Continuity of Care across age transitions: Understanding the systemic barriers in healthcare service sector for adolescents and young adults (AYA) transitioning from paediatric to adult health care system

by Aakash Sibasis Bhadra

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Abstract

Continuity of care (CoC) is a well-recognized principle of the primary care discipline critical for Adolescents and Young adults (AYAs) with complex care needs transitioning from paediatric to adult care in Ontario Healthcare system.The objective of this study was to investigate the care practices employed by family physicians and general practitioners when providing continuous care across levels of care. This study sought to develop an understanding of healthcare practitioners experience of providing age transitional care for the AYAs. Five participants with a background in family practice and sub-speciality care in Ontario were recruited for this study. Data analysis was conducted through open inductive coding applied to transcripts from interviews. Themes related to Adolescents and Young Adults (AYA) continuity transition journeys were identified as (1) Systemic Barriers to Care, (2) Local and regional care provision, and (3) Characteristics of care practices. Brenda Dervin's Sense Making Methodology was fundamental for the study inquiry to understand critical incidents experienced by the practitioners when providing continuous care for AYA's.

Acknowledgement

I am grateful and indebted to have Dr. Peter Jones as my academic advisor, mentor, and colleague. The word “Guru” is exploited on many fronts here in Western civilization and, understandably, any new term or metaphor that stands apart from the lived psyche of the masses will not be accepted without any considerable resistance. The innate fear associated with new revelations and discoveries are often experienced with a greater feeling of discomfort. While this uncomfortable feeling might invigorate one to seek comfort in myriad of instances when proceeding with the demands of life. The act of seeking comfort may develop an affinity towards safe spaces. Though such spaces provide a sense of security on the other hand this may also lead to building of nested boundaries that fortify individual sense of being. The process of individuation and relational formation of an identity could be misunderstood if one believes that true agency could be practiced based on the rational choices enacted in a society. Thus, it could be argued that the will to act freely is bounded by the relational positioning of oneself in a social milieu. While failing to situate a relational position may give rise to labyrinth of unexplored terrains inducing a sense of meaninglessness, as the rational capacity critical to any decision-making situation is majorly hampered by failing to make sense of the present unfolding pluriversal realities. I believe seeking change and embracing changing circumstances is a processual development that naturally occurs for every living being. Gradual shifts experienced in regard to ever changing spatiotemporal positionality, which necessitates for continuous sense-making of transitioning paradigms or transitional continuity of realities. We have come to recognize ourselves through self-preservation of identities, and often forget what the identity longs for.

Guru is the person who helps you to perceive the other side that shall not be greener but brighter. He helps you to channel this brightness onto the unresolved darker terrain that might have not been explored but should, by establishing a dialogue with the master. The brightness could be used to carve a reality by realizing that a picture could be only fathomed when the background and the foreground are perceived in unison. Guru could be any individual who showers with unconditional love during this process of realizing the self. On this behalf, I would also like to thank my mom who has provided with unwavering faith and support in my becoming.

The epiphany of being grateful is that you are, only in relation to others. To speak, I am grateful to every soul who has touched and helped shape the vessel that I reside in.

The journey of becoming is nothing less than designing journeys for systems.

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Research Question

Given the age continuity care concerns in the Ontario care system, what opportunities might emerge in systemic service design to address the continuity care breakdown?

Introduction

Canada being a confederation of sovereign states was founded on the Indigenous lands and a former unification British colony in 1867. It is responsible for a substantial political power and policy responsibilities, thus considered to be among the world's most delegated federations (Martin et al., 2018). The decentralization of the Canadian sovereignty could be recognized in health care system known as Medicare, which is not nationally governed but rather is an amalgamation of provincial and territorial health insurance plans that are subjected to national standards (Marchildon, 2004b; Marchildon & WHO, 2013). The taxation-based, and publicly funded universal health programmes usually cover core medical and hospital service for all eligible Canadian and are free at the point of care. While 70.9% of total health expenditure is publicly funded mainly through general taxation, whereas approximately 30% of private expenditure is paid by the patients and private supplemental health insurance plans (Flood & Haugan, 2010).

Though primary care services are covered under the universal healthcare coverage which are generally accessible to most of the populations, however, the rising shortage of primary care providers such as Family physicians (FPs) and General Practitioners (GPs), is a growing concern amongst most of the provinces as reported by the Ontario College of Family Physicians (More Than Four Million Ontarians Will Be Without a Family Doctor by 2026 - Ontario College of Family Physicians, 2023). In 2019 according to Statistics Canada, approximately 4.6 million Canadians did not have regular access to a primary care provider. Meanwhile, a press report released by the Canadian Medical Association (CMA) has urged the key stakeholders in the healthcare industry to work together to address the structural issues that are impacting the primary care's capability of providing accessible and comprehensive care across the country (Critical Family Physician Shortage Must Be Addressed: CMA, n.d.). Pre-existing structural issues which include fewer physicians, hospital beds and advanced imaging scans per capita as well as lower proportion of health care spending on primary care as compared to most of the OECD member countries.

Primary care is a key pillar of modern, people-centred health care system. Investing in the primary care sector represents good value for money as it can help avoid costly admissions to hospitals, improve care coordination and improve health outcomes, particularly for the growing number of adolescents and young adults with chronic conditions who have complex care needs. Planning for the work force required by primary care department to maintain its efficiency and increase the productivity entails health care governance practices in relation to part-time versus full-time practice; roles and scopes of practice; office staffing and overhead; time spent with patients; impact of electronic records and records keeping; and time required for care coordination, administration, and paperwork (Glazier, 2023).

Health systems across the globe with strong primary care are associated with greater equity; lower mortality, premature mortality, and infant mortality; and fewer disparities in measures of health outcomes and health care use (Macinko et al., 2003; Shi et al., 2002)

In 2019 a total of 4.6 million Canadians over the age of 12 years reported to not a have regular health care provider when seeking care or advice for their health (Government of Canada, Statistics Canada, 2020). Interestingly, compared to all other age groups, those aged 18 to 34 were most likely to be without a regular health care provider.

The universal coverage of Medicare consists of medically necessary hospital, diagnostic physician services. According to the Canada Health Act these services are financed through general tax revenues and provided for free at the point of service. It is a single-payer layer of financing that is highly decentralised in terms of service delivery (Does Equity in Healthcare Use Vary Across Canadian Provinces? 2008). Doctors usually practice as independent contractors, meanwhile billing public insurance plans on a fee-for-service or other remuneration models of care (Canada, n.d.). Considering that Primary care providers (PCPs) work within the boundaries of regional or provincial health authorities and in hospitals that are financed almost entirely publicly, it has been found that few accountability relationships exist between physicians and health authorities, hospitals or governments.

Further hospitals, health authorities and other organizations often have their own independent boards and separate budgets, and thus make decisions about the kinds of service they will provide independently of other parts of the system. There are several factors which inform government, care providers and the public when addressing the important health policy challenges, as these factors are common across many countries in the OECD. The factors are fiscal constraints, population ageing and the social determinants of health, and other factors might include geography and patterns of migration.

Meanwhile, the College of Family Physicians of Canada (CFPC) wants to increase the length of family medicine residency from two to three year as an approach to prepare doctors for complex patients. However, concerns are arising over the increasing shortage of family doctors at a time when six million Canadians don't have access to one (Pauls, 2023).

"Family doctors, in particular, as the front line of health care … are really facing a changing picture in terms of an aging population, social complexity, unprecedented levels of concern about addiction and mental health", (Pauls, 2023).

While increasing the tenure for clinical residency will prepare the graduating medicine students for increasing complex care needs, but few adversaries have conveyed that increasing the length of the residency program will have deleterious consequences as currently majority of the population aren't able to access family physicians. However, the federal government had earlier announced that country's immigration system will be used to recruit healthcare workers which are more in demand (Tasker, 2023). Though it seems that the government is committed to bringing in more immigrant health-care workers, but there remains an ever-present concern of the ongoing issues with foreign credential recognition.

