

APRIL 15-16, 2021 - CANADIAN HEALTHCARE NAVIGATION CONFERENCE POSTER SESSION ABSTRACTS

Title: Navigation Framework: A Standardized Approach to Support Patients and Families Through Their Health Care Journey

Authors: Agnes Gibson, Michelle Samm

Abstract:

The literature as well as our experience validates that the healthcare system is fragmented and often difficult to navigate. Patients often face barriers to accessing and receiving timely care and treatment, dissatisfaction, and have difficulty coping; systems navigation is one well-documented strategy to support patients as they move through a complex and often fragmented health care system. Markham Stouffville Hospital (MSH) highlighted patient navigation as a key strategic priority to improving transitions in care and providing an exceptional patient experience, in response to the growing complexities of health care services and its rapidly growing, diverse population. Over time, the organization introduced navigators across various clinical programs, in an attempt to facilitate seamless care. However, the organic implementation of navigation resulted in a model where navigators often operated in silos and lacked a standardized approach to their work. Additionally, navigators had minimal connection with each other and often served as a 'catch-all' to address program-level gaps in services. As a result of lessons learned, MSH decided to slow down in order to speed up. In essence, MSH undertook a thoughtful approach to designing an internal patient navigation process in order to achieve standardization in transitions support. This renewed approach ensures that the model meets our community's current needs, while strategically aligned to fit seamlessly with the broader integrated care work of the Ontario Health Teams (OHTs). To achieve this, a working group of key stakeholders, including physicians and patient advisors, came together to co-design a Patient Navigation Framework. The development of a shared definition and vision for navigation, standard work, core competencies, and defined measures of success, positions MSH navigators to better support patients while ensuring sustainability and flexibility to meet future needs as the system evolves and the OHT matures.

Title: Predictors of Symptoms and Functioning in Youth with Mental Health and/or Addiction Concerns Accessing Navigation

Authors: Alessandra Ceccacci, Roula Markoulakis, Anthony Levitt

Abstract:

Background: Despite the increasing recognition that system navigation may be of value to youth with mental health and/or addictions (MHA) concerns and their family members, little is known about the impact of navigation on change in symptom and functioning severity for these youth. This study investigated which factors may be associated with youth symptom and functioning at baseline and after four months of navigation, from the caregiver's perspective.

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Methods: This pre-post study was part of a larger program evaluation conducted at the Family Navigation Project in Toronto, Ontario. Participants were caregivers of youth with MHA concerns and aged 13-26, who accessed services between March 2018 to July 2019. Caregivers completed the Symptoms and Functioning Severity Scale (SFSS) at intake and after four months of navigation use as a measure of their perception of youth mental health symptoms and functioning. Multiple Linear Regression was conducted on demographics and survey responses for clients with complete data for selected variables at intake. Mixed ANOVA was conducted for those with complete data at intake and at four months of follow-up.

Results: The study sample of youth at intake had a mean age of 18 years. 58% were male, 57% had been diagnosed with a mental health condition, and 43% were using substances.

At intake, using regression analysis ($n=192$), caregiver strain ($\beta=.500$, $p<0.001$), youth completion of ADLs ($\beta=-.217$, $p=0.001$), and youth motivation ($\beta=-.143$, $p=0.021$) were found to be the only significant predictors of symptoms and functioning ($R^2=.455$, $p<.001$), such that higher levels of caregiver strain predicted more severe symptoms and functioning in youth, and greater youth completion of ADLs and greater youth motivation predicted less severe symptoms and functioning.

Comparing complete pre/post data ($n=77$), ANOVA revealed a main effect of time on youth SFSS scores ($F(1, 69) = 5.089$, $p=.027$). Furthermore, the interaction effect of time, youth completion of ADLs (low vs high), and youth motivation (low vs high) was significant ($F(1, 69) = 6.337$, $p=.014$). Post hoc observations revealed that youth with low motivation and low participation in ADLs at intake experienced the largest improvement in symptoms and functioning following four months of navigation.

Conclusion: In youth with MHA concerns accessing navigation services, caregiver strain, youth motivation, and youth completion of ADLs were found to be significant predictors of symptom and functioning severity at navigation intake. Furthermore, youth motivation and youth participation in ADLs at intake, two factors that are traditionally associated with lower likelihood to engage in treatment, significantly impacted change in symptom and functioning after four months of navigation. These findings suggest that family-type system navigation may be particularly useful for youth with MHA concerns that may be less likely to spontaneously seek or engage in treatment.

Title: Major Challenges for Parents of Children with Medical Complexities

Authors: Amélie DesLauriers, Teresa MacMillan, Lillian Kitcher, Michele Haynes, Chantal Krantz

Abstract:

Parents of children with medical complexities (CMC) experience many challenges when caring for their child, directly impacting the social determinants of health. Parents are these children's life line, when they are not well their children suffer. Among the highest concerns experienced by parents caring for a child with medical complexities are the effects on the physical and mental health of the parent, social isolation and the

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significant financial impact. Providing early screening and intervention will ensure that families thrive and are supported to provide the best life for their children and youth. The Navigator program, a 5 year federally funded program has been collecting information on gaps and solutions to some of the major challenges that parents experience when caring for their child with medical complexities. By sharing what works across Canada, the group has created a national tool kit website called “Changing Your Lens” that houses resources and tools to help educate, build awareness and capacity within hospitals and community organizations such as schools and home care, children’s treatment centers, primary care provider and employers on how to support parents.

This presentation will describe the top 4 challenges that parents face and showcase the tools and resources that can help organizations tackle these challenges in the following 4 areas:

- Supporting Emotional and Physical Health for Parents
- Financial/Employment
- Reducing Social Isolation
- Respite for Parents

Resources on how to build a navigator program to better support parents of medically complex children and youth will be shared. Participants will leave with tools that are user friendly, easy to implement and replicate within their organization. The goal of the Changing Your Lens website is to help teams across Canada be better equipped to support parents of medically complex children and youth.

Title: Exploring the Role of Lay and Professional Patient Navigators in Canada

Authors: Amy Reid, Dr Shelley Doucet, Dr Alison Luke

Abstract:

Introduction: Patient navigation (PN) is a model of care that employs lay and/or professional navigators who help individuals and their families navigate a complex maze of services and programs across sectors. Currently, there is no consensus on when employ a lay navigator versus a professional navigator in this model of care, with little research on this topic in a Canadian context. It is important to gain an understanding of what model of PN is best suited for different contexts to ensure that resources are being allocated efficiently and to ensure the optimal delivery of PN services.

