Symbolic boundaries in transition to adult care

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Abstract

Adolescents and young adults (AYAs) experience inadequate healthcare. The relative newness of the field of adolescent care reflects the “in-between” category societies ascribe to adolescents and young adults – in between the innocence and hope childhood represents, and fully formed and “productive” citizens that adulthood represents. AYAs have distinctive bio-social needs that represent a fluid and multi-faceted transition between childhood and adulthood. Previous research has acknowledged health challenges of and service inadequacies for AYAs, as well as perceived differences between pediatric and adult care systems. Yet, little research has explored in detail the perspectives of, and processes engaged in by various stakeholders of adolescent care that enact such differences between pediatric and adult care, and responses to those differences. Such research is needed to understand bio-medicine’s linear response to adolescent health, and what is, in reality, required to care for AYAs into the future. The aim of this research is to explore the multi-level influences and meanings that coalesce around particular communities in the care of AYAs. To do so, the research relies on sociological theory relating to social and symbolic boundaries. Such theory accounts for the way people come to share common perspectives and behaviours that distinguish them from other groups and exercise agency in crossing professional and organizational boundaries. Set within an interconnected health system in a large urban centre of Quebec, Canada, an interpretive qualitative strategy was engaged, featuring 43 semi-structured interviews with young adults, parents, and pediatric, adult, and primary care providers. A thematic approach was used to analyze narratives between and within the different groups identified. The findings show that the transition from adolescent to adult care involves two fundamentally different cultures of care that can collide with each other. Pediatric care is rooted in the family and the emulation of a safe, home-like environment, while adult care focuses on the autonomous individual and their ability to care for themselves. Intergroup differences and tensions impede patient transfer, most typically by slowing it down and disconnecting patients from the specialized care to which they had been accustomed. In response, the professionals who comprise health organizations, and patients and families, extend their boundaries to manage the challenges of transition from pediatrics to adult care. In their informal work, they reflect and create interdependence in the form of coordinated health corridors that form practice structures for colleagues to follow. Nevertheless, such processes, reliant on the goodwill of individuals rather than being institutionalized, have limited impact in terms of penetrating strong service boundaries to coordinate care for AYAs, sustainable knowledge transfer and shared experiential learning within and across professional and organizational boundaries. Furthermore, the generalist equivalent of pediatricians for adult care – family physicians and primary care professionals – perceive and are perceived as not being sufficiently integrated, and therefore do not benefit from being recognized as part of the process. Through informal work and the resulting corridors of care, actors involved in transitional care adjust their identities and render boundaries more permeable, fostering organizational learning, and structuring new norms in the adult care system. The resulting adaptive regulation models sustainable structures and, hence, paves the way for reforms to more formally institutionalize optimal transitional practice structures from adolescent to adult care. The focus on boundaries, perceptions, identities, processes and meaning-production shows the adaptive strength of actors, individually and collectively, and the lack of institutionalization of practice that hinders the sustainable delivery of adolescent-friendly health. These findings underpin advice for future researchers, healthcare providers and policy makers to undertake work to redress the fragmentation of current approaches and interventions to AYA healthcare, guide new models, and improve practice for families, healthcare providers, and organizations to better serve the health needs of vulnerable and marginalized populations more broadly.

Résumé

Cette recherche explore les défis et les dynamiques des soins de santé pour les adolescents et les jeunes adultes (AJA), une catégorie souvent négligée entre l'enfance et l'âge adulte. Les AJA reçoivent des soins de santé inadéquats. La relative nouveauté du domaine des soins aux adolescents reflète la catégorie d’"entre-deux" que les sociétés attribuent aux adolescents et aux jeunes adultes – entre l'innocence et l'espoir que représente l'enfance, et les citoyens pleinement formés et "productifs" que représente l'âge adulte. Les AJA ont des besoins bio-sociaux distinctifs qui représentent une transition fluide et multifacette entre l'enfance et l'âge adulte. Des recherches antérieures ont reconnu les défis de santé et les insuffisances des services pour les AJA, ainsi que les différences perçues entre les systèmes de soins pédiatriques et adultes. Cependant, peu de recherches ont exploré en détail les perspectives des différents acteurs des soins aux adolescents, les processus qu'ils engagent pour mettre en œuvre ces différences entre les soins pédiatriques et adultes, et les réponses à ces différences. De telles recherches sont nécessaires pour comprendre la réponse linéaire de la biomédecine à la santé des adolescents, et ce qui est réellement requis pour prendre soin des AJA à l'avenir. L'objectif de cette recherche est d'explorer les influences et les significations multi-niveaux qui se regroupent autour de certaines communautés dans les soins aux AJA. Pour ce faire, la recherche s'appuie sur la théorie sociologique relative aux frontières sociales et symboliques. Cette théorie explique comment les gens en viennent à partager des perspectives et des comportements communs qui les distinguent d'autres groupes et exercent leur capacité à franchir les frontières professionnelles et organisationnelles. Située dans un système de santé interconnecté dans un grand centre urbain du Québec, Canada, une stratégie qualitative interprétative a été engagée, comprenant 43 entretiens semi-structurés avec de jeunes adultes, des parents, et des prestataires de soins pédiatriques, adultes et primaires. Une approche thématique a été utilisée pour analyser les récits entre et au sein des différents groupes identifiés. Les résultats montrent que la transition des soins pédiatriques aux soins adultes implique deux cultures de soins fondamentalement différentes qui peuvent entrer en collision. Les soins pédiatriques sont ancrés dans la famille et l'émulation d'un environnement sûr et familial, tandis que les soins adultes se concentrent sur l'individu autonome et sa capacité à prendre soin de lui-même. Les différences et tensions intergroupes entravent le transfert des patients, le ralentissant le plus souvent et déconnectant les patients des soins spécialisés auxquels ils étaient habitués. En réponse, les professionnels qui composent les organisations de santé, ainsi que les patients et les familles, étendent leurs frontières pour gérer les défis de la transition des soins pédiatriques aux soins adultes. Dans leur travail informel, ils reflètent et créent une interdépendance sous forme de corridors de santé coordonnés qui forment des structures de pratique pour leurs collègues. Néanmoins, ces processus, dépendants de la bonne volonté des individus plutôt que d'être institutionnalisés, ont un impact limité en termes de pénétration des frontières de service solides pour coordonner les soins pour les AJA, le transfert de connaissances durable et l'apprentissage expérientiel partagé au sein et entre les frontières professionnelles et organisationnelles. De plus, l'équivalent généraliste des pédiatres pour les soins adultes – les médecins de famille et les professionnels des soins primaires – sont perçus et se perçoivent comme n'étant pas suffisamment intégrés, et ne bénéficient donc pas de la reconnaissance en tant que partie du processus. Grâce au travail informel et aux corridors de soins qui en résultent, les acteurs impliqués dans les soins de transition ajustent leurs identités et rendent les frontières plus perméables, favorisant l'apprentissage organisationnel et structurant de nouvelles normes dans le système de soins adultes. La régulation adaptative qui en résulte modélise des structures durables et, par conséquent, ouvre la voie à des réformes pour institutionnaliser plus formellement des structures de pratique de transition optimales des soins pédiatriques aux soins adultes. L'accent mis sur les frontières, les perceptions, les identités, les processus et la production de sens montre la force adaptative des acteurs, individuellement et collectivement, et le manque d'institutionnalisation des pratiques qui entrave la prestation durable de soins adaptés aux adolescents. Ces résultats sous-tendent des conseils pour les futurs chercheurs, prestataires de soins de santé et décideurs politiques afin d'entreprendre des travaux pour remédier à la fragmentation des approches et interventions actuelles en matière de soins de santé pour les AJA, guider de nouveaux modèles et améliorer les pratiques pour les familles, les prestataires de soins de santé et les organisations afin de mieux répondre aux besoins de santé des populations vulnérables et marginalisées de manière plus large.

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List of abbreviations

AJA	Adolescents et jeunes adultes
AYAs	Adolescents and young adults
AHP	Allied health professional
CH	Centre hospitalier (*hospital center*)
CHSLD	Centres d'hébergement et de soins de longue durée (*Residential and long-term care center*)
CIUSSS	Centre intégré universitaire de santé et de services sociaux (*Integrated health and social services university center)*
CISSS	Centre intégré universitaire de santé et de services sociaux (*Integrated health and social services center*)
CLSC	Centres locaux de services communautaires (*Local community services centres*)
FMG	Family medicine group
HCP	Healthcare professional
MSSS	Ministry of Health and Social Services
PCP	Primary care provider
PG	Parents-Guardians

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Originality of the research

This doctoral research, conducted by Maud Mazaniello-Chezol, represents an original contribution to the field of healthcare by illuminating the way the transition from pediatric to adult and primary care services for adolescents and young adults with chronic conditions is understood and enacted. Most previous work in adolescent healthcare has focused on healthcare outcomes and care contexts and lacks theoretical framing. The present work builds on previous research by uniquely exploring meanings, processes and identities associated with adolescent healthcare, in terms of the differences and relations between pediatric and adult healthcare. The concept of symbolic boundaries is engaged to deliver such understanding. The research is also unique in exploring the engagement of primary healthcare in the transition process, a critical aspect often neglected in existing studies. By incorporating primary healthcare, the research explores new perspectives, priorities, and solutions that might enhance the overall transition experience and outcomes for patients, addressing a notable gap in the current literature.

Maud Mazaniello-Chézol designed the study, recruited participants, conducted interviews, analyzed the data, and authored the entire dissertation. A research assistant provided verbatim transcriptions of the interviews, which Maud Mazaniello-Chézol subsequently validated for transcriptional accuracy. Dr. Peter Nugus, the PhD supervisor, reviewed the study design, protocol and dissertation, offered insightful comments, and made structural revisions, contributing to the refinement of this work.

The study combines multidisciplinary insights from sociology, health services research and educational studies, and lessons from studies of clinical interventions concerning the development of transition-age youth. This broadly-based strategy contributes to a more comprehensive view of the transition process, encompassing more than only biomedical dimensions. Emphasizing the importance of involving adolescents in the design and development of healthcare services, this research highlights how their input and perspectives can lead to increased uptake and improved outcomes. This inclusive approach is crucial for tailoring services to better meet the needs of young patients.

The study generates new knowledge and offers practical recommendations aimed at improving the transition from pediatric to adult and primary care services. These insights are designed to enhance the experience and outcomes for adolescents and young adults living with chronic conditions, thereby filling a critical gap in healthcare research. By addressing these neglected areas, this doctoral research makes an original contribution to healthcare and health social science research, particularly in the context of transitioning care for young individuals with chronic conditions.

Chapter I. Introduction

Introduction

The importance and inadequacies of adolescent healthcare have come to prominence because adolescents coping with chronic conditions are now facing longer lifespans than in previous decades, owing to medical advances (Badour et al., 2023). Although this population was well known in pediatric care settings, their entry into adulthood and transition from pediatric to adult care requires a fundamental shift in the landscape of pediatric and adult healthcare (Castillo & Kitsos, 2017). This dissertation addresses under-recognized ways that this dramatic change in healthcare needs is managed. What is more, this work addresses how adolescent healthcare is and ought to be understood, as a foundation to improve healthcare policy and practice. Three questions are posed: *How is the transition from pediatric to adult care understood to operate across different stakeholder groups? What are the processes activated to improve the operationalization of the transition? What learning is generated and mobilized?* This chapter presents an overview of the approach of the dissertation, then outlines the unique nature of adolescence, and outlines the chapters of the dissertation.

The unexpected increase in the lifespans of adolescents with chronic conditions has called adult healthcare providers to adapt to this new demographic (Allen et al., 2022; Chafe et al., 2019). In addition to this adaptation from healthcare providers, the transition from pediatric to adult care settings is a complicated process, contingent upon a multitude of factors that do not always correlate with the health stability of adolescents and young adults (AYAs) (Toulany et al., 2022). These factors include AYAs and healthcare professionals' (HCPs) relationships, availability, adequacy, accessibility, collaboration and organization of healthcare resources (Gray et al., 2018; Morsa et al., 2017).

Healthcare systems have largely failed to establish a comprehensive framework to facilitate the delivery of timely and optimal care for the AYA demographic, including the non-biomedical aspects of healthcare (Ghavamabad et al., 2021; Kilbourne et al., 2006; Riley, 2012). Many AYAs experience gaps when transitioning from pediatric to adult care, leading to discontinuation of medical surveillance and follow-ups (Castillo & Kitsos, 2017; Schraeder et al., 2020; Varty et al., 2020). Such discontinuities pose significant health risks to this demographic, portending a deleterious impact on the future of societies (Foster, 2015; Toulany et al., 2022; Varty et al., 2020). This research focuses on the complex challenge posed by the transition from pediatric to adult care, which demands a more explicit conceptualization than has been available of the intricate interplay between healthcare providers, organizational structures, and the unique needs of AYAs.

Adolescent healthcare is the focus of this dissertation, exploring the transition of young people from pediatric to early adulthood. To do so, a sociological perspective is engaged to explore the mechanisms and processes of transition in terms of the symbolic and social boundaries that organize the healthcare system, and other structures with which this system interacts. Furthermore, the mechanisms and processes of transition are seen to emanate from human and social relationships, just as these relationships are in turn affected by the mechanisms and processes of transition. A constructivist approach is put forward to buttress the engagement of this research with the phenomenon of transition of care in the health and social services environments. Constructivism is geared towards unraveling the mechanisms through which a phenomenon is constructed through negotiation of meanings in interaction (Berger & Luckmann, 1991). It explores the processes underpinning this ‘construction’, and identifies the entities implicated in crafting and perpetuating specific interpretations of ‘reality’. A social constructivist approach enables the understanding of social interactions and cultural contexts in shaping individuals' behaviours, learning and interpretations of particular situations (Charmaz, 2014).

Consequently, this dissertation presents a qualitative empirical study to identify and understand the mechanisms of the transition process from one healthcare setting to another, through interviews with various different actors involved in the process. For this research, I interviewed 43 key players of transition care from a pediatric hospital, various general hospitals, and family medicine centers in a large Quebec metropolis, enabling a degree of transferability of the findings of this work to other broadly equivalent pediatric, adult and primary care settings. Through the lens of symbolic and social boundaries, this research shows the extent to which and how healthcare services fail to reach acclaimed ideals and standards of adolescent care. The dissertation traces the intricate efforts through which individual patients, carers and healthcare professionals stitch care strands together that are otherwise left hanging. The findings provide an empirically-informed conceptual scaffold on which to hang future policy, educational and practical interventions to enable adolescent care to be recognized as a separate entity. This dissertation sought to address the challenges brought by the way adolescent healthcare is understood, as studies in this field have currently failed to capture the complex intricacies that make the delivery of continuous care to adolescents suboptimal.

The specific aims of the dissertation are, therefore, to explain how transition to adult care is understood and enacted across different stakeholder groups involved in the transition process, to identify the mechanisms used to enable the transition process, and, how these mechanisms are learned, transmitted or modified. Informed by the symbolic and social theory, this work generates a deeper understanding of the complex and multifaceted nature of adolescent transition to adult care. The terms “transition” and “transitional care” will refer to the transition between adolescent and adult care. Those who are transitioning from pediatric to adult care are referred to as “adolescents and young adults” or AYAs (14-25 years).

What is adolescence and how are adolescents’ health treated?

Currently, adolescents are often underrepresented in health research, leading to a lack of comprehensive data on their specific health needs (Committee on Adolescent Health Care, 2016; Zolfaghari et al., 2022). Most youth inclusion in research happens after the implementation of interventions rather than during their development. Additionally, research involving young people tends to focus more on lifestyle rather than on preventing adult diseases (Hunleth et al., 2022). Such limitations of data hinder our understanding of adolescent health and the development of evidence-based interventions to improve adolescent healthcare access and delivery (Zolfaghari et al., 2022).

While traditional views of adolescent healthcare have often conceptualized this period as a linear transition from childhood to adulthood, contemporary research underscores the complexity and specificity of adolescence as a demographic (National Academies of Sciences et al., 2019). Being an adolescent and young adult in Western countries has evolved. It has traditionally included people aged from 14 to 29 (Statistique Canada, 2019). Adolescence represents a critical and distinct phase in human development, characterized by a multitude of changes across various domains (Sawyer et al., 2018). The biological and physiological transformations occurring during adolescence have garnered substantial recognition within the adolescent healthcare research field (National Academies of Sciences et al., 2019). Beyond biological changes, AYAs experience a significant change in their identity, closely tied to the dynamic evolution of their social responsibilities and roles, as they navigate the transition from childhood to adulthood (Wood et al., 2018). Adolescence is recognized as a period where young people develop their identities and self-understanding, build relationships outside of their primary social circle, gain autonomy and independence from their primary caregivers, and identify their vocation and area of study (Kelly & Wray, 2020).

How can and should we conceptualize adolescent health and care?

Medical advances have seen increased survival rates of adolescents with chronic disease, representing a new demographic for health systems to serve (Badour et al., 2023). Recent research underscores the ongoing refinement of clinical care models within pediatric and adult care to inform the development of innovative practices (Nguyen et al., 2017). Studies have highlighted the critical importance of these models in contributing to effective transitions and continuity of care for young patients moving from pediatric to adult healthcare systems. For example, a systematic review on transition models for Type 1 Diabetes emphasizes the need for integrated, multidisciplinary approaches to improve patient outcomes during the transition from pediatric to adult care. These models often include components such as telehealth and person-centered care, which are continuously refined to enhance accessibility, acceptability, and satisfaction among patients, caregivers, and healthcare providers (Zurynski et al., 2023).

However, adolescent care, which straddles the boundary between pediatric and adult healthcare, is devoid of a robust ideological foundation necessary for the formulation of the requisite services. For instance, the American Academy of Pediatrics emphasizes that despite the recognized importance of tailored adolescent healthcare, there is still a significant gap in implementing, theory-based approaches to integrated care (Alderman & Breuner, 2019). The lack of a solid ideological framework limits the ability to create and sustain healthcare models that fully address the complex biopsychosocial needs of adolescents as they transition to adulthood (Alderman & Breuner, 2019). Additionally, adolescent care, in practice, is not seen to align well with existing pediatric or adult care models, and often fails to take account of the evolution of adolescents' healthcare needs throughout the adolescent period (National Research Council et al., 2007). To adapt to the new demographic of AYAs with chronic conditions, healthcare services need to redress the under-development of healthcare models to address the specific needs of this population (Colver et al., 2020; Zolfaghari et al., 2022).

In Western societies, the construction of adulthood as a binary opposite to childhood significantly influences how both adults and children are treated within healthcare systems (Barnes et al., 2024; Jenks, 2004). This dichotomy is particularly evident in the transition from pediatric to adult healthcare services, where the recognition of children as active participants in their care is often overlooked until they approach the transition age (Fegran et al., 2014). This cultural phenomenon is rooted in the WEIRD (Western, Educated, Industrialized, Rich, and Democratic) societal framework, which tends to compartmentalize life stages and undervalue the agency of children in their healthcare decisions (Chakravarty, 2022; Henrich et al., 2010). Research indicates that pediatric healthcare providers frequently fail to acknowledge the evolving roles of AYAs until they are on the cusp of transitioning to adult care. For instance, it has been shown that AYAs often find their new adult primary care providers unfamiliar with their specific health needs and preferences, which can lead to a disjointed care experience (Cook et al., 2013). This lack of preparation and recognition can result in significant gaps in care continuity, as evidenced by a co-located transition model, in which pediatric and adult providers worked collaboratively, leading to improved retention in adult care for adolescents and young adults (AYAs) with chronic conditions such as sickle cell disease (Howell et al., 2021).

The absence of such collaborative frameworks can exacerbate feelings of alienation and confusion during this critical transition period (Steihaug et al., 2016). Moreover, the transition process is often marked by systemic barriers that hinder effective communication between pediatric and adult healthcare providers (Toulany et al., 2022). Research emphasizes the need for improved collaboration and linkages between pediatric and adult care providers, suggesting that structured transition education programs could enhance outcomes for young adults with chronic conditions (Nakhla et al., 2017). The lack of a formal transition protocol has been seen to deliver inefficiencies and redundancies in care, further complicating the transition experience for young patients (King et al., 2024). This is particularly concerning given that many pediatric services do not begin the transition process until late adolescence, which can leave young adults ill-prepared for the complexities of adult healthcare (Israni et al., 2023).

The implications of cultural constructs around adolescence extend beyond individual patient experiences; they reflect broader societal attitudes towards childhood and adulthood. The Children have been perceived as passive recipients of care, rather than as active participants (Spray & Hunleth, 2023). This assumption can hinder the ability and potential of children to advocate for their health needs. Involving AYAs and their families as co-experts in the transition process can facilitate a smoother transition and empower AYAs in their healthcare journey (Doug et al., 2011). The development of comprehensive transition models requires collaboration among healthcare teams to address the unique needs of patients with chronic illnesses, in particular (Lewis & Slobodov, 2015).

Conceptualizing the way adolescent transition to adult care is understood is, therefore, essential to provide stakeholders with adequate information to support the implementation of more effective care strategies for AYAs (Brazil et al., 2005). In health research, theory serves as a guide to make sense of a social phenomenon as the foundation of interventions, policies, practices. Much research in healthcare remains atheoretical (Parker et al., 2022), or focused only on specific individual elements of a problem. Such a linear view limits potential solutions, because it ignores the multi-level influences with which a phenomenon interacts.

So far, research has focused on looking at adolescent healthcare emphasizing individual roles (Heath et al., 2017), models or interventions (Paul et al., 2015), or enhancing gaps by focusing on diseases and departments (Gray et al., 2018). Perspectives and experiences of AYAs, healthcare professionals (HCPs) and parents or guardians regarding adolescent healthcare are often considered separately to systems, and narrowly focus on the specific interventions or programs (Culnane et al., 2022; Haig-Ferguson et al., 2023; Marr et al., 2022; Morgan et al., 2022; Stocker et al., 2022). To date, the passage from pediatric to adult care is limited by a linear perspective that fails to look at non-tangible aspects of healthcare (Cooley, 2013a).

The linearity of adolescent healthcare research and practice is evident in approaches that perceive adolescent health as a linear progression from childhood to adulthood, overlooking the unique needs, influences and challenges that arise during this developmental stage. Such an approach often results in an inadequate understanding of developmental needs, with the majority of adolescents reporting that healthcare providers neglect important issues like mental health, sexual health, and substance use (Kobulsky et al., 2022; Vreeman et al., 2017). Preventive measures are frequently overlooked, as evidenced by the fact that only 16% of adolescents receive the recommended preventive visits, missing opportunities for early intervention (Rand et al., 2007). Additionally, linearity is represented in disease-specific approaches that tend to overlook intersectionality and comorbidities. This is despite the fact that youth with chronic conditions are twice likely to suffer from a mental illness (Adams et al., 2019) with long-term adverse effects especially on their quality of life (Chen et al., 2006), care continuity, and health outcomes (Russo, 2022). As few as 20% of young people with mental health problems receive appropriate care (CDC, 2022).

Discontinuity of care during the transition to adult healthcare is a critical shortcoming of adolescent healthcare. More than one-third of young adults with type 1 diabetes experience a significant gap in care over six months, leading to poorer health outcomes and higher hospitalization rates (Agarwal et al., 2016; Pyatak et al., 2014). Lifestyle challenges to adhere completely to treatment protocols is prevalent among adolescents with chronic conditions, and this phenomenon has been associated with adverse health outcomes (Agarwal et al., 2016; Salvador et al., 2023). Furthermore, a simplified view of the transition to adult care for adolescents, focusing almost exclusively on biomedical phenomena, overlooks the impact on health literacy on transition readiness and clinical outcomes. It has been shown, however, that 57% of young people with chronic conditions have limited health literacy (Baranwal et al., 2024). Such unfavourable conditions and outcomes highlight the urgent need for a more tailored, comprehensive, and integrated healthcare approach for adolescents.

A failed transition to adult care for adolescents with chronic diseases can have severe consequences, underscoring the urgency of effective transitional programs. Poorly managed transitions can result in significant lapses in care, leading to deteriorating health outcomes. For instance, research indicates that adolescents with type 1 diabetes who do not receive adequate transitional care experience a marked increase in hospitalizations and microvascular complications due to poor glycemic control (Ali et al., 2021). For this population, the transition period between pediatric and adult care has led to an increase in their glycemic markers (HbA1c) from 7.5% to 9.2%, while only 14% of patients in the transition age range meet the glycemic markers target (Iyengar et al., 2019). Furthermore, young adults with congenital heart disease who fail to transition effectively are at heightened risk for critical cardiac events and increased mortality rates (Greutmann et al., 2014). Additionally, a lack of structured transition processes has been linked to decreased adherence to medication and follow-up appointments among adolescents with cystic fibrosis, exacerbating disease progression and reducing life expectancy (Faint et al., 2017; Hatziagorou et al., 2022). These examples highlight the pressing need for systematic and supportive transition programs to ensure continuity of care and improve long-term health outcomes for this vulnerable population.