Increasing complexity of patient care needs than ever before has resulted in extension of residency programs, as family physicians will need a wider breadth of understanding and training to provide comprehensive and continuous care. While longer training

period could further exacerbate acute shortages in both family and emergency medicine in smaller communities placed in the rural areas which have a much boarder scope of practice than urban settings. The regional differences in family practice complexity may point to the fact that family physicians, general practitioners and the clinics in the rural areas are provided with insufficient administrative support and stagnant payment models, the costs to maintain a family practice are becoming unsustainable (Geographic Variation in FP and GP Scope of Practice in Ontario: Comparative Provincial Study, 2018).
Family physicians are typically the coordinators and gatekeepers for their patients access to and navigation of health care systems in many developed and developing countries (Gross et al., 2000). Although the responsibilities of FPs can encompass primary, secondary and tertiary levels of care (Flood et al., 2002), considering they have the broadest potential patient base compared to other medical specialities, which requires a broad knowledge base overlapping with many other medical specialities. Family physicians face immense pressure, whether it is administrative tasks such as updating electronic medical records, completing medical forms, coordinating care across multiple agencies and providers, or managing increasingly complex care plans for an aging population, the expectations of family physicians are at all-time high. Many also work in hospitals, in long-term care facilities and in specialized areas of practice including obstetrics, anaesthesia and emergency medicine that take time from office practice. Without access to family doctors, patients turn to emergency departments, overwhelming other parts of the health care system (Critical Family Physician Shortage Must Be Addressed: CMA, n.d.-b).
“Family medicine is the foundation of our health care system. We need federal leadership and collaboration with provinces and territories to reimagine family medicine and move to interdisciplinary team-based care. This will improve efficiency, increase health system capacity, and better meet the needs of patients and physicians in a holistic, responsive and timely manner.”
According to the Joint Health Accounts Questionnaire – an international data collection gathering estimates of health spending across function (what types of services are provided?), provider (who provides the services), and the financing schemes (who pays for the services).

General outpatient curative care (e.g. Routine visits to a GP or nurse for acute or chronic treatment)
Dental outpatient curative care (e.g. Regular control visits as well as more complex oral treatment)
Home-based curative care mainly refers to home visits by GPs or nurses.
Preventive care services (e.g. immunization or health check-ups) except for epidemiological surveillance and disaster and emergency response programmes.

The primary advantages of this system pertain to managerial and organizational level factors. Conversely, the primary disadvantages pertain to patient level and outcome factors.

Though points of care provide access to health services, however western health systems are dominated by the paradigm of a disease-focused view, which neglects the underlying causes of health and wellbeing (Plochg et al., 2009). While care provision could be envisioned as a collective activity, specialization of healthcare on the other

hand treats each medical condition separately, compare to providing care as an institutionalized specialized practice. Treating each medical condition separately increases the likelihood for fragmented and suboptimal care that fails to consider interrelated health and social care needs.

The growing number of individuals suffering from chronic and overlapping health issues (Nolte & McKee, 2009), majorly impact the disease focused care provision dysfunctional. We have come a long way since the time when medical care could be described as the unpredictable encounter between one or several physicians and a person at home (P Starr, 1982). Clinical practices are based on assemblage of collectively accumulated, shared, and validated knowledge and know-how (Cambrosio et al., 2006; Foucault, 1963; Freidson, 1988), while a health-seekers care network consists of countless exchange of information in terms of tasks accomplished by many actors relevant to care-seeking behaviour. The network of care is relatable to an industry-inspired analogy, "Therapeutic change", generally used to describe complex assemblages of interventions and professionals (Bergeron & Castel, 2011).

Medical care is rarely delivered in a single healthcare organization with many professionals having specialised in types of care, where they are functionally interconnected and cooperating according to a pre-established plan. Patients often shuttle to seek care for the same health condition between different neighbourhood doctors and hospitals, general practitioners, and specialists, or between various hospital services that have managed to preserve some degree of autonomy. Meanwhile, health care providers rely on their ability to treat fatal infections, prevent heart attacks, provide care to early childhood onset diseases and transplant failing organs. But despite technological progress, doctors often lack to make sense of how the illness under medical attention might progress when caring for AYA's with developing complex health conditions. It therefore seems essential, when a patient is rostered to a care model, to understand how the division of labour will be determined concretely, how it will be organized and what logics underpin the functional distribution of labour and services.

Healthcare is changing rapidly, considering the increasing complexity introduced through development of informational data which is applicable to only certain health situations. The healthcare services are constantly required to be updated depending upon the health-seeking behaviour that is guided by the unfolding nature of an illness. How does one know that multiple information systems are capturing the interpretive subtlety of the accessed information and its applicability to one's own health condition? Healthcare organizations depend on textual practices to coordinate, monitor and organize caregiving activities. The governance of clinical activities includes developing and maintaining care pathways for treating the medical condition under investigation. Care pathways are amalgamation of workflow systems and a record of care. It could be situated in a context of transitional shift and emergence of new modes of governance where trust shifts from professional expertise to confidence in systems and auditable rules and procedures (Power, 1997).

Provision of care being an institutional practice requires many organizations to collaborate and convene to provide care through a service delivery model. The services could be rendered as a certain set of rules and procedures, which not only aids in care

provision but also an object for communication across boundaries of systems of care. Also, this could be envisioned as a mechanism for creating partnership clinicians and health system managers to bring about improvements in service quality. Quality of care when qualitatively measured involves longitudinal exchange of information across the levels of care.

The scope for the research study was to examine the phenomenon of an emergent continuity paradigmatic problematic that will unfold with greater complexity and can be understood as a wicked problem. Further, the study explores the gaps in the care continuum for adolescents and young adults seeking care when transitioning from a paediatric to adult health care in the Ontario healthcare system. The phenomenon of care continuity and the types of breakdowns experienced while in the process of caregiving across levels of healthcare systems was critical for the undertaken study. Caregiving practice as a continual process through systems of care was examined through a cross-case study which involved interviewing primary care practitioners.

While young adolescents diagnosed with chronic ailments and multimorbid health conditions require complex, coordinated and often invasive treatment. The sheer number of clinicians, consultants and caregivers coordinating the rapid delivery of life saving therapy to these group of patients with evolving physiology in an ever-changing environment can make it challenging to ensure that all patients receive appropriate and evidence-based care. The chances of receiving optimal care and to decrease the possibility of unnecessary variation in practice is to create protocols that explicitly delineated desired care pathways as an individualized care protocol.

Complexity in Healthcare Organizations

The Ontario Healthcare system has been mapped through an iterative inquiry (see figure 1) to understand the complexity of relations and interconnected dynamics shared in between levels of care. Considering the levels of care and medical specialization are bounded separately within a policy and insurance framework (often shown as a final containing system). Initially, iterative inquiry of the healthcare system was undertaken to identify the health purpose associated with each level of function unique to a certain care regime.

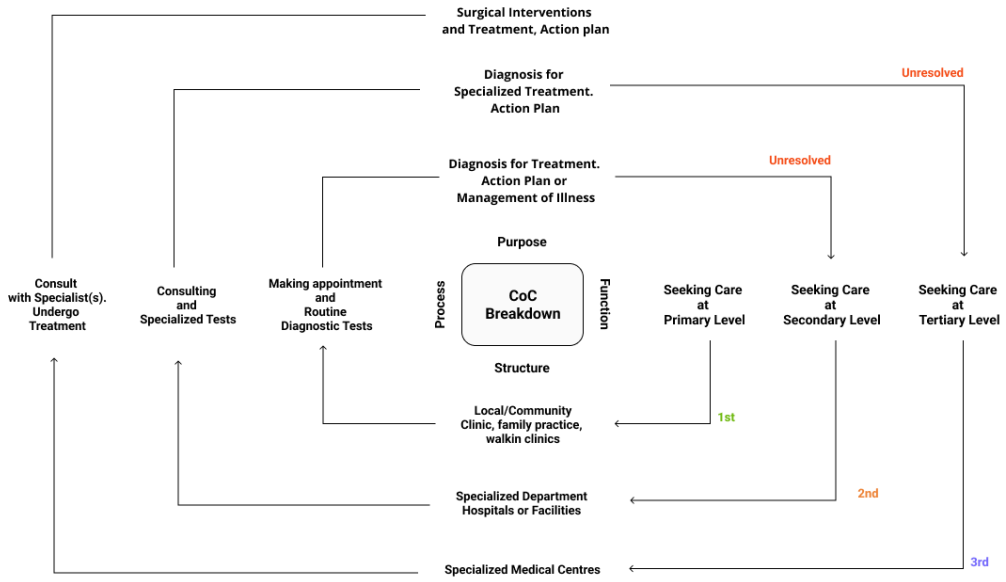

Figure 1: Mapping of Ontario Healthcare System through iterative inquiry.

Care regime signifies the scope professional boundaries and extent of care services provided based on the purpose of each care level. The increasing numbers of children with chronic or complex care needs have necessitated the demand for continuous care for this group of population transitioning between paediatric and adult care that needs to be managed well, or the burden of developing care needs during their adolescence and adult life will end up utilizing extra healthcare resources. Research studies with young adults have confirmed that many experience the transfer to adult care as disjointed and find it difficult to adjust to their increased responsibility for their own care when using adult services (Anthony et al., 2009; Dovey-Pearce et al., 2005).