Methods: The purpose of this qualitative descriptive study was to explore the roles of patient navigators in different settings and situations for various patient populations in Canada, and to understand the rationale for implementing lay and professional models of PN in a Canadian context. Participants were purposefully recruited based on the results of an environmental scan of PN programs across Canada. Data was collected through individual semi-structured interviews with patient navigators from eight Canadian provinces who serve various patient populations across diverse settings.

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Braun and Clarke's six phases of thematic analysis were used to guide the analysis of interview transcripts.

Results: Findings indicate that a navigator's personality and experience (personal and work-related) may be more important than their specific designation (i.e. lay or professional). Thus, it seems that the best suited individual to provide PN services is not tied to one type of navigator or discipline.

Implications: This study has the potential to inform future research, policy, as well as the delivery of existing and future PN programs, particularly those in Canada. Additional perspectives from relevant stakeholders on models of PN could inform the development of training programs and regulations for the role of patient navigators in Canada.

Title: Nurse Navigator: A Novel Role from the Coached Coordinated Enhanced Neonatal Transition (CCENT) Study

Authors: **Analyssa Cardenas**, Kimberly Colapinto, Annette Van Bergen, Rosanna Manarin, Kate Robson, Kayla Esser, Paige Church, Karel O'Brien, Nathalie Major, Eyal Cohen, Julia Orkin

Abstract:

Introduction: Many Canadian paediatric complex care programs incorporate a "key worker", where a family with a medically complex child (e.g. neonate with multiple congenital anomalies) has a designated health care provider (e.g. a nurse) who functions as a point person to support with care coordination, medical needs and enhanced communication across acute care, primary care, rehabilitation, home and community care providers. Previous research has demonstrated that comprehensive care coordination delivered through a pediatric complex care program may improve the health outcomes of children with medical complexity and high risk neonates. Key workers are currently not a part of standard neonatal care or follow up for families of high risk of neonates in Canada. The Coached, Coordinated, Enhanced Neonatal Transition (CCENT) study is a clinical trial that is currently taking place across seven different Canadian hospitals. CCENT is testing a new neonatal follow-up (NNFU) model, where a keyworker, known as a nurse navigator (NN), are supporting families through various avenues such as a care coordination.

Design: CCENT is a randomized-controlled superiority trial. Specifically, the trial will use two-arms which are parallel groups with a 1:1 allocation ratio to the CCENT model vs. standard NNFU.

Lessons Learned: NNs found parents of high risk neonates find the experiencing overwhelming, exhausting, stressful and isolating and feel it is important for NICU patient-families to find and build a relationship with someone that can help navigate the health care system for the child and parent. NNs help empower families to ask questions, express their concerns and seek resources and support early on.

Conclusion: NNs may be a feasible role to integrate within NICUs and NNFU clinics to allow for better coordination of care, more efficient health care utilization, improved

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parent mental health and improved service delivery for high-risk neonates and their families.

Title: Navigation and Other Professional Roles that Connect Individuals with Mental Health and/or Addictions Concerns to Services: A Scoping Review

Authors: **Andrea Rossos**, Roula Markoulakis, Anthony Levitt

Abstract:

Many barriers to care exist within the healthcare system for individuals looking for mental health and addiction (MHA) resources. Navigators work to reduce these barriers by helping connect individuals with MHA concerns to supports. The role of navigation functionally overlaps with other roles within MHA services, and no widely accepted distinction exists, which poses a challenge for both access and delivery of appropriate services.

This aim of this project is to identify the various roles that exist within the MHA system to connect individuals with services, and to determine and compare the function of both navigation and other identified roles.

A scoping review of relevant literature was conducted. A grey literature search of roles that connect individuals to MHA services informed the white literature search. Criteria for title, abstract, and full-text scan were defined by two team members. Numerical analysis on search results, and thematic analysis of role descriptions were conducted. 14 main functions were described for navigation, with the most consistent being finding and connecting to MHA services and practical community supports. No other roles had complete functional overlap with navigation, with case management being the most similar. The numerical results of the literature demonstrate biases towards reporting on specific roles, and unequal representation of roles in grey versus white literature. Navigation is defined by a focus on connecting individuals to needed services and supports and includes a unique combination and breadth of services not found in other roles. There is a lack of agreement and reporting on the functions of the roles that connect individuals to MHA services, and further research and reporting on role function is required to increase standardization and role clarity.

Title: Exploring the Outcomes of System Supports for Youth with Mental Illness and/or Addictions and their Families: A Randomized Controlled Trial of the Family Navigation Project at Sunnybrook

Authors: **Andreina Da Silva**, Roula Markoulakis, Anthony Levitt

Abstract:

Youth mental health and addictions issues can be a source of strain across the whole family. Caregiving for an individual with MHA is more stressful than other caregiving roles. A main source of stress is finding MHA services. Navigation involving the family may improve access and lead to better outcomes for the family. The objective of this

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pilot study was to examine whether youth ages 13-26 with MHA concerns and their families who receive Navigation services experience improved clinical outcomes compared to youth and families who interact with the MHA system on their own. Participants (N=51) were randomly assigned 1:1 to one of two conditions: Navigation or Self-Navigation. Each condition lasted four months and participants completed surveys and interviews. Preliminary findings showed caregivers in the navigation condition experienced a greater reduction in days of lost productivity from baseline (M=4.18) to follow-up (M=2.11) when compared to caregivers in the self-navigation condition from baseline (M=2.18) to follow up (M=2.23). Caregivers in both conditions experienced similar improvements in caregiver strain. Youth in the navigation condition experienced greater improvement in role limitations due to emotional concerns from baseline (M=23.19) to follow-up (M=33.33) compared to youth in the self-navigation condition from baseline (M=24.24) to follow-up (M=30.3). Youth in both conditions experienced similar improvements in days of lost productivity. Qualitative interviews were analyzed through thematic analysis using MAXQDA software. Four main themes arose from caregivers in the Navigation group: feeling emotionally supported, being connected to services that were a good fit, being provided with a unique mechanism of support, and the extensive knowledge of the navigators being an asset. Overall, families experienced improvement in both groups. Greater statistical power is needed to determine whether one group experienced significantly greater improvement.