The transition from pediatric to adult-oriented healthcare for young people with chronic health conditions is, therefore, a crucial period that requires careful planning, mentorship and support (Cooley et al., 2011; Michalovic et al., 2020). However, current research on transition to adult care often focuses primarily on biomedical aspects, such as medical management and disease-specific outcomes, while neglecting the non-biomedical aspects of transition (Harris et al., 2011). This gap in research leaves important factors unexplored, such as the psychological and emotional impact of transitioning, the challenges faced by both patients and their families in navigating the healthcare system, the social and environmental factors that can influence successful transition outcomes, and the active agency to seek a pathway forward in integrated health for others to follow. Furthermore, existing research often fails to address the perspectives and experiences of the young people themselves, who are ultimately the ones undergoing this transition and affected in their future capacity as social agents (Zolfaghari et al., 2022).

Without expanding the interpretation of adolescent health to incorporate such non-biomedical aspects, healthcare providers and policymakers may struggle to develop effective interventions and support systems for young people transitioning to adult care. In addition, current data also fail to address the organizational flaws within healthcare systems that can significantly hinder the transition process. Issues such as poor communication and relationships between pediatric and adult care providers (Gray et al., 2021; Gray et al., 2018), lack of trust and collaboration between HCPs (Fox, 2002; Sakurai et al., 2022), lack of coordinated care plans (Choi, 2017; Lanzkron et al., 2018), and the absence of a standardized transition protocol (Srinivas et al., 2024) can create substantial barriers to adolescents' healthcare and outcomes. Such organizational weaknesses undermine the potential for a seamless healthcare transition, leaving young individuals feeling unsupported and confused during this critical phase.

As such, the lack of emphasis on systemic issues suggests a narrow view of transition that does not fully account for the complexities involved. Transitioning to adult care is not merely a biomedical process, but involves significant changes in the roles and responsibilities of the patient and their families, as well as the HCPs (Berens et al., 2020; Schraeder, Dimitropoulos, McBrien, et al., 2020). A more comprehensive approach to transition must, therefore, include strategies to improve coordination and communication within healthcare systems, as well as interventions aimed at preparing young individuals for the broader aspects of adult healthcare management (Betz, 2018; Imelda Coyne et al., 2019; Momplaisir et al., 2023). Furthermore, the ability of health systems to provide adequate healthcare for adolescents, especially those with chronic disease, demands provision of conceptual tools to understand the complexity of adolescence and attempts to provide optimal adolescent care.

By overlooking the extent or character of organizational and systemic impediments to care, the current body of research misses the opportunity to develop a more holistic understanding of what constitutes successful transition to adult care. This oversight not only limits the applicability of research findings, but also restricts the potential for innovative solutions that could address the multifaceted nature of healthcare transition. Without a more inclusive focus that encompasses non-biomedical and organizational aspects – beyond a linear perspective on healthcare delivery – efforts to support young people in pediatric to adult care transition may continue to fall short, leading to poorer health outcomes and increased use of scarce healthcare resources. Furthermore, to advance the field, research must expand its scope to explore these critical dimensions of transition. Despite the growing recognition of the importance of non-clinical aspects in the transition to adult care, current research still predominantly focuses on biomedical outcomes and overlooks the broader context in which the transition takes place, and processes involved in it, which hinders the development of effective interventions that can address the organizational and systemic barriers to successful transition (Delisle, 2013; Vernon-Roberts et al., 2023). In this vein, most transitional care interventions have been shown to be ineffective in addressing the non-biomedical aspects of transition, such as coordination of care, communication between healthcare providers, and contextual support for development of self-management skills (Campbell et al., 2016).

Although adolescent healthcare is often seen in a simplistic linear fashion, it requires complex organizational mechanisms and processes. Even within an organization where multiple types of care are provided, different healthcare professionals are called upon to collaborate with each other despite significant differences in professional cultures and the norms that govern each profession (Momplaisir et al., 2023; Schraeder et al., 2020). This raises the issue of cohesion of interdisciplinary and interprofessional teams in the delivery of patient care. For patients with chronic conditions, the quality of care depends in particular on the way in which care is planned and delivered in a long-term perspective (Berntsen et al., 2018). Multidisciplinary care planning requires a level of team and individual coordination that directly affects care and patient outcomes (Goodwin et al., 2013).

What needs to be conceptualized to advance adolescent healthcare?

Since the late 1990s, the rise of the concept of New Public Management, emphasizing efficiency and accountability in public services to reduce costs, has led to care fragmentation (Li, 2023). Additionally, organizational structures in healthcare and their forms of regulation are currently based on hyperspecialization of services offered to the population and of health professionals. A defining feature of modernity, hyperspecialization in healthcare refers to a high level of specialization in a specific field or area, focusing on a narrow area of expertise, and contributes to care fragmentation with increasing morbidity levels (Prior et al., 2023). Nevertheless, such intense specialization has enabled healthcare professionals to provide improved care that is specifically tailored to a particular pathology or medical condition that used to be undertaken by one person originally (Malone et al., 2011), for instance, presenting better options and outcomes for patients with specific medical needs (Pronovost et al., 2002). Despite its potential benefits, hyperspecialization in healthcare has engendered a state of fragmentation whereby each specialized domain largely operates in a silo, fostering an environment of exclusive care provision. Such fragmentation manifests as a lack of versatility or adaptability in addressing broader healthcare needs, despite an increase in complex multi-system chronic diseases among populations (Farron & Hoffmeyer, 2012). In contrast, integrated care entails the multi-level involvement of care participants, engaged as necessary, to enhance the quality and effectiveness of patient care (Nugus et al., 2010). Indeed, the segmented distribution of care has partly generated the fragmentation of care that characterizes many health systems today and which has serious consequences in terms of the quality of care, hospitalizations and mortality (Cohen-Mekelburg et al., 2019; McCrum et al., 2020; Snow et al., 2020; Turbow et al., 2021). The organization of care in a fragmented environment makes it difficult to follow the demographic curve of chronic diseases requiring a completely different type of care and services that reflect the chronicity of the pathologies – that is, over the long term and in a holistic manner that takes account of biomedical and non-biomedical aspects of health.

Above all, the linearity that prevails in healthcare systems involves treating components in silo. This approach encounters contradictions when addressing the particularly intricate phase of human development situated between childhood, typically served by pediatric services, and adulthood, predominantly managed by general health services. Despite sporadic attempts to amalgamate services and individual endeavors, predominant healthcare models lack an emphasis on complexity over linearity and specialization. Additionally, there exists a notable dearth of conceptual frameworks to guide a complexity-informed model tailored specifically for adolescent care.

Social and symbolic boundaries

Therefore, we need for a more sophisticated perspective to better understand transition to adult care, one that encompasses not only biomedical aspects but also the social, organizational, and systemic factors at play. Given the complexity of healthcare systems and the diverse needs of young individuals transitioning to adult care, without addressing such non-biomedical aspects, the way transition to adult care is managed may not fully meet the needs and preferences of young individuals, their families and HCPs leading to continued suboptimal outcomes and potentially exacerbating existing health disparities (Harris et al., 2011; Nakhla et al., 2017; Reilly et al., 2020).

Sociology offers conceptual tools for comprehending the interconnected factors that collectively influence phenomena (Pope & Mays, 2020). Specifically, the theory of social and symbolic boundaries provides a framework for understanding the complexities of social interaction and identity formation that shape human engagement with systems and how one acts in relation to such systems. The theory of social and symbolic boundaries suggests that individuals and groups create boundaries, both tangible and symbolic, to differentiate themselves from others and establish a sense of identity that will define and be defined by their behaviours and values (Bourdieu, 2001; Bowker & Star, 1999; Lamont et al., 2015; Lamont & Molnár, 2002a). Symbolic and social boundaries help examine the relationships between structures and stakeholders (Unruh, 1980). In this vein, the idea of social and symbolic boundaries represents a response to linear and compartmentalized approaches by addressing interrelationships between elements of influence.

By understanding how social and symbolic boundaries are created and maintained during adolescent transition to adult care, we can gain insight into the dynamics that shape the interaction between stakeholders involved in the process, including AYAs, their parents, and pediatric and adult care providers. Looking at behaviour through the lens of symbolic and social boundaries theory enables understanding of how each group with a stake in adolescent care operates in relation to their identity and organizational affiliation, and how their orientation in turn influences the transition process. In this vein, the theory of social and symbolic boundaries allows us to comprehend the non-linear and complex nature of the adolescent transition. It highlights that transition processes are inevitably influenced by non-human elements and individual, organizational and social norms and values. In turn, a boundary perspective will offer guidance, and support comprehensive interventions by taking account of a complex array of influences.

In this chapter, I have highlighted, firstly, the challenges brought by how adolescent transition is featured in research that takes a linear view of adolescent healthcare. Secondly, I outlined the consequences of such a view for adolescents. In a complex and adaptive healthcare environment, actions between actors and non-human elements must be considered in terms of non-linear continua (Nugus et al., 2010). Exploring and conceptualizing the experiences and perspectives of various actors involved in the transition process is an essential for improving the way situated processes occur and are learned in relation to the everyday work contexts of healthcare professionals and the influences on and of the communities they believe they belong to or aspire to belong to.

No study was found that integrates the voices of communities implicated in transition, including adolescents, parents or guardians, and healthcare professionals, to understand how the structures and processes of health services affect adolescent care and the experience of the transition process for patients and their families. Thus, integration of care is in some ways at the crossroads of a contradiction, that of hyperspecialization and independent modes of operation of health and social service professionals, whereas integration worthy of the name requires a symbiosis. Integration of care is often studied from an intra- or inter-organizational approach, demonstrating the complexity and multi-level focus that integrated care demands (Burkhart et al., 2020; Goodwin, 2016; Taylor & Gorrie, 1958).

Outline of the dissertation

Taking the empirical case of the transition process from pediatric to adult care for adolescents with chronic conditions, this research brings a multi-level lens to the establishment of boundaries, their negotiation, and ultimately their attempted reconciliation. Figure 1 illustrates the structure of this work.

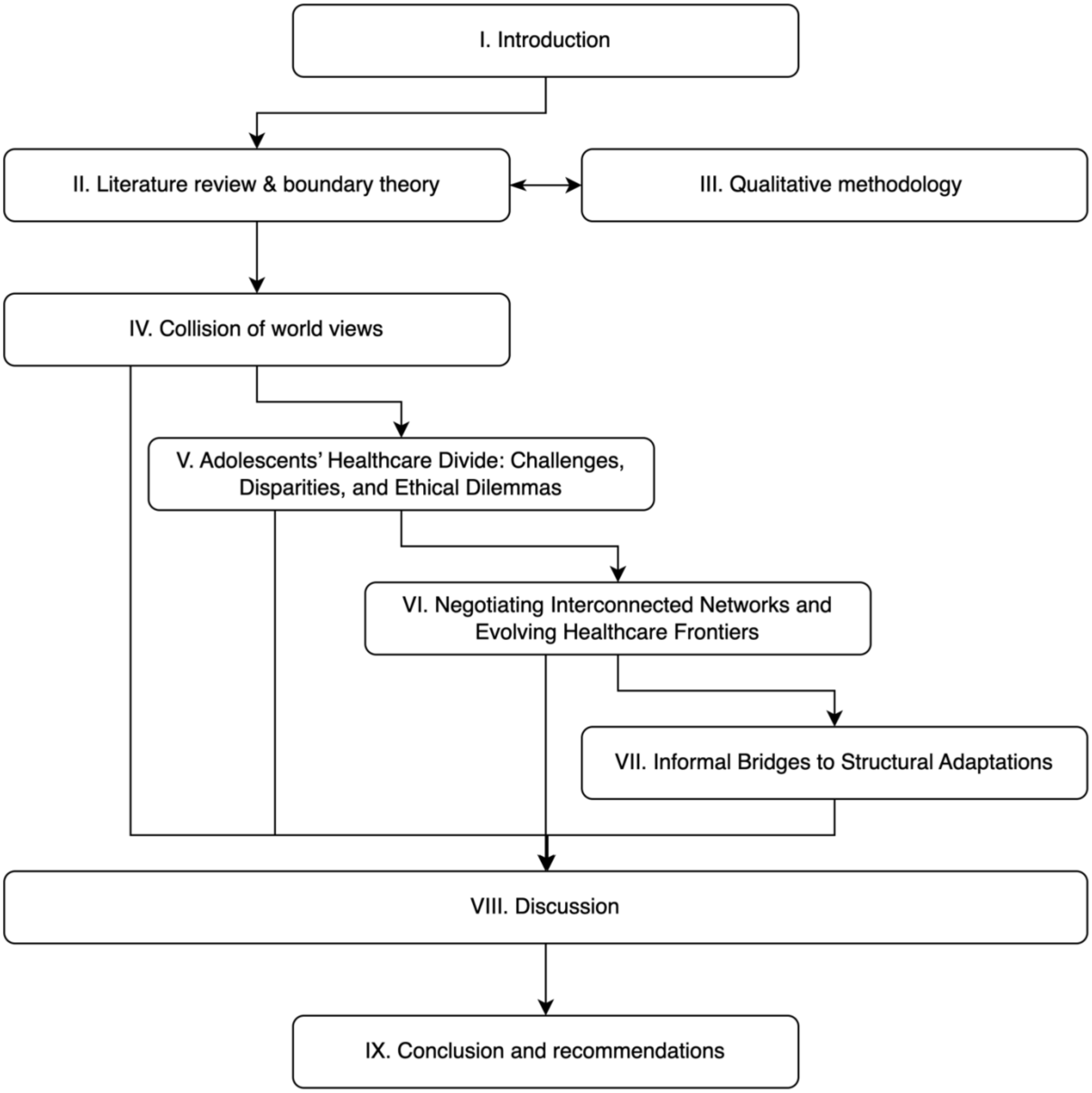

Figure 1 Structure of the dissertation

In the following chapter, I will look more closely at how adolescence, adolescent health and adolescent health research have been considered, and I will discuss transitions of care and the potential of engaging the theory of symbolic and social theory. The transition from pediatric to adult care represents a dramatic example of lack of care integration. It can showcase the dynamics manifest in efforts to provide services across different departments, organizations and actors implicated in the transition process.

The methodology of this study is presented in Chapter III. It is based on a socioconstructivist sociological approach, the main method being semi-structured interviews with the actors involved in the transition process from pediatric to adult care. The thematic analyses and the iterative process informing the analysis as it proceeds will be detailed. The contribution of qualitative research in health research will be explained.

Chapter IV will articulate the manifestation and function of social boundaries. In particular, I will explain the systemic dimensions of social boundaries in relation to the integration of care. The chapter will show how the structuring of different boundaries ultimately contributes to two distinct worldviews that impede the integration of care.

Chapter V explains the concept of adolescent healthcare “in the void”, highlighting the way the healthcare system places adolescence outside its scope and the lack of integrated care models that bridge the divide between pediatric and adult care. It then explores the unique challenges faced by adolescents who find themselves caught in the middle of two medical realms, experiencing a non-standard adolescence that is often overlooked.

In Chapter VI, having navigated existing boundaries, I investigate the negotiations of boundaries by the various stakeholders involved in the transition from pediatric to adult care. Healthcare professionals as well as families and parents seek to compensate for the disparities AYAs face while transitioning to adult care, disparities induced by the social boundaries established at the systemic level. In doing so, they fill in the gaps in the system, and, in the process, negotiate their identity, and by extension their own boundaries. However, efforts to plug gaps in care and enact a public identity provoke tension and conflict related to power dynamics that are present and sometimes exacerbated by professional and social role negotiation.

Chapter VII discusses strategies for bridging the gaps created by individual stakeholders to facilitate the integration of care. By highlighting its absence, the chapter emphasizes the necessity of institutionalizing a transition culture—moving beyond dependence on personal initiatives—to ensure a smooth transition for AYAs into adult care. At the individual level, a reorganization occurs between HCPs, AYAs, and their caregivers, forming informal pathways of care. These pathways act as temporary spaces while awaiting a confirmed and secure transition into the formal adult care system.

Finally, the Discussion chapter VIII examines the unique capacity, and hence contribution of the dissertation, of symbolic and social boundaries to illuminate the emergence of informal work within formal institutional frameworks governed by norms and regulations across various levels. The Discussion chapter also provides implications for future research. The Conclusion chapter considers implications for policy, practice and education.

Chapter II. A Literature Review and Theoretical Framework for Understanding Adolescents' Transition to Adult Care

Introduction

In the context of healthcare, which is structured around distinct categories manifested through hyper-specialization, adolescents inhabit an intermediary position between pediatric and adult care specialties. This positioning often results in their exclusion from receiving appropriate healthcare services. This chapter, structured in four sections, reviews current knowledge on adolescent healthcare and elaborates on how the traditional linear view in healthcare and structural fragmentation have led to inadequate services for adolescents.

The first section focuses on the healthcare conditions that are uniquely prevalent among adolescents. It highlights the specific physiological and psychological changes that occur during adolescence, which necessitate tailored healthcare interventions. This section not only serves to identify these unique health needs but also examines how these needs are currently being addressed within healthcare systems.

The review progresses to a synthesis of adolescent transition in health services which enact adolescent healthcare. Specifically, this section provides an analysis of the current literature on healthcare transition, examining definitions of success and failure in this context and exploring the resultant implications for adolescent patients and healthcare systems.

The third section addresses the nature of adolescence in society, exploring the socio-symbolic concept of adolescence as a state of “betweenness”. This part of the review interrogates how societal perceptions of adolescence — as neither childhood nor full adulthood — impact adolescents' access to and experiences within the healthcare system. It reflects on the implications of this betweenness for healthcare policy and practice, emphasizing the need for approaches that recognize and bridge this unique societal role. As such, this part of the chapter elaborates the concept of social and symbolic boundaries that frames the present research.

Lastly, the chapter considers the social construction of the healthcare system and its professions. This section elaborates on how healthcare systems and professional roles within them are constructed and understood within society. It explores how these constructions influence the interactions between healthcare professionals and adolescent patients, and the overall effectiveness of the healthcare system in addressing adolescent needs.

Although relatively few in number, studies on transition have been conducted in the disciplines of sociology, nursing, medicine and education. In sociology, though the object of rare attention, transition is has been seen as a set of multidimensional processes, including through a socio-ecological approach to reveal and better understand how different interrelated mechanisms operate (Bronfenbrenner, 1977). In education sciences, it is evoked as three phases, a phase where one enters the transition, a phase where one is in the transition and a phase where one leaves the transition (Schlossberg & Goodman, 2005). In nursing science, it is defined by its complexity in the life course of patients and by the different levels of role played by the actors involved in the transition (Meleis, 2010). Moreover, the role of caregivers is more developed in the latter discipline. In medicine, the emphasis is on transition readiness, including HCPs' training, and AYAs' health outcomes from transition to adult care (Ho et al., 2023; Toulany et al., 2022).

Overall, this literature review synthesizes a range of scholarly discussions and empirical studies to offer an overview of adolescent healthcare through the frameworks of social and symbolic theory. By doing so, it highlights the need to understand the complexities involved in providing effective healthcare to adolescents and to develop complexity-informed knowledge to better meet their unique needs.

Adolescent Healthcare

Currently, to comprehend adolescent healthcare, research frequently encompasses a spectrum of dimensions, ranging from physical and mental well-being to sexual and reproductive health, as well as the intricate web of social determinants influencing health outcomes. Specifically, researchers examine factors such as growth, sexual maturation and associated risks, nutrition, physical activity, and the prevention and management of diseases specific to this age group (Alvarez-Pitti et al., 2020; Hannon & Arslanian, 2023; Hargreaves et al., 2022; Norris et al., 2022; Sluijs et al., 2021). As such, studies address physical health, explaining the major physiological changes and development adolescents go through that affect their health. For example, it is now widely acknowledged that the maturation of the adolescent brain persists until approximately the age of 25, exerting a significant impact on their cognitive and decision-making capacities and therefore on their medical treatment and healthcare (Arain et al., 2013; Diekema, 2020; Icenogle & Cauffman, 2021).

Neuroimaging studies have revealed varied changes in neural structures and connectivity patterns that underlie the ongoing refinement of cognitive functions (Morita et al., 2016). These developmental processes associated with emotional state play a pivotal role in shaping an individual's ability to assess risks, anticipate consequences, and exercise prudent decision-making (Breaban et al., 2016). The importance of sleep in brain development (i.e. plasticity and synaptic pruning) during adolescence is also highlighted in various studies as a vital factor of youth development, showing the inter-relationships between various aspects of adolescent health (Galván, 2020; Telzer et al., 2013, 2015).

In addition to physical health, adolescent mental health is a closely related and rapidly evolving area of research. Recent studies have investigated the prevalence, risk factors, and consequences of mental health disorders, including depression, anxiety, eating disorders, substance abuse, and self-harm. For instance, it has been shown that major mental health disorders have onset during adolescence, with 50 percent starting at the age of 14, yet typically not being treated and addressed within the following six years of onset (Committee on Adolescent Health Care, 2017). Adolescent mental health is also known to predict their physical health, as well as future academic performance (Murphy et al., 2015). Moreover, there has been an increase in mental ill-health among adolescents and young adults, besides the main factors contributing to poor mental health, such as socioeconomic situation, parental education, stressful life events (Reiss et al., 2019), low level of physical activity (Bell et al., 2019), lack or poor quality of sleep, excessive social media use and smartphones (Alonzo et al., 2021; Keles et al., 2020; Wacks & Weinstein, 2021), and the COVID-19 pandemic, which exacerbated the increase in mental health disorders. Indeed, meta-analyses showed an increasing prevalence of depression, anxiety, sleep disorders and posttraumatic stress symptoms among AYAs during the pandemic and over time (Deng et al., 2023; Ma et al., 2021).

Further, a large body of research addresses issues related to sexual development, sexual behavior, contraception, sexually transmitted infections (STIs), pregnancy, and reproductive health services. Although in higher-income countries, the incidence of STIs and early pregnancy is decreasing due to the increased use of contraceptives, prevalence of ovarian and breast cancer are slightly increasing and found at a more aggressive stage when diagnosed among adolescent women compared to older women (Hannon & Arslanian, 2023; Latif et al., 2022).

Social norms are demonstrated to influence sexual and reproductive health among adolescents while transitioning to adulthood. The way AYAs receive and internalize social expectations related to their gender affects their behaviors accordingly (Pulerwitz et al., 2019). These findings highlight the need for implementing screening and education on sexual and reproductive health, and social norms.

Current research also explores topics such as sexual education, gender identity, and sexual orientation, implicating them in adolescents' sexual health, healthcare access, and quality of life of those with a chronic disease (Grubb et al., 2020; Kirkpatrick et al., 2020; Ogden et al., 2020). As such, youth may identify as genders other than the traditional female-male binary (Diamond, 2020), and this gender expression is known to affect their social support, and risk of abuse and victimization. As a result, research shows that AYAs have specific health needs that require special attention (Chew et al., 2020).

With increasing specialization in healthcare and improved treatment options, more children with chronic, and sometimes previously life-threatening, conditions are reaching adulthood. Many of these conditions were previously rare in adult medicine, and the proportion of pediatric patients with chronic conditions is steadily increasing (Arnett et al., 2014). The transfer of pediatric patients to adult care occurs during the emerging adulthood phase, between the ages of 18 and 29, which is also characterized by instability (Foster, 2015). It has been widely demonstrated that health frequently deteriorates after discharge from pediatric care, and that levels of hospitalization and mortality increase when the transition is not successful (Berens & Peacock, 2015; Bhawra et al., 2016; Han et al., 2018; Schwartz et al., 2011; Singh, 2009; Zhou et al., 2016). A large body of literature has demonstrated that difficulties in the period of transition can result in poor patient outcomes, both physically and psychologically (Schwartz et al., 2011; Singh, 2009). Coping with chronic disease in early adulthood is particularly challenging, and there is a relatively high rate of complications and loss to follow-up in virtually every disease group (Jalkut & Allen, 2009; Overholser et al., 2017; Singh, 2009).