Complex care needs result from a combination of co-existing chronic health conditions, which requires support from multiple healthcare and social services to manage treatment, symptoms, and activities in daily living (Barnett et al., 2012). The current design of healthcare and social care systems does not meet the needs of people requiring multiple, integrated interventions. At a broader level, discontinuities in

healthcare and related social services can result in fragmented rather than integrated care. One of the core qualities of primary care is considered to be continuity of care (CoC), where care integration involves several challenges concerning organizations and managerial aspects, as well as aspects related to coordination and team collaboration (Van Servellen et al., 2006; Uijen et al., 2011; Gjevjon et al., 2012; Flink & Ekstedt, 2017; Oksholm et al., 2018; Kneck et al., 2019). Many overlapping terms such as integration of care, patient-centred care, case management and coordination of care are found in the healthcare literature which are used to define CoC.

CoC is also believed to be a core quality of family medicine that improves physician and patient satisfaction and patient outcomes (Guthrie & Wyke, 2006c; Darden et al., 2001c; Ridd et al., 2006c; Saultz, 2004c; Gray et al., 2003c). The ideal of CoC raises the idea that one physician cannot be substituted for another like replaceable parts of a machine (cite). The capacity to maintain and manage a continuing relationship with a family physician is associated with increasing the likelihood of receiving preventive care, keep-up appointments, compliance with prescribed medications, shorter hospitalizations, lower health care costs, further affective health promotion and disease prevention.

Managing and maintaining a continuing relationship with a regular family physician is associated with an increased likelihood of receiving preventive care, keeping follow-up appointments, compliance with prescribed medications, shorter hospitalizations, lower health care costs and more effective health promotions and disease prevention. There are predisposing factors which exist before the onset of illness and create a greater propensity for some patients to use more services than others (cite).

The concept of continuity of care (CoC) was first described by Hennen (1975) and consisted of 4 domains: chronological or longitudinal (the repeated use of patient observations over time as a diagnostic and management tool), informational (the availability of accurate information from one health care encounter to another), geographic (care of the patient in a variety of locations) and interpersonal (the physician-patient relationship). Since then, the concept of CoC has developed to include the dimensions of interdisciplinarity (the management of several body systems and diseases at the same time) and family (knowledge about understanding of the patient and his or her family) continuity of care. In the large Ontario healthcare system, continuity of care is primarily recognized as the continuous provision of care between levels of attention to the patient, from primary to secondary and specialized care, or in this case, between age ranges, where care provision and payments are associated with different providers and case types.

Considering that relational continuity contributes to better clinical outcomes and patient satisfaction, it is important to investigate characteristics of value logics shared amongst healthcare practitioners in the primary care context in Canada.

Furthermore, the greater the continuity of care, or the longer the patient-doctor relationship, the greater the likelihood of better health indications. Maintaining relational continuity of care can be a challenge in the context of a team-based approach, especially with the addition of new team members within the patient's circle of care—particularly the addition of learners such as family medicine residents and clinical clerk. In their study, Wetmore et al. (2014) consider that it is neither possible nor necessary

that the patient see the same doctor or any doctor at each visit - multidisciplinary teams could enhance patient satisfaction with care by adopting practices that facilitate continuity with other team members, as well as with the doctors, where appropriate. This would help to reinforce the concept of team-based continuity with patients.

Primary Care – A complicated system within a complicated system

In their research study Kiran et al., (2023) have categorized patient enrolment models in Ontario healthcare system into 3 categories. In the Enhanced fee-for-service model (e.g., Comprehensive Care Model, Family Health Group), physicians receive approximately 80% of remuneration through fee-for-service billings, 15% from capitation payments per enrolled patient adjusted for age and sex, and 5% from financial incentives and bonuses with no additional funding to hire nonphysician health professionals. While in the non-team capitation (e.g. Family Health Network, Family Health Organization) 70% of funding is from capitation, 20% from fee-for-service billings, and 10% from incentives and bonuses with no additional funding to hire nonphysician health professions. Meanwhile, the team-based capitation, the type of payment is the same as nonteam capitation, but physicians are part of a group that receives funding to hire health professions such as nurse, nurse practitioners, social workers, pharmacists, and dieticians.

According to Kiran et al. (2016), patients left behind from medical home reforms are more likely to be poor, urban, and new immigrants and receive lower quality care, the patients who aren't successfully enrolled into any of these models experience more gaps as compared to patients voluntarily transitioned to medical homes as a strategy to improve health outcomes and reduce cost.

In their research study McLeod et al. (2016) found that most physicians who provided more traditionally oriented family medicine and who had a unique relationship with their parents (with respect to visit frequency and visit group) have transitioned to the newer models (new model: enhanced fee-for-service; old model was fee-for-service). Physicians practicing under the fee-for-service model work fewer days per year, have small practices and see patients only once, whereas physicians practicing under different enrolment models see their patients more than 6 times a year (McLeod et al., 2016).

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Coordination of Care & Clinical Governance

The term clinical governance was first introduced in the 1990s in the National Health Service (NHS) in the United Kingdom (Scally & Donaldson, 1998). Clinical governance gained popularity as response to a series of concerns about the quality and safety of health care in the UK (National Health Service 2000), Canada (Baker & Norton, 2002) and elsewhere (Kohn et al., 2000).

Increasing records of breach of patient safety incidents, initiated patients' willingness and ability to stipulate what they required from the health system, as escalating costs and threatened use of litigation were collectively perceived when things went wrong or led to increased pressure on health systems to get things right. Therefore, the need to include clinicians in reforms from the grassroot level, also meant involving them in the governance processes. This suggests that quality and safety had to be taken very seriously and the resulting problems from clinical errors could not be ignored. In order to change the health system for the better required multiple strategies which could be envisioned to be longitudinal task.

Systems change happens rarely, only when there is a crisis promoting immediate, thoroughgoing transformation. Transformational change at an organizational level requires considerable required effort from numerous stakeholders situated across levels of care.

Meanwhile, corporate governance is concerned with running organizations and business as usual, within legal constraints. This involves effective management of corporations, discharging fiscal responsibilities, creating acceptable returns on investment, the direction and control of boards and executives and the structures and decision-making process to achieve corporate goals. While corporate and clinical governance share similar aspects, while the prior is concerned the fairness, transparency, and ethical business practices, whereas the latter is concerned with accountability, effective end results, acceptable resource use and appropriate ways of working and behaving (cite relevant article).

Clinical effectiveness as one of the main tenants of clinical governance strives to ensure that practice is based on the best available data and evidence. According to Glanville et al. (1998), “Clinicians will need to be able to access information on clinical effectiveness in order to improve the quality of care and to stay well informed on developments in specialist areas (p.200).” This may seem difficult to approach largely because of the complexity of patient care and the lack of or equivocality of some research evidence. Nevertheless, boards and executives face the need to put in place measures that support the ongoing education of clinicians an encourage them to jeep informed about developments in their specialty area.

Care Integration across levels of care
Multi-Level Perspective and the concept of integrated care

First, health systems could achieve care integration by influencing the individuals and entities within them. We propose that a systems' influence on integration is observable in the degree of consistency in their staff's descriptions of integration.

Perceived integration will be more consistent among staff within health systems than across health systems.
Second, we suggest that care integration degrades as care diffuses within and outside health systems. Perceived integration will be highest within practice sites, followed by POs, and health systems, and lowest outside health systems.
Third, Singer et al. (2020) conceptual model suggests that clinical process integration most directly impacts care patients receive and its outcomes High perceived clinical process integration will relate to high perceived quality and job satisfaction and low burnout.

Primary health care (as a set of principles and policies) and primary care (as a set of clinical functions) are the main foundations of any health care system (Starfield et al., 2005). The basis for a health system to be developed is based on the principles of primary care which are first contact, continuous, comprehensive, and coordinated care, to achieve better health and greater equity in health than systems with a specialty care orientation (Starfield & Shi, 2002b). The current specialization in health systems (e.g., disease-focused medical interventions) causes fragmentation of services threatening the holistic perspective of primary care (Stange, 2009b).

Considering the fragmented supply of health and social services as a result of specialization, differentiation, segmentation, and decentralization (Kodner, 2009; The World Health Report 2008 - Primary Health Care: Now More Than Ever - World, 2008; Stange, 2009), the present Canadian healthcare system - the aggregation of the federal/provincial/territorial systems is one of the most expensive among developed countries. The cost of Canada's healthcare system is about 30 percent higher than the OECD average (Toward a Healthcare Strategy for Canadians | McGill-Queen's University Press, n.d.)