Title: There Goes the Neighborhood: Coordinated Service Planning in Eastern Ontario

Authors: **Angele Lefebvre**, Caroline Campbell, Chantal Beauchamp-Drouin, Jennifer Knarr, Melanie Biggar, Alicia Biafore, Adele Ois, Chantal Krantz, Josee Seguin

Abstract:

Our program is a provincial initiative here to improve service experiences for children and youth with multiple and/or complex special needs and their families by connecting them to cross-sectorial services, through a Coordinated Service Plan.

This means ensuring that the care team members know clearly what the child and family's vision and goals are as well as to ensure that they have good communication between themselves, so that everyone can best consider how they can work together toward a common vision and goals. We work in partnership with the capable youth and/or guardian and care team to get everyone on track to reach the child and family's vision and goals

We also facilitate communication and collaboration amongst ongoing care team members and develop a Single Plan of Care in partnership with everyone. In doing so, our role is to take the lead in helping to open a dialogue between care team members, strengthen partnerships between care team members and coordinate services so that all members of the care team are working together toward a common vision and goals. Once the care team is on-track to meet the child and family's vision and goals, service from a Service Planning Coordinator will be complete.

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Title: The Role of the Indigenous Patient Navigator Internationally: A Scoping Review

Authors: **Aric Rankin**, Andrea Baumann, Bernice Downey, Ruta Valaitis, Amy Montour, Pat Mandy

Abstract:

The purpose of this scoping review is to understand and explore the role of the Indigenous Patient Navigator (IPN) in Canada, the United States, Australia and New Zealand. Findings include key roles and activities of IPNs as well as barriers and enablers IPNs address.

Title: Aspects of Navigation that Address Barriers to Mental Health and/or Addictions Service Access as Identified by Caregivers

Authors: **Chloe Ahluwalia**, Roula Markoulakis

Abstract:

Background: Caregivers of youth with mental health and/or addictions (MHA) concerns often play a significant role in seeking and accessing care for their youth. However, many individual and systemic barriers prevent caregivers from connecting their youth to services. While findings have shown that caregivers are satisfied with navigation services as a means of support in finding needed care, their perspectives regarding how navigation helps them overcome barriers are unknown. The aim of this study was to identify the aspects of navigation that caregivers view as helpful in addressing the barriers they face when trying to access MHA services for their youth.

Design: This was a secondary analysis of a qualitative descriptive study within a mixed-methods randomized controlled trial (RCT) evaluating navigation vs. self-navigation. Participants were caregivers of youth aged 13-26 with MHA concerns assigned to the navigation condition. One-on-one, semi-structured interviews explored experiences and involvement with navigation. A subset of transcripts (n=18/41) discussing barriers to care were selected from the navigation condition for thematic analysis.

Results: Caregivers identified the emotional support provided by navigators, connections to services that were a “good fit,” the unique mechanism of support in the navigation process, and the extensive knowledge of the navigation team as helpful in addressing the barriers to care experienced. The barriers addressed included the lack of knowledge of the MHA system, locations and unavailability of nearby services, wait times and unresponsiveness of services, and the emotional labour associated with searching for care.

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Conclusion: Identifying the barriers to care experienced by families seeking navigation services and aspects of navigation that address these barriers is essential for ensuring the development and delivery of navigation supports that meet and address youths' and families' needs.

Title: OnTRACK to unleash potential: A new healthcare student-led environment for navigating the transition to adulthood for youth with disability

Authors: **Darlene Huble**, Gobika Sithamparanathan, Samantha Jagasar, Laura Hartman, Laura Thompson, Kathryn Parker, CJ Curran, Ami Armagost, Tyler Tompsett

Abstract:

Introduction/background: Holland Bloorview Kids Rehabilitation Hospital holds the vision of creating “the most meaningful and healthy futures for all children, youth and families.” Integral to the vision of healthy futures is a meaningful transition for youth with disability to adulthood. Specialized funding provided to our hospital to transform the healthcare landscape through innovation has led to a new approach to transition which includes a partnership in navigation between youth with disability and healthcare students.

Design: The hospital's Transition Strategy team and Teaching and Learning Institute collaborated with youth, families and community partners to develop a new service for transition-aged youth which engages healthcare students as leaders. The student-led learning environment (SLE) called, “OnTRACK-transition-navigation” now offers outstanding collaboration for navigating the multitude of transitions into a meaningful adult life for transition-aged youth and families.

Results: The presentation will outline the team's experience using human-centred design to co-create our service and highlight elements of the navigation service in its current iteration. Our hopes for program impact and an outline of the preliminary program evaluation will be offered.

Conclusion: Success in system navigation for meaningful transition to adulthood can be achieved through partnership, creativity and the application of human-centred design. SLEs can build system capacity and lead system navigation by unleashing the potential of healthcare students as emerging innovators and caregivers and promote upstream changes in our system

Title: Terminology and Conceptualizations of Services that Connect Children with Neurodisability and Their Families to Needed Supports: A Scoping Review

Authors: **Emily Gardiner**, Vivian Wong, Anton Miller, Grace Lin, Andrea Ryce

Abstract:

Background: Children with neurodisability represent a significant population with a demonstrated need for coordinated support. Patient navigation is founded on the

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principles of patient-centredness with a primary focus on successfully connecting fragmented systems. Given the distinct needs of children with neurodisability and their families, such programs built upon such core concepts could be of great benefit, yet there is little research examining this specific context. This challenge is enhanced by the diversity of terminology encompassing navigation-related concepts and activities, such as care coordination, case management, and family support. As such, this scoping review examined published articles on navigation-type services or models for children with neurodisability and their families, looking particularly for the terminology and descriptions being used.

Design: The scoping review was conducted according to the Joanna Briggs Institute methodology. A preliminary search was completed on PubMed (NCBI), MEDLINE (Ovid) and CINAHL (EBSCO) to identify initial search terms, upon which a full search strategy was developed and executed. After screening records according to our inclusion and exclusion criteria, a full-text review of relevant articles was conducted and data extracted using a researcher-developed tool.

