurring keyword sets	VOSviewer output	Q4 (how often equity terms and K* terms appear together)
Node Size (VOSviewer)	Based on term or author frequency or citation count	VOSviewer output	Q3, Q4 (indicates influence or centrality in the map)

Category	Description / Purpose	Data Source / Tool	Aligned Research Question(s)
Cluster (VOSviewer)	Cluster ID showing grouping of similar terms or articles	VOSviewer output	Q4 (topic clusters based on term similarity and co-occurrence)
Betweenness Centrality	Measures how often a node connects different parts of the network	Gephi	Q2, Q3 (identify bridging institutions/authors or concepts)
Degree Centrality	Number of direct connections a node has	Gephi	Q2 (author/institution collaboration density); Q3 (network prominence)
Modularity Group	Automatically detected community/cluster structure	Gephi	Q2, Q4 (visualizing clusters of terms/authors by geography or discipline)

Note. K* = knowledge mobilization.

Full records from Web of Science will first be imported and analyzed using VOSviewer, a tool specifically designed for bibliometric mapping (https://www.vosviewer.com/). To answer our research questions, we will run three analyses in VOSviewer. First, we will conduct a keyword co-occurrence analysis and generate a map showing how frequently different keywords appear together in articles. This will help identify thematic clusters—for example, whether “knowledge translation” appears frequently with terms like “public health” or “implementation.” Second, we will conduct a citation and co-citation analysis to identify the most influential authors, journals, and papers based on how often they are cited. This will reveal the intellectual foundations of the K* field and the actors shaping its development. Third, we will examine authorship and country co-authorship patterns across countries or institutions, identifying which regions are central or peripheral in the global K* conversation.

VOSviewer automatically clusters related terms or authors using colour-coded visualizations. Each node represents an entity (e.g., keyword, author, or publication), and its size corresponds to frequency or citation count. The proximity between nodes shows the strength of their relationship. These maps will be useful for identifying dominant themes and gaps in the literature at a glance.

In addition to importing data into VOSviewer, we will import data into Gephi (https://gephi.org/) where we can run a layout algorithm to distribute nodes spatially in a way that reflects their relationships. We will calculate various network statistics, such as degree centrality (how many connections a node has), betweenness centrality (how often a node serves as a bridge between others), and modularity (which nodes naturally group into clusters or communities). These metrics will help us identify key players, tightly connected groups, and structural inequalities within the field. Gephi will allow us to customize visualization attributes—such as country, discipline, or institutional affiliation—and use this metadata to assign colours, shapes, or node sizes. For example, we might colour nodes by geographic region to visualize global participation in K* research, or size nodes by citation count to show influence.

We will interpret the maps by combining insights from analyses in VOSviewer and Gephi, and descriptive statistics from Excel. VOSviewer will provide a high-level thematic overview, while Gephi uncovers deeper structural patterns, such as which institutions dominate the K* conversation or how well equity-related terms are embedded in influential research. We will generate compelling visualizations and evidence-based narratives that shine light on the dynamics of K*. We will reveal patterns that have not yet been widely understood or discussed, the influence of language within disciplines, and the degree to which K* features with research with equity- and/or sovereignty-deserving communities.

Discussion

Through our bibliometric analysis, our main objective is to uncover patterns in how K* terminology is used, cited, and associated across various disciplines, geographic regions, authors, and journals. Specifically, we will examine the ways K* language has evolved and circulated in the literature, identify key contributors and influential publications, and analyze how equity-related concepts intersect with reporting of K* research. We will generate accessible and visual data representations that offer a high-level overview of the field, while also revealing deeper structural dynamics that will likely warrant future investigation. This includes exploring how K* discourses align, or fail to align, with the goals of equity- and/or sovereignty-deserving communities.

This bibliometric analysis offers a systematic and visual approach to understanding how K* has been cited and shaped across disciplines, geographies, and time. To our knowledge, this is the first bibliometric study to map the K* landscape through the lens of research with equity- and/or sovereignty-deserving communities, building on prior reviews that have addressed related topics such as knowledge translation in policy (Lawrence et al., 2019; Nguyen et al., 2020), implementation science (Middleton, 2017), and Indigenous health contexts (Morton Ninomiya et al., 2022). While previous reviews have offered valuable conceptual and theoretical insights, this study applies a large-scale, data-driven method to trace how K* terms are used in the literature, how frequently they are cited, and how they cluster across author networks, institutions, journals, and geographic regions—over time.

The bibliometric approach enables us to examine important structural patterns in the field, particularly related to the distribution of influence. By identifying the most cited authors, journals, and institutions, we can assess the extent to which K* discourse is shaped by a concentrated group of actors. As we explore geographic differences, we can identify whether certain countries or regions are more represented in the K* literature (written in English) and how this may reflect broader global research dynamics.