Recognition of the adverse effects of poor transition has led to the development and rapid expansion of a new field in pediatric and adult medicine, “the transition from adolescent to adult care” (Maddux et al., 2017). The consequences of an unsuccessful transition to adult care can be significant. A successful care transition (also labelled medical transition, transitional care, or healthcare transition) can be considered continuation of specialized and coordinated care than takes account of changes and influences on the individual at various levels. Without a successful transition to adult care, young people with chronic health conditions may experience a range of negative consequences. For example, when adolescents are excluded from or have limited access to the healthcare system, the implications extend further, affecting not only their health but also society at large (Garney et al., 2021). However, the literature does not provide sufficient information on the general determinants of success or failure in the delivery of transition services in the pediatric and adolescent phases of the life course (Davis et al., 2014; Prior et al., 2014).

In many different ways, adolescents face unique healthcare needs that distinguish them from both children and adults (Committee on the Neurobiological and Socio-behavioral Science of Adolescent Development and Its Applications et al., 2019). The imperative for the development of health services specifically tailored to adolescents stems from the recognition of adolescence as a distinct developmental stage characterized by unique biosocial experiences and status (Brittain et al., 2015). The new responsibilities adolescents gain entail profound personal implications, as they form the cornerstone of an individual's transition into adulthood and their capacity to manage personal health (Ravert et al., 2015). Concurrently, they encompass substantial social repercussions, reflecting the resources individuals possess—or are deprived of—which are critical for their contribution to society, as citizens (Gaudet, 2018; Mameli et al., 2019). In order to create a solid foundation for their adult lives, adolescents firstly need to seek autonomy and independence by challenging parental authority and peer influence, negotiating rules, and beginning to make decisions about their lives (Allen & Loeb, 2015). For example, adolescents may resist curfews, dress codes, and other restrictions imposed by parents or guardians. Occasionally, this can lead to conflicts and tensions within families, schools, healthcare services, resulting with negative consequences for adolescents' well-being, academic performance, and health (Choe et al., 2014). The search for autonomy represents a pivotal developmental objective during adolescence, primarily due to its intimate connection with processes of individuation and the shaping of one's identity (Fleming, 2005).

Secondly, adolescence is a period of time when youth are developing social connections and senses of belonging by forming close friendships, joining social groups, and participating in activities that bring them together with peers (Ferguson et al., 2022). For example, AYAs may join sports teams, music groups, or clubs at school to connect with others who share their interests. In addition to the primary socialization that occurs during childhood with the nuclear family, expanded social activities represent a secondary socialization that will influence how AYAs will behave and transition to adulthood, by enabling them to understand and process new norms, beliefs and expectations, along with their peers (Smetana et al., 2014). Consequently, such behavioural developments affect AYAs' health conditions, especially when moving from childhood to adulthood (Allen et al., 2022).

Adolescent healthcare is delivered across pediatric and adult care settings, necessitating specialized approaches to cater to the unique developmental needs of this population (Betz & Coyne, 2019). However, the healthcare services provided within pediatric and adult care settings often fail to adequately cater to the distinct and nuanced requirements of adolescents (Toulany et al., 2022). This demographic, undergoing a critical phase of development, as documented earlier, encounters subpar healthcare delivery precisely when it is crucial to stabilize chronic illnesses to enable them to enact their citizenship (Pais et al., 2012). A failed transition from pediatric to adult care can lead to a range of negative outcomes for adolescents with chronic illnesses. Medical complications can arise, along with a decrease in outpatient attendance and a decline in treatment adherence (Gore et al., 2011; Thomsen et al., 2022).

Service segmentation in the transition to adult care

The literature on adolescent healthcare, as mentioned, has tended to focus on biomedical pathways of single diseases. There has been less research recognized contextual, processual and constructed dimensions of care, that recognize the active agency of participants and the interrelationships of various influencing factors. The start of the process of conceptualizing integration is the recognition of the existence of categories that distinguish healthcare categories, such as different populations by age. The process of moving from pediatric to adult healthcare settings involves not only a shift in medical services, but also a change in social interactions, the expectations and support available to young adults. Moments of care transition represent critical periods of time for patients and in the long term for the health system. This is because they are moments during which patients move from one well-delineated category to another. In its ideal form, transitional care is defined as:

> "*a set of actions designed to ensure the coordination and continuity of healthcare when patients transfer between different locations or levels of care within the same location.*"
> (Coleman & Boult, 2003)
> *"Transitional care relies on a comprehensive plan of care and the availability of healthcare practitioners who are well-trained in chronic care and have up-to-date information about the patient's goals, preferences and clinical status. It includes logistical arrangements, patient and family education, and coordination among healthcare professionals involved in the transition. Transition care, which encompasses both the sending and receiving aspects of the transfer, is essential for individuals with complex care needs."*
> (Naylor & Keating, 2008)

An example of transitional care is an inpatient hospitalized person who is transferred to home care or a long-term rehabilitation center, or an elderly person hospitalized for delirium is transferred to a residential and long-term care center (CHSLD). Transitions of care occur frequently and have a major impact on the healthcare system (particularly in terms of the cost of resource use), but have only recently been studied, commencing in the 1990s (Schumacher & Meleis, 1994). People with chronic conditions are distinct from other patients who enter healthcare settings on an *ad hoc* basis following acute conditions that do not require long-term follow-up and care. The nature of the care needs associated with a chronic condition (such as diabetes, congenital heart disease or mental health disorders) requires long-term follow-up coordinated among different stakeholders, to allow for better outcomes related to the stability of the condition and improvement in the individual's quality of life. Interventions that improve transitional care can reduce hospitalizations and emergency department visits, and prevent complications or progression of chronic conditions (Colineaux et al., 2019; Loeffler, 2016; Peel et al., 2013). Nevertheless, a growing body of research shows that transitions of care are poorly formalized in healthcare institutions and in the community, with disturbing consequences for the health of those involved in the continuum of care (Hart et al., 2019).

As healthcare has become hyperspecialized, each department or service is dedicated to an increasingly exclusive group of people, including segmentations in the types of care received, and this concerns the medical, paramedical, and social dimensions of care. A classic source of categorization relates to the expertise of a particular organ being treated. For example, in a cardiology department, there will be healthcare professionals who have received specialized training in cardiology, whether formally according to the institutions governing the professions (university training or continuing professional education) or through informal in-house means (training provided in the hospitals or medical centers). Thus, the hyperspecialization of healthcare professions has led and continues to lead to a mode of operation that concentrates on particular parts of the human body (Cooke, 2013).

The transition from pediatric to adult care has only received scientific attention in the past decade. Although the first literature was published in 1991, it was not until 2009 that new research findings were published and on a more regular basis. An analysis of this research has made it possible to highlight the pivotal moments of the transition and the different steps included in each major phase, the tools used and potential obstacles to consider. A literature search identified a total of 162 publications from the databases Scopus, Medline and PubMed.

Seven best practice guides from major healthcare institutions were also included in the review. Studies on transition to adult care specifically targeted adolescents with congenital cardiovascular disease (n=24), lung disease (e.g., cystic fibrosis) (n=22), sickle cell disease (n=16), chronic inflammatory bowel disease (e.g., Crohn's disease) (n=14), and kidney disease or transplantation (n=7). Studies were primarily from Canada, the United States and England. Participants were separated by group and included healthcare professionals, parents and adolescents. An increasing number of studies aim to test the effectiveness of interventions developed to facilitate the transition process (Le Roux et al., 2021, 2022; Nabbout et al., 2019; Testa et al., 2019; Williams et al., 2020).

Indicators of successful transition included clinical markers of disease, but also psychosocial markers, such as isolation, self-esteem, quality of life and employment status, and systemic markers, such as access to care and cost of care (Bloom et al., 2012; Dallimore et al., 2018; Heery et al., 2015; Nehring et al., 2015). In order to account for a variety of elements perceived as important in the management of adolescents and young adults with chronic diseases, this literature review reports on the different actions, tools and intervention models identified to facilitate the transition from pediatric to adult care.

The fundamentals of transition

In terms of the fundamental components of transitional care, many healthcare systems, such as in France and Quebec, see children followed by pediatricians and other childhood specialists up to the age of majority (18 years), depending on the case. The young adult then depends on adult medicine services, with family physicians (called general practitioners in some countries) and specialists in adult pathologies. In most countries, the age of transfer to adult care depends on the age limit for follow-up in pediatric care, placing transfers between 12 and 24 years of age (Yassaee et al., 2019). When an adolescent requires regular care with follow-up by a pediatric team, then further care would be expected to involve transfer to the adult care system.

Transition to adult care was originally defined as “the intentional and planned movement of adolescents with a chronic illness between child-centred and adult-centred care” (Blum et al., 1993; Canadian Paediatric Society, 2007). The central concepts of transition are that care is uninterrupted or continuous, coordinated, developmentally appropriate, and that the young person being transferred is physically and mentally healthy before and during transfer to the adult system of care.

The transition of adolescents to adult care therefore requires coordinated sets of actions involving pediatric and adult medical specialties (Antonelli et al., 2008; Maddux et al., 2017; Toomey et al., 2013). This transition has been identified as a complex, longitudinal process that carries high stakes for adolescent patients entering adulthood, as it is widely recognized that poorly executed transition processes result in poor patient outcomes, both physically and psychosocially (Bhawra et al., 2016; Han et al., 2018; Mazur et al., 2017; Schwartz et al., 2011; Singh, 2009; Singh & Tuomainen, 2015; Zhou et al., 2016). Numerous publications demonstrate the need to improve transition preparation and support when patients transition from pediatric to adult care (Cooley, 2013b; Schwartz et al., 2011).

The different stakeholders in the transition to adult care process, as presented in the literature, are illustrated in Figure 2.

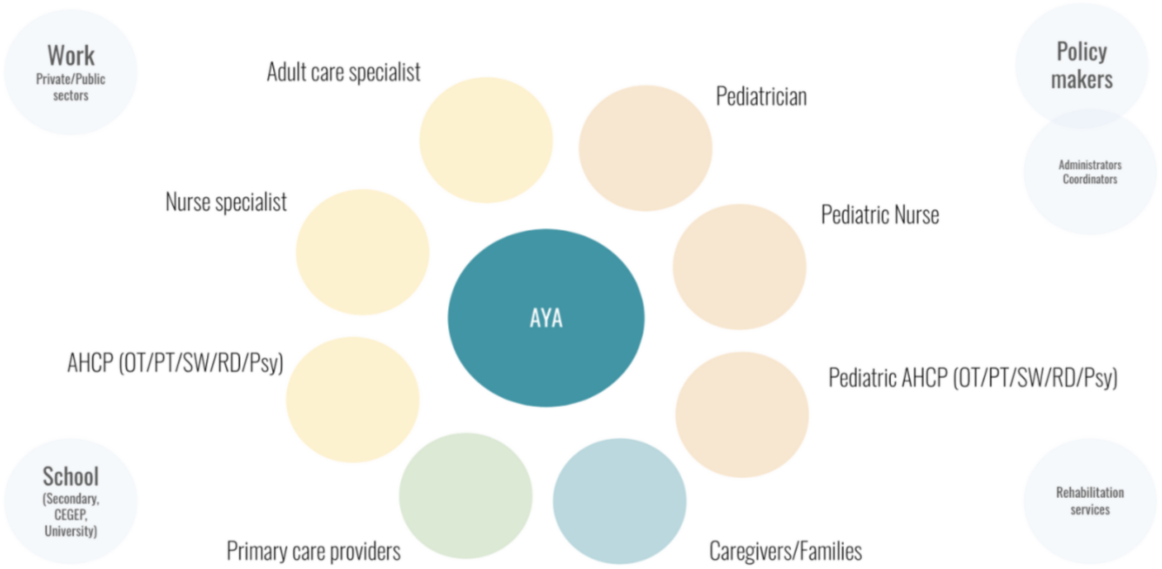

Figure 2 Stakeholders involved in the transition to adult care process

The transition to adult care can be viewed at different levels. From a psychosocial perspective, transition is a dynamic process in which adolescents with specific health needs are prepared to take charge of their lives and health as adults. From a health services perspective, it is the deliberate planning of the transition from family- and child-centered pediatric care to adult care (Acuña Mora et al., 2016; Agarwal et al., 2015; Blum et al., 1993; Meadows et al., 2009). It is clear that the definitions of transition all commit to the development of adolescent autonomy with the goal of improving the quality of life of young adults and their potential as adults in society through the coordination of care and resources that enable the development and support of patient autonomy. Thus, transition is both idealized as optimization of autonomy, and also idealized as being enacted in the everyday work of being a healthcare professional, caregiver or patient. Therefore, it can be considered both normatively and empirically – as an ideal of a mutually enacted process which may or may not reach that ideal.

The phases and milestones of the transition to adult care

The transition process from pediatric to adult care can be seen in terms of three main phases, concentrated around transfer: before, during, and after transfer. This is shown in Figure 3. As will be discussed, transition is idealized as more than mere handover, or handoff, of care. While transition defines the entire process, handoff refers to the moments (the event or series of events) during which the care of adolescents with chronic conditions moves from a pediatric to an adult care setting (Acuña Mora et al., 2016; Meadows et al., 2009). This is when the pediatric team's formal follow-up ends.

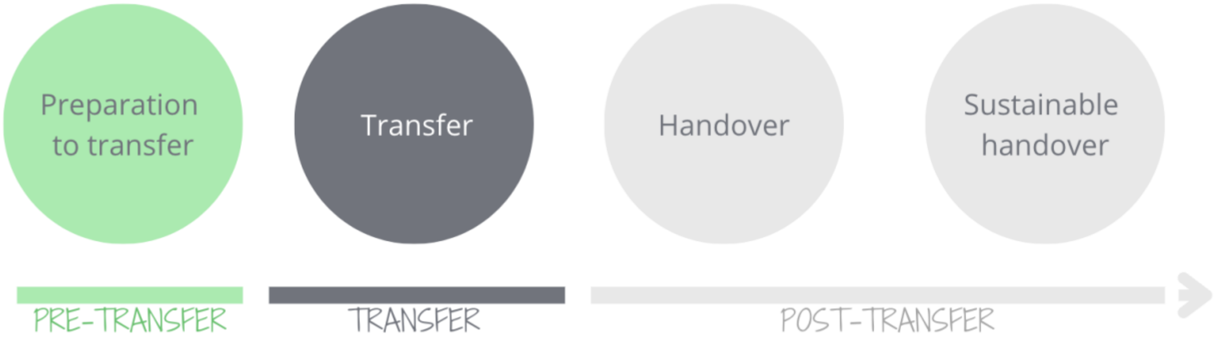

Figure 3 Phases of the transition to adult care process

The following actions in relation to each phase are ideal-case scenarios, as conveyed in the literature. In the first phase of the transition (pre-transfer), the pediatric multidisciplinary team prepares the youth for the transfer through therapeutic educational workshops, discussions with the parents and youth – together and then separately – identifying the adult care facility or services. At this stage, it is recommended that a transition coordinator be identified to accompany the youth and family through the transition, including ensuring the movement of health information from one service to another, and ensuring continuity of care. During this same phase, the involvement of the adolescent in his or her care and follow-up is reported as being valued in order to build autonomy. For example, parents are ideally encouraged to begin discussing the transition with their child by inviting them to co-construct a guide with essential information about their health in order to make it their own (e.g., “health passport”). Adult care should be involved in this phase of preparation for transfer, in transition planning.

In the second phase, at the time of transfer, the transition coordinator should have contacted the various players involved in the transition from pediatric to adult care in order to organize a meeting with the parents and the adolescent. Such a meeting provides an opportunity to review the adolescent's health history, his or her management by the pediatric team, the stability of his or her condition and the resources available to him or her. This moment is crucial for the optimal follow-up of the adolescent, particularly through the transfer of the medical file, including, for example, notes from HCPs, images and recent results.

Upon completion of the transfer, the final phase would ideally consist of a final transition visit with the pediatric team to ensure the handover of the necessary paperwork for the youth's follow-up. The transition coordinator would support the follow-up by involving the appropriate resources for the teen's situation, such as a general practitioner, or referring the youth to apply for adult disability benefits, if needed. Once the transfer is made, the young adult would be called upon to handle his or her case as the primary actor – or with the help of parents or relatives when they are present. Whenever possible, the young adult would be expected to know the contact persons in the adult and primary care services. Table 1 presents these phases in more detail by stakeholder group.

The transition from one phase to another requires skills or knowledge from the different actors in order to guarantee the fluidity of the transfer and to avoid negative incidents (e.g., by oversight, lack of knowledge, preparation, communication or coordination). Tools have been developed in this vein and are promoted for use to ensure the appropriate timing of the process (Schmidt et al., 2020). Some tools used in the transition are presented in the table by phase and objective.

	Phase 1: pre-transfer	***Phase 2: transfer***	***Phase 3: post-transfer***
Main objectives	Preparation and monitoring of the evolution of clinical signs	Transition Clinic Training and assessment of understanding of key points of care management	Monitoring of clinical signs and support for care management
Examples of tools expected to achieve objectives	● Transfer checklist ● Questionnaires to assess adolescent readiness	● Questionnaires on understanding the chronic conditions ● List of services and contacts ● Summary of the patient record	● Feedback on the transition ● Care Satisfaction Questionnaire ● Self-care skills assessment
Examples of actions to achieve the objective	Structured discussion of the transition process during a dedicated consultation	Adolescent physical therapy in the adult medical setting	Appointment and follow-up with adult specialist and multidisciplinary team

Table 1 Idealized phases and assessment tools in the transition from pediatric to adult care

Successful transition to adult care

Depending on the perspectives of different stakeholders, successful transition is described with varying emphasis, and is thus not conceptualized in the same way by health professionals, adolescents, and their families (Dallimore et al., 2018). The ideal transition is reported to correspond to the primary objectives established by societies, such as the US-based Society for Adolescent Health and Medicine, which advocates that the coordination of care correspond to the adolescent's level of development (Yassaee et al., 2019). Success, therefore, is seen to involve both systemic and individual aspects, including the maturity and development of the young person, which will affect the pace and duration of the transition. (Annunziato et al., 2014). The success of the transition is largely based on the notions of self-care and autonomy skills, thus emphasizing individual responsibility for the care of the transition and its consequences once the adolescent is in the adult system. Although research findings demonstrate the need for transitional care arrangements to address the increased demand for self-care and independence in a new care setting, this definition of success often overlooks the ecosystem in which young adults find themselves (Heath et al., 2017).

Beyond managing their illness, adolescents will face the transition to adult care in a period marked by many changes. As mentioned, these changes are psychological, biological, physiological (e.g., brain development) and social (e.g., school system pushing towards autonomy, need for peer recognition, identity construction) – in other words, a period that in itself already includes many challenges that adolescents must face. This pivotal period is also the basis for long-term effects. For example, it has been shown that common untreated mental disorders in adolescence have both physical and mental consequences in adulthood (Cullins et al., 2016). The risk factors for physical and mental health are numerous and are most noticeable during childhood (Arango et al., 2018; Silva et al., 2020). While this period is key to the social integration and identity formation of young people, it becomes, by its unstable nature, the cradle of many psychological complications (Jacquin & Gerardin, 2019).

Indeed, diseases that are diagnosed during childhood or even adolescence – such as diabetes, kidney disease, chronic inflammatory bowel disease – are diseases that adolescents will have to deal with at the same time as they define themselves as social individuals. Adolescents will have to learn to manage their disease, that is, their symptoms and treatments, but also to navigate the healthcare system in which they will receive care throughout their lives. Beyond the clinical aspect, these young adults will be called upon to develop habits (e.g., making an appointment with the family doctor or a specialist, doing the recommended regular follow-ups, knowing the symptoms of hypoglycemia and the methods of resugaring for diabetics). This care management involves optimizing the continuity of care to meet the nature of chronic illnesses and support towards autonomy. Such support demands an understanding of the interdependence between the young person and care services. The transition from pediatric to adult care can thus benefit from the literature on continuity of care, coordination and integration of care. This process involves a complexity of interdependent transitions occurring in parallel, as discussed earlier.

Better understanding and management of pediatric diseases now requires a transition process from pediatric to adult care. However, this process is far from optimal, and its flaws lead to catastrophic outcomes whose effects are effective over the medium and long term (Annunziato et al., 2014; Bloom et al., 2012; Gray et al., 2018). The lack of mobilization of health services to address this problem augurs delayed effects that will further burden health systems (Canadian Paediatric Society, 2007, 2022; Hergenroeder & Wiemann, 2018). Improving the transition of healthcare for adolescents with chronic diseases is thus essential.

Pitfalls in the transition to adult care

As interventions to improve the transition from pediatric to adult care have been implemented, many elements that limit the successful completion of the transition have been identified. The literature on adolescent transition to adult care identifies these barriers as being of different natures, but all interrelated. Indeed, these determinants are found at different levels of analysis that are difficult to extract from the whole.

First, the **systemic**, health network-related context is access to care that incorporates the idea of navigating care services once leaving pediatric care (Bloom et al., 2012; Gray et al., 2018). This also includes health insurance for which the adolescent is now responsible, especially in largely privatized systems such as that of the US, and which does not necessarily cover all the care required and therefore requires financial responsibility by the young adult. Lack of access to institutional resources, such as transportation or other home care support resources, undermines the ability of adolescents to contribute to their transition to adult care (Paul et al., 2018). The lack of clear institutional policies regarding a standardized transition process that would allow for standardization of practices hinders the implementation of transition programs (Nehring et al., 2015).

Second, the **organizational** context with elements that facilitate or impede the transition process primarily focus on cooperation, care coordination, and collaboration among healthcare professionals, although these are central elements of inter-organizational relationships (Castañer & Oliveira, 2020). While the existing literature on the transition from children to adult care has identified strong collaboration and coordination between healthcare professionals from different services – pediatric, adult and primary – as a prerequisite for successful transition (Han et al., 2018). However, collaboration is often hampered by significant gaps between these systems of care (Naert et al., 2017). Indeed, the different cultures of care among healthcare providers can be accentuated at the transition frontier (Singh & Tuomainen, 2015). This makes transition a concentration of the broader tensions that exist between professional cultures in healthcare (Easley et al., 2016, 2017). Specialties and sub-specialties, fragmentation of healthcare and lack of integration are all barriers to collaboration and coordination of care.

Transition from one service to another involves a culture change. This includes two or even three different approaches to care (pediatric care, adult care, and primary care), which on the one hand hinders the transition from one setting to another and on the other depends on many resources and coordination, or integration, of care (Fegran et al., 2014; McLaren et al., 2013). However, these prerequisites are not always considered in the transition from pediatric to adult care for adolescents with chronic disease (Canadian Paediatric Society, 2007, 2022). These changes in services, instead, have been found to result in disruptions of care due to lack of collaboration and communication (Anderson et al., 2018; Nehring et al., 2015). In addition, the expectations and needs of both adolescents and healthcare professionals can slow the transition from pediatric to adult care when stakeholders have biases about the types of care received – especially when the models of care conflict, such as family-centered pediatric care versus patient-centered adult care (Gray et al., 2019; Kronschnabel et al., 2016).

The relationship between medical or surgical specialists and primary care physicians has been identified as an important area to develop to facilitate successful transitions from pediatric to adult care (Bhawra et al., 2016; Han et al., 2018). Most of the literature has tended to focus on transitions between specialists, ignoring the important role that family physicians, nurses, allied health professionals, patients, caregivers and families play in the long-term management of adolescent care after transition (Han et al., 2018). The literature has also tended to focus primarily on the experiences of transition to adult care in specific disease groups (e.g., children with cystic fibrosis) (Bergström et al., 2010; Telfair et al., 2004).

A systematic review of systematic reviews found that the literature on young adult care transitions focuses primarily on type 1 diabetes and recommends new studies that highlight common pediatric diseases and transition needs during a transition process (Hart et al., 2019). Thus, there is a need for empirical research to guide progressive handoffs across a range of professionals and services, with the goal of addressing poor patient outcomes that occur as a result of poor transition from pediatric to adult care. As such, we need to understand how conditions of care in multiple pediatric and adult care settings succeed, fail, or can be further improved from the perspectives of the multiple stakeholders involved: patients, their families and caregivers, and healthcare professionals (i.e., nurses, specialists, social workers).