Results: Of the 2589 papers identified, 33 were included in the final review. From the included papers, a total of 49 terms were extracted, 20 of which were unique. Articles provided detailed and rich descriptions of their utilized terminology in relation to the values and core roles encompassed.

Conclusions: This scoping review addresses a gap in our knowledge related to how navigation and related supports have been specified as applied to the specific context of children with neurodisability and their families. Given the particular needs of this population, we hope that this review will generate a context-specific understanding of terminology, which may ultimately facilitate more efficient and clear communication and dissemination about such services and their impact.

Title: Results of A National Delphi Study Prioritizing Core Components of Child to Adult Mental Health Care Transitions

Authors: Emma McCann, Kristin Cleverley

Abstract:

Introduction: This poster will outline findings of a novel Delphi study that seeks to inform the development and evaluation of interventions to support transitions from child to adult mental health care. Little is known about the factors necessary to implement successful transition programs or assess continuity of care between services. Delphi studies are an ideal methodology to engage stakeholders in research to address these knowledge gaps and ensure that the priorities of all participants are equally weighted. The purpose of this study was to identify and prioritize core components of child mental health service transitions.

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Design: Utilizing patient-oriented research principles, a multi-panel Delphi study was conducted with youth, caregivers, and clinicians and administrators from across Canada using two rounds of online surveys. Participants were asked to edit and rate the importance and feasibility of transition components. Final components were identified through consensus (>70% highly important or feasible) within panel, meaning all three panels did not have to agree for the component to be retained.

Results: In total, 26 core components were refined and selected. While a high level of agreement for importance was found among the three panels, there was little agreement regarding what was feasible. Qualitative analysis of participant comments identified important gaps in the feasibility of implementing the core components, particularly cross-jurisdictional and cross-boundary barriers.

Conclusion: Identifying core components of transitions permits the design and evaluation of interventions to support effective transitions from youth mental health care. Collaborating with stakeholders, including youth and caregivers, strengthens insights into how transitions are coordinated and experienced from multiple perspectives. The final list of core components can be operationalized as transition interventions and implemented as part of care navigation processes.

Title: Creating ‘Always Events’ to support enhanced navigation for clients and families

Authors: Joanne Maxwell, Darlene Hubleby, Stephanie McFarland, Aman Sium, CJ Curran, Dolly Menna-Dack, Clara Ho, Elaine Cook

Abstract:

Introduction/background: In 2019, our organization identified a need to better support clients and families in system navigation. Always events® are those aspects of the patient experience that are so important to patients and families that health care providers must aim to perform them consistently and reliably for every patient, every time (Institute for Healthcare Improvement, 2018). For service navigation this involved creation of a continuum of supportive roles, processes and information that clients and families can depend on as they move between and meaningfully access services.

Design: This work has 6 pillars of activity focused on equity, access, and partnership: 1. Launch of an Emergency Transit Fund; 2. Co-creation of a series of workshops (“Solution-Focused Conversations (SFC) with Families”) including sessions on advocacy, conflict resolution, goal setting and self-care; 3. Implementation of a translation initiative; 4. Website redesign; 5. Launch of Welcome Desk/Infoline, and 6. Establishment of a student-led navigation hub.

Results: 1. Emergency Transit Fund was successfully operationalized in December 2019; 2. SFC family workshops are now offered monthly (all virtually) and are co-led by

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trained family leaders; 3. Over 100 frequently-used documents were translated into our top 5 languages (print and digital); 4. Website design provides improved consistency and formatting of information for every program, and enhanced filtering functions; 5. Welcome Desk/Infoline were launched in May 2020 with live support 4 days a week; and 6. The Client & Family Navigation Hub launches in March 2021 with a focus on connecting clients and families to needed internal and external services and resources, and addressing social determinants of health.

Conclusion: Our “Always Events” approach provides a foundation upon which we can continue to build authentic partnerships and ensure delivery of services that promote equitable access and positive experiences.

Title: The Experience of the Toronto Acquired Brain Injury Network: Comprehensive Navigation Support and Building Capacity in the System

Authors: **Julie Osbelt**

Abstract:

Introduction/ Background:

The Toronto Acquired Brain Injury Network was established in 1995 at the request of service providers to improve coordination between hospitals and the community. There was a belief that the existing system was fragmented, resulting in inequitable access to rehabilitation. Today, the Toronto Acquired Brain Injury Network helps hospitals and community based programs connect people with acquired brain injury to the services they need. As a recognised leader in Acquired Brain Injury, the Acquired Brain Injury Network works with our members and other stakeholders to improve the quality and availability of publicly funded acquired brain injury services and support. We are a strong collective voice for the needs of those with acquired brain injury.

Design:

This presentation will describe how the Acquired Brain Injury Network:

- Supports providers with comprehensive navigation support to find and access inpatient and community-based rehabilitation and support programs for their patients/ clients
- Builds capacity within the system
- Provides a strong collective voice for acquired brain injury
- Connects people to services
- Involves the role of Acquired Brain Injury Navigator within the Network

Results: This presentation will describe the value add components of the Acquired Brain Injury Network according to the Network members including:

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o The benefits of convening members and stakeholders on a regular basis facilitates discussions between organizations to resolve issues and provides transparency.

o Having the Network as a central hub of information for patients and organizations

In conclusion, the Toronto Acquired Brain Injury Network has become a model for the development of other networks, across Canada and internationally.

Title: Navigation Relationships: Building and strengthening relationships with clients, families, stakeholders and systems through collaboration, coordination, and advocacy

Authors: Katie Wicik

Abstract:

Introduction/Background: The relationships that a navigator builds and works on strengthening are the cornerstone of effective navigation. This presentation will explore how to build and strengthen the various mental health and addiction navigation-related relationships with external stakeholders throughout systems of care.

Design /Methods: This presentation will explore navigation relationships with external stakeholders through the lens of practice-based experience.

Navigations relationships can be built and strengthened through collaboration, coordination, and advocacy.

Results/Lessons Learned: Relationships with External Stakeholders:

Building networks and relationships are one of the best ways to learn the specifics of how each of the moving parts of the systems work, who the players involved are, and how they interact with each other. Systems of care (i.e. mental health, addictions, dual diagnosis, concurrent disorders, and physical health) do not always talk with each other and they often function in isolation of each other.

This presentation will share practical approaches to developing and maintaining networks and relationships in Mental Health and Addiction Navigation, as well as lessons learned.