According to Veillard et al. (2010), "A growing body of research indicates that the use of strategy-based performance management tools in the public sector can result in substantial improvements in both health outcomes and cost-effectiveness." Canada lacks the desired environment required to support system-level performance management, and the differing interests of provincial health ministers fail to align health system design with strategic goals, resource allocation, and incentives (Toward a Healthcare Strategy for Canadians | McGill-Queen's University Press, n.d.).

While performance measurement and reporting have acted as key policy instruments and are tightly connected to the emergence of performance management as the dominating paradigm in the delivery and management of public services. This movement of performance management is rooted mainly in the influence and expansion of different waves of new public management and management by results since the 1970s (Groot & Budding, 2008). The objective of this movement is to have a greater focus on managing performance and service improvement when transforming public services (Osborne & Gaebler, 1992).

The increasing realization across the healthcare system by the leadership teams have been that value is not created through silos of speciality, but through a team-based clinical practice that enables to integrate and improve care across the care cycles (Porter & Lee, 2016). A strategic implementation by the University of Utah Health Care team involved providing care for specific patient conditions, as it helped in understanding the limits of the typical approach of targeting "generic '' high-cost areas that includes all patients, such as reducing readmission. (Porter & Lee, 2016))

The crowded field of performance measurement, marked by multiple players and a proliferation of indicators has led to a situation that has been described as "indicator chaos" (Saskatchewan Health Quality Council 2011). In practice, the focus on measurement has taken hold and indicators have multiplied, from a holistic point of view, there has been inadequate focus in developing an overarching logic for this activity of measurement indicators a consistent purpose, common standards, coordination, and coherence.

How could the provincial level system stakeholders contribute towards regional level shifts in policymaking that act as feedforward loops maintaining the feedback loops that help in reducing system fragmentation considering from a pan-Canadian strategic framework lens?

Continuity of Care as a phenomenon across levels of care and practices

Complex care needs result from a combination of co-existing chronic health conditions, which requires support from multiple healthcare and social services to manage treatment, symptoms and activities in daily living (Barnett et al., 2012). The current design of healthcare and social care systems does not meet the needs of people requiring multiple, integrated interventions. At a broader level, discontinuities in healthcare and related social services can result in fragmented rather than integrated care. One of the core qualities of primary care is considered to be continuity of care (CoC), where care integration involves several challenges concerning organizations and managerial aspects, as well as aspects related to coordination and team collaboration (Van Servellen et al., 2006; Uijen et al., 2011; Gjevjon et al., 2012; Flink & Ekstedt, 2017; Oksholm et al., 2018; Kneck et al., 2019). Many overlapping terms such as integration of care, patient-centred care, case management and coordination of care are found in the healthcare literature which are used to define CoC.

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Two main aspects of a continuing relationship with a family physician which are managing and maintaining a continuing relationship with a regular physician is associated with an increased likelihood of receiving preventive care, keeping follow-up appointments, compliance with prescribed medications, shorter hospitalizations, lower health care costs and more effective health promotions and disease prevention. There are predisposing factors which exist before the onset of illness and create a greater propensity for some patients to use more services than others.

Hennen (1975) first described the concept of continuity of care (CoC) having 4 domains: chronological or longitudinal (the repeated use of patient observations over time as a diagnostic and management tool), informational (the availability of accurate information from one health care encounter to another), geographic (care of the patient in a variety of locations) and interpersonal (the physician-patient relationship). Since then, the concept of CoC has developed to include the dimensions of interdisciplinary (the management of several body systems and diseases at the same time) and family (knowledge about understanding of the patient and his or her family) continuity of care. In the large Ontario healthcare system, continuity of care is primarily recognized as the continuous provision of care between levels of attention to the patient, from primary to secondary and specialized care, or in this case, between age ranges, where care provision and payments are associated with different providers and case types.

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At a broader level, discontinuities in healthcare and related social services can result in fragmented rather than integrated care. To counteract fragmentation of care, a conceptual framework was developed by Valentijn et al. (2013), which consisted of a combination of functions of primary care with dimensions of integrated care. According to this framework, both vertical and horizontal integration are needed. The dimensions of integrated care are structured at macro (system), meso (organizational) and micro (clinical) levels. The needs of health-seekers across the continuum of care could be accommodated through macro level tailored combinations of structures, processes and techniques.

Methods

Dervin Sense-making Methodology (SMM)

The research design adopted Brenda Dervin's sense-making methodology which comprises a meta-theory, methodology, and a series of research techniques. SMM mainly incorporates a rigorous and descriptive method for interviewing and discerning experience patterns, while also mapping to a theoretical framework that guides analysis of participant data and assessment of its meaning. Here sense-making assumes there is something systematic about individual behaviour when the individual is reconceptualized not as an entity but as an entity behaving at a moment in time-space (Foreman-Wernet, 2003). In most general sense, the methodological approach that is called Sense-Making is an approach to studying the constructing that humans do to make sense of their experiences. A central assumption behind this approach is that communicating activities, the verbs of communication, can be explicitly tailored to communicative purposes. These mainly investigates how people pursue goals and make sense of events, develop mental models and interpret data in problem solving and how people in organizations form a collective understanding of situations. Also, this approach integrates a method of experiential enquiry- an interview and analysis method that provides a research framework for addressing questions of the individual's encounter with resources and information in his or her negotiation of everyday complexity.

Based on the assumption that the individual constructs ideas of specific moments, the constructing's themselves could be strategies. Mainly constructing's are repetitions of ideas used in the past and sometimes newly created because of how the individual defines a new situation which has been never experienced by them. Further, it is assumed that the individual will implement his or her picture using behavioural tactics which are responsive to the individual's ideas use of information and information systems are responsive to the situational conditions as defined by that individual. (Foreman-Wernet, 2003). In essence, the individual defines and attempts to bridge discontinuities or gaps. The focus relies on the gap-defining and gap-bridging which is seen as offering a way of introducing order to conceptualizations of individual behaviour. It is not the individual entity that is seen as ordered but rather the gap-defining and gap-bridging that is ordered.

According to Dervin (1999), the methodology as a way of inquiring into the authentic experience of informants from their perspective, in their own words and related to their own purposes:

The point is that Sense-Making aims to arrive at a useful understanding of human sense-making to be used in the design of information and communication systems and procedures. In method, then, Sense-Making asks actors if they bridged gaps and how. The how is not constrained: actors are explicitly asked what emotions they felt, what feelings they had, what ideas or conclusions they came to; and actors are asked how each of these helped and/or hindered.