Furthermore, the organizational level also features the acquisition and development of knowledge and skills of healthcare professionals. There are concerns about knowledge, particularly for HCPs on adult wards who are perceived to have limited knowledge of pediatric illnesses and also of the entire transition process (Jordan et al., 2013). However, in pediatrics as well, a lack of training has been noted, with some medical residents feeling that they had not received enough education about chronic diseases (Sharma et al., 2014). The lack of knowledge also applies to families and young adults, particularly with respect to their skills (e.g., in self-management) (Gray et al., 2019). These different levels of knowledge and skills between HCPs, patients and families create tensions between the stakeholders in the transition process, affecting their relationships. Obviously, these barriers vary depending on the time of the process, i.e. whether the adolescent is in pre-transfer or post-transfer. Moreover, these barriers are not exclusive of each other and are common to adolescents with different chronic illnesses and therefore with complex care needs (Gray et al., 2015). Although the lack of knowledge and skills is highlighted, little detail is provided on what might be appropriate solutions to overcome these barriers to transition to adult care.

Third, the **interpersonal** context concerns the interactions between providers and adolescents and their families. Interpersonal relationships are regularly mentioned in the literature, whether in regard to the patient and his or her close caregivers, or in regard to health professionals. A prominent focus is the role and work of HCPs in pediatric services given that the relationship built during childhood can become strong and emotional. It can then be difficult – after having developed a long lasting relationship – to let go of this relationship in order to build a new one with new personnel among adult healthcare professionals (Jones et al., 2019; Nehring et al., 2015). Indeed, the emotional attachment of parents and adolescents to pediatric HCPs has been seen as hindering the transition process (Heery et al., 2015).

Fourth, the **individual** level of engagement focuses on adolescent attributes including complexity of medical condition, stigma towards particular conditions, social network, development, and maturity (including autonomy and self-management skills, and expertise). Young people's vulnerability in relation to their self-esteem influences the degree to which young adults are seen to be "compliant" and "medically adherent", seen to be putting them at greater risk for health complications. The desire to appear like others, "by being normal", affects adolescents' interactions with their social network (Dallimore et al., 2018). In addition, the transition is affected by the complexity and instability of one's health condition, potentially leading to an eventual interruption of care. Low levels of family support and unstable living conditions interfere with the smooth transition to adult care, leading to poor health outcomes later in life for the young adult (Gray et al., 2019).

While studies discuss the transition perspectives of healthcare professionals and sometimes parents, there is a notable deficiency in research that encompasses the different pathways of the actors involved in the process of transition from pediatric to adult care. In addition, few studies focus on the transition to primary care or on the role that primary care professionals can play in this process (Scal, 2002).

Towards the implementation of transition clinics and the identification of a coordinator

Already in 1997, the notion of a transition clinic was emerging, particularly at the Royal Liverpool Children's Hospital in the United Kingdom. In a study led by Appleton and colleagues (1997), the establishment of a transition clinic that would bring together health professionals from pediatric and adult care of the adolescent in transition showed promising results in terms of follow-up with adolescents with epilepsy. The intervention also showed promise in terms of confirmation of the young person's diagnosis and treatment. This clinic also allowed for discussion of the young people's concerns regarding their education and professional life with the disease, the risks (for driving, in case of forgetting or stopping the anticonvulsants), or questions regarding the more independent life that was coming. The importance of interdisciplinarity in the transition clinic is reinforced in many studies, particularly in regard to the condition of epilepsy (Geerlings et al., 2016). The importance of interdisciplinarity in the transition clinic has been reinforced in many studies, particularly in epilepsy, although this element, which is valued in the course of the transition, is not the subject of dedicated tools. The development of transition clinics is therefore seen to be an important component to identify related risk factors that compromise transfer to adult care (Camfield et al., 2019; Gaydos et al., 2020).

Another pitfall identified in transitional care is the challenge of identifying healthcare professionals in adult services with knowledge and openness to include the family in the care process. A lack of communication between HCPs in adult services and family caregivers is highlighted in various studies (Camfield et al., 2019; Lu et al., 2020). Thus, the role of a transition coordinator is seen as a potential pivotal point to improve the transitional process and thus enhance the chance of its success. However, the implementation of a coordinator role is highlighted as being difficult due to budgetary restrictions (Bloom et al., 2012).

The coordination role is often reserved for nurses, as part of a specialization that can be incorporated into the expertise of specialized nurse practitioners or *advanced* practice nurses (Betz & Redcay, 2005). In addition, studies involving a transition coordinator have highlighted the pivotal role of this actor. As part of both the pediatric and adult care teams, the transition coordinator role is intended to centralize information and guide the adolescent through the care system, with the hope of reducing the risk of lost information and “loss to follow-up” (Annunziato et al., 2013; Gray et al., 2019).

Research focus on practice improvement interventions

Although studies on transition to adult care increasingly espouse or commit to engagement with theory (in sociology, nursing and education), in general, studies in the field remain strongly focused solely on the findings of empirical studies and associated indicators. Recently developed conceptual frameworks have been put forward for intervention development. To study adolescents' changes in self-care capacity, one pilot study based its intervention on the psychosocial theory of self-determination (Weigensberg et al., 2018). Some studies have used grounded theory as a methodology to try to explain the transition phenomenon and thus take an approach that is considered inductive (Boyce et al., 2020; Giarelli et al., 2008; Iversen et al., 2019; Sobota et al., 2015; Verma & Sahay, 2019). Increasingly, pediatric care units have been implementing spaces, programs or interventions to facilitate the transition to adult care. However, the theoretical underpinnings were not always presented. Of the 89 studies that described a transition program, only 24 were explicitly grounded in theory.

Standardized transition process tools and programs

The literature converges on the need to implement programs or interventions aimed at standardizing the processes of transitions to adult care in order to ensure quality of care and, above all, a protocol that would increase the effectiveness of transitions through being based on evidence (Canadian Paediatric Society, 2022). However, the implementation of interventions is local, often limited to a specific department or condition (Grant & Pan, 2011; Saulsberry et al., 2019). Numerous studies have shown that transition programs from pediatric to adult care are often considered late in coming, or that the services initially offered are not sufficiently comprehensive (Boyce et al., 2020), or that the services initially offered were not provided or not conducive to adequately preparing young adults for entry into the adult care system (Colver et al., 2018). In addition, there are few research programs or effective tools to guide the transition process. When such tools do exist, they tend to focus on patient characteristics, ignoring the systemic and ecological nature of the transition from pediatric to adult care (Schwartz et al., 2011). More importantly, existing tools have failed to engage the multitude of stakeholders involved in the transition process, although patients, families, family physicians, physician specialists, nurses, and allied health professionals have been identified as having significant and interrelated influences on the success of the transition process (Bhawra et al., 2016; Han et al., 2018; Mazur et al., 2017; Naert et al., 2017; Schwartz et al., 2011).

In North America, at least five transition of care programs have been developed following studies of the needs of young adults. A review of five such programs, based on recommendations from the Canadian Paediatric Society and the US-based Society for Adolescent Health and Medicine, concluded that evaluations of program effectiveness were lacking, although early results from some programs were promising, for example, in reducing the rate of adolescents leaving care once they are in the adult system, which is known to be indicative of future health status (Grant & Pan, 2011).

Best practice guides

Concurrently, the period of adolescence represents, for those with chronic conditions, a crucial juncture to cultivate the autonomy and capacity to manage the multifaceted ramifications of their chronic conditions on various facets of their lives. There is an increase in the prevalence of adolescents living with chronic conditions necessitating ongoing follow-up across both pediatric and adult healthcare settings (Amed et al., 2018; Marani et al., 2020). The literature review shows that various care models have been introduced in efforts to sculpt appropriate and effective healthcare services (Jennings, 2008). Such models are intended to guide healthcare delivery according to available resources while promoting an approach deemed to be the most appropriate for a particular demographic, such as AYAs (Jennings, 2008). Many of the models are presented as guidelines.

To improve transitions for adolescents with chronic conditions, many “best practice” guidelines have been implemented in health centers. These guidelines are generally either based on systematic reviews of the literature or on interventions tested in other health centers (often for a specific disease, e.g., irritable bowel syndrome) or on a broader scale covering transitional care for various conditions. Thus, to ensure change that takes into consideration the different levels interacting with each other, such guides recommend a multi-stakeholder and cross-sectoral approach to the issue of transition from pediatric to adult care.

In France, recommendations, or “good practice” guides list actions for the different teams (pediatric, adult and primary care), often attached to a transition program while following the pre-transfer-post phases. Examples are the healthcare network for rare liver diseases in adults and children [*Filfoie*] (Antonini et al., 2020) or the “checklist for the transition from pediatric to adult care” of the Healthcare network for rare autoimmune and auto-inflammatory diseases *[Filière de santé des maladies auto-immunes et auto-inflammatoires rares]* (Georgin-Lavialle et al., 2021). Other guides or protocols also recommend a care pathway for the follow-up of certain specific pathologies; for example, for the physical medicine and rehabilitation care of patients with Spina Bifida, by the *Haute Autorité de Santé de France* (Centre de référence Maladies Rares Spina Bifida, 2015). Many of these guides specifically aim to enhance the understanding of adults who are less familiar with childhood pathologies.

However, to my knowledge, there are no nation-wide guides outlining the processes of transition to adult care. There is ample evidence of the lack of standardization of transition protocols in pediatric and adult services (e.g., a lack of standardized procedures for transition to adult care) (Al-Jahdali et al., 2017). There are few procedures in place. This is in a context where transition tools are perceived and evaluated as important and critical to the success of the transition intervention. The use of ongoing evaluation methods has helped to improve transition programs while systematically assessing the different levels of transition that occur at the same time, including using the *Six Core Elements of Health Care Transition* model proposed by the US-based “Got Transition” resource centre (McManus et al., 2015). The literature, in general, lacks recommendations that could reflect the multidimensional complexity of transition to clarify the implications of the process and the expectations and needs of each stakeholder.

Adolescents’ “between-ness” in light of fragmented services

The sociology of childhood prescribes the importance of focusing on children's agency and recognition in healthcare settings, challenging traditional views that often depict children as passive recipients of adult decisions (Corsaro, 2024). This perspective emphasizes the importance of recognizing children as active social subjects who possess agency and the capacity to influence their environments and experiences (Kosher & Ben-Arieh, 2019). As a post-childhood-but-pre-adulthood category, adolescence faces an even greater struggle for legitimacy as a social category worthy of agency. Critical perspectives from the sociology of adolescence demand denaturalization and critique of the way adolescents are viewed in health settings, particularly by exposing the age-based power dynamics and prejudices that shape these interactions. Adolescents are often positioned within paternalistic frameworks that emphasize their perceived immaturity, vulnerability, and impulsivity, which undermines their agency, autonomy, and capacity to participate meaningfully in decisions about their care (Bessant, 2008; Lesko, 2012).

Adolescence is a unique and complex social category, often overlooked or misunderstood (Moore Heslin & McNulty, 2023; Sawyer et al., 2018). It is a transitional period between childhood and adulthood, where individuals navigate through various physical, emotional, and psychological changes (Andrews et al., 2021). During this time, adolescents are neither fully children nor fully adults, making them an exclusive social category that does not easily fit into the existing social structures. The majority of social frameworks are predominantly tailored to accommodate the needs and attributes of either children or adults, thereby placing adolescents in an ambiguous state, and consequently exposing them to unmet needs.

Adolescents face the challenge of developing their identities and understanding their place in society while still undergoing significant biological growth (Pfeifer & Berkman, 2018). This transitional period is marked by a search for autonomy and self-discovery, as adolescents try to establish their own identities separate from their family and childhood (Branje et al., 2021). It is a time of experimentation and exploration, where young people seek to understand their place in the world and how they fit into society (National Academies of Sciences et al., 2019). They are caught in a state of "in betweenness," as they are no longer children but not quite adults (Casey et al., 2010). This stage of life is physiologically and socially characterized by exploration, risk-taking, and a search for independence (Romer et al., 2017).

The transition from childhood to adulthood is seen in the adolescent healthcare literature as a passage – a temporary state. Consequently, adolescents experience a unique set of needs and challenges that are often neglected by existing healthcare services. The absence of targeted support can lead to a plethora of long-term consequences that will affect their future social role as citizens. In this critical phase, adolescents require comprehensive and specialized services that acknowledge their unique position within social structures.

Social representations of adolescence

Adolescence is an abstract and, to some extent at least, socially constructed categorization. This category is a period between childhood and adulthood and involves many changes happening simultaneously. Often portrayed as a difficult period for individuals, adolescence represents a time of life with much turmoil, sensitivity and risk. Much of the literature, particularly in the health sciences regarding the care of adolescents, has focused on the risk behaviors of this group (Hurrelmann & Richter, 2006; MacArthur et al., 2018; Wegner & Flisher, 2009). Much of the medical literature, in particular, focuses on the harmful consequences of behaviors considered inherent to adolescents. The emphasis on medical complications related to adolescents' conditions gives them a vague status for which time – in terms of maturity and development – is expected to resolve the issues. However, an increasing number of scientific and institutional reports use this period of life and the individuals who embody and go through it in a positive way as if to use language as a motor for changes in social representations (Benson et al., 2007; Bourdieu, 2001; Edberg et al., 2017).

Adolescence is a type of category to which all social actors have belonged or will belong by default during the passage from childhood to adulthood. With nuances in terms of delimitations since, according to the culture, the belonging to this category evolves. Defining adolescence presents challenges when confined to a prescriptive perspective. Initially conceptualized by psychologists at the beginning of the 20th century, the definition was predominantly focused on developmental aspects, thereby insufficiently capturing the social dynamics that influence its evolution (Galland, 2008).

Adolescence varies significantly across cultures, time periods, and environments, each characterized by distinct values and criteria (Committee on the Neurobiological and Socio-behavioral Science of Adolescent Development and Its Applications et al., 2019). To contextualize adolescence and understand its inherent challenges, I will examine it through the lens of collective identity, as described and applied in the human and social sciences. Historically, life spans have served as benchmarks for establishing age categories, often based on biological, sociological, or economic criteria. Sociology, in particular, has traditionally examined youth as a distinct social status and a unique culture (Mead, 2001). Adolescence represents a critical and universal phase in an individual's life narrative, serving as a mandatory transition from childhood to adulthood—a process sociologically described as the transformation from being an “object” to becoming a social “subject”. While not all adolescents conform to the same youthful archetype (some may not fit the sociological definition of youth), every young person has experienced, is experiencing, or will experience this pivotal period. It is through this phase that individuals invariably and irreversibly engage with life and society, becoming active agents and contributors (Cuin, 2011).

What distinguishes adolescence from other periods of life has to do with the social changes experienced, which are evoked by de Singly (2006) as “*a moment of non-coincidence between the family we and the generational we*”. In other words, adolescence is a period marked by a divergence between the identity formed within one’s family and the broader generational identity that adolescents start to develop as they interact more with society outside their family. Adolescents establish themselves in a transitional category through an oscillation between autonomy and economic independence, balancing their roles within the family and among peers. (Galland, 2008). The identity duality that this framework poses places the adolescent as a social agent in categories whose attributes coexist with difficulty.

A category like no other

In Western countries, the conceptualization of adolescence is marked by an ambivalent discourse. On the one hand, adolescence represents the idealization of youth, strong and constantly evolving. On the other, it is framed within a biomedical perspective, where adolescence is viewed as an inherently transitional stage marked by cognitive, physical, and social development, yet lacking the maturity associated with post-formal thought processes (Piaget, 1964).

Thus, adolescents are often defined primarily as risk-takers. The main causes of death in this population group are accident (by trauma) and suicide in first place, followed by cancers and cardiovascular diseases (congenital heart disease in particular) (Masquelier et al., 2021; Unicef, 2021). Pediatric diseases are causing fewer and fewer deaths in adolescents, and due to medical advances, more and more sick children are surviving adolescence into adulthood. This is the reason why an increased demographic of sick children – who used to stay on the pediatric side until their death – are now reaching adulthood and going to adult wards despite a chronic and sometimes severe pathology. Therefore, the volume of patients who must make a transition of services is increasing. While mortality among children and young adults is declining, chronic disease is increasingly affecting young people, even though socially, adolescence – and youth – is often pictured as healthy. The chronic diseases that tend to increase from a very young age are asthma, childhood obesity, mental disorders or neurological disorders (Perrin et al., 2014).

Recognizing the uniqueness of medical conditions emerging in childhood, healthcare and associated social services have been organized in a dedicated pediatric environment. Childhood – – and the category that underlies it – is more likely to attract a sense of compassion and care that changes as childhood reaches adolescence and then adulthood. The consideration and compassion that an individual will have for a child is stronger than for an adult. The notion of life time is often linked to this (Leung & Guria, 2006). The value of children is depicted in the care and in the approach of the HCPs towards them. In this vein, pediatric *care* is part of a family from which it cannot be separated, even in a hospital context (Lombart, 2015).

While in some countries, adolescence or the transition to adulthood is faster and earlier in an individual's life, the period of adolescence in industrialized countries tends to extend over a longer period of time and includes more individuals. What is the implication of such a change? And how does it influence the transition to adult care?

The notion of adolescence can be highlighted in terms of its boundaries with the category of adulthood, which follows adolescence. These two categories are essential since young people are called upon to move from one to the other. Adulthood maintains a relatively paradoxical position from a sociological point of view. On the one hand, it is a central category as it occupies a pivotal role that serves as the foundational reference from which numerous other categories are derived. It effectively functions as a "default" category, often utilized "as-is" without further scrutiny as an object of research or as an influential phenomenon. On the other hand, despite its widespread application and influence in the social world, its significance and impact are seldom examined or critically addressed in scholarly discourse. Adulthood tends to be approached with a psychological, individualistic focus. Such limited uses of language and perspective on adulthood have resulted in a phantom definition, as embodied in all social events involving people who are neither children nor people at the end of their lives (Blatterer, 2007). Some attempts have been made to name this passage from one state to another, as Arnett formalized with the notion of "emerging adulthood" (2014). Erikson (1968) depicts the emergence of adulthood as an "*in-betweenness"* not yet crystallized in the literature, although some developmentalists have addressed the extended period of adolescence mainly in industrialized countries, where the end of adolescence is more like a role experiment but does not immediately initiate the entry into adulthood. Young adults, aged 18 to 25, do not consider themselves either adults or adolescents when asked (Arnett, 2000).

The transition to adult care generally takes place between the age of 14 (to prepare for transfer) and 25 years and older to account for the transfer and one's installation in the adult system. These terms, therefore, encompass the social situations found among individuals who experience the transition to adult care in the healthcare system between the ages of 14 and 25 (and beyond).

The role of the adolescent as an adult "in the making", is an emergent category in terms of the social contribution they are expected to make in society. Schooling and other forms of socialization contribute to the intended formation of adolescents as future citizens. This demographic therefore occupies a pivotal position intersecting economics and democracy. Within a neoliberal context, the social impact and contribution of adolescents often manifest during early adulthood.

Adolescent citizenship in a neoliberal context

> "*Citizenship, in its classical sense, is related to modern society or, to use the accepted term, to modernity, the latter corresponding to the rationalist conception of the world, society, and the individual."* (Ellefsen et al., 2002, p. 89)

The idea of citizenship as we understand it today is a product of the rationalist worldview that underpins modern society. Essentially, neoliberalism is an ideology by which the free market is the prevailing determinant of value in society (Bourdieu, 1998; Foucault, 2008). The type of citizenship that is valued is itself shaped by neoliberalism. By prioritizing individuals' market value and their capacity to generate economic, social, or cultural capital, neoliberal frameworks erode collective social identities and reconfigure group belonging around market-based citizenship (Bourdieu, 1998). This process fosters prescriptive group classifications, where individuals are evaluated and grouped not by shared social or political solidarities but by their relative contributions to market systems or their access to power-capital resources. Consequently, systemic inequalities are reframed as personal failings, as neoliberalism shifts the onus of success or failure onto individual responsibility rather than structural conditions (Cardona, 2021; Pavićević et al., 2023). This focus on individual accountability undermines collective action, as it detaches individuals from broader systemic critiques and instead inscribes their worth within the logic of market productivity. Thus, neoliberal capitalism dissolves traditional collective identities, replacing them with atomized, market-oriented categorizations that perpetuate systemic inequalities while obscuring the need for structural change.

The rationalist interpretation of citizenship implies that citizenship is not just a legal status but also a role shaped by the rational organization of society, where individuals are seen as autonomous agents with specific rights and duties defined by a social contract within the nation-state. Under rationalism, individuals are encouraged to evolve into social agents and integral members of the citizen community by engaging in productive work within a capitalist economy, thereby making social contributions to their respective groups. It is through training and education that the path to work is made possible and valued in modern society. Education – although almost universally valued – takes on its full meaning in the preparation of individuals for capitalist citizenship. Through the school, the institutional structure transmitting the discipline and the tools to contribute individually to the social group, the transformation towards a productive activity for the citizen community is then possible (Gaudet, 2018). Work is recognized as the foundation of citizenship, to the point that it becomes its main condition. In other words, it is expected from all members of the citizen community, this large social group, that these members are at work by producing via an activity (Isin & Turner, 2002). The notion of citizenship is closely linked to collective identity, to the gathering of peers who, in order to take part in the community and its order, engage in work (Karolewski, 2009). This common will involves a sharing of values and symbols that allow for the holding of standardized behaviors. The latter behaviours are the result of social interactions guided by the shared symbols involved in building of social norms that allow for the status of citizens.

This then underlies a period of bringing individuals into membership in the social community. In the process of transitioning to adult care, adolescents additionally transit into this category of citizens. Although the status of children and adolescents is institutionally recognized, it remains nebulous in application and in the issues that condition it. The particularity of young people, their recent (adolescence, emerging adult, young adult) and ever-changing social categories, their *agency* – the development of their individual practice – clashes with the somewhat normative definition of citizenship or rational social contribution (Freire, 1970).

As they are about to enter adulthood, the phases of this period, such as studying, leaving home, entering the labor market, forming a couple, are likely to be disrupted by their medical conditions and thus may slow down their passage to adulthood. The social representation of adolescents takes into account these particularities of adolescents on the way to becoming adults and thus to taking part in the community of citizens, through the expected values of autonomy and responsibility, notably through the need to reason in order to reach this status of "age of reason" (Gaudet, 2018).

The account of an adolescent as an emerging but incomplete citizen captures the complexity of the collective identity of this group that represents the patients of healthcare professionals. As presented earlier, one group's perception of another affects their interactions symbolically (Berger & Luckmann, 1966). The multiple psychosocial transitions nested within the transition to adult care makes it all the more interesting as an example of an adolescent healthcare study in the implementation of care integration. Adolescence and the emergence of adulthood occurs as a social process and is interwoven with the transition of care.

During adolescence, individuals are developing their understanding of citizenship and their roles within society. Access to healthcare services and the quality of care they receive greatly influence their ability to participate fully in society (Garney et al., 2024). Adequate healthcare empowers adolescents to maintain their physical and mental well-being, pursue education, engage in employment opportunities, and contribute positively to their communities (Committee on the Neurobiological and Socio-behavioral Science of Adolescent Development and Its Applications et al., 2019). Conversely, barriers to healthcare access or inadequate healthcare provision can hinder adolescents' development and limit their opportunities for active citizenship. Issues such as lack of access to healthcare services, stigma surrounding certain health issues, or insufficient support for mental health can impede adolescents' ability to fully engage in society and exercise their rights as citizens (Garney et al., 2021). Therefore, examining the link between adolescence citizenship and healthcare is crucial for understanding how to support adolescents in navigating this critical phase of life and fostering their meaningful participation in society. A supported adolescent population is critical for a thriving society. However, the question arises – how well does the current healthcare system align with the specific needs and evolving rights of adolescents as both developing citizens and individuals with unique health considerations?

The social construction of the healthcare system and its professional work

The preceding section examined the construction of social and collective identity, with a focus on adolescents and emerging adults. To clarify this concept, the discussion focused on adolescents' roles as emerging citizens in a modern neo-liberal society. This social context emphasizes the containment of society within capitalistic goals, where individuals or elements are valued solely based on their market value (Clarke, 2005). The collective identity of a young adult in formation is significantly shaped by their anticipated future social and economic contributions (Branje et al., 2021). This analysis highlights the dynamic and evolving nature of identity boundaries in this demographic. We have seen that the care received by adolescents occurs in a specialized pediatric setting. The following section presents this environment, its structure and how it weaves its influence to shape apparently fixed categories of service delivery that do not necessarily reflect the needs of its users.