Conclusion: The implications of a way of practice for building and strengthening navigation relationships through a mental health and addictions navigation lens could be explored in the broader field of healthcare navigation. By building connections throughout systems of care for clients and their families, navigation lessens the health burden on the families and the external stakeholders involved.

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Title: Insights from a Family Support Specialist: How to incorporate parent voices in a neonatal intensive care unit

Authors: Kayla Esser, Kate Robson, Paige Church, Julia Orkin

Abstract:

Parents of babies experiencing a prolonged neonatal intensive care unit (NICU) hospitalization often have increased stress and may feel overwhelmed by the change in their parental role due to the fragility of their newborn. NICUs across North America have been gradually integrating graduate NICU family members into their units in a variety of roles. At Sunnybrook Health Sciences Centre, graduate parents started off in volunteer positions, and the first Family Support Specialist (FSS) was hired in 2010. This poster will share the insights of an FSS currently working in the Sunnybrook NICU.

The FSS role is a flexible one, with the goals of providing peer support to NICU families, offering anticipatory guidance, designing programming and educational offerings to support the social and learning needs of family members, and collaborating with the unit to ensure family-centered care.

In practise, this family-centred care has come to include a robust parent program that includes weekly education sessions and social gatherings, a parent-designed website and booklet to introduce families to the NICU and prepare them for discharge, and the integration of family representatives in all unit committees and activities to ensure parent voices are part of all decision making and program design. There are now 3 parents on staff in support roles and 5 parents in volunteer positions, and a peer mentor education program has been developed to ensure all parent representatives know how to support NICU families safely and effectively.

These experiences can help inform the future of healthcare navigation, by demonstrating how to include the previously excluded perspectives of graduate parents in education and practise. Empowering and educating families makes them feel more comfortable in the NICU and prepares them for the transition home. This translates to better long-term outcomes for babies including better overall development and fewer re-hospitalizations.

Title: Experiences of Lesbians Using Reproductive Healthcare Services in Ontario

Authors: Kelly Gregory

Abstract:

Introduction: The use of assisted human reproduction (AHR) represents a meaningful and important life event for lesbians who wish to create biologically related families. Despite increasing numbers of lesbians utilizing AHR services, barriers to access continue to persist for this group who is uniquely dependent upon this service.

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Design: Drawing on semi-structured interviews, this study applies Grounded Theory and situational analysis to examine the experiences of lesbians who have utilized or attempted to use reproductive services in Southern Ontario, Canada, since December 21, 2015.

Results: Findings reveal a range of experiences, with some very positive narratives. However, patients desired more support in navigating a complex and costly medical journey through a system that is largely not designed for their needs. Some mandatory provisional steps perceived as irrelevant or redundant were frustrating to lesbian patients, particularly when direct fees were incurred. Private fertility clinics as the environment for accessing publicly-funded services may contribute pressure to pay out-of-pocket for add-on medical procedures.

Conclusions: Insufficient understanding of the full medical journey may reduce a patient's capacity for informed consent and participation in shared-care decision-making. Recommendations include a priori patient education on the medical journey and individualized approaches with lesbian patients which assume sufficient fertility until proven otherwise

Title: Newcomer Navigation by the Numbers

Authors: Kimberley DeLaunay, Julia Kurzawa, Sahar Zohni, Christine Kouri, Seeta Ramdass, Adoniran Santos, Lauren Provost

Abstract:

Background: New Canadians (i.e. refugees and immigrants) face many linguistic and cultural barriers in access to health and social services. In response, organizations have begun investing in health and system navigation support for newcomers; yet they often work in silos and with limited funds. This need prompted CHEO to develop the first of its kind, National Newcomer Navigator Network (N4). N4 will provide various learning and collaborative opportunities to staff in health and settlement organizations, including a database. The database will house primary data (from member organizations) and secondary data (from government and industry sources) around Canadian newcomers' access to health and settlement services, resources available, and immigration trends nationally and locally. To our knowledge, this is the only proposed database to house and share immigration data across the health and settlement sector at a national level.

Methods:The N4 team conducted a needs assessment, follow up interviews, and a pilot test of database tools with key stakeholders. These activities were conducted to inform the development of the database. Results are presented below.

Results: Organizations struggle with timely and accurate data collection. Many organizations do not collect client information beyond country of origin, language preference, and services accessed; Fewer yet collate and review this data regularly.

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One of the greatest challenges identified was sharing data across organizations, which the N4 database aims to achieve at both the local and national level.

Conclusion: Results from the database development activities highlight gaps in data in healthcare navigation, as it pertains to newcomers, and opportunities for further research

Title: Identifying interventions and strategies to support youth navigating into post-secondary education with pre-existing mental health concerns: Results from a scoping review

Authors: **Kristin Cleverley**, Savani Paul, Tim Fricker, Andrea J Levinson, Tony Pignatiello

Abstract:

As the number of students reporting mental health concerns steadily increases in post-secondary settings, it has become increasingly important to identify and understand interventions that support these youths effectively. Research to-date has mostly focussed on outcomes of counselling or academic support for students once they are on-campus. However, up to 75% of mental illness has its onset prior to age 18, therefore a large proportion of youth are likely transitioning into post-secondary settings with a pre-existing mental illness. As such, there is an urgent need to understand what, if any, interventions exist to support youth with mental illness as they navigate into post-secondary settings. Therefore, the aim of this scoping review was to synthesize the literature on interventions to support youth with pre-existing mental health and/or addiction concerns as they transition into post-secondary settings.

Using an established scoping review methodology, this review examined 19 peer-reviewed and non-academic documents to identify interventions, their components, and/or recommendations or strategies to facilitate effective transitions into post-secondary settings for youth with pre-existing mental health concerns.

This review identified three interventions supporting youth with mental health concerns transition into post-secondary settings. The interventions differed in their mode of service delivery, service philosophy, intervention components, and target populations. Apart from these interventions, we also identified 8 strategies to improve transitions for youth with pre-existing mental health concerns transitioning into post-secondary settings.

Rigorous evaluation of the existing transition interventions is strongly recommended, with youth with lived experience ought to have a pivotal role in the evaluations. Future research also needs to focus on development of indicators to evaluate transition programs that support youth during this transition.