Sharp End of the healthcare system

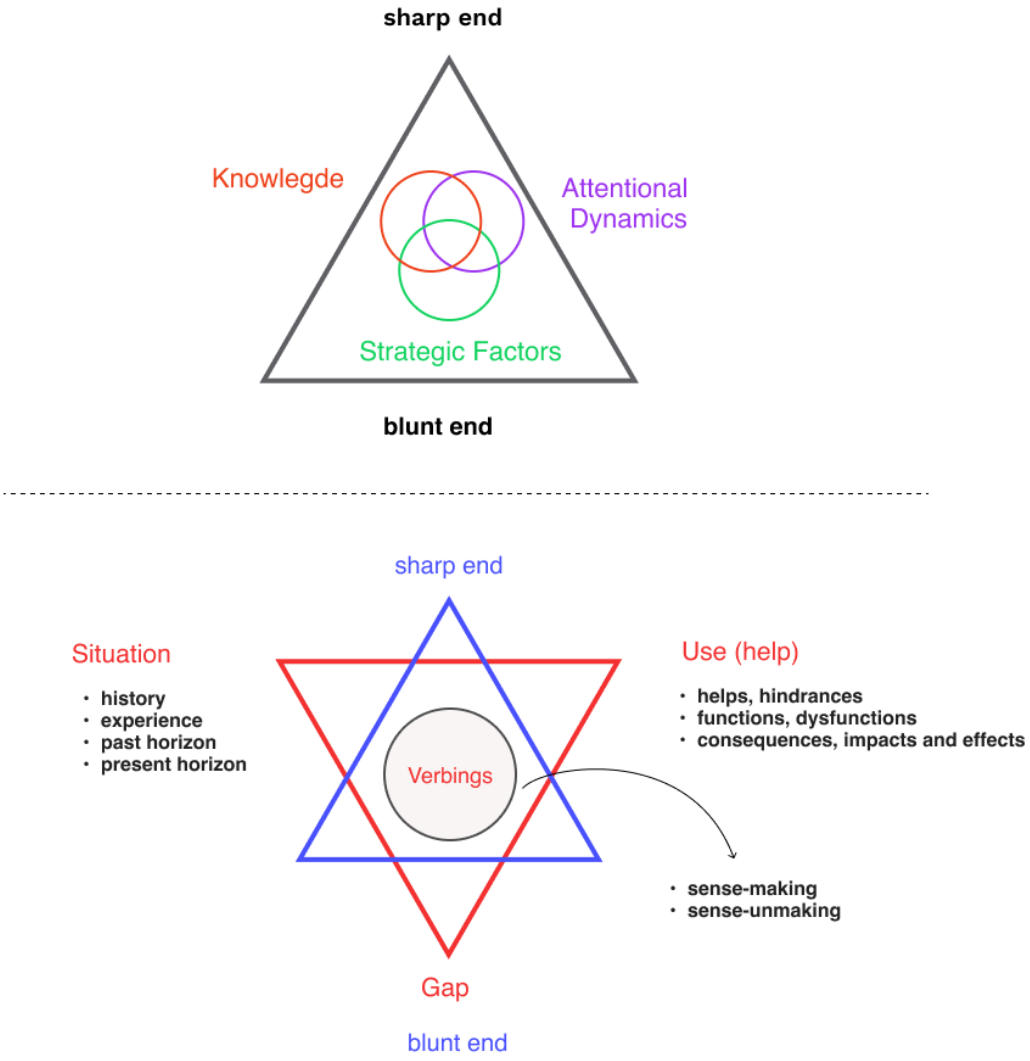

Figure 2: Composition of blunt and sharp end with SMM.

According to Cook and Woods (2018), practitioners at the sharp end usually interact and operate with the hazardous process in their riles as pilots, physicians, spacecraft controllers, or power plant operators. In medicine these practitioners could be the anaesthesiologists, surgeons, nurses and few technicians who are physically and temporally close to a patient. While at the "blunt end" of the system, safety is mainly affected through the systems effect on the constraints and resources that majorly impact the practitioners at the sharp end. On the other hand, the blunt includes managers, system architects, designers and suppliers of technology.
In medicine, the blunt includes government regulators, hospital administrators, nursing managers and insurance companies (Cook & Woods, 2018). In order to understand the sources of errors at the sharp end where mainly the healthcare providers work, it must be understood that proper examination of this larger system shall be conducted, and it

shall be of greatest concern to see how the resources and constraints at the blunt end shape the behaviours of practitioners situating at the sharp end.
Meanwhile, broad class of factors arises from the blunt end of the system and includes the resources and constraints under which the practitioners function. Earlier studies on human error had recognized the importance of the organizational context in system failures (Cook & Woods, 2018). This context influences both the physical and cognitive resources available to practitioners as they deal with the system.
The highest-level goal a practitioner is to protect patient safety. But that is not the only goal. Also, there are other goals, some of which are less explicitly articulated. These goals might include reducing costs, avoiding actions that increase the chances of being sued, maintaining good relations with the surgical service, maintaining resource flexibility to allow for handling unexpected emergencies and others (Cook & Woods, 2018).
In Senders (1993) view, an error can only occur if there was or should have been an appropriate intention to act on the basis of a perceived or a remembered state of events and if the action finally taken was not that which was or should have been intended.

Recruitment

Ethics approval was obtained from the OCAD University Research Ethics Board on November 10, 2023. Recruitment was procured utilizing email scripts (see Appendix C), and responses were followed up on an individual basis. Recruitment criteria during this initial phase included family practitioners and general physicians providing care to adolescent and young adults with complex care needs in Toronto, Ontario and surrounding cities including Hamilton, Kingston and Brampton. Participants were purposively sampled, and potential participants eligible for the research study were further sampled and recruited through snowballing technique. The participants were outreached and recruited through email. The consent form was provided along with email communication which provided a greater transparency for the healthcare practitioners, meanwhile, fast tracking the recruitment process.
More than 20 participants were purposively sampled based on the scope of their practice that met the criteria for the research study. These included academic care practitioners, emergency family physicians, nurse practitioners and providers practicing internal medicine. Only 5 participants agreed for a 30-60 min semi-structured interview. The participants were recruited from major hospitals located in Greater Toronto Area and mainly were part of a family health team. In addition, practitioners associated with hospitals that provided sub-speciality care for paediatric patients with complex care needs were also approached.

Participants

A total of five participants agreed to take part in the research study. Most of the participants had a background in providing primary care as family physicians. Out of five participants, four were practising family physicians (FPs) working mainly in a family health team (FHT) model and emergency care department, while the other participant nurse practitioner provides sub-speciality care for neonates at a research-intensive hospital providing child and family centred care across Canada. The care providers mainly practised across different hospitals located in the Greater Toronto Area and Brampton.

Characteristic	Number of participants
Gender	
Male	3
Female	2
Years in practice	
Primary practice Activities	
Primary Practice Setting	
Family Health Team	3
Emergency Department	1
Neonatal specialist care	1

Table 1: Voluntary basic participant practice and demographic background information

The research study employed a cross-case study approach that allowed for in-depth exploration of complex continuity of care (CoC) issues faced in real-life practice settings. This method was specifically selected for exploration of the CoC phenomenon experienced by the adolescents and young adults (AYAs) when transitioning from paediatric to adult healthcare service system. This included understanding the patient's episode of care through a care providers perspective and experiences generally 'to investigate contemporary phenomena within its real-life context' (Yin, 2009).

Data collection and analysis

The research design incorporated several methods of iterative and collaborative data collection and analysis. Data was primarily collected through semi-structured interviews with an average length of 30-45 mins collected between November and December 2023. The semi-structured interview guide incorporated neutral questioning which was adapted based on the SMM framework (Dervin, 2003). Additional information was gathered through email correspondence based on an initial analysis of interview transcripts.

Coding began with the first set of collected data, from which a code list was identified. These codes were categorized into themes related to participants' experiences of providing care while interacting with the levels of healthcare system: (1) primary care; (2) secondary care; (3) tertiary care. Initial codes were developed based on an opportunistic coding method developed based on the inductive grounded technique to analyse data. The constant comparative open coding approach was practiced while using the research question as a guide for analysis of data. Initial group of codes helped in development of set of questions which were unique to each of the participants. This set of additional questions were mainly developed to further understand the phenomenon of research problem inquiry. Identified themes and codes were summarized in a preliminary summary of findings which informed further development of additional set of question unique to each participant.

Findings

The findings from this research address the calls to engage youth in developing a more informed understanding of their experiences and preferences with digital mental health interventions. To showcase participants' experiences and preferences with digital mental health interventions, the findings are categorized by themes related to the youths' use journeys: (1) Systemic Barrier to care, (2) Local and regional care provision and (3) Finding relief.

Systemic Barriers to Care

Social Determinants of Health (SDH) was considered to play a major role in health-seeking behaviour, thus impeding access to comprehensive care. Multiple non-medical factors influence the health status and health seeking behaviour of adolescents and young adults (AYA). Socioeconomic factors could be considered to have a major impact on the health status of an AYA with complex care needs.

"Countries that have more developed, educated populations, better access to food, shelter, clean water, right, often those people are healthier in Canada. Again, fortunately, things are relatively consistent, but even within that, but there's a big disparity", Family Physician A

Further, SDH could disrupt the care seeking behaviour while unable to access a family physician. The drawback of not having a FP who provides continuous care may give rise to seeking episodic care which is usually driven based on need. Though needs-based care could be achieved by accessing the Walk-in clinics, this further entails paying fee-for the services that health seekers end up using. It could be also considered that socioeconomic factors contribute to a needs-based care seeking behaviour. While AYA's also visit the Emergency department for episodic health needs, this entails loss of health record and instances when the AYA experiences trust issues.

"I think most of the paediatric patients I see are for episodic things, meaning that they are sick, and they come in. So usually flu, like stuff cold cough there, you know, vomiting, diarrhoea, things like that", ED Family Physician.

"I think for episodic care, it's pretty much driven by need", ED Family Physician.

"I think it becomes a little bit more difficult in terms of mental health things because they are going through a transition from like childhood and dependence to adulthood and independence. Some of the mental health concerns that they have, at least from my experience, I've been things that they're not so comfortable sharing with. Some of them trust the adults in their world. So, at a walk-in clinic we will see kids, teenagers, who might have a family doctor but don't feel comfortable talking about things that disclose their sexual identity and things like that", ED Family Physician.