Modern specialization: from division of labor to hyperspecialization

The division of labor is a fundamental concept that elucidates how societies organize and operate. It refers to the allocation of tasks, roles, and responsibilities among individuals or groups within a community or society (Durkheim, 1893; Smith, 1776). Through this division, social order and cohesion are maintained as a structure. At its core, the division of labor involves the specialization of individuals or groups in particular tasks or occupations based on factors such as skills, expertise, resources, and societal norms. Specializations allow individuals to focus on one set of skills that represent an expertise, leading to increased productivity and efficiency in various economic and social activities (Bell, 2001; Granovetter, 1985).

Moreover, the division of labor implies interdependence among individuals and groups within society. However, by relying on each other's specialized skills and contributions, members of a community or society are asked upon to collaborate and cooperate to meet their collective needs and goals (Granovetter, 1985). Additionally, the division of labor can lead to the development of social hierarchies and inequalities, as certain occupations or roles may be valued more highly than others within a given society. This can result in disparities in wealth, power, and opportunities, shaping the social structure and dynamics of the society (Bourdieu, 1986; Marx, 1867; Tilly, 1998).

The social division of labor, or more commonly called in modern society specialization or hyperspecialization, has an ambivalent status. On the one hand, it has allowed a new structure of production activities improving yields and expertise, on the other hand, this process has not been without loss (Malone et al., 2011; Prior et al., 2023; Snow et al., 2020; Turbow et al., 2021). While it created new social identities, it also erased some of them. The institutions that have integrated this new social order have thus propagated new norms and values that have infiltrated the different social strata. These fundamental changes have thus restructured the existing symbolic and social boundaries and constitute the mode of production that we need to recognize when studying intra- and inter-organizational interactions (Carter & Keon, 1989; Lamont & Fournier, 1993). This modality indeed conditions the social relations that occur within it.

The phenomenon of hyperspecialization, characterized by an intense focus on developing expertise in narrowly defined domains, has permeated various organizational spheres, significantly transforming the nature of work and professional identities (Couture, 2005; Malone et al., 2011). This evolution in specialization has led to a restructuring of tasks and information processing, resulting in a workforce comprised of individuals with highly specialized skills. Such developments have been extensively documented in academic literature as influencing both the means of production and the professional landscape itself (Chauvenet, 1972; Farron & Hoffmeyer, 2012; Malone et al., 2011; Moyal, 2020; Pronovost et al., 2002).

For instance, in healthcare, hyperspecialization has led to the emergence of roles such as clinical nurse specialists and pediatric oncology radiologists, reflecting a deeper focus on highly specific areas of knowledge and practice (Mirmoeini et al., 2020; Weissman et al., 2013). This shift has not only enhanced the capacity for targeted patient care but has also introduced challenges related to collaboration and communication among healthcare professionals (Topcu et al., 2017). A pertinent example of this is in the management of complex multi-system diseases such as diabetes, where endocrinologists, dietitians, podiatrists, and primary care physicians must work in concert to provide effective care. The necessity for these professionals to collaborate highlights the paradox of hyperspecialization: while it fosters unparalleled expertise, it also necessitates a greater degree of interprofessional coordination to address the multifaceted needs of patients.

Thus, while hyperspecialization enhances individual proficiency, it simultaneously demands an expansion in collaborative practices and interdisciplinary knowledge sharing. The implications of this are profound, necessitating adjustments in professional training and systemic integration to facilitate effective teamwork across specialized domains. This balance between deep specialization and collaborative integration remains a critical challenge in the evolving landscape of professional practices, particularly within the health system (Millgram, 2015).

Categorizing and collaboration in health services and professional work

As a major social institution, the health system itself of course reflects if not epitomizes specialization. To observe the organizations of the health system is to observe the social order that operates in an institutionalized environment. The social division of labour operates in the environments of the health system. It is easy to think of the specialization of health system professions as directly influencing professional culture. More symbolic and social boundaries are then established as specialization occurs, increasing intra-group tensions. For example, the nursing profession represents a recognized and distinct occupational group. However, as much as the professional culture of a pediatric nurse will be shaped by the pediatric environment, the shared norms and values within the pediatric hospital will differ between acute and complex pediatric care. This is the challenge of integrating care. How can care be coordinated to achieve a common goal when the actors are embedded in groups with increasingly differentiated norms, values, and behaviors? While this issue represents many factors, it is compounded by other organizations with their actors evolving in still different contexts.

Care is then sectorized by pathology, by type of care, allowing for a greater turnover and care of patients. By virtue of their mandate as public health and social services - reinforced by health systems with so-called universal coverage, as in Canada and France – hospitals and medical centers are called upon to cover the needs of the population. The objectives are also segmented, depending on the main mandates of the health centers. For example, a university hospital operates on the basis of curative and preventive treatment mandates, including teaching and training the next generation, compared to a rehabilitation center. The interactions in these two institutions will be relative to the actors interacting in each institution but also according to the mandates and the adaptation needs that the institution must make to achieve the mandate. As I have introduced, the health system and the organizations that make it up are a set of complex and adaptive interactions (Braithwaite et al., 2013; Cilliers & Preiser, 2010). Thus, changes in the political and historical context have an effect on the behavior of the organization and *ultimately* on its ability to integrate care, in our study, on the interactions leading to the effective transition of adolescents to adult care.

For example, in a study of structural changes in CLSCs in Quebec, aimed at covering mandates in three sectors: medical, social and community; integration and adaptation were seen into the group of new health professionals was hindered by the division of new tasks creating an imbalance of power dynamics between the actors in this new group. On the other hand, certain roles were affected, such as that of the nurse or the family doctor. The new structure has contributed to the redefinition of professions in this context (Couture, 2005). Restructuring and model changes are still commonplace in the healthcare system today. These changes are not without consequences for the establishment of symbolic and social boundaries and for the ability of organizations to carry out their common project.

In health and health services research, the issue of boundaries is studied at an organizational level. Work boundaries between health professionals, particularly in multi- or interdisciplinary teams. Specialization in work – beyond its contribution to the market economy – induces the acquisition and development of certain abilities, skills and knowledge that can be translated into organizational knowledge. All the specializations grouped into a set of skills and tasks represent the competence of the organization in which these specializations are operationalized. However, depending on the systems with which an organization collaborates, specializations may instead reduce organizational response. In order to better understand how specializations in healthcare settings may interfere with the transition of care and contribute to the problematic of this complex phenomenon, it is necessary to understand how the specialization of professions in the healthcare system results in, among other things, a reinforcement of the symbolic and social boundaries of each professional group.

Interprofessional boundaries

The field of *professional boundaries* is receiving attention in health services research and sociology (Nugus et al., 2010; Paradis et al., 2014; Reeves et al., 2010). In particular for health professionals, given that collaborations between HCPs are central to the functioning of the health system and by extension to the population health outcomes of care. As is often cited as a starting point for attention to interprofessional relationships in healthcare settings, communication is one of the major sources of medical error (Dingley et al., 2008; Topcu et al., 2017). This is more than errors related to the techniques of care (although these still exist). Although the social boundaries of professions are often reduced to the division of tasks and roles of professionals, it is in fact a way of understanding what it takes for professions to foster communication between groups of distinct professions.

Professional boundaries significantly influence the dynamics of collaboration and coordination of care, particularly as health systems aim to adopt models that integrate health and social care (Reeves et al., 2017). The complexity inherent in professional relationships is largely attributable to the distinct boundaries set by each profession. These boundaries, while defining specific roles and responsibilities, paradoxically necessitate interdependence among various professions, due to the specialization required to execute segments of the overall healthcare task (Nancarrow & Borthwick, 2005). This interdependence underscores the need for effective interdisciplinary communication and cooperation to enhance patient outcomes within integrated care frameworks (D'Amour et al., 2005). For example, a study showed how close collaboration between nursing and respiratory therapy teams significantly reduced the incidence of BiPAP-related pressure ulcers in a pediatric care unit, demonstrating that interdisciplinary teamwork is crucial for improving patient outcomes (Acorda, 2015). This highlights the important link between how and when interdisciplinary care is performed according to the situation and the quality of care and patient outcomes. This interdependence is in itself the *raison d'être* of interprofessional coordination, in this case on the understanding of the distribution of tasks by the actors involved in the coordination and the adoption of a common behaviour to achieve a common work (Castañer & Oliveira, 2020), especially during critical events such as in intensive care units or emergency rooms (Lin et al., 2022). In concrete terms, it is a question of knowing who does what, when and why; this knowledge will enable the pooling of resources, the communication of these resources and the expected actions.

Coordination as a concept is based on the determination of needs for the common objective. The cooperation of the actors is based on the actions of implementing coordination, including behaviors that allow for the integration of care. Interprofessional collaboration is based on the attitude of the actors during interactions as well as the outcome of the interactions. Collaboration enables cooperation in the sense that it relies on the actors helping each other to achieve the common goal established by the coordination. The results then differ according to the objectives of the collaboration required. The collaboration of health professionals evokes objectives of quality of care, patient safety and satisfaction with care delivery, from the point of view of both patients and HCPs for the latter objective (Castañer & Oliveira, 2020). Integration of care needs to be seen as structured through the effective coordination of care, which is further implemented through active cooperation and collaboration. All of these phenomena occur within relatively stable professional and organizational boundaries.

The role of nurses is highlighted as crucial in both pediatric and adult healthcare settings due to their unique mandate and distinct responsibilities in patient care. Nurses' professional identity encompasses essential attributes that are critical in this context. The literature frequently underscores nurses' pivotal role in care transitions, particularly in coordination, which is rooted in the theoretical foundations of nursing culture. The concept of "caring", initially introduced by Watson and later developed in various models such as the McGill model, is central to nursing culture (Paquette-Desjardins et al., 2023; Watson, 2013). It comprises skills and empathetic attitudes directed toward patients and their communities. This approach considers the patient's environment, recognizing its influence on their health (Lombart, 2015; Watson, 2013).
The vision of holistic care, integrating biological, physiological, and psychosocial aspects as a unified whole, is a fundamental component of nursing education (Paquette-Desjardins et al., 2023). This approach aligns with the principles of the biopsychosocial model of care, particularly in its emphasis on integrated care, which mirrors the objectives of the nursing profession (Engel, 1981; Watson, 2013). Recognizing the unique skills of nurses, distinct from those of other health professionals who may focus more on diagnosis and treatment — such as in the medical profession — highlights the vital role nurses play in care transitions. As the population ages and the prevalence of chronic diseases, complex infectious conditions, and mental health issues rises, healthcare interventions are called upon to prioritize fostering collaboration among professionals from various specialties and healthcare settings (World Health Organization, 2015). Ensuring smooth transitions between different professionals and institutions is essential, emphasizing the critical importance of continuity of care.

Limitations of the transition of care literature

In contrast to much previous literature on adolescent healthcare, it is important to take into consideration the similarities, as well as the differences, between specific pediatric diseases, in relation to the transversal aspects that are related to the organizational system of the care services. Programs that outline the major stages of transition have been shown to be effective in standardizing activities and providing resources that explain the process, increase understanding of the disease, provide psychosocial support, and develop independence (Sobota et al., 2011; Steinbeck et al., 2008). However, the effectiveness of transition-of-care interventions is poorly researched and documented, and interventions to improve transition to adult care focus on preparation for transfer and tend to overlook the needs of young adults during and after transfer to adult services (Hart et al., 2019).

To optimize interventions, many tools have been developed and validated. During periods of transition, there are specific factors or elements that emerge as critical predictors of success or failure (Shimbre et al., 2024). These elements can vary depending on the context of the transition but often include factors such as preparation, support systems, adaptability, self-efficacy, and access to resources (Alassaf et al., 2017; Gray et al., 2018; Prüfe et al., 2022; Pundyk et al., 2021; Reilly et al., 2020). By recognizing and assessing these indispensable elements, it becomes possible to predict the likely outcomes of a transition. For example, individuals who are well-prepared, have strong support networks, exhibit adaptability, possess self-belief, and have access to necessary resources are more likely to experience successful transitions. On the other hand, those lacking in these elements may face challenges and potentially encounter negative consequences (Speller-Brown, 2023). The outcomes of transitions significantly impact individuals' lives and can have broad consequences. Positive outcomes, such as successful transitions into desired educational programs or fulfilling careers, can lead to increased satisfaction, personal growth, and improved well-being (Tofft et al., 2022). Conversely, negative outcomes, such as unsuccessful transitions, can result in unmet needs, and potentially hinder future opportunities for AYAs (Lyons et al., 2014). The definition of transition success is currently focused on indicators that are biomedical in nature and not necessarily social or non-clinical. The development of fields such as epigenetics demonstrates the importance of considering lifestyle, nutrition, physical activity, sleep and therefore social life in the management of disease and prevention of co-morbidities (Lorenzo et al., 2022; the BIOS Consortium et al., 2019). Thus, research on the involvement of lifestyle, including social and cultural aspects and their diversities is needed to fill these gaps.

Autonomy (framed also as *empowerment* in the English-language literature) of adolescents and young adults is a notion that systematically recurs in care towards transition. Often prescriptive, autonomy does not take into account the interdependence between the young adult and the healthcare system in which he or she is called upon to navigate and deploy resources (Schuiteman et al., 2020). In this sense, future studies to understand the development of interdependence between adolescents with chronic illnesses and their healthcare system are encouraged to develop resources that promote the appropriation of this interdependence on both sides, that of the individual and his or her social network and that of healthcare professionals.

The literature emphasizes the importance of involving a multidisciplinary team – consisting of pediatric and adult physicians, generalist and specialist, nurses, psychologists, and other members essential for therapeutic patient education such as dietitians-nutritionists, or more specific depending on the chronic condition (e.g., respiratory therapists) and the social condition (social workers) (Gorter et al., 2011; Gray et al., 2015; Winocour, 2014). Nevertheless, multidisciplinary follow-up remains difficult to maintain during the transition to adult and primary care, a task that is concentrated on nurses who are more likely to take charge of transition activities (Jordan et al., 2013).

Furthermore, few studies focus on the impact of the intersection between the different social identities that youth represent. Resources and barriers vary depending on parental socioeconomic status, parental and youth literacy levels, culture, and gender. Consideration of systemic phenomena on individual life courses – either by applying the intersectionality framework – would highlight the adaptation of individualized care transition plans with a goal of equity (Rambajue & O’Connor, 2022).

The transition from pediatric to adult care consists of four to six core components and three main phases grouped around the transfer event. Transition is differentiated from handoff, which consists of the single event of changing care providers by sending the patient's record from the pediatric specialist to the adult medical specialist (Got Transition, 2014; Toulany et al., 2022). Each phase has specific actions and indicators of success that must be considered before moving to the next step in the transition process. These indicators of success, however, are not established by all actors involved in the transition process and require more precise definitions to enable their widespread use. Thus the indicators offer only one perspective on the notion of transition success – primarily that of the providers – and should be determined with a view to evaluating the interventions (Nehring et al., 2015).

Moreover, the development of programs and other interventions to improve transition struggles to consider the full range of voices of the actors involved, being subject to a partial view according to some actors. The literature includes publications on transition from disease-specific care (e.g., diabetes, chronic kidney disease, liver disease, growth disease, HIV) (Shimbre et al., 2024; Vakharia & Stanley, 2023; Vazquez-Ortiz et al., 2023; Vittorio et al., 2023; Zurynski et al., 2023). Most of these articles take into account the perspective of either patients and their families or healthcare professionals, but not both. No studies were found that compared or integrated the perspectives of various health professional groups with those of patients and families, despite the fact that various roles are critical to the success of transition services. Knowledge of the obstacles attached to particular stages makes it possible to anticipate the hindrance of the transition process by putting resources in place and thus prevent the failure of the transition and the associated consequences. Although the transition phenomenon is interdisciplinary in nature, there is little involvement in the literature of research from the social sciences. A combination of social scientific and health research could highlight the mechanisms of transition and their interdependencies in order to facilitate the transition process.

The organizations in which transitions occur are part of the healthcare system. As such, these organizations are nestled in a complex and adaptive operation that involves learning that allows for the internal problem solving of the organization without which it cannot function on an operational basis. Organizations such as those in the health system are constantly learning processes and methods in order to continually adjust and function. The knowledge and expertise of health system actors contribute to the learning of organizations and *ultimately* to their productivity and effectiveness. As care transitions are part of the mechanisms that are integrated into the services of organizations, they can benefit from this form of learning. Little has been written about organizational learning as an element influencing care transitions. Indeed, although the literature reviewed highlights the lack of knowledge and expertise of health professionals, particularly with respect to medical education, the way in which the acquisition of knowledge influences knowledge and behaviours in organizations has not been studied. Behaviours in the organization influence the organization as a whole.

While it is highlighted that when knowledge is integrated at the organizational level (beyond the actors in the organization), this knowledge can then be transmitted to other affiliated organizations and so on (Boerner, 2016). These behaviors are relevant to the study of transitions of care processes, as they involve both intra- and inter-organizational mechanisms. Three ways have been identified to promote the acquisition of knowledge from one organization to another. A first form of learning is when technical knowledge is passively communicated between organizations; this involves annual reports and reviews. A second form is the more active analysis of an organization's information, for example by monitoring. While the third form is interactive and is based on partnerships between organizations, such as hospital affiliations with other health centers, research centers and universities (Griliches, 1991). It is through these means that learning is best transferred from one organization to another, allowing new knowledge to be applied and exploited by the organization that has just acquired it.

Communities of practice represent an opportunity for the development of the field of care transitions, and specifically the transition to adult care. This is because these formal and informal organizations share common interests and learn together to improve processes related to their interests. Interactions between members of the same community of practice allow for the acquisition of knowledge, the co-construction of knowledge and the consolidation of expertise necessary to respond to the issues of the phenomenon in question. More and more communities of practice are emerging and are popular as a collaborative work tool (Arcand, 2017). Depending on the degree of recognition of the community of practice at the institutional level, this can help to integrate new knowledge into the environment.

The study of organizational learning would shed light on the development of skills related to the improvement of transition processes but also on the organizational behaviors that will have influenced and hindered the success of transitions to adult care for adolescents with complex needs. In other words, the transition from pediatric to adult care for adolescents and young adults living with a chronic condition sheds light on the reorganization of symbolic and social boundaries influencing organizational learning capacity.

In this work, I further explain how symbolic and social boundaries influence the capacity for organizational and inter-organizational learning. In other words, in order to improve an organization's own processes (organizational learning) and those of an ecosystem (inter-organizational learning), organizational, professional and individual boundaries slow down or make possible the creation, retention and transfer of intra- and inter-organizational knowledge. These mechanisms all have an influence on the systemic capacities for change and *a fortiori* for process improvement.

Traditionally, structures have played a crucial role in providing guidance and support for adolescents as they navigate the complexities of their lives. However, it has become apparent that structures alone are inadequate in capturing the nuanced experiences of this unique stage of human development. The myriad of challenges and opportunities faced by adolescents necessitate a comprehensive conceptualization that can accommodate the rich tapestry of their experiences. Such a conceptualization must account for the interplay between biological, psychological, and social factors that shape their development. The rigid categorization imposed in society and medicine fails to acknowledge the individuality and diversity within the adolescent population. To optimally address the needs of adolescents, it is crucial to challenge the prevailing fixed categories and embrace a more flexible and inclusive framework. This new paradigm should recognize the fluidity of adolescent experiences, allowing for personalized support and tailored interventions.

Scope of this study and research questions

This work presents the transition from pediatric to adult care from the perspectives of the different groups of actors who are involved in the process of chronic care transition for adolescents and young adults. By comparing and contrasting the different voices on the phenomenon of transition of care, I include the diversity of angles of approach to this issue. As social boundaries are at the heart of this work, I hope to contribute to this field of study, in particular by providing elements of understanding of aspects of group mutation and intra- and inter-group relations.

More specifically, the transition from pediatric to adult care proves to be an ideal example for studying social boundaries. Beyond departments and specialties, age category plays a role in the transition process. Pediatric care being representative of the child category (neonatology for newborns and infants, pediatrics for children, and sometimes when available in hospitals, adolescent medicine). In any society, adolescents represent the next generation and, by extension, the future of a society or human organization. However, it is known that current healthcare delivery is suboptimal for them. In order to develop integrated population-based healthcare and ensure the sustainability of healthy populations, the unique responsiveness of health services to the health needs of adolescents has been identified as one of the key cross-cutting elements that play a major role in the health of societies (Chatterjee et al., 2015).

The way health services are structured and implemented for adolescents is intended to address their complex needs as well as their help-seeking behaviors. However, in health research fields involving adolescents, findings often focus on the relationships between adolescents and adults, and how these are perceived by adults (Fabbrini et al., 2017). For example, a review of the literature shows that interventions are often based on modifications of adolescent behaviors when transition occurs in a changing environment that needs to be considered and known to better accommodate (Anderson et al., 2018). The use of participatory methods has emerged in research to promote the participation of children and young adults in research, particularly in the development of tools or interventions concerning them (Cooper et al., 2022; Jacquez et al., 2013; Schwartz et al., 2013). In sum, previous literature on adolescent healthcare has tended to focus on specific disease, care outcomes, or parts of processes, with less attention to contextual, processual and constructed dimensions of care, recognizing the interrelationships of various influential factors and the active agency of participants in the transitional care process. To be able to account for the complexity of transitional processes, this dissertation engages a theoretical perspective grounded in the notion of symbolic and social boundaries.

A symbolic and social boundaries perspective on adolescent healthcare

As the issue of adolescent healthcare and its shortcomings are examined in this work, it is essential to consider how healthcare structures are shaped in a way that allows for the multi-directionality of influences to be taken into account. This contextualized perspective allows us to understand how social processes and power dynamics impact the delivery of healthcare. Moreover, by analyzing the various influences on adolescent care, we can gain insight into the underlying beliefs, attitudes, and cultural norms that shape healthcare organizations. Multiple influences play a crucial role in shaping the healthcare system, especially in the context of adolescent healthcare. Boundaries formed among and between actors not only influence the delivery of healthcare services but also impact the overall experience of adolescents within the healthcare system. Such influences represent and reflect factors that contribute to the disparities and inadequacies in adolescent healthcare. Furthermore, understanding the influence of these boundaries is paramount in devising strategies to bridge the gaps and create a more inclusive and effective healthcare structure for adolescents.

Social boundaries around adolescence

> “There are two consciousnesses in us: one contains only states that are personal to each of us and that characterize us, while the states that the other contains are common to the whole society. The first represents only our individual personality and constitutes it; the second represents the collective type and, therefore, the society without which it would not exist.”
> (Durkheim, 1893, Chapter 2)

The foundation for addressing the complexity of transition stems from recognizing the fundamental components of different services of systems. Rather than vague or flippant espousals of collaboration, this starts with unapologetic recognition that particular services are distinct and have actionable boundaries. Boundaries do not merely separate services; they facilitate cross-boundary work, and boundaries themselves change and expand in their crossing

(Bowker & Star, 1999). Foregrounding an exploration of *perceptions* and *processes* of transition – beyond *outcomes* – across services requires engagement with the concept of symbolic boundaries.

Boundaries define the society in which we live (Tilly, 2015). Adolescents exist in an intermediary state, straddling the thresholds of childhood and adulthood (Sawyer et al., 2018). Analogously, within the realm of healthcare services, they find themselves ensnared within the compartmentalized bifurcation of medical attention, oscillating between pediatric services and specialized adult-oriented care. Boundaries serve to delineate territories, leaders of those territories, organizations, departments, teams, professions, families, and couples as groups and categories. They also serve to recognize what is part of a group or category and what is not (Charles Tilly, 2004; Lamont & Molnár, 2002b). Social or symbolic boundaries are reflected in the categorization (*classification*) of social facts. Boundaries are the limits of classes; they indicate what is considered in a class and especially what is considered as "other" or excluded from this class. It is the delimitation between "us" and "them" (Bowker & Star, 1999; Lamont & Fournier, 1993). Boundaries are reinforced or attenuated according to the categories and categorization that constitute the mundane activities of social life. In this way, many classifications have become so entrenched in societies that they have become norms, common entities, taken for granted, and assumed as what goes without saying. They are moreover for the most part "ordinarily invisible", so imbricated are they in everyday social interactions (Bowker & Star, 1999). Fundamentally important in the social structure, the standards that these categories establish constitute powerful entities, and their impact is inescapable (Foucault, 1990a). The most common classifications, however, are the object of important social issues and distinctions such as racism, sexism, elitism, ageism, or stigmatization.