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Title: Systems Level Collaboration in Mental Health Navigation: Where do we begin?

Authors: Liisa Kuuter, Adina Hauser

Abstract:

Research shows that access to appropriate and timely mental health and addiction support can be a complicated and lengthy process. Challenges are further exacerbated by lengthy waiting lists, barriers to equitable supports and service, poor health literacy, cultural barriers, and disparity between available public and privately sourced services. Growing research demonstrates that navigation can help ease these burdens and increasingly mental health navigation services are emerging across the sector. The Family Navigation Project (FNP) with Sunnybrook Hospital and the Transitional Youth Program at Michael Garron Hospital are two such services aimed at addressing these challenges by assisting youth with navigating the Mental Health and Addiction system. But navigation programs are often developed in silos based on geography, complexity, or community, and so execution of navigation across the system can become fragmented itself. Finding commonalities within navigation has the potential to create better service utilization and improved outcomes as well as better cohesion within the sector.

We will look at the rationale for embarking on a system's level collaboration between navigation programs that will include the following:

- 1) Identification of key components to building a successful collaboration
- 2) Discussion of the knowledge transfer skills required to successfully navigate families and youth through a complex system
- 3) Consideration of what is required to reduce silos, address duplication, and increase knowledge and competency at a service level
- 4) Identification of gaps in services with the goal of improving outcomes for families and youth

Title: People Accessing Care Teams (PACT): Healthcare Navigation as part of team-based care in a marginalized community

Authors: Maniola Sejrani, Derrick Chunga, Cyril Borgai

Abstract:

A partnership between primary care providers, PACT was developed to improve clients' access to interprofessional care teams. Physicians connect complex clients to services at Black Creek CHC sites in two sub-regions – North York West and North York Central. The community served is largely newcomers (mostly racialized) living in poverty, with a

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high prevalence of chronic disease (Diabetes, mental illness, hypertension). Healthcare navigators are at the centre of coordinating patients' healthcare requirements and provide support to clients in English and French to ensure ease of movement within the healthcare system.

The main project objectives include reduced visits to ER and enhanced coordination of services.

In 21 months, 423 physicians referred 2746 patients to over 3150 services. The majority of services referred to so far are medical/physical (2218), followed by mental health and/or addictions (606) and social supports (394).

"We see this investment in the short and long term, leading to outcomes that will result in reduced Emergency Room visits to hospitals and enhanced quality of life for all members of our community"...Physician feedback.

"I was trapped in addiction and debt. Thank you for connecting me to the harm reduction and counseling programs. With your support, I have been able to find resources to move on with my life" ...Client feedback

Title: Connect, learn, and collaborate around newcomer navigation

Authors: Mariah Maddock, Christine Kouri, Kimberley DeLaunay, Julia Kurzawa, Sahar Zohni, Seeta Ramdass, Adoniran Santos, Lauren Provost, Andrew Tomayer, Yvonne Kienast

Abstract:

Background: Newcomers to Canada face many linguistic and cultural barriers in access to health and social services. Newcomer navigation, the act of helping immigrant and refugee clients to navigate the complex health and social services system, can mitigate these barriers to an equitable experience. Organizations have begun investing in newcomer navigation programs; yet they often work in silos and with limited funds. This need prompted the development of the National Newcomer Navigation Network (N4), a national platform for newcomer-serving staff to connect, learn and collaborate around system navigation.

Design: N4 aims to provide settlement and healthcare staff with educational opportunities, facilitate collaboration across sectors, and improve the collective impact of newcomer navigation programs. N4 will develop eLearning modules and webinars, conferences, a forum for staff to connect with peers, a database of immigration trends at the local and national level, and will partner with Saint Paul University to develop an online program around newcomer navigation.

Projected Outcomes: As a result of project activities, N4 will:

- Identify best practices in newcomer navigation

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- Promote knowledge exchange between newcomer-serving professionals
- Partner with Saint-Paul University to develop an online program in newcomer navigation for 75-90 professionals from the health care and settlement sectors across Canada
- Provide national and local level data facilitating research opportunities
- Improve integration between the health and settlement sector

Conclusion: The National Newcomer Navigation Network will support health and settlement staff in their work with newcomers, ultimately ensuring that Canadian newcomers have a consistent and equitable experience in navigating health and social services during their settlement

Title: Patient Navigation Education: Developing a Learning Pathway

Authors: **Marianne Koh**, Rosemary Kohr

Abstract:

Patient Navigation is an emerging role in the health care sector. Patient navigation functions are neither regulated health professions nor controlled health acts. The need to to verify and validate these skills based on a standardized framework that meets industry needs is imperative.

This presentation will describe lesson learnt from the development of patient navigation training and a learning pathway towards a Patient Navigator Professional Certificate that allows for integration and contextualization within each health care setting. The use of micro-credentials and digital badges to articulate patient navigation skills will also be described.

This presentation will help inform policy around the training and hiring of patient navigators, and the integration of navigation practices within a workplace.

Title: The perceptions and experiences of care providers as clients of NaviCare/SoinsNavi: A patient navigation centre for children and youth with complex care needs

Authors: **Naythrah Thevathasan**, Kerrie Luck, Shelley Doucet, Alison Luke

Abstract:

INTRODUCTION: NaviCare/SoinsNavi is a bilingual patient navigation centre for children and youth 25 years of age or younger with complex care needs in New Brunswick. This research-based center employs two bilingual patient navigators, one a

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registered nurse and the other a lay navigator, who assist children/youth, family members, and the care team by facilitating more convenient and integrated care using a personalized family-centred approach. The purpose of this study was to explore the perceptions and experiences of care providers who use NaviCare/SoinsNavi. This study builds on ongoing research exploring the experiences of children/youth and their families who are clients of NaviCare/SoinsNavi.

DESIGN: Interviews were conducted with 10 care providers (N=10) from various sectors including social support services (n=6), primary care (n=2), mental health services (n=1), and acute care (n=1).

RESULTS: Qualitative interviews were conducted and five themes related to the participants' perceptions and experiences with NaviCare/SoinsNavi emerged, including a: 1) trusted source, 2) connector, 3) capacity builder, 4) partner, and 5) time saver. The overall impression of NaviCare/SoinsNavi was positive in the service's ability to help support care providers and streamline the care they provide to their clients.