Although bibliometrics cannot directly assess the quality or depth of engagement with equity- and/or sovereignty-deserving communities, it can reveal patterns in how these themes are associated with K* terms. For example, the frequent appearance of terms like "community engagement," "equity," or "Indigenous health" alongside K* terminology may suggest emerging thematic intersections. Conversely, their absence or confinement to isolated clusters may signal conceptual fragmentation or under-representation of certain perspectives. These patterns can guide future research by highlighting underexplored intersections or identifying disciplines and journals where equity-related K* work is less visible.

One of the strengths of this approach is the use of visual data to communicate findings. Tools like VOSviewer and Gephi allow us to generate network maps that depict relationships, including temporal relationships, among terms, authors, and regions. These visualizations are not only analytical outputs but also tools for K* themselves by making bibliometric patterns accessible to a range of audiences, including those outside of academia. While these visualizations cannot capture nuance or lived experience, they can help democratize understanding of who is shaping the field and where opportunities for greater inclusion may lie.

The findings from this bibliometric analysis will be complemented by our concurrent scoping review (Barhouche et al., 2025) that is exploring how K* is defined and applied in research with equity- and/or sovereignty-deserving communities, with particular attention paid to community involvement and reported outcomes related to well-being. Together, the bibliometric analysis and scoping review will deepen understanding of both the conceptual, influential, and practical dimensions of K*. Insights from the bibliometric and scoping analyses will also inform a newly funded study examining how K* is practised in federally funded community-campus research with equity- and/or sovereignty-deserving communities in Canada.

Finally, this protocol contributes to the growing field of critical bibliometrics by offering a replicable approach. While bibliometric methods have limitations and do not assess content quality, community engagement, or lived experience, they are well-suited to identifying and visualizing patterns in scholarly communication. By making these patterns visible, we hope this work will support a more reflexive and accountable approach to K*, one that is responsive to the priorities of equity- and/or sovereignty-deserving communities and that draws attention to systems that reify exclusionary and discriminatory practices and policies.

Strengths and Limitations

Our bibliometric analysis was conducted alongside a scoping review. This methodological choice allows for a rigorous process that saves time and resources. This combined approach also enables us to address a broader range of questions from a shared body of literature. While our bibliometric findings are restricted to citation data (and do not include full text analysis) within Web of Science, they further complement the scoping review, which addresses gaps by examining the following: (a) how terms and concepts around knowledge mobilization (K*) are used, defined, and cited in the literature; (b) how community partners are involved in K* priorities, planning, and efforts; and (c) what well-being-related impacts and outcomes are reported in communities through K* efforts.

The bibliometric analysis will include only papers published in English. There is a lack of uniform terminology on the topic of K* across disciplines, communities, and geographies. As the topic of K* for research involving equity- and/or sovereignty-deserving communities remains unexplored, there are no consistent subject headings for the research team to reference or use as a guide for the literature searches. Using another citational relation database would also have helped with creation of the data set. Our analysis draws heavily on keywords that we have identified as relevant; however, relying on these keywords introduces bias, as we are the people generating the keyword list and then using that list to elucidate additional terms that are being used.

Conclusion

The meaningful involvement of equity- and/or sovereignty-deserving communities is essential to advancing research that addresses health inequities and honours the principle of "nothing about us without us." Yet, the diverse and inconsistent terminology surrounding K* hinders its translation of research-related knowledge into action. This protocol outlines how a bibliometric analysis will map the K* landscape in research with equity- and/or sovereignty-deserving communities since 2010, identifying patterns in terminology, citations, authorship, and geographic distribution. By generating accessible visual data and highlighting structural dynamics, the study aims will support more reflexive and accountable approaches to K* that better align with community priorities and advance inclusive K* practices, such as the creation of visualizations to represent K* accompanied by a Creative Commons license that allows for the reuse, redistribution, and sharing of overall results to communities and the general public.

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Conflict of Interest

The authors declare no conflict of interest.

Declaration of Ethics

Ethics clearance was not required for this work.

Author Contributions

Tse, S: conceptualization, formal analysis, investigation, project administration, writing; Barhouche, R: conceptualization, formal analysis, investigation, project administration; Khalil, J: formal analysis, investigation, writing; Inglis, F: conceptualization, formal analysis, investigation, writing; Chaves, D: conceptualization, formal analysis, investigation, writing; Allison, E: formal analysis, investigation; Colaco, T. W: formal analysis, investigation; Morton Ninomiya, M. E: supervision, funding acquisition, conceptualization, writing.

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