It is then well established that the social world is elaborated not at all or not only from objectively real phenomena, but is only given meaning from the *human* principle of classification, materialized by symbolic and social inclusion and exclusion (Bowker & Star, 1999). From these categories, the borders that delimit them can move. In other words, they can extend or substitute themselves for others. Two types of boundaries are discussed in this work, in symbolic boundaries and social boundaries. These two types of boundaries are to be distinguished. On the one hand, symbolic boundaries constitute conceptual differentiations instantiated by social agents to classify objects, persons, practices, and even temporal and spatial dimensions. These boundaries serve as instrumental apparatuses that enable individuals and groups to engage in both conflict and consensus over the delineation of reality. Their study captures the dynamic dimensions of social interactions as groups of actors in a system attempt to assert the production, dissemination and institutionalization of new categorizations. Symbolic boundaries are a means of acquiring social status, new roles, and corresponding resources (Lamont & Molnár, 2002a).

Symbolic boundaries have received increasing attention since the 1960s, particularly through their association with discussions of indirect forms of power, notably through the sociological, anthropological, and philosophical literature of Bourdieu, Elias, Goffman, Douglas, and Foucault (Lamont et al., 2015). On the other hand, social boundaries represent reified expressions of social disparities, evident in the inequitable access to, and distribution of, both tangible and intangible resources, as well as social opportunities. These boundaries are further exposed through enduring behavioral patterns. Boundaries thus become social, after their symbolism has largely entered into a binding form of power then ready to infiltrate social structures and merge into every day and mundane life where they are reinforced and extended (Lamont & Fournier, 1993). Indeed, the symbols are first established and delimit the membership to a group, or the attributes of inclusion and exclusion to be then social by the social stratification (Douglas, 1997; Edgell et al., 2020).

Symbolic and social boundaries have shed light on many phenomena that respond to issues of occupation (Gieryn, 1999), gender and ethnicity (Hall, 1992), class (Marx & Engels, 1965), and democracy or religion (Becker et al., 1999). Anthropologist Mary Douglas (1966) starkly illuminated how interaction promotes inclusion and exclusion of symbolic categories through strong emotions distinguishing what is desirable through being represented as clean and “pure”, and what was dangerous by being promoted as unclean. Furthermore, Descola's (2003) anthropological works have exposed the social conception of nature, through the elaboration of dichotomous boundaries between nature and culture.

Thus, the evaluation of social and symbolic boundaries works in different contexts and can shed light on the most complex social phenomena while maintaining the interconnections at multiple levels of analysis that induce complexity. Widely used in the social sciences as a basis for addressing issues in many different fields, social and symbolic boundaries theory offers an angle to examine inter- and intra-group relations, as is the case in the adolescent care transition.

A person is taken in this work as a social *agent*, who interacts in society. Their interactions are assumed to be molded by and for the society in which they have evolved, just as their interactions will in turn shape the society. Belonging to a group is particularly dynamic, in the sense that it is constructed as it goes along and evolves with time and in the environment in which it develops. An identity is not fixed; it oscillates according to the periods of life which constitute in themselves categories with normative and non-normative events which compose it (Tilly, 2015). One's identity exists and moves according to its interactions with the other identities which complete it, confront it or reinforce it. This is how people identify themselves not with one label (as a woman, a person of color or a young adult) but with a panoply of identities that coexist, thus maintaining interconnections.

Social identity can, therefore, be conceived in terms of an interactionist approach. It is the conception of self in which social input intervenes. Indeed, identity is seen as constructed and in motion according to the cognitive processes involved in predefined social interaction contexts (Hogg, 2016). This definition takes into account the importance of the effect of the groups on the formation of the self, as much on the image projected towards the others as on the reflected image of the other actors on oneself. It represents the effect of intra- and interpersonal interactions on the individual, but also on the way individuals influence groups according to their recognized identity (Loseke, 2016).

Identity is central to the study of symbolic and social boundaries in that it embodies boundaries by echoing norms and behaviors that are seen as attributes of inclusion or exclusion from a group. This concept allows us to account for the macro effects of symbolic and social boundaries at the micro level. Indeed, it is in this way that studies on social movements, for example, the work of Jaquet (2014), have been able to show the passage from one social class – economically disadvantaged without cultural capital or political power – to another (*transclass*), changing the life trajectory that would correspond to social reproduction. Although transclass cannot be considered as an identity as such, the concept evoked by Jaquet refers to a social adaptation of identity when changing group membership. However, this notion indicates a process of evolution of self-definition and understanding of the social world and its classifications (Jaquet, 2014).

Moreover, the recognition of one's identity on an individual level and the social inclusion norms of certain groups can then induce a profound identity change involving social modifications on the perception of one group on another. Social and collective identity can be summed up as social influence, which leads to a change in the behavior and relationships of a social agent in his environment and his relationships with other groups, organizations and institutions. It can be accomplished by constraint or by acceptance. In either case, it emanates from a social structure shaped by its categories and boundaries (Abrams & Hogg, 1990).

Social influence is, of course, at play in the construction and social representation of an adolescent's identity and its influence on their interactions with the health system. To be able to account for the adolescent, accounting must be made for the notion of adulthood, which also involves highlighting the symbolic and social boundaries of particular socially-sanctioned age categories and associated roles. The following section on the symbolic and social boundaries of the healthcare system elaborates on dimensions of professional identity of healthcare providers, in particular through the concept of professional boundaries (*bounded work*), to highlight what is implied by the collective identities of health professionals in the health system in which they evolve to work with the adolescent population.

Understanding how the boundaries involved in the process of transitions from pediatric to adult care are formed, transformed, and abolished allows us to deconstruct the invisible ordinariness that constitutes the set of inter- and intra-group transactions and thus reveal the social dimensions inherent in the process. This is the first study to our knowledge to employ such a theory to bring a new angle of analysis to the transition of health and social care. As this field of investigation is still recent, it remains poorly conceptualized, which limits our understanding of the issues.

The use of symbolic and social boundaries in the study of transitions of care involves the recognition of social factors in the construction of the healthcare system in which this process takes place. Studies to date have failed to recognize the contribution of these factors in impeding the process as a whole. To overcome this theoretical shortcoming, the application of an analytical grid involving symbolic and social boundaries requires a complementary micro and macro focus. It is indeed considered that the micro aspects invest the macro level and vice versa (Collins, 1988). It is therefore important to recognize the issues and the workings of these aspects by including them in this analysis of transitions in care in order to offer a more comprehensive view of the phenomenon. In contrast to previous research, integrating the perspectives of various stakeholders would facilitate understanding of transition processes and challenges at micro, meso and macro levels, providing a foundation for practical recommendations for health service improvement.

The healthcare system is based on fixed but evolving structures that include many boundaries that influence the way healthcare services operate. This work aims to shed light on these boundaries, using the example of adolescent chronic care, including their manifestation and negotiation. This involves identifying the mechanisms of transitions or overlapping social boundaries. More specifically, I ask the following questions: *How does the transition from pediatric to adult care operate across different stakeholder groups? What are the processes activated to improve the operationalization of the transition? What learning is generated and mobilized?*

In this chapter, I have presented the body of literature and conceptual dimensions of this work, (Al-Ababneh, 2020; Crotty, 1998). To operationalize the research questions above, the next chapter describes the approach and methods used to study the mechanisms of transitions to adult care.

Chapter III. Methodological approach

Introduction

This chapter charts a pathway to explore the influences and categories that emerge in the neo-liberalized context of healthcare provided to emerging adults. This chapter empiricizes the contradiction between the social contexts of hyperspecialization and fragmentation, and the espoused impulse of health services towards the integration of pediatric and adult services. To do so, qualitative research was used because it provides a platform for ontological and epistemological positions that takes account social exigencies.

As presented in the previous chapter, I position this work in a constructivist philosophy, that is, I consider that several realities coexist and form the social reality, which can be perceived according to the positioning of the social actors (Berger & Luckmann, 1966). Knowledge, as such, is co-constructed by the social actors. Thus, in order to observe and understand a phenomenon, it is essential, from this epistemological perspective, to take into account a diversity of perceptions of the phenomenon in order to understand how it is formed and transformed through the social interactions of the actors (Mead, 1934). Since symbolic and social boundaries are evident in their effects in interaction, this dissertation work is anchored in the a qualitative research approach – which facilitates documentation and analysis of the words with which boundaries emerge, are shared and are modified (Patton, 2014). Well-established and increasingly used in the health sciences, qualitative research enables the exposition and hence analysis of social phenomena (Pope & Mays, 2020).

This chapter outlines the methodological approach that sets the stage for this dissertation. First, I establish the **scientific rigor** introduced in the chapter on theory. The methods are detailed along with the strategies used to ensure scientific rigor as this work evolves, from its conceptualization to the synthesis of the data and its translation or dissemination. Secondly, **the interpretive approach** used is explained with its role and application in this work. Thirdly, **the particular context of the field** studied is set out, given that any study focuses on a research object situated in time and in a social, cultural, political and environmental context whose factors influence the phenomena that are part of it. Fourth, **the methods of data collection and analysis** are detailed. The preparation, organization and conduct of the semi-structured interviews are outlined before discussing the thematic approach used for the analysis. The design of the outcome indicator grid for the adult transitions to care process is discussed. All research involves **ethical issues**; these will then be presented. Finally, the chapter closes with **a focus on the findings**, namely how I arrived at the interpretation of the data as it is presented in this doctoral dissertation.

Scientific rigor

This work followed a systematic process in order to optimize rigor – that is, to deliver knowledge in a way that is disciplined in terms of its intellectual assumptions and its execution (Herfeld & Lisciandra, 2019; Lincoln & Guba, 1986). Based on Lincoln and Guba's four elements of scientific rigor and authenticity in qualitative research, I consider credibility, confirmability, trustworthiness, and transferability throughout the consecutive stages of the research (Lincoln & Guba, 1985). *Credibility* is the confidence in the veracity of the findings, i.e. when the findings are recognizable in the lived experiences of the participants. It is the correspondence between the interpretations made by the researchers and the perspectives of the people who experienced the phenomenon under study (Tobin & Begley, 2004). *Transferability* means the applicability of the findings in other contexts, notably for this study to other hospital settings with the same attributes as those in the Quebec healthcare system. *Dependability* refers to the congruence, consistency and potential replicability of the study's findings; this requires that the research be traceable and documented. *Confirmability* refers to the extent to which the findings are derived from the data of the research participants and not from the researcher's personal motivations and interests. Confirmability of research is only possible when the other three criteria are met (Lincoln & Guba, 1985). To enable the achievement of these fundamental criteria of scientific work, I include markers and reminders throughout this dissertation of the reasons for the theoretical, methodological, and analytical choices, and their articulation together to enable readers to understand the overall research strategy leading to the proposed findings and conclusions (Koch, 1994; Nowell et al., 2017). The reliability of the research is, therefore, reflected in each part of this work by the methods used and their explicit presentation. Here, the aspects that I have developed throughout this work are summarized and presented.

To facilitate these elements of research rigor, triangulation of methods and theories, reflexivity, and peer debriefing was primarily used (Lincoln & Guba, 1985). Triangulation of methods involves employing multiple research methods to examine the same phenomenon, thereby enhancing the rigor and comprehensiveness of the findings by mitigating the limitations inherent in each individual method (Arias Valencia, 2022). Despite its criticism for claiming comprehensive targeting, as positivism would, triangulation has been interpreted as a combination of different methods to enrich the findings and, hence, the picture of the phenomena under investigation (Arias Valencia, 2022). Peer debriefing primarily occurred during supervision meetings, as well as during research committee and hospital site expert meetings. During data collection, I was able to consult with team members to enhance confirmability.

Table 2 outlines the specific elements that were emphasized to ensure scientific rigor based on the timing of the research. This occurred in three main phases of this research, i) prior and during the conceptualization of the research and preparation for data collection, ii) data collection and analysis, such as the period of data collection from informants and their analysis in an iterative process; to make sense of the data primarily through triangulation of methods and theories, and iii) synthesis, when the previous two phases allowed me to generate new knowledge about the process of transition from pediatric to adult care, and interpretation to produce transferable findings.

	Before	During data collection and analysis	Data synthesis
Credibility	Triangulation of theories Reflexivity Discussion with the dissertation committee Presentation of the protocol for committee and peer review	Sampling strategy	Positioning of the researcher
Confirmability		Collaboration with experts and family representatives	Peer review and scientific community
Reliability		Discussion with the dissertation committee	Data comparison (theory triangulation, groups)
Transferability		Note taking, memos, analysis log	Reflexivity

Table 2 Strategy for maintaining scientific rigor throughout the research, from conceptualization to data synthesis

Prior to data collection and during the conceptualization of the research, the scientific literature and the expert committee formed for this study served as the knowledge base to initiate the methodology of this research. Access to previous work, meetings with committee members, and supervisory discussions of the research helped to establish the roadmap. The expert committee consisted of an interdisciplinary team, including health and social science researchers, patient representatives, clinicians (physician specialists, advanced practice nurse, and social worker), and medical residents. The contribution of an interdisciplinary vision makes it possible to cover the complementary angles of the phenomenon and to triangulate the theoretical and practical perspectives (Denzin, 2017). It was at this stage that the research ethics committee evaluated the research from a scientific and ethical point of view and gave its approval.

During data collection and analysis, the sampling strategy and ongoing collaboration of the expert panel members ensured that the intended sample was achieved, and discussions of the initial analyses allowed for refinement of the collection and analysis methods as interviews were conducted, until data saturation was achieved for each stakeholder group included as participants or when no new information or themes were observed in the data, indicating that further data collection is unnecessary (Saunders et al., 2018). During data collection, verification of understanding, and an interpretive pathway, were undertaken with participants, and analysis notes written during, and revised after, the interviews were compiled to supplement the verbatim transcript for analysis. An analysis log was developed to track the progress of the interpretation as the interviews progressed and reflect on how my background may influence the process (Finlay, 2002).

For data synthesis, once the data had been transcribed, analyzed, and interpreted, evaluation of the interpretation took place through discussions with the dissertation committee and the expert panel members. The presentation of the research as this dissertation was also part of the evaluation criteria process especially for establishing dependability. In sum, this pathway of using verification, iteration, reflexivity and triangulation techniques contributes to the scientific rigor of this study. The systematic and consistent manner in which I sought to conduct the research is elaborated below, enhancing the resonance that this research would have for other researchers and those in other comparable settings.

An Interpretive Approach to Transition of Care

This research is based on the interpretive paradigm rooted in social constructivism, that is, the epistemological position considering the social construction of phenomena by actors (or social agents) (Berger & Luckmann, 1966; Bourdieu, 1990; Giddens, 1993). This approach focuses on how social interactions construct what is considered reality – in this case the interpretation of the world – and how these interactions are normalized and transformed. In this perspective, the interpretation of the world emanates from the lived experiences of the actors who make sense of it according to a space, a temporality, a language and a history (Bourdieu, 2001). The actor is thus perceived as being part of the systems they model. However, as suggested by Crozier and Friedberg:

> *"There are no fully regulated or controlled social systems. The individual or collective actors who compose them can never be reduced to abstract and disembodied functions. They are actors in their own right who, within the often very heavy constraints imposed*

> *on them by "the system", have a margin of freedom that they use strategically in their interactions with others"* (Crozier & Friedberg, 1977, p. 30).

This margin of freedom, which passes through the interactions between the actors of the same system, is under study in this work. The way in which the actors understand the organization of the system in which they operate influences their behavior, which in turn influences the way in which the system functions (Chevrier, 2013). Thus, in order to understand organizational mechanisms, we must look at the behaviors and meanings given to these behaviors and actions by the actors involved in the mechanisms in question. It is then a matter of interpreting the meanings and beliefs of the actors. To do this, an interpretive approach is used, since it allows us to deconstruct the meaning-making process and the way in which meaning is embodied in social interactions, via the language and behaviors of social actors (Schwandt, 1994). This paradigm comes from the theories of interpretive practice initially developed by the philosophers Gadamer (1976), Heidegger (1962) and Husserl (1983). This approach allowed light to be cast on the lived experiences of the actors on a phenomenon by presenting new methods leading to new knowledge, in particular in the fields of management sciences, in the study of organizations (Schwandt, 1994).

In practice, I approached the research object using a hybrid of inductive and deductive reasoning, called abductive reasoning. Although historically anchored in the pragmatic current, abductive reasoning takes into account both theory and empirics, and is well within the field of constructivism (Dewey, 1922; Peirce, 1905). The production of research and the generation of knowledge to contribute to the chosen field of research, in this case social boundaries, cannot be taken to be objective. The positioning of the researcher is by no means free of color. In other words, socialization (including family, academic education) has shaped the researcher's thinking, way of analysis and their understanding of the events of social life. Although I tried to be as rigorous as possible, the research includes my interventions and theoretical sensibilities as an interviewer and analyst co-constructing data with participants. In this vein, the scientific analysis of narratives cannot be totally inductive, as Anadón and Guillemette mentioned (2007, p. 26). It is indeed "illusory to seek exclusive induction", and thus … "any approach to understanding implies moments of logical deduction".

In order to shed light on the transition from pediatric to adult care of adolescents living with a chronic condition, and taking into account the broad context in which it is operationalized, this research endeavours to take account of the macro (structural and institutional), meso (organizational, professional), and micro (individual) levels of this phenomenon, accounting for the complexity of healthcare (Braithwaite et al., 2013). This can be expected to provide in-depth insights through a detailed and dense description of interprofessional responsiveness to youth health and social care needs, integrated within the overall social context (Geertz, 2008). Empirical data will be triangulated (perceptions, documents, theories) to enhance the credibility of the data collection and analysis, and thus the rigor of the study (Lincoln & Guba, 1986).

Qualitative research finds its roots in theory. By using empirical cases, qualitative research produces new knowledge on the phenomenon studied "empirically" which in turn feeds the theory. This means that practice is found in theory and vice versa. Thus, transition of care ought to exemplify the challenges of complex healthcare work across professionals and services. This work is based on the theoretical framework of symbolic and social boundaries with an interpretive approach, which takes into account the general context of the phenomenon under study, with systematic data collection and analysis including the reciprocal influence of micro and macro levels (Patton, 2002). This is, therefore, the focus of this research, namely, to question the common sense and perceptions of social actors about a phenomenon. I sought to investigate the way in which the transition from adolescent care to adult care operates according to the actors involved, by means of how each actor perceives it, and finally what they understand about this operation, through an initial theoretical study allowing for an initial deductive analysis. The empirical part of this work completes the approach by allowing praxis to be confronted with theory.

The value of qualitative research lies in the ability to explore common phenomena in order to deconstruct them and analyze them according to a specific reading grid. Thus, the descriptions and interpretations provided by patients who have experienced the transition to adult care, or by HCPs who have accompanied patients in this transition from healthcare, allow us to draw out a set of reflections on the nature of the transition and, more broadly, on the integration of care in the healthcare system.

As seen previously, the concept of social boundaries is based on social constructs that develop by taking into account the existence of an object (for example, adolescence) according to points of view anchored in different social realities (Bowker & Star, 1999; Lamont et al., 2015). This is how the notion of adolescence is socially constructed, i.e. via a multitude of interrelated understandings (Cuin, 2011; Galland, 2008). It is not a question of invalidating one perception in favor of another. It is only a question of highlighting the contrasts of perceptions, in order to understand them and to try to explain their origin and their effects. The next section explains where and how the perspectives of the different stakeholder groups involved in the transition process were gathered, as a foundation for the interpretations presented in subsequent chapters.

The context of the study: the transition from pediatric to adult care in Quebec

In order to provide a clearer understanding of the research context, this section outlines the conditions under which the research took place. The CoV-SARS 2 pandemic had a major impact on many social systems (Verma & Prakash, 2020), requiring health systems to adopt new organizational behaviors related to crisis management (Lal et al., 2021). Given the upheaval that affected the health system during the data collection period, consequences and what was done to mitigate them are explained here. Although the effects of the pandemic were not the focus of the research, they contributed to the increased barriers faced by users of health systems and, by extension, those involved in the adult care transition (Blumenthal et al., 2020), further illuminating the themes of this research.

Transfer to adult care in Quebec

Although transition processes occur in many different areas of healthcare, this study looked specifically at the transition of adolescents from pediatrics to adult care in a large city in a Canadian province. In the province of Quebec, as in healthcare systems in high-income countries, children are assigned to and followed by pediatricians from birth until they are 16 or 18 years old. At age 18, adolescents can only be treated by adult care physicians, with exceptions made for special cases (e.g., impending death, or unprecedented situation such as the pandemic). When a disease is diagnosed in childhood, the family is referred to the children's hospital for follow-up, often with a dedicated multidisciplinary team. For example, in the case of type I diabetes (mainly diagnosed during adolescence), the pediatric care team will consist of an endocrinologist, a nurse, a nutritionist, and possibly a social worker. At age 18, the young adult will be transferred to adult care, referred by the pediatrician or a family physician. Family physicians are the primary care physicians in Quebec and may be involved in the follow-up of chronic diseases in adolescents. However, few young adults have a family physician assigned to them. For example, in metropolitan Montreal, only 54.4% of 15–24-year-olds[1] have a family physician (Institut de la statistique du Québec, 2013). Figure 4 illustrates the flow of patients through pediatric healthcare to adult care while (depending on their situation) having a dedicated a family physician.

Figure 4 Interaction between the actors in the transition to adult care

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[1] Adolescents can register on waiting lists for a family doctor from the age of 14.

The children's hospital as a starting point

This work was conducted in a pediatric hospital in the Montreal metropolitan area, the largest in the province of Quebec in Canada. In Montreal, there were more than 307,000 families with children, of whom 20.5% were single-parent families. Young people between the ages of 15 and 25 represent 12% of the population of Montreal (Institut de la Statistique du Québec, 2018, p. 43). Chronic diseases are of growing international concern, and Canada has 44% of adults over 20 years of age with at least one of the ten common chronic conditions (including asthma, diabetes and cancer) (Public Health Agency of Canada, 2019b).

Our starting point for this study was the pretransfer phase, during which the transition to adult care is initiated – that is, the phase that occurs between young adults, their families, and pediatric health professionals at the children's hospital. This meant that the families were being followed or had been followed at the children's hospital and the pediatric health professionals were working at the children's hospital. Health professionals working in adult healthcare services and primary care settings (such as family medicine groups, hospital-based family medicine units, or local community service centers) worked in settings affiliated with the same university health system. Thus, all participants shared a common context of being immersed in a healthcare system driven by values based on the same political and ideological environment.

Data collection methods

Qualitative research is about understanding a phenomenon under study that is governed by broader cultural, political, social, institutional, and organizational norms, in which particular beliefs and reproductive patterns are embedded (Denzin & Lincoln, 2011). In order to identify, understand and explain them, the interview is one of the relevant and appropriate methods because it captures how individuals' account for the relationship between their individual actions and systemic influences (Green & Thorogood, 2018). Thus, to gather the perspectives of the actors involved in the process of transition to adult care, semi-structured interviews were conducted with medical specialists, nurses and allied health professionals in pediatrics, and adult care, family physicians (representing primary care), and adolescents and parents of adolescents who have experienced the transition to adult care in the context of a chronic condition.

Participants and sampling strategy

To gather multi-stakeholder perspectives on the transition of adolescents from pediatric to adult care, a purposive and snowball sampling strategy was applied to recruit stakeholders who are directly involved in the transition process (Suri, 2011). Indeed, as a first step, I planned to recruit participants with relevant characteristics to provide a rich narrative about the transition to adult care, i.e., participants involved in adolescent transitions. This strategy made it possible to collect data related to the process from the perspective of the actors most involved, who had therefore acquired and developed a significant knowledge of the mechanisms and analyze their actions and their understanding of the phenomenon. By having access to the four groups of actors mentioned earlier, all with a high degree of involvement and a detailed knowledge of the processes experienced, contrasting the common themes to highlight the intra- and inter-group interactions was possible. This sampling strategy also allowed us to collect the perceptions of the transition phenomenon from a variety of actors involved, providing insight into the social boundaries studied vis-à-vis their effect on the integration of care via a diversity of voices.

Second, once recruitment began, participants were asked to identify individuals with extensive experience in the transition from pediatric to adult care. With an emphasis on social boundaries, and specifically on the effect of institutional, organizational, professional, and individual boundaries on integration of care, I formed groups of participants representing variations in roles according to the actors identified in the transition process, taking into account different variables. These included:

1) The caregiver-patient dyad, including the two major groups of healthcare professionals on the one hand and the family on the other.
2) The different health services involved in the transition to adult care, involving the three levels of pediatric, adult and primary care.
3) The different professions involved, with the inclusion of physicians, nurses and allied professionals for pediatric care.