Adolescents not rostered with a Family Health Team (FHT), or a family physician is compelled to seek episodic care at the Emergency Department, which further leads to breakdown in continuity of care. It was found that FHT's are provided with limited

resources to capitate new patients, which is another major factor that impacts care continuity, as a result AYA's seek urgent and need based care at private clinics or ED's.

"Then you know the only real part of all of these healthcare resources that are available that I can control is the allocation of my time.", Family Physician C

Walk-in clinics are based on Fee-For-Service model, which requires individuals to pay for services that have been rendered at the point of care. While AYA's experiencing financial hardships will have increasing difficulty to pay for these services, which fundamentally impacts and delays seeking care. Unable to access care from a family physician involves delayed referral to a specialist for acute care.

"I think the availability of counselling and psychotherapy is the single biggest problem. You know, medicines in Ontario are covered up until the age of 24. So, I can prescribe anything, and you know that will be available to people for free. It is not true that there is widely available counselling and what is available is often difficult to access. The service is limited, so there's a long wait list. I'm practically speaking, unless young people have parents who are going to pay for it, people cannot afford $200.00 an hour for counselling. You know, it's just a huge barrier", Family Physician C

"But we know that here you can't go directly to specialist", Family Physician C

"There's no refer to family physician - that unfortunately also doesn't exist.", ED Family Physician.

While breakdown in continuity could result from multiple systemic factors that majorly influence a AYA's care seeking behaviour, this could result in low adherence to the care plan prescribed by an ED physician. Failing to keep a record of patient history and the prescribed medication or care plan at an ED, further propagates episodic care seeking behaviour. The developmental needs of an AYA, necessitates for maintaining relational and informational continuity, which could be achieved when rostered with a family health team that provides comprehensive development care.
"We do see people frequently in the emerge that have maybe been there before, things didn't really get better with whatever treatment was prescribed", ED Family Physician.

"Your child's going to be 17 1/2 like. Have you made these applications yet? Do you know why you need to make them? So, I think that there's lots of systemic things, I think that Ontario has a good health care system, but some of the some of the, some of the systemic things don't make a whole lot of sense, right? Like why there's so many different agencies that don't talk to one another in terms of funding models and that which I'm just learning", Nurse Practitioner.

"Why do they have to tell this person this person and this person the same thing? Why can't they just have told one person and then it notifies like a system? It's like everything's computerized, right? So, why do parents have to enact certain things when they're told they're eligible for funding? But unless you make a certain phone call, they will give you the funding. Like, why? Why not?", Nurse Practitioner.

“Probably and lots of in a very low socioeconomic status for the patients because we ask questions about socioeconomic status and quantify it. So low income. yeah, that's the practice,... I think some of the most complex patients, like people who are marginally housed and were older and had multiple illnesses, some of them have passed away. Unfortunately, maybe they've disengaged in care. Some of them have died, sadly, and so the most unwell patients probably are not part of the practice. Some patients have been like successful from a like a like a pop culture kind of perspective like they've done well. They've moved out of their apartment and Regent Park, and they've moved to Brampton primarily, and they bought houses in Brampton. So, lots of healthy young families have moved from Bangladesh, have bought houses in Brampton”, Family Physician B.

Scope of Care

The family health team (FHT) is a care model which includes several healthcare providers who work together providing community-centred primary care services. Main function of FHT is to provide care to an individual from birth to end-of-life. These teams provide primary care services based on local health and community needs which encompasses health promotion, disease prevention and chronic disease management. Though FHT provides care for the full spectrum of life, it could vary based on the demographic distribution of individuals in a community. Main characteristic of the FHT care model is providing comprehensive care. While FHT is a type of care model providing comprehensive care, on the other hand care comprehensiveness could be associated with operational functionality of “continuity of care” as a care model.

“Like it's not that the family doctor must do everything, but a lot of education and things can be done by other members of the team. So, as you may have learned, not every family clinic is fortunate to work in a team model”, Family Physician A.

“So first, I think most of the paediatric patients I see, I'll be honest, have followed me from the get-go, right, they're born, I see them. I know them”, Family Physician A.

Though FHT’s provide comprehensive care to communities, however, clinics providing primary care which are not enrolled into this model of care, could render services inefficient as the health-seeker might not avail continuous care from a single point of care, rather experience breakdown in relational and informational continuity.

While failing to enrol into a Family Health Team model means that health-seekers in need of specialized services might experience fragmented care, as it was reported that patients seeking episodic care at the Emergency Department are usually referred to a specialist care provider. While the required time to see a specialist from the time of referral by an ED physician takes longer than a family physician enrolled into a FHT model.

Social determinants of health were reported as another factor that impedes longitudinal care accessing behaviour. The inaccessibility to seek care resulted in fragmentation of rapport building with the patient throughout their life span. This shall lead to broken care continuity and unfamiliarity with patients through their care seeking journey across points of care. While health seeking at points of care entail effective

communication across levels and departments of care, building of trust during the referral process was found to be critical for maintaining patient rapport.

Maintaining and building continuous rapport with patients could be also hindered based on their health-seeking behaviour. Patients seeking sporadic care usually visit the Emergency Department, which breaks the continuous flow of health information between care levels and providers. Seeking sporadic care at ED could also mean inaccessibility to see a primary care provider enrolled into a family health team model. Maintaining longitudinal patient history is difficult when seeking sporadic care at an ED, mainly due to the time constraints experienced by a general practitioner. Though ED's serve a host of patients, either insured or uninsured, who use the ED for nonurgent primary care because doing so is faster, cheaper, or more convenient than scheduling an appointment at a clinic or private practice.

"I guess in the episode you're not getting a lot of new information. It's built on kind of a longitudinal relationship you have with that person", ED Family Physician.

"The other piece is do they have access to the family Doctor, paediatrician or not? And if they don't? coming back to the emerge again could be a bit difficult, maybe not relevant for their condition. Maybe it is, but we may refer them to clinics within the hospital, for example, that if they had a family doctor paediatrician, we wouldn't have to", ED Family Physician.
"I mean, there's no refer to a family physician that unfortunately also doesn't exist. They can go to walk-ins if they want", ED Family Physician.

"You know that's a big part of family medicine practice. Is this sort of socioeconomic and demographic context in which people operate, because of course, that has a massive contributor to their mental health", Family Physician C.

"I think those questionnaires are very helpful because in the first two minutes you get a pretty good sense of what's going on", Family Physician A.

"You know typically diagnosis are approached and then whether they need ongoing follow up right. So sometimes you might see somebody you Give your opinion cares, transferred back to the referring provider. Sometimes you keep seeing families and then they're transition to adult services. Adult specialty services, right, we don't do primary care at SickKids. So, everything is like referred", Nurse Practitioner.

Local and Regional Care provision

Practitioners reported time constraints to be a major impeding factor when providing care longitudinally. The main factors which were critically important for comprehensive care provision entailed maintaining relational and informational continuity. These aspects of continuity are critical when a AYA transitions through levels of care and care practices. Patients referred to a specialist usually consult with their family physicians as the continuity of trust if not established when referred to a specialist or a sub-specialist.

"So, she went to SickKids Hospital, where she is in consultation with a paediatrician in the community who's a paediatric neurologist (brain specialist). But now they're

working on how to transition her to an adult neurology clinic. So not only is this transition happening at primary care, but this is happening in specialties too", Family Physician A

"There's nothing really in writing at my institution, at least. And it's an emerge.", ED Family Physician.

"Like it's a resource intensive for healthy kids to see paediatricians. So that's sort of interesting.... Like lots of babies will never see a paediatrician, but if you do see a paediatrician, then the ones that have successfully come over to me are people where the paediatrician knows me personally. Like I've trained under them, and they say that the team, oh, I know her. She's so nice. I would imagine it would say something like that and then they help book the appointment and it's very cozy and easy. I think that helps. And then the patient comes in with a little bit of trust because otherwise they're suspicious of you potentially. But that's sort of a neat trick that I've seen the paediatricians do, or it's apparent where the parent is at my patient. And then I start seeing their kid. And then the parent can say, oh, this doctor is OK. I think that's helpful. So that's kind of interesting", Family Physician B.

Characteristics of Care practices

While care provider adaptability can be considered as a corner stone of primary care practice considering that adolescents and young adults have pre-assumed intentions different from a primary care provider which guides their care-seeking behaviour and is mainly based on subtle values which are concurrently influenced by the SDH factors. The study also found that FP's booked extra appointments to understand the values that guided AYA's care seeking behaviour. Booking extra appointments helped to establish an interpersonal and reciprocal relationship between the care providers and the health-seekers. Building of trust and rapport with paediatric patients and their family members was found to be main tenets of primary care practice.