CONCLUSIONS: It is within every healthcare provider's scope of practice to provide navigational support to essential programs and services; however, due to limitations in time, resources, and capacity, novel services such as NaviCare/SoinsNavi can be used to help close gaps in care that exists for children/youth with complex care needs and their families

Title: Navigation through Healthcare services: Transition of individuals with autism to adulthood

Authors: Parisa Ghanouni

Abstract:

Background: Transition from adolescence to adulthood is a natural developmental milestone. However, for many adolescents predisposed to mental disorders, including individuals with autism spectrum disorder (ASD), the challenges of transition to adulthood will be amplified. People with ASD often face an interruption in receiving health services during the transition to adulthood. This project aims to uncover barriers and facilitators related to health services during the transition of adolescents with ASD to adulthood.

Design: We interviewed 18 stakeholders, including 6 youth with high functioning ASD aged 15-25 years old, 6 parents of individuals with ASD; and 6 healthcare providers from inter-professional practice who work with individuals with ASD (> one year working experience) from across Canada. In-depth and semi-structured interviews were employed using open-ended questions to identify healthcare challenges in the transition to adulthood of adolescents with ASD. Interviews were transcribed verbatim and analyzed thematically to develop overarching themes.

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Results: Using thematic analysis yielded three themes including (a) availability of ASD-specialized professionals; (b) navigation and accessibility of healthcare services; and (c) trauma from a healthcare experience. This project is one of the first studies to involve key stakeholders to highlight barriers of healthcare services during transition of individuals with ASD to adulthood in Canada.

Conclusion: The findings from this project will improve our understanding on how to improve healthcare services during the transition to adulthood. The knowledge generated from this project can be used to enhance healthcare practices, education, and policy, and will be applicable to a broad range of transitional healthcare in future studies.

Title: Patient Navigation in a Patient-centred, collaborative care world.

Authors: Rosemary Kohr

Abstract:

Introduction: Terms such as “patient-centred care” and “collaborative care” have been part of the healthcare vocabulary for many years. In the 1970s, the psychiatrist Dr. George Engel coined the term “person-centred care” and provided a model that offered a more holistic view of the person than the previous biological (medical) model. Most healthcare providers and institutions support the view of individuals as having unique biopsychosocial characteristics. Many organizations pride themselves on Mission/Vision/Value statements that highlight the importance of patient centred care.

Yet the reality of complex healthcare issues, increasingly scarce resources and timely access to appropriate services as well as gaps in health literacy, have challenged our ability to truly carry out patient-centred, collaborative care. The role of the Patient Navigator seems to be a potential solution to address many of the limits to the current system. Patient Navigators can support effective patient care, as they work to link with other members of the healthcare team and help patients and their families in their journey.

However, it is evident from discussions with individuals currently in the role of Patient Navigator, that the role is not well-understood by administrators, other members of the healthcare team or the public.

Design/Content: In this presentation, a philosophy of Patient Navigation, which has evolved from the model described by Engel, will be discussed, using examples from real-world Patient Navigator experiences. This philosophy provides a future-forward perspective of how Patient Navigators can be defined and developed.

Conclusion: In order to effectively implement the role of Patient Navigator, all parties (including administrators, other members of the healthcare team and patients/families) need to have a common framework to best understand how to successfully engage in patient-centred, collaborative care.

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Title: Navigating Caregiver Strain: Predictors of Caregiver Strain for Caregivers of Youth with Mental Health and/or Addictions Issues accessing Navigation Services

Authors: Roula Markoulakis, Kaiwen Song, Anthony Levitt

Abstract:

Introduction: Caring for youth with mental health and/or addictions (MHA) concerns can cause caregiver strain, which is associated with negative consequences for youth, their caregivers, and the mental health system. These negative consequences may be mitigated by caregivers and/or youth receiving assistance in navigating the health care system. Understanding caregiver strain may be important in developing and implementing navigation services for such families; nonetheless, limited evidence currently exists regarding the predictors of strain in caregivers seeking navigation support. This study aimed to determine whether (1) the mental health profile of youth and (2) the home and family situation contribute significantly to strain in caregivers that access navigation services for their youth with MHA concerns.

Design: Data was collected from 66 adults caring for at least one youth with MHA issues accessing Family Navigation Project services between March and August, 2018. Multiple linear regressions were conducted to determine which factors are associated with caregiver strain.

Results: The first regression model exploring youth-specific independent variables (adjusted $r^2 = 0.478$, $F(6,47) = 9.086$, $p < 0.001$) demonstrated that higher levels of caregiver-rated youth health ($\beta = -0.577$, $p = 0.001$) and lower levels of youth mental health symptom severity ($\beta = 0.077$, $p < 0.001$) significantly predicted lower levels of strain. The second regression model (adjusted $r^2 = 0.348$, $F(5,54) = 7.287$, $p < 0.001$) showed that higher levels of family functioning ($\beta = -0.089$, $p < 0.001$) significantly predicted lower levels of strain.

Conclusion: The association of caregiver strain with youth symptoms and functioning as well as the home and family situation suggests that navigation services supporting families of youth with MHA concerns may provide resources targeted at these areas in order to better support caregivers seeking care for their youth.

Title: System Navigation- The "Whatever It Takes" Approach

Authors: Sabrina Samsudeen, Colette George

Abstract:

For over 15 years, the Whatever It Takes (WIT) program has been providing intensive, clinical case management services designed to support infants, children, youth and families with complex clinical profiles (multiple diagnoses including mental health, developmental, and/or medical issues) and complex service situations (multiple service

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providers across sectors). The WIT approach is a combination of the core competencies of case management and service navigation.

Our key takeaways include:

- The urgent need for advocacy within service navigation, when working with these complex profiles and service situations.
- Service navigation is not simply giving someone a map but walking with and guiding them on their journey.
- Complex profiles require intentional collaboration and working together – as Henry Ford said, “Coming together is a beginning, staying together is progress, and working together is success.”

What Makes WIT Work?

- A Client centered approach that recognizes the challenges within the system
- Works with the client and service providers to be open to exploring alternative options, or modifying existing ones, and as such fosters hope and the belief that progress is possible
- Purposefully working to build a strong, clinically sound relationship with families, who often may have had negative experiences within the system, which necessitates rebuilding trust and respect with the system
- WIT’s strength-based collaborative approach aims to create a customized, comprehensive clinical treatment plan that is subject to modification and allows for capacity building
- Ensuring timely communication with all parties, advocating, managing, and supporting families in navigating the system

Title: What are the Key Features and Outcomes of Family Navigation Services? A Delphi Study.