The choice of not recruiting allied professionals from adult and primary care was based on the principle of purposive sampling. Adolescents and young adults are no longer followed by the same allied professions when they transition to adult care.

To begin data collection, a group of health professionals and a group of care recipients were formed. These two groups were then divided into sub-groups, in order to represent the first sphere of actors directly involved in the transition process.

In the case of those cared for in children's hospitals, the family has been involved in the adolescent's care since the beginning of his or her care in the hospital. For this reason, parents of children who have experienced the transition to adult care were included. In the case of health professionals, three services are regularly involved in the transition from pediatric to adult care in a cross-sectional manner; pediatric care, adult care, and primary care were included. Within these groups, in order to study the effect of professional boundaries, maximum variation was used to recruit professionals from different specialties. To anchor this variation for the participant group, young adults and their parents who had experienced transition to pediatric care due to various chronic health conditions were recruited.

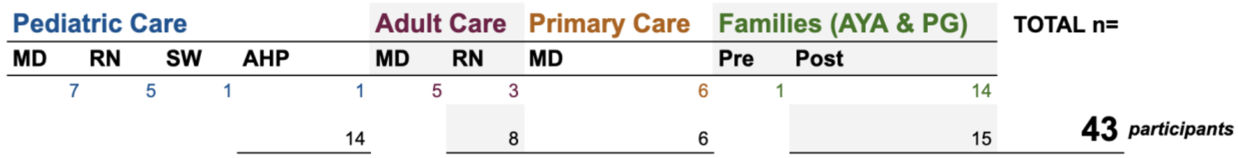
There are other actors who navigate the transition of adolescents to adult care. Depending on the chronic condition of the adolescent or young adult, many actors from various sectors will interact with the actors in the transition. Among them are the rehabilitation network (especially for young adults with so-called “complex” health needs), those from the school and transportation systems, and also the administrators and public policy makers who formulate the health and social services agendas. Although concerned with the transition from pediatric to adult care, I limited this research to those actors who directly and actively interact in this transition from specialized services to others. Moreover, as documented in the literature review, the main pitfalls occurring during the transition process stem from inter- and intra-organizational aspects involving pediatric and adult care services.

Finally, the participants were thus separated into four groups, and each of these groups into two or three subgroups. The healthcare providers thus formed three groups: 1) pediatric care was composed of pediatric specialists, pediatric nurses, and pediatric healthcare providers; 2) adult care was composed of adult care specialists and adult care nurses; 3) primary care was composed of family physicians; and 4) families were composed of parents of adolescents and young adults living with a chronic illness. Families were considered a unit, represented by either the adolescent/young adult or the parent. Most parents interviewed had a child with complex care needs. Participating healthcare providers were from the same university network hospitals. To be eligible to participate in the interviews, healthcare professionals had to have cared for adolescents or young adults with chronic conditions who had experienced the transition to adult care services. Families were eligible when the adolescent or young adult had experienced the transition from pediatrics to adult care for a chronic illness.

Reflexivity concerning trauma was a central aspect of my approach to interviewing AYAs and parents, many of whom had experienced various forms of trauma in relation to AYAs' health condition. I sought to embed trauma-informed research principles throughout the research process, which shaped how I engaged with participants (Huo et al., 2023; Isobel, 2021). A key priority was to empower the voices of AYAs by fostering their active inclusion in the study. This was pursued by creating a safe and welcoming environment during both the recruitment and interview processes. For example, during interviews, I ensured that my background was visible (not blurred) to establish transparency and a sense of trust.

To minimize the risk of re-traumatization, I adhered to several trauma-informed strategies (Muskett, 2014; E. Reeves, 2015). These included seeking to hold acute attention to participants' emotional readiness to engage in the interview, conducting the interview as a respectful dialogue that honored their autonomy, regularly checking in with them throughout the conversation, and providing a debriefing at the conclusion of the interview. This reflexive approach not only helped me prioritize the well-being of AYAs but also engage with ethical sensitivity when working with participants who have experienced trauma.

Sample size in qualitative research is much-debated, as it is sometimes compared – inappropriately – to the sampling requirements of quantitative research designs (Rapley, 2014). Thus, participants were recruited based on the group to which they belonged and until data saturation, i.e., until no significant and new themes emerged, consistent with the research questions and the conceptual framework adopted (Guest et al., 2006; Saunders et al., 2018). For each group, and sub-group, the objective was to wait for what is considered saturation, which is a means of ensuring that the themes emerging from the intra- and inter-group analyses no longer allow – at the time of the analysis and the data collection period – for new theoretical articulations to emerge. It is thus important to situate "saturation" in the context in which it was reached. Table 3 presents the sampling strategy per group. In the pediatric care group, physicians, nurses, social workers and allied healthcare professionals were included. In the adult care group, physicians and nurses were included. In the primary care group, family physicians were included. Families included AYAs and parents or guardians of AYAs. This distribution represents the organization of the different groups. The participant count by group is shown in Table 3.



Pediatric Care				Adult Care		Primary Care	Families (AYA & PG)		TOTAL n=
MD	RN	SW	AHP	MD	RN	MD	Pre	Post	
7	5	1	1	5	3	6	1	14	
			14		8	6		15	43 participants

Table 3 Participant count by group

MD= Medical Doctor; RN= Registered Nurse; SW= Social Worker; AHP: Allied Health Professional; AYAs= Adolescents and Young Adults; PG= Parents-Guardians

In order to gather the perceptions and experiences of the actors involved in the transition process from pediatric to adult care, semi-structured interviews were conducted. Semi-structured interviews balance having a pre-ordained interview guide with flexibility to vary the guide, whether by including additional follow-up questions, changing the order of questions, or leaving out particular questions, as optimizes an individual participant's contribution to the study (Green & Thorogood, 2018). This type of interview is a form of social interaction in which the participant is guided to present his or her perspective, thoughts, and understanding of the phenomenon under study (Pope & Mays, 2020). The semi-structured interview allows for elaboration from the general to the specific according to the research agenda – that is, in relation to the research question. It is a method that involves the researcher in a co-construction of data. In fact, the interview is an exchange between the researcher and the participant during which the researcher is expected, by responding to certain points made by the participant, to allow the latter to elaborate on these remarks, to give them meaning or to question them (Denzin & Lincoln, 2011). This whole process is used in the analysis of the data, through a preliminary analysis that is detailed in the next sub-section of this chapter (data analysis).

The positioning of the researcher on the one hand and the participant on the other also influences the interview (Pope & Mays, 2020). Therefore, it is essential to pay attention to the power dynamics stemming from both the relationship between the researcher and the participant, but also within the participant's narrative. For example, simply being affiliated with the Department of Family Medicine at McGill University gives the participant a set of preconceptions before even beginning the interview. I have a background as a trained healthcare professional, having briefly worked in both pediatric and adult care settings. This experience has informed my recognition of the critical role that interprofessional collaboration plays in healthcare practice and research. When I began the interviews, especially with the young adults who were going to testify about their experiences with the healthcare system, I specified my status as a doctoral student without a clinical role in Montreal. This relationship obviously works both ways, so it was also important to take into consideration any power dynamics that could lead to misinterpretation, for example, making sure that we both understood technical terms, ideas, or jargon sometimes used by health professionals, researchers, and AYAs.

In this section the methods of data collection, on the one hand, and analysis, on the other, are presented in a linear and sequential manner as guided by its current writing. However, in this research, the methods were intertwined and used concurrently while allowing for refinement of the respective methods as the research progressed (Flick, 2014). Conventionally presented in sequence, data collection and analysis took place at the same time. This iterative technique, which involves the systematic repetition of the data collection-analysis duo without being confined to it, is common and established in interpretive qualitative research because it has several purposes (Green & Thorogood, 2018).

Indeed, in addition to making the method systematic, the iterative process also allows for a deeper understanding of the data collection and analysis as cognitive processes (Miyake, 1986), contributing to the dependability that the findings of other similar studies could be coherent or consistent – all other things being equal. Furthermore, iteration reinforces the contribution of the researcher's reflexivity, which allows for interpretation through the meaning given to the information processed (Srivastava & Hopwood, 2009). Figure 5 presents the iterative process applied in this work for data collection and analysis. Each part will be explained according to whether it applies to data collection or analysis in the following sections.

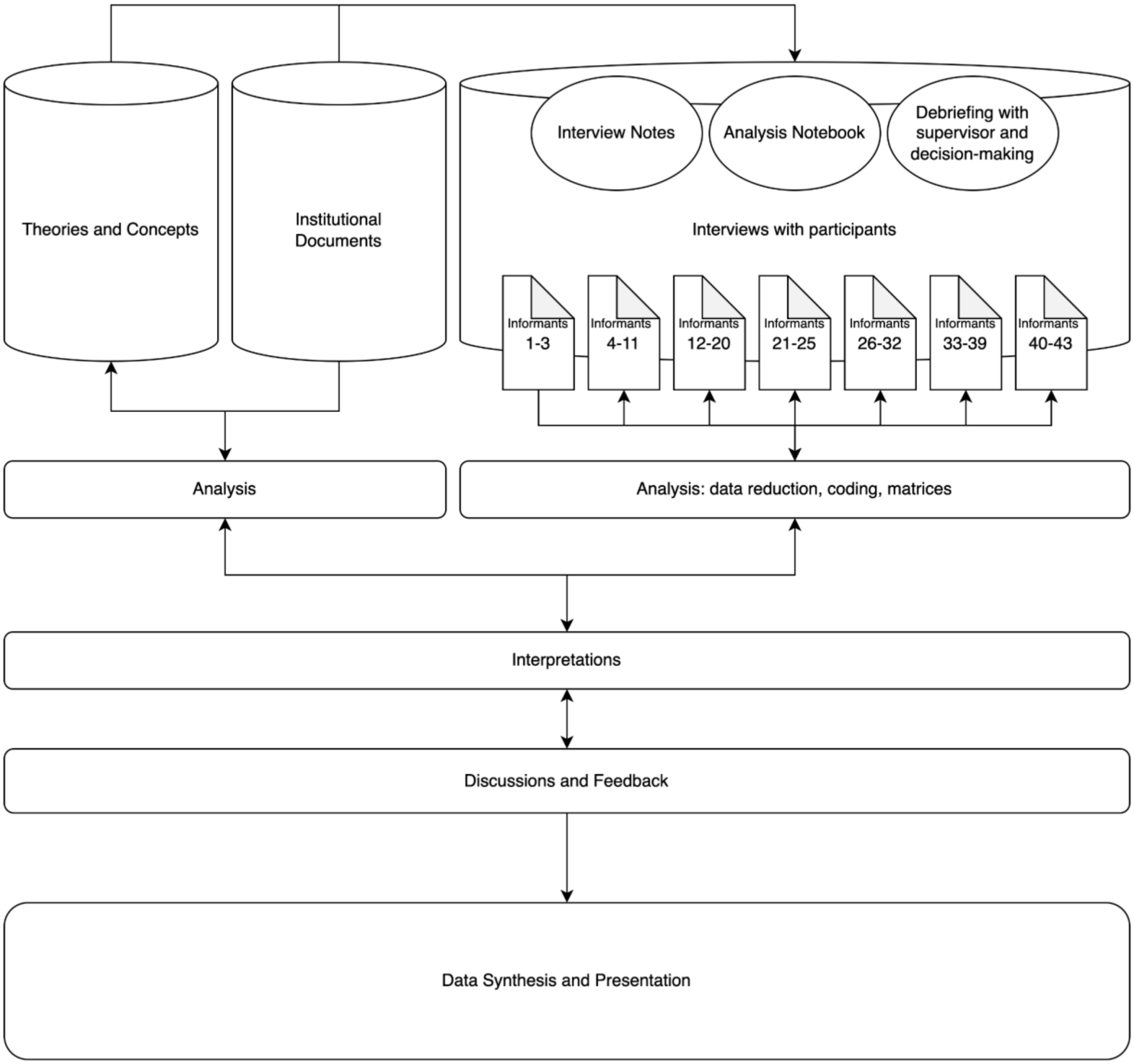


Figure 5 Iterative process of qualitative research data collection and analysis

The interviews were conducted following a guide for each group (See Appendices B, C and D). All interviews followed the same direction and clusters of questions depending on the participant being interviewed. However, some questions or prompts were gradually added, taking into account the content of previous interviews to inform subsequent ones. With families, I discussed their overall experience with the transition from pediatric to adult care, prompting them to talk about positive and negative situations, or possible changes they were making to improve their experience. With healthcare providers before (pediatric care) and after (adult and primary care) transfer, we discussed their experiences with the transfers they had helped to make and the learning opportunities they had gained from those experiences. They were also asked about potential indicators to consider for successful transitions to adult care.

The interviews were conducted in English and French, depending on the interviewee's preference. In Montreal, nearly 60% of the population declares itself capable of conversing in French and English, 27% in French only and 11.5% in English only. We were not able to include allophones (native speakers of neither French nor English), who represent 2.4% of the population in the agglomeration. However, all HCPs can communicate in either French or English (or both). For families, with the increase in population, mainly due to immigration, children whose mother tongue is other than the official languages of Canada, must attend school in French as a priority in Quebec (with some exceptions made to integrate the English school system). However, even English schools have requirements for a considerable quantity of French-language education. These measures have institutionalized the knowledge of French among young people, especially for immigrant families.

A total of 43 participants were interviewed from September 2020 to June 2021, including 14 pediatric HCPs, eight adult HCPs, six family physicians, and 14 families (5 parents and 10 AYAs), until saturation within and across groups was reached – that is, until no new themes were identified. Interviews were conducted in person (at the hospital) and online (Zoom and telephone) in accordance with public health rules during the pandemic. The average length of an interview was approximately 45 minutes.

With fears related to the pandemic, and given adolescent participants' vulnerable health status, parents and adolescents were inclined to participate remotely via a Zoom video conferencing tool. The use of digital communication tools allowed the interviews to be conducted despite government-constrained confinements and physical distancing rules that were imposed from 2020. Although the conduct of interviews was initially designed to take place physically in person – thus allowing for observations of non-verbal discourse in the analysis and calibration of follow-up questions – the qualitative research community gradually adopted the use of virtual methods, allowing for participants to be reached in contexts that did not have the conditions to participate in the study otherwise (Deakin & Wakefield, 2014; Weller, 2017). Moreover, a recent study indicates that the use of such tools was perceived as a positive experience by participants, particularly for reasons of accessibility and time-saving, requiring no travel to the site (Gray et al., 2020).

In addition, to enhance the quality of data collection during the interview, strategies were used to minimize the depersonalization of the report that can result from the use of digital communication tools. Initially, the relationship between the interviewer and the interviewee was established prior to the interview through telephone and email exchanges during recruitment, explanation of the study, the interview, consent, and then later for the planning of the interview. This initial relationship with the same person facilitated familiarity and trust during the actual interview, which contributes to the researcher's ability to collect sufficiently rich data for analysis (Weller, 2017). Secondly, during the virtual interview, I used verbal and non-verbal methods to reinforce this rapport and ask the participant to elaborate, for example through gestures, nodding, or maintaining a presence through interjections, gaze[2] and facial expressions indicating active listening. To do this, I paid particular attention to the facial expressions, tone of voice and gestures of the participants. Finally, the follow-up questions, which were very targeted and put into context what had been said previously by the interviewee, demonstrated listening and interest in the participant's story. The technical aspects of online interviews did not appear to be a source of problems, either for the participants and myself, with both parties benefiting from an Internet connection of sufficient quality to conduct the interviews smoothly.

Tables 2 and 3 present the characteristics of the 28 healthcare providers and the 15 patients and their parents, respectively. Among the 14 HCPs at the pediatric hospital, seven medical specialists (in nephrology, urology, allergology and immunology, pulmonology, complex care), five nurses from the nephrology, cardiology, and complex care departments, and two allied

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[2] Although the participants cannot really detect if I was really looking at them – since we were looking at each other through cameras – looking at the screen allows accounting for a concentration and an active listening.

health professionals in the form of one psychologist, and one social worker were interviewed. All had more than 10 years' experience in their profession. Of the eight health professionals working in adult services in university general hospitals, five were medical specialists and three were nurses. All had more than 10 years' experience in their profession. The six primary care professionals were family physicians practicing in family practice groups, hospital family practice units, or an adolescent medicine clinic affiliated with a teaching hospital. Echoing the introduction to the theoretical framework for this research, the family physicians had a sub-specialization, either formal or relative to the patient population served. The majority had been practicing family medicine for more than 10 years (83%). The majority of HCPs on the pediatric and adult wards were women. The characteristics of the HCP participants are indicated in Table 4.

	Pediatric care (N=14)	***Adult care (N=8)***	***Primary care (N=6)***
Type	Women (78%), Men (22%)	Women (87%), Men (13%)	Women (50%), Men (50%)
Profession	Physicians (N=7) Nurses (N=5) Allied Health Professional (N=2)	Physicians (N=5) Nurses (N=3)	Family Physicians (N=6)
Seniority (in the same profession)	> 10 years of practice (100%)	> 10 years of practice (100%)	> 10 years of practice (83%) < 5 years of practice (7%)
Subspecialty	Allergology & Immunology Cardiology Complex Care Endocrinology Gastroenterology Nephrology Urology	Endocrinology General Intern Medicine Nephrology Rheumatology	Addiction Adolescent Medicine Infectious disease

Table 4 Participant characteristics: Pediatric, Primary, and Adult Healthcare Professionals (N= 28)

The family group consisted of two main actors, adolescents and parents of adolescents who had experienced the transition to adult care. On the one hand, the 10 adolescents were living with a chronic condition diagnosed in childhood or adolescence (before age 18). The conditions involved, in the majority of cases, follow-ups with several specialists. The table indicates the main healthcare department in which the adolescents were followed. Of the 10 AYAs, transfer was imminent for only one of the participants, and even this case was a few months from transfer; two had been transferred for less than a year; eight had been transferred for more than a year but less than five years; and three for more than five. On the other hand, of the five parents or guardians of adolescents who had experienced the transition to adult care, four were mothers and one was a father. One parent was the parent of an interviewed adolescent. In this case, the parent and adolescent were interviewed separately. The characteristics of the AYAs and family participants are indicated in Table 5.

				Transition phase (N=14 adolescents)				
		Care Department	*Diagnosis of AYAs*	*Pre-transfer*	*Transfer*	*Post-transfer*	*AYAs gender*	*AYAs years of age*
15 participants from 14 families (One parent and child were interviewed separately)	AYA (N=10)	Medicine Adolescence (N=3) Complex Care (N=1) Nephrology (N=3) Psychiatry (N=2) Gastroenterology (N=1)	Autism (N=1), Cancer (N=1) Coeliac disease (N=1), Eating disorders (N=4), Encephalomyelitis (N=1), Epilepsy (N=1), Genetic disease (N=3), Kidney failure (N=3), Lupus (N=1), Type 1 diabetes (N=1).	N=1 (7%)	< 1 year (N=2, 14%)	> 1 year (N=8, 57%) > 5 years (N=3, 22%)	Women (N=8, 57%) Men (N=6, 43%)	<18 (N=1, 7%) 18-20 (N=9, 65%) 21-25 (N=2, 14%) 25-30 (N=2, 14%)
	PG (N=5)* *4 mothers and 1 father	Endocrinology (N=1) Complex care (N=2) Nephrology (N=1)						

Table 5 Characteristics of participants: families (adolescents and parents) (N=15)

The interviews were recorded and transcribed *verbatim* by a transcriber who anonymized the data in order to preserve the confidentiality of the participants' personal data. The quality of the transcripts was then checked by reading and listening to the audio simultaneously. This verification made it possible to avoid errors of interpretation linked to a lack of rigor in the processing of the data collected (Poland, 1995).

With families, the focus was on AYAs' experiences in transitioning from pediatric to adult care services. Examples of questions were: "What was the best experience or situation that occurred during [your] transition from pediatric to adult care?" "What do you wish had happened differently?" With healthcare professionals, we discussed their experiences with young adults transitioning from pediatric to adult or primary care, including their understanding of pitfalls. This included asking, for example: "What was the most difficult/comfortable experience in transitioning patients from pediatric to adult care?" "Why?", "What were your strategies for overcoming [a particular challenge]?" "What have you learned about transitioning healthcare from pediatrics to adult care?" "What would a successful transition to adult care look like for you?" Such questions were intended to optimize the participants' interpretations and meanings in relation to transition.

Data analysis methods

A hybrid thematic approach was taken to analyze the data (Swain, 2018). A preliminary analysis was conducted incrementally on the interviews as they were completed and transcribed. This allowed for familiarity with the data and adaptation of questions for subsequent interviews, while ensuring redundancy of themes, or saturation (Denzin & Lincoln, 2011).

Thematic analysis

Data analysis in qualitative research is taken to be a broadly three-step process: data reduction, data presentation, and formulation and verification of conclusions (Huberman & Miles, 1991; Miles & Huberman, 1994). Data reduction is achieved through coding methods, data presentation is achieved through themes and categories emerging from coding, and formulation and verification is achieved through data synthesis – that is, articulation of findings. The analysis is done through an iterative process and, as such, it is carried out progressively, in a continuous manner (Pope & Mays, 2020). The analysis process begins with the development and conceptualization of the research, and continues in the field where choices are made about what to take notes on during the interviews, in addition to the audio-recording, how to navigate the interview guide with spontaneous or follow-up questions, what follow-up questions to ask, and what elaborations to ask for. This is especially important when the time of the interview is limited, since it needs to be fitted into the schedule of health professionals who – although freed up for the end of the interview – have to resume their activity at a specific moment or are sometimes even interrupted during the interview.

The emergence of the theory was grounded in a systematic process of qualitative data analysis. I began by revisiting the verbatim transcripts, which allowed for both a secondary familiarization with the data and a quality check. Subsequently, I progressed to data reduction, generating codes derived either directly from the verbatim text or through paraphrasing. These codes were then organized into broader thematic categories through a process of grouping. The data primarily centered on changes in social identities, sense of belonging, and the definition of legitimacy. This analytical process ultimately led to engaging with social and symbolic boundary theory. As a sociologist, the concept of social and symbolic boundaries strongly resonated, providing a theoretical lens that aligned with the findings. Moreover, it offered a retrospective critique of the linear frameworks often employed in the literature on AYAs (Braun & Clarke, 2012).

The documents

Organizations are known to produce a considerable amount of documentation, which illuminate the intentions of particular policies (Bowen, 2009). In order to complete the data collection and understand the functions of these documents, tools used by the health centers, guides, reports from local health authorities (e.g., from the CIUSSS), and other local policy documents were also analyzed and triangulated with the interviews. Although document analysis is not commonly used, documents can add important details to accounts of reported events (Atkinson & Coffey, 2004). Document analysis sheds light on the direction of the policy, particularly the implication of the policy for practice, to provide context or with which documents are able to be compared. The tools mentioned by the participants were given special attention to better understand the context of the interview narrative in question, and also to refine its analysis.

Findings indicators

To achieve one of the secondary aims of this research, the thematic analysis was used to identify one type of data in particular, namely, the indicators of success in the transition to adult care as perceived by the participants, and, therefore, by the different groups of actors. In order to confront the mechanisms involved in the process of transition to adult care with the pitfalls reported by the literature review, and the actors in the process in question, I sought to establish the key elements of the transition from the perspective of the actors involved. This was intended to highlight the elements for which the actors have a convergent view and the other elements that are specific to particular categories of actors. In other words, the hybrid thematic analysis made it possible to evaluate the indicators from the different stakeholder groups identified for each phase of the transition process. The analysis matrix also allowed for the systematic extraction of data, enabling the analysis of each indicator in terms of the purpose for which it was mentioned and the tool by which the indicator could be assessed during the transition process.

Table 6 presents the evaluation grid for the outcome indicators used in the thematic analysis. As with the thematic analysis, the indicators were developed in what might be considered an emergent fashion through the process of conducting and transcribing the interviews. In this way, the information assimilated was used to develop the follow-up questions for the following interviews (Pope & Mays, 2020).

Indicators (*outcome*)	**Reason**	**Actor(s) involved**	**Experience**	**Pre-transfer**	**Transfer**	**Post-transfer**
Verbatim Code Group of actors	Verbatim Code	Actor(s)	Verbatim Code	Yes/No	Yes/No	Yes/No

Table 6 Evaluation grid for identified findings indicators

Ethical considerations

This project received Research Ethics Board approval from the McGill University Health Centre, number MP-37-2020-5816, from 2020 to 2022, which was the duration of the study (See Appendix A). No adverse incidents occurred. Participant recruitment was facilitated by

Children's Hospital collaborators, including members of the expert panel. After a brief introduction to the project by clinicians who had contact with the youth in the past, when they were cared for on pediatric wards but now transferred to adult wards, the youth or parent could either contact me directly or agree to receive a call from me.