"I think you go in with expectations that it'll take some extra time maybe to find the right care plan that matches what their values, so I think just making more appointments and trying to be more patient", Family physician B

"They really would love to have a drop in kind of Open Access mode is my impression, because teenagers don't necessarily plan ahead super well and maybe they'd have a problem tomorrow and they want to be seen that hour. So, if our if our setup was more like walking clinic Open Access casual that would be great for them", Family Physician B

"You hear from them like, yeah, no, I can't afford tofu, or, like, I can't afford more meat when you're figuring out why their iron is low. So, I guess you just keep an ear out and you learn that way and you try to naturally gather information and feedback like culturally appropriate support", Family physician B.

"So many of the appointments we have are based like they're preset based on the kid's age. Now, if their child has an illness or they get a respiratory illness or some problem or eczema, you know anything comes up. You know, parents might book additional

appointments if they don't feel they can wait until you know what I mean. Like the appointment for the vaccine", Family physician A.

"I guess in the episode you're not getting a lot of new information. It's built on kind of a longitudinal relationship you have with that person", ED Family physician.

"So, if we suggest, for example, that someone takes medications, they may not take the medications. It's not because they can't afford them. You know that is actually not a problem for young people and in Ontario. But people may not want to, or people may have side effects of medications. And then stop them right away. And I, you know all I can do is try to provide close follow up. Try to, you know, take people's context into consideration. And so, the use of, you know, close follow up I think is an important intervention here", Family Physician C.

"I think like all patients like they're not that different like they follow care plans about as well as like an old guy would follow care plans A and so I think you go in with expectations that it'll take some extra time maybe to find the right care plan that matches what their values, so I think just making more appointments and trying to be more patient", Family physician B.
"So, I think making sure that you have a support system to help you with that. Because I think people talk fast, I think people use complicated medical language and I think it must be a very scary sort of place to be. So, I know that we have some resources that are available to people, but like I'm sure there's a lot of people who don't access things just because they don't know, and nobody's ever told them", Nurse Practitioner.

"The patient that chooses to go to the ER detracts from continuity, but it is really what drives them away from 'continuity' options that detracts. I also caution that continuity as we understand it often conflates relational and informational continuity", ED Family Physician.
Discussion

The Cynefin a sense-making framework, which means that its value is not so much in logical arguments or empirical verifications as in its effect on the sense-making and decision-making capabilities of those who use it a sense-making device which was developed to help people make sense of the complexities made visible by the relaxation of these assumptions.
The Ministry of Health Ontario represents the landscape, while the primary, secondary and tertiary care, and community health care is considered here to represent the regime level. Considering, that regime level in Ontario Health system Niche Level represents actors from different care levels and services provided to adolescents and young adults, further presenting the relationship shared amongst different actors at the level of providing care while adapting actor-network theory.

According to Rotmans and Loorbach (2009b), transition management involves stimulating niche development at the micro level. The research findings have identified that intervening through strategies at the niche level will help the level of care practices to provide continuous care not only to a particular age group transitioning from one care practice to another, but also provide transitional support that enables for continuous care provision at different levels of care, further, finding new attractors at

the macro level. When looking from a multi-level perspective model, macro level here represents the Ministry of Health Ontario. Considering that niche level development will be the strategic intervention plan that connects with the attractors at the macro level. Attractors at the macro level shall be the Ministry of Health which acts as an enabler for institutional change based on the institutional sensemaking (integration of care pathways) amongst actors situating at the micro level. The intervention plan acts as a transition pathway in-between the micro and the meso level informing the macro level (MOH) as a type of transitional image.

A transition from the chaotic to the complex is a matter of creating multiple attractors, or swarming points, around which un-order can instantiate itself, whereas a transition from the chaotic to the known requires a single strong attractor (Kurtz & Snowden, 2003)

The Ontario Ministry of Health represents the landscape, while the primary, secondary and tertiary care, and community health care is considered here to represent the regime level. Considering, that regime level in Ontario Health system Niche Level represents actors from different care levels and services provided to adolescents and young adults, further presenting the relationship shared amongst different actors at the level of providing care while adapting actor-network theory.

"Cognitive abilities do not reside in 'you' but are distributed throughout the formatted setting, which is not only made of localizers but also of many competence-building propositions, of many small intellectual technologies", (Latour, 2005, pg 211).

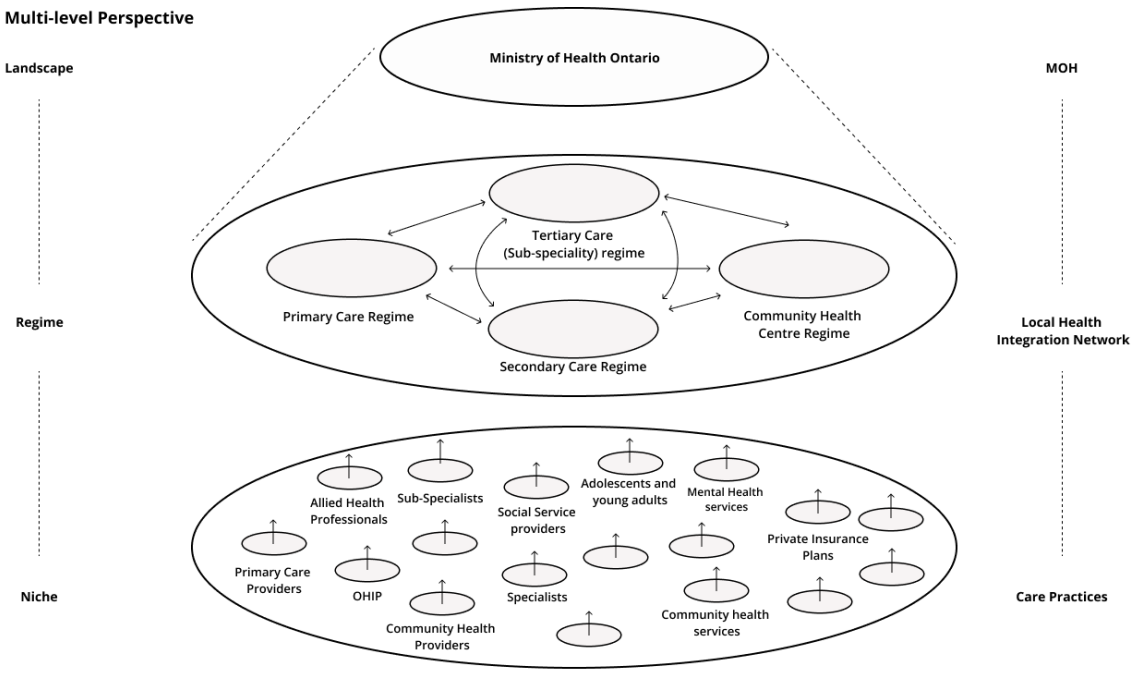

Figure 3: Transitional change through service-system levels

Limitations

The challenges of time and resources were the most significant limitation of this research. The main challenge of working as only researcher had wider implications for the recruitment process, which had to overcome and resulted in low sample size. Recruitment delays resulted in timeline shifts, which meant holding the expert interviews near the end of the year when participants usually experienced busy schedules at their workplace, resulting in low response to the recruitment conducted. Due to the shortened project timeline when considering the scope of the research, only semi-structured interviews as narrative inquiry to understand the relationality of were facilitated. Additional, co-design workshops could have been initiated that would have further fostered increased engagement and helped propose intervention strategies for successful CoC transitions in a primary care context.
Family Physicians with ties to academia showed developed interest in the study, which may have affected the recruited participants dynamics, in terms of participants willingness to discuss topics related to organizational factors affecting physicians' decision-making.

Conclusion

Continuity of Care as a phenomenon could be experienced at different levels of care and care practices in the Ontario Healthcare system which may further differ in relation to the scope of practice (SoP) and variation in clinical activity based on environmental and demographic factors (Wenghofer et al., 2018).

While gaps in access to care were identified which results in fragmentation of care as a service provided at the level of primary care. The primary care providers are bounded to provided limited service or extend the scope of their services due burgeoning constraints in terms of resources is encountered when providing complex care to adolescents and young adolescents in Ontario Health care system.