Authors: **Samantha Chan**, Roula Markoulakis, Anthony Levitt

Abstract:

Family navigation services have been increasingly recognized as a viable resource to support youth with mental health and addiction (MHA) issues and their families in connecting with services within the complex and fragmented systems. However, there is limited understanding of the features and outcomes of current family navigation services.

Through a modified Delphi method, the aim of the study was to establish consensus among a group of experts on the 1) key features of a successful navigation process, 2)

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features of a good match between youth/families and services, and 3) outcomes of importance in family navigation. Participants were Family Navigation Project (FNP) team members, current and former FNP clients, and MHA services provider in the GTA.

Across three Delphi phases, participants generated and rated a list of items on the three navigation components. Items rated as “very” or “extremely” important by 80% or more of participants in Phase 3 had achieved consensus and are reported. The intra-class correlation was .84 for the list of finalized items, indicating excellent agreement among participants. A successful navigation process was characterized by highly individualized and flexible services and extensive expertise for well-informed resource-matching based on youths’ and families’ needs. Families’ motivation to change and service providers’ provision of effective and caring evidence-based practice were thought to contribute to a good match between youth/families and services. Three important family navigation outcomes identified were improvement in youth and families’ functioning, effective and timely service delivery, and families’ connections with appropriate services.

Findings illustrated the core factors that promote success in family navigation services. This study adds to the limited literature on the unique features of family navigation and outcomes for optimal navigation programs and guides service delivery for emerging navigation services.

Title: The Development of a Navigation Centre for Children with Complex Care Needs: When Research Informs Practice

Authors: **Shelley Doucet**, Alison Luke, Krystal Binns, Rima Azar, William Montelpare, Patrician Charlton, Nicky Hyndman, Roger Stoddard, Daniel Nagel

Abstract:

Introduction: Childhood is a time of good health for most children; however, approximately 15% of North American children have complex health conditions that impact their health and causes limitations in their lives. Little is known about the needs of this population when accessing services and navigating the healthcare system in Canada.

Purpose: The four objectives of this NB and PEI led CIHR PIHCl Quick Strike project were to a) develop a conceptual definition for children with complex health conditions (CCHC); b) explore the needs of CCHC and their families; c) conduct an environmental scan of services for CCHC and their families; and, d) test a customized algorithm to extract data relevant to CCHC from administrative databases in two Canadian provinces.

Methods: A mixed-methods study design was used that comprised of three qualitative components and one quantitative component appropriate to each objective, including:

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(1) a concept analysis; (2) 121 interviews with CCHC, family members, and various stakeholders across sectors; (3) an environmental scan of services and programs; and, (4) adaptation, refinement and testing of a computerized algorithm on patient databases.

Results: Our findings identified a need for integrated service delivery models for CCHC and their families. We will describe how our Quick Strike research project informed the development and implementation of NaviCare/SoinsNavi, a research-based navigation centre for children and youth aged 25 years or younger with complex care needs and their families in New Brunswick. The centre was launched in January of 2017 thanks to a generous donation from the New Brunswick Children's Foundation and is free for families and health care providers.

Conclusion: Our findings are informing research, practice, and policy around new and existing integrated and innovative service delivery models, including patient navigation, for CCHC and their families.

Title: Navigation & Education – The Perspective of a Navigation Student

Authors: Stephanie Hutton

Abstract:

Navigation services have emerged nation-wide throughout various systems, including healthcare. This movement calls for individuals who are provided the knowledge and training to be able to enter the specific role of a navigator. While there are a number of professionals with diverse backgrounds that can fill the role of a navigator; there is a tremendous and unparalleled value in having an education specific to creating and supporting an integrated and person-centred care network.

As a navigation student I have had the opportunity to delve deeper into the various systems to truly understand how they work from both the professional and client perspective. I have learned how to create and promote a person-first strength-based environment and approach to care. Through immersive practice, I have acquired various skills that not only allow me to assist in a diverse spectrum of scenarios but have also fine-tuned the ability to seek out the necessary supports in the most efficient and effective ways. I have been exposed to a number of services and supports that until my navigation program had no knowledge of their existence and how they can help clients. My experience allows me to offer a unique perspective while teaching and empowering the client to embrace taking the lead in their health and well-being.

In this proposed presentation, I will discuss my journey as a navigation student with a health science background. I will detail how I came to learn about the field, what sparked my interest in learning more, and share how a formal education in navigation services has provided me with a valuable and unique skillset that will further help transform the healthcare system.

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Title: Patient Navigation as an Approach to Improving Access to Integrated, Family-Centered Care

Authors: **Taylor Fearon**, Dr Shelley Doucet, Dr Alison Luke

Abstract:

Introduction: Children and youth with complex care needs require more and varied healthcare services than the average population, as well as a high degree of coordinated care. Evidence has shown that these individuals have better outcomes if they have access to integrated, family-centred care. Patient navigation programs are a novel approach to support the integration of care and transitions across the lifespan, particularly for individuals with complex care needs. NaviCare/SoinsNavi is a new research-based patient navigation centre in New Brunswick that aims to facilitate more convenient and integrated care to support the needs of children and youth up to the age of 25 and their families using a personalized family-centred model of care. The centre employs a bilingual patient navigator, a registered nurse, who assists youth, family members, and the care team by helping coordinate patient care; facilitating transitions in care; connecting families with resources; helping families understand the health, education, and social services available to meet their needs; and acting as a resource for the care team. All clients are required to provide consent to participate in this research centre.

Design: A mixed methods approach is being used, with data collection ranging from surveys, in-depth semi-structured interviews, client records, as well as audio/video diaries to explore the clients' experiences over time.

Results: The findings suggest that families are extremely satisfied with the center. Emerging themes include feelings of relief, reduced feelings of stress, improved care coordination, and increased knowledge of programs/services.

Conclusions: Key insights and lessons learned from the perspective of the patient navigator will be shared, including coordinating care when not imbedded in a care team, engaging vulnerable populations, and providing support for families where there are no services available.