Further, the study recommends for co-designing and development of intervention strategies while identifying leverage points which will enable care providers at different levels of care to form a coalition that informs scope of care continuity for AYA's transitioning with developing complex care needs. The resulting intervention strategies resulting from the co-designing session will increase the standard of care not only in the milieu of primary care but also reduce shifting the burden experienced at this level. Not only this shall enable for better continuity care approaches and increase interprofessional accountability for AYA's transitioning. However, for an integrated approach to be successful steps need to be taken to make sure mental health care is made available to all through public health coverage.

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Appendices

Appendix A: Semi-structured interview guide

Introduction

Thank you for agreeing to participate in this interview. I will be interviewing you to better understand the experiences of care transitions for young adolescents diagnosed with chronic diseases and having complex health care and social needs. There is no right or wrong answers to any of our questions, I am interested in your own experiences while providing care to young adolescents.
Participation in this study is voluntary and your decision to participate, or not participate, will not affect your clinical practice. The interview should take approximately half hour depending on how much information you would like to share. With your permission, I would like to audio record the interview because I don't want to miss any of your comments. All responses will be kept confidential. This means that your de-identified interview responses will only be shared with research team members, and we will ensure that any information we include in our report does not identify you as the respondent. If any additional information is required that helps to inform the credibility of the research study, you may provide it over email. You may decline to answer any question or stop the interview at any time and for any reason. Are there any questions about what I have just explained?
May I turn on the digital recorder?

Background

Tell me something about your practice… how long are you practicing here?
(In case of long practice) How different this area was when you started the practice?
Collect basic demographic data of participants (gender, age, years of practice, field of specialization)
What are the usual reasons for which paediatric patients seek care?
Questionnaire

What are the factors that help you to access the situation of the patient? Could you elaborate? For example, their socio-economic, socio-cultural, and eco-psycho-social factors influence their health.
Could you walk us through the steps that you follow to understand their medical condition? How do you adapt to understand different health-seeker cases?
How do you understand their lifestyle choices? And how do you form a correlation between these lifestyle choices and the medical condition under investigation?
Do changing circumstances also affect their health condition? Could you explain the appropriate measure you took in order to understand these circumstantial changes affecting their health condition?
How do you measure their value for a healthy lifestyle? Could you explain the process you followed to understand these values?
Did you experience any setbacks or constraints while providing care to these young adolescents? How did you recognize and revised your caregiving plan?

Could you walk us through the revised caregiving plan when experiencing these constraints in the healthcare system? Also, if you could let us know what measures you took were different?
If you could explain the follow-up procedure with young adolescents?
Do all young adolescents adhere to the care plan? If they do not, what changes are required on your end and how do you implement this change in the care plan? Could you also explain the factors that you consider while modifying the care plan?

Appendix B: Set of additional questions developed based on initial synthesis of collected data.

Academic Family Physician A

What are the primary measures undertaken by a family health team to provide continuous care to a young adolescent experiencing social determinants of health issues - e.g. if a patient experiences barriers to obtain prescribed medications?
What aspects of rescheduling an appointment are sensitive to continuity breakdowns-e.g. if a patient transitions to a different level or place of care?
What conditions are favorable to establishing trust with young adolescents and what resources are entailed while forming an interpersonal relationship-e.g. if patients fail to adhere to a care plan?

Emergency Family Physician

What aspects of episodic care are sensitive for a follow-up procedure at the Emergency Department (ED) - e.g. if a patient with chronic disease is not rostered with a family physician?
What are the contributing factors that may help or impede providing ongoing care - e.g. patients seeking sporadic care for ongoing conditions via the Emergency Department?
How does the referral process unfold for patients seeking acute episodic care at ED - e.g. if patients diagnosed in ED must be referred to a family physician or specialist?

Family Physician B

What aspects of care planning are more sensitive to continuity breakdowns - e.g. if a patient transitions to a different level or place of care?
What are the factors that may help or impede the follow-up care provision - e.g. if patients are experiencing social health determinants?
How efficient is follow-up care and what resources does it entail in a primary care department - e.g. if a patient is referred to a specialist or fails to adhere to the prescribed care plan?

Family Physician C

What aspects of care planning are sensitive to continuity breakdowns - e.g. if a patient needs social assistance?
What are the factors that help or impede in acquiring resources by a family health team for rostering patients seeking urgent longitudinal care?

What aspects of referral are critical for follow-up care by the family health team- e.g. if a patient is referred to a specialist?

Nurse practitioner

What aspects are sensitive when providing holistic care - e.g. if a patient is seeking care at a community health center as compared to SickKids?
How does SickKids provide transitional support to patients seeking episodic care? How is ongoing support provided to these categories of health-seekers?
What factors help or impede specialty continuity of care when patients are transferred from specialty to specialty or sub-specialty care departments?

Appendix C: Informed Consent form for Narrative Inquiry/Semi-Structured Interview Participants

Project Title: Exploring Continuity of Care as Clinical Service Transition Design

Principal Investigator: **Student Investigator:**

PURPOSE & DESCRIPTION

This research study is for a graduate Major Research Project at OCAD University that aims to explore the gaps in continuity of care in adult therapy transitions within the Ontario health system from the clinical perspective. We are interested in the systemic factors that influence clinical decision-making and aim to analyze the transition of care process for young adolescents into young adulthood. We expect the findings to benefit patients in the health system by sharing a systems analysis of factors that underlie the discontinuities in care transitions and design recommendations for their resolution. The research will collect and analyze contributions of best practices they have employed when providing care to these individuals. The knowledge gathered will help to map the care transition pathways in the Ontario healthcare system. In turn, this will allow the researchers to propose a service or policy intervention plan that leverages the insights gathered through the study.

REQUEST

We request your participation for a virtual (Microsoft Teams or Zoom) recorded interview. The interview would take either 30 or 60 minutes, depending upon your availability and ability to contribute to the research at that time. The interview can be tailored based on your time availability. Information collected will be kept confidential by default and your identifying information will not be disclosed.

POTENTIAL BENEFITS AND RISKS

There may be significant benefits to clinicians who participate who would have the unique opportunity to provide insight and feedback leading to improvements in care transitions in young people in Ontario, and to enhance patient and point of care communications. The contribution to this study can benefit other clinicians and patients in the future based on the findings, thus improving patient experience and the

guidelines for many future patients across Canada. Knowledge gathered during the research study could help inform healthcare policymaking by developing pathways for continuity of care. And research could illuminate different approaches applied and practiced by healthcare practitioners for different cases.

There are few risks to participants. A risk of emotional concern or anxiety is always possible when someone is asked to share personal knowledge from their experience. However, the focus of this interview is based on questions of professional practice and not personal experience. There could be a risk of disclosure of internal information about practice in Ontario, which we will aim to mitigate so that unintentional disclosure is avoided.

Participants will be provided a chance to review and confirm their interview transcript before the data is used in analysis. There are no physical risks for this remote interview.

CONFIDENTIALITY & DATA RETENTION

The study will maintain all personal identifying information gathered, intentionally or unintentionally, as confidential. Data collected during this study will be stored on a secured online repository at OCADU, password protected and shared with only the two named researchers. Data will be retained for no longer than 6 months. Summaries of the study may be maintained indefinitely but will not disclose names of participants.

Shortly after the interview has been completed, a transcript will be emailed to you to offer an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. All participants will be provided a copy of the final report when the study is completed.

Data will be kept for the period of investigation till the end of December 2023 after which the data will be anonymized with pseudonyms and retained on OneDrive at OCAD University.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary and completely under the control of you the participant. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time, for any reason. You can elect to allow us to retain the data or request the exclusion or withdrawal of your data in the study.

To withdraw your data from the study, please contact Aakash Bhadra, providing us the reason for your withdrawal from the study no later than 25th November. If you may consider withdrawing from the study, then the next set of procedures will include disposing of the data gathered during the interview.

PUBLICATION OF RESULTS

Results of this study will be published as a Major Research Project report at the OCAD University and may be published as a scholarly article in the future. In any publication,

data will be presented in aggregate. Quotations from interviews will not be attributed to you without your permission.

Audio or Video recording

I agree for the interview to be recorded for the purposes of transcribing accurate data. I understand how the recordings will be stored and destroyed.

I prefer:

Audio
Video
No preference

AGREEMENT

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____ Signature: _____

Date: _____

CONTACT INFORMATION AND ETHICS CLEARANCE

Please contact the student investigator or principal advisor if you have any questions about this study or require further information. This study has been reviewed and received ethics clearance through the Research Ethics Board at OCAD University REB Application 102411. If you have any comments or concerns, please contact principal advisor, listed above.

If you have questions regarding your rights as a participant in this study please contact: Research Ethics Board research@ocadu.ca

Thank you for your assistance in this project. Please keep a copy of this form for your records.