Recruitment of healthcare professionals was accomplished through the snowball sampling method (Handcock & Gile, 2011; Parker et al., 2019). After recruiting the initial participants – in a purposive manner, based on their role and experience in the adult transition process – I asked them at the end of the interview if they could recommend other potential participants who shared their level of interest in the process. The clinical collaborators were only involved in identifying and referring potential participants. In no case did participants have access to the raw research data (e.g., verbatim from families or other health professionals) – only presentations of preliminary findings in which data were aggregated and anonymized so that no participant could be recognized.

The implication of consenting to participate was explained to the participants, and then a consent form was either hand-delivered or electronically transmitted to the participants. Due to the pandemic situation, which prevented many participant interviews from taking place in person, emailed written and verbal consent was obtained prior to the interview, in accordance with the ethical approval of the MUHC Ethics Committee. Data were anonymized in the transcription of the interviews as part of the process of maintaining confidentiality. Thus, no directly identifying data were shared.

Participants were reassured that, to ensure privacy and confidentiality, all future reports and publications would include de-identified data. All direct and indirect participants were informed that they could refuse or discontinue participation in the study at any time. Participants were not compensated. However, interviews with healthcare professionals were conducted on their work time, in accordance with the ethical agreement with the hospital departments. In addition, AYAs and parents received a gift card of CAD$20 as compensation for the time spent in the interviews. The gift cards were sent electronically at the conclusion of each interview. These actions provide symbolic recognition of the time participants spent on the research.

With respect to the vulnerability of the adolescent group, the injustice caused by suboptimal and unmet health and social service needs justifies their inclusion in this research as participants in order to have their voices heard. In addition, Section 5 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans “emphasizes inclusion in research and equitable distribution of direct and indirect benefits of research”, especially for vulnerable populations (Interagency Advisory Panel on Research Ethics Government of Canada, 2022). This research is intended to provide findings that can underpin improvement in healthcare delivery for this underserved population during a time exacerbating their vulnerability.

Highlighting the findings

In this section I explain how the presentation of findings over the next three chapters took shape. In order to reflect critically on the interpretations reached, I sought to document the methodological choices that led to the conclusions. Not that the articulation of the findings requires an interpretation on its own, but introducing it helps to justify this presentation and the points of reflexivity that built it (Creswell & Poth, 2016).

The findings presented in the next chapters emerge from the articulation of the theory of symbolic and social boundaries and the lived experience of the actors involved in the transition from pediatric to adult care. The data were thus interpreted with a focus on interactions as constructed by boundaries and their meaning in the transition process. Among the behaviors analyzed, I categorized those related to navigation in the system where the boundaries are established and anchored, institutionalized. I then categorized the behaviors and meanings given to them in the negotiation of new boundaries to allow the pathway of young adults to adult care with the fewest obstacles possible according to the actors. I then categorized the behaviors and actions aiming at reconciling the boundaries to go beyond the existing boundaries by understanding the barriers in order to propose solutions to, if not allow, and hence improve, the transition to care for adults.

The findings are thus represented as a whole following the transition process in light of the symbolic and social boundaries it influences. I use narrative norms which are common in social science disciplines to present the interpretation of the data. Thus, to illustrate the points made, I use a participant code reflecting only his or her group. Table 7 summarizes the codes according to the participants' groups of affiliation, which will be found in the following chapters.

Participants	**Abbreviations**
Family	
- Adolescents and young adults (AYAs)	AYAs (ex. *AYA004*)
- Parents or guardians of AYAs transitioning to adult care	PG (ex. *PG004*)
Healthcare providers The subgroup is specified before the participant code:	HCP (ex. *HCP004*)
- Primary care providers	PCP-HCP
- Adult care HCPs	A-HCP
- Pediatric HCPs	Pedes-HCP

Table 7 Participant identification codes

Philosophical anchors: Researcher position and scientific integrity

Although this research is empirical, drawing on the lived experience of the phenomenon under study by the actors who create it, it is essentially nestled in theory. Indeed, the role of theory in research is central for transferability, in addition to allowing for the conceptualization of the study (Crotty, 1998). It serves as a grid for reading the data collected to interpret it and by extension, understand the research object. Theory, often perceived as abstract in opposition to the empiricism of the field, ought in fact to be operationalized in each stage of the research, to bridge the gap between theoretical constructs and empirical observations (Collins & Stockton, 2018; M. Kelly, 2010). Research is seen in this dissertation to inform the theory as it operationalizes its concepts through social events that make the theory an explanation of a phenomenon applicable to others. The theory employed reflects the assumptions of a particular philosophical perspective or perspectives (Crotty, 1998). Philosophy is in this sense important for the advancement and production of new knowledge in science, since it provides the general principles for theoretical thinking (Popper, 1959). The two essential areas of philosophy to be considered for theoretical thinking are ontology and epistemology (Moon & Blackman, 2014).

Ontology represents the concept of the “real” and is often defined as the study of being. The determination of what is real depends on the chosen approach, which in turn influences what is considered in the research (Katz, 2002). It is the basis for determining what reality(ies) will be involved in a study and how they will be studied. Although often studied as a binary concept “realism” and “idealism or anti-realism”, ontology is much more nuanced in what is defined as real (Pope & Mays, 2020, p. 16). As I consider the social construction of the social aspects of reality – in this case that society is the product of everyone's representations – I understand that different realities operate in parallel, giving meaning and existence to social phenomena (Berger & Luckmann, 1991). For example, the transition to adult care may be perceived as part of the work of pediatric health professionals, while it may be perceived as an outcome or an endpoint by specialists in adult services. For adolescents and their families, the transition may be understood as a loss of personalized services or as a stepping stone to adulthood. All these different perceptions contribute to the definition of the transition from pediatric to adult care by constituting a plausible assemblage of differing realities. In this work, the various perceptions purposively sampled are taken into account in the analysis in order to have an inclusive portrait of the transition to adult care. The focus of this dissertation is evident social phenomena. Although there may be a reality beyond those constructed by social actors, the focus is on what socially constitutes the social phenomenon under study and how actors experience and understand it.

Epistemology, or the representation of knowledge, is considered to be “the study of knowledge” or “the science of knowledge”. It defines what will be considered valid in the research, as well as the scope and methods of acquiring knowledge about a particular research object (Al-Ababneh, 2020). The epistemology thus follows from the ontology approached in this work. The present research is based on a constructivist approach considering the social context in which all knowledge is inscribed. More specifically, a constructivist paradigm postulates that society is the product of interactions and verbal and non-verbal exchanges between social actors. These exchanges are based on actors’ understanding of the world and, in turn, build understanding and new knowledge (Vygotsky & Cole, 1978). Thus, conversely, a constructivist perspective accounts for the meaning that each actor makes from their interactions with others in society, and which they extend and modify in their future interactions (Vryan et al., 2003). This qualitative study starts from these postulates in order to analyze social processes constructed in their environment by social actors who interact together according to the meaning they give to a phenomenon, and according to an understanding of the role that each one should play in the phenomenon in question, in this case health and the continuity of healthcare.

From these philosophical positionings, the theory of social and symbolic boundary construction offers a lens through which to view the complex process of multi-faceted transitions to adult care. In this work, the social and symbolic borders relate to two levels: macro, in terms of the borders of knowledge and professions, and the micro with the social and collective identities of individuals – recognizably bounded, but permeable, to allow influence and change. These two levels intertwine and influence each other. By highlighting the boundaries, it is possible to understand how they infiltrate social interactions and thus organizations and their structure.

As seen above, the researcher's position strongly influences the conceptualization of research. Indeed, philosophical positioning intervenes inevitably, and leaves its footprints throughout the research process and its own outcomes and outputs. As such, the researcher cannot be external to the research as they model it according to their understanding of the world, of reality, of how knowledge is generated and how to produce new knowledge, taking into account these *preconceptions*. In this way, in this work and according to the philosophical foundations I have outlined in this chapter, the question of subjectivity or objectivity is less relevant, because the two are intertwined – subjects making objects and objects making subjects. The empirical approach and research strategy to address the issues at hand is in itself a position from which this work has been conducted. Subjectivity then lies in the approach used, including the experience and ambitions of the researcher. On the other hand, objectivity – so dear to the so-called pure sciences – lies in the exposure of the researchers' position and any underlying interests that may influence the research.

Conclusion

Because it at least acknowledges, and seeks to expose, the integration of subject-object, that underpins constructivism, a reflexive approach shows inevitable humanness of research. In this way, a constructivist approach can strengthen scientific rigor. This chapter has outlined the decisions made for this research in regard to scientific approach, setting, participant sampling, recruitment, data collection, data analysis, and decisions about how to reflect on the research process and make that process and its outcomes more transparent and rigorous. As such, the chapter is its own experiment in reflexivity. Beyond correlating philosophical and then theoretical foundations to a research object, the scientific approach requires in a certain way an unveiling of understanding (Manen, 2016). As an empirical dissertation the following chapter opens the findings section, which unveils this understanding, in terms of the systems shaping and shaped in adolescent healthcare.

Chapter IV. Collision of worldviews

"Well, I think it's a change of culture, [...] It's a real culture shock. It's like [the patient's] come into a new culture." (HCP013)

Introduction

This chapter reports how qualitatively and cohesively different perspectives manifest between pediatric care for children and adult care, and it examines how such differences impede the transition of young people from one care setting to the other. While both pediatric and adult care services operate within the broader framework of healthcare, these two settings possess dissimilar approaches and cultures. Pediatric and adult care settings are recognized for implementing unique methodologies and cultural frameworks that impact the delivery of healthcare services for adolescents with chronic conditions. These divergent approaches significantly influence the manner in which adolescents and their families access healthcare and are integrated into the healthcare system as a distinct population requiring specific care. Furthermore, the way adolescent healthcare services are constructed and provided is closely related to how this population is expected to engage in their care according to prevailing standards of care. This chapter elaborates on how the manifestations of these standards impede a continuum of care between pediatric and adult care services for adolescents and young adults (AYAs).

Adolescent healthcare symbolically occupies a unique space within the healthcare system, situated between the realms of pediatric and adult care. This chapter presents the collision of these two world views that occurs when transitioning from pediatric to adult care, shedding light on the challenges faced by adolescents in receiving appropriate and comprehensive healthcare. By examining the fundamental differences between pediatric and adult care, this chapter explores how these differences represent the clash of norms that excludes adolescent healthcare, resulting in a healthcare system that struggles to accommodate the specific needs of young adults.

The first section of this chapter investigates the systemic dissociation between two distinct cultures of care. It delves into the fundamental differences between pediatric and adult care, highlighting how these disparities manifest as a conflict of norms. It then further explores how pediatric care, traditionally designed for children, is often considered a “normal” environment for young adults, while the health system itself is built around the adult standard of care. This section sheds light on the challenges that arise when attempting to navigate the complexities of healthcare provision for AYAs during their transition to adult care.

As pediatric and adult care settings are fundamentally distinct in their care cultures, the second section explores the different ways in which pediatric and adult care function, especially in terms of accountability and patient engagement. It examines the transfer of social responsibility that occurs as individuals transition from pediatric to adult care, highlighting the contrasting dynamics of collective and systemic responsibility in pediatric care versus individual responsibility in adult care. This section explains the shifting dynamics and expectations faced by AYAs as they transition through the healthcare system.

These findings include the voices of AYAs who transitioned from pediatric to adult care with a chronic condition, their parents or guardians (PG), pediatric, and adult and primary healthcare providers (Pedes-HCP; A-HCP; PCP respectively) – including specialists, nurses and allied health professionals. By analyzing the collision of world views in adolescent healthcare, this chapter seeks to shed light on the complexities and challenges faced by AYAs as they traverse the boundaries of pediatric to adult care.

Two distinct cultures systemically dissociated

This section presents the systemic hurdles encountered in adolescent healthcare, highlighting the underlying institutional framework that neglects the unique needs and experiences of AYAs. The section shows how prevailing healthcare structure fails to adequately encompass the realities of this transitional population, caught between two disparate cultures of care. As AYAs transition from pediatric to adult healthcare, they traverse a path from familiarity, acknowledgement, and inclusivity to unfamiliarity and exclusion.

This shift brings into focus the contrasting perspectives on normalcy, with pediatric care serving as a reference point, juxtaposed against the prevailing adult-centric healthcare system that sets the standard for care provision. In this exposition, I initially elucidate the fundamental distinctions between pediatric and adult care, laying the groundwork for our subsequent focus on the conflict of norms encountered during the transition to adult care. The boundaries between the two services are interactionally reflected, produced and maintained, but are evidently strong, enhancing their influence over health and healthcare, and difficult to change. The divergence in cultural approaches to healthcare of pediatric and adult services introduces the pediatric setting as the prevailing norm for AYAs and their parents. However, the healthcare system is primarily structured around adult care services, which may appear unconventional and unfamiliar to AYAs.

Fundamental differences between pediatric and adult care

Healthcare services are typically categorized into distinct settings: pediatric care and adult care. Pediatric care is specifically dedicated to addressing the health and developmental needs of children and young adolescents, ranging from birth to the age of 18. In contrast, adult care primarily caters to individuals who have reached the age of majority (18 years of age and over). This division acknowledges the boundaries distinguishing physiological, psychological, and social characteristics of patients in the different age groups, ie., the pediatric population from birth to 18 years of age and the adult population starting from 18 years of age. However, as all groups of participants highlighted, the transition from pediatric to adult care is primarily initiated based on the initial criterion of age, recognizing that while age is indeed one of several variables that contribute to an individual's overall health, it must be acknowledged that the choice of age as the determining factor is ultimately an arbitrary decision within the complex realm of healthcare management, especially for young adults living multiple changes at once.

The transition at the age of 18 is qualified as "*difficult, horrible and brutal*" (PCP002, A-HCP010). While age serves as a marker of physiological evolution, it falls short in capturing the entirety of social life categories such as childhood, adolescence, and adulthood, as well as the nuanced variations that can exist within and between each category. As stated by all participants, there are, in the province sampled, no dedicated services to represent the changes adolescents experience moving to adulthood. The resources provided by adult care settings after 18 years of age do not account for the biological and psychological changes AYAs are experiencing when transitioning to these new services. Essentially, healthcare services are perceived to fail to account for a transition period between childhood and adulthood. As stated by a primary care physician:

> “*[...] [S]ometimes adolescence can happen late. So, the behavior that is classically associated with adolescence can be seen at 18-20-22. Then you have to have the right attitude, judgments and all that. If you detect that you're in that period, you mustn't ask that young person to act as if he or she were fifty years old, because that will never work and will break the doctor-patient relationship.*” (PCP019)

Participants described this transition as akin to a leap from one reality to another, symbolizing the profound and often abrupt change they experienced in the process of transitioning to adult care. They described many environmental differences between pediatric and adult care, mentioning the physical aspects (e.g., waiting room, assessment room) as well as the approach to adult (e.g., “colder” in the adult care setting).

Pediatric care seeks to provide a comprehensive approach that addresses the unique healthcare requirements of children and young adolescents, as pediatric HCPs, AYAs and their caregivers expressed. AYAs, along with HCPs, emphasized the pediatric HCPs’ proximity and accessibility. They argued that pediatric care involved a specialized healthcare workforce consisting of pediatricians, pediatric specialists and AHCPs who possess expertise in the treatment, and management of conditions commonly affecting children. These healthcare professionals are trained to evaluate growth and development patterns, diagnose and treat childhood diseases, and provide age-appropriate interventions. The focus of pediatric care was understood to go beyond the treatment of illnesses, including preventive measures, such as routine check-ups, which played a vital role in promoting the overall well-being and development of children who felt supported by their HCPs. As pediatricians mentioned, the role of pediatric care is to be ‘proactive’ as opposed of being ‘reactive’, as is perceived to be the case in adult care (P-HCP01, P-HCP09). In this vein, adolescents and their parents perceived pediatric care as more specialized and intimate than adult care settings.

The knowledge the pediatric healthcare team developed and shown to AYAs and their parents over the years as being responsive and proactive to their needs influenced the trust AYAs and their parents had for pediatric healthcare professionals. The approach, and specifically the communication (how pediatric HCPs would talk to young adults and their families), was described as 'calmer and nicer' which prompted the perception that HCPs were 'amazing human beings' (AYA004). AYAs and their parents expressed feelings of belonging towards their pediatric care teams. For pediatric care specialists too, the type of relationship between HCPs and the young adults was perceived to shift from close and comfortable to distant when AYAs' transition to adult care.

This perceived change in relationship and trust created fear and anxiety among AYAs and their families. As one nurse from pediatric care stated:

> *"I think fear of the unknown is a really big one. [...] Well, I think there's an attachment with our clinic all the same. But, the element of protection might allow them to be maybe feeling like that. [...] And they know us really well. We take care of them [...] ensuring that they don't fall through the cracks [...]. And they're aware of that because I talked to them about that quite regularly. I talked to the patients about what it's going to be like. We prepare for it so that it's not a surprise, but it causes, I think, a lot of anxiety and fear. So, I would say that's probably one of the greatest things – is this fear of the unknown and also fear of not having what they had with [...] our team [when they transition to the adult team]."* (P-HCP005)

Additionally, in the sampled province, the multidisciplinary structure of pediatric teams did not seem to exist in adult care, which was described as a mismatch between the two settings. Indeed, the structure of pediatric services brought various advantages that AYAs, their families and HCPs acknowledged. For example, reduced delays to receive care contributed to better access to comprehensive care enabled, which the multidisciplinary teamwork in pediatric care enabled.

Conversely, adult care revolved around the health concerns and conditions that typically emerged during adulthood. Healthcare providers in adult care settings, such as primary care physicians and specialists, were deemed to be equipped to manage medical issues specific to adults, including chronic diseases and age-related conditions in a reactive manner. This means that, typically, adult issues, including chronic and age-related issues, were addressed when they manifested as acute illness. Given the higher prevalence of older populations in adult care, the environment of general hospitals was described as cold, generic and impersonal by both HCPs and AYAs patients. Additionally, as an adult care specialist mentioned:

> "*[T]he patient goes from being the oldest in the waiting room, to all of a sudden, they're the youngest in the waiting room. That must be pretty brutal for them. [...] You know that adult hospital is sometimes a scary place. You see a lot of kind of decrepit old people in wheelchairs. And that must be a shock for some of those kids who have never been in an adult hospital.*" (A-HCP010)

Furthermore, HCPs in adult care settings mentioned that there is a greater emphasis on patient autonomy in adult care, ostensibly to empower young adults to actively participate in their own healthcare management and decisions:

> "*For them, it's mainly the change, the demand for autonomy. With the new generation, it's a little more difficult. Sometimes parents are very intrusive because they used to control everything.*" (A-HCP027)

This latter aspect of healthcare management – the expectation of a degree of privacy – was highlighted by HCPs and AYAs as a potential positive evolution of healthcare for young adults. Some young adults preferred not to share their health status with their parents, especially for sensitive topics such as sexual health. In certain instances, the inclusion of AYAs' parents in their care was already viewed as disruptive in pediatric settings.

All participants acknowledged the differences between pediatric and adult care environments. The differences between these care settings were perceived to have a profound impact on the delivery and reception of healthcare. In pediatric care, parents or guardians typically assumed a central role in decision-making and communication with HCPs. Conversely, adult care emphasized patient autonomy and required young adults to assume more responsibility for their health decisions. The transition process involved changes in healthcare providers, the transfer of medical records, and adjustment to a new healthcare environment. Such adjustments were often overwhelming for young adults as they navigated a shift from a more family-centered approach to a more individual-focused approach. AYAs emphasized the change of approach in terms of a change from warmth to coldness; from personal to impersonal communication:

> "*At the [children's hospital], I knew almost everyone because I'd been there since I was very, very young. So, the people who did my blood work knew me. In Nephrology, sometimes the secretary knew me. So, when I came in she'd say, "Hi, how are you? It's been a long time." But, with adults it's "Hello/Hi. Give me your card. Okay, bye," like we were numbers. It's, like, it's not the same vibe. It's definitely not the same universe.*" (AYA001)

With relatively firm boundaries between the two main domains of healthcare services, young adults transition at the age of 18, moving from a known and welcoming environment into the unknown.

<u>The conflict of norms: from known and included to unknown and excluded</u>

Adolescents move from being well known by their pediatric services team members to being relatively unknown by new healthcare professionals they do not know. The shift involves more than just a transition from one service to another with a few different modalities. For adolescents and their parents, the transition from pediatric to adult care has several symbolic aspects that translate into changes considered essential to the delivery of health and social services. These changes are in the relationship with HCPs, and in the approach to care. The relationship with HCPs is about becoming unknown to one's care team 'overnight' (i.e., at the age of majority) and the approach to care is about the family-like culture of care in pediatrics compared to the independent culture of care in adults.

In this section, we will see that transition changes the status of the young adult and their relationship to the healthcare system. Transition is experienced as an abrupt change from an environment in which young adults were recognized by the care team and in which the young person and his or her family were included, to an exclusive environment where they become unknown. Although, in theory, it is the same technical care to be received, this divide manifests an inherent conflict in the healthcare system between the standards of pediatric and adult care.

The loss of AYAs' reference points during their transfer to adult care is explained by them in terms of their lack of knowledge of the environment, and particularly as a lack of knowledge by the new HCPs who will take over the care from the team in pediatrics. This lack of knowledge was associated by AYAs to a lack of readiness by healthcare providers:

> *"[Adult care] was still new to me. […] I had to go for my eyes, my heart; and I did some lung appointments too and all that. So, it was a lot and, at that age, I felt like I was still pretty young too, to feel mature enough to go to all these appointments on my own […]. So, if the transition would have been more easy, then maybe I would have felt more ready. But, I felt like as if I was pitched, like, 'let's go', without any knowledge really … like I was just thrown there and then I was, like. 'Okay, where am I? What do I do?'"* (AYA006)

Moreover, one adult nephrology nurse explained that, whereas young adults were used to receiving care from a relatively coordinated team in pediatrics, the care provided by adult services is very often limited by the involvement of a primary referring caregiver, who is the physician, as well as the nurses (A-HCP027). However, departmental care staff change more frequently than in pediatrics. In pediatrics, nurses, physicians, and allied health professionals tend to have more stable placements. As a result, young adults lose the familiarity and trusting relationships they build over time. They miss out on the consistency of visiting the same department, where they become known and recognized. The loss of a particular person of reference involves the end of recognition by HCPs and, by the same token, a depersonalization of the care on which young adults feel that they rely and depend. A young adult who had been in transfer for over a year explained that he had lost the feeling of being supported, being able to anticipate what will happen, and being able to discuss his care and concerns (AYA001).

The influence of the young adult's recognition by healthcare professionals and their familiarity of the environment thus changes the relationship the patient developed with the care environment. Although not related to caregiving *per se*, young adults mentioned the transfer of relationship as a “loss”, even “abandonment”. Such a feeling was also shared by young adults to their HCPs in the pediatric settings, who reported to experience feelings of guilt. Young adults felt they lost a sense of ease in interacting with new HCPs. They described it as starting from scratch after years spent with the same HCPs. With their previous HCPs, they had developed a trusting relationship and felt comfortable asking developmental questions as they grew into adolescence.

The nurses emphasized that trust is essential for addressing adolescent behaviors and questions. This trust then helps in prevention efforts and maintaining the young person's compliance. Even though a pediatric nephrology nurse noted she could not always prevent risky behaviors due to the young person's medical condition and the pathology's stage, regular contact was beneficial. Communicating simply and responsively, such as by text message, helped manage unavoidable complications quickly.

Moving to an unfamiliar environment with new contacts who do not recognize the youth's status can be interpreted as social downgrading for AYAs. To better understand this social downgrading, it is appropriate to first understand how the pediatric environment becomes the norm, and then to shed light on the societal level in which the standard of care is that of adult services. This contrast in norms experienced by the young person in transition to adult care is synonymous with their social downgrading in chronic care based on their new adult status, which, as we saw earlier, does not always correspond to their self-identity.

Pediatrics as a “normal” environment for young adults

For young adults with a chronic condition diagnosed in childhood, or before they reach the age of majority, pediatric services represent the reference environment for their health and social services. It is the place where children received their diagnosis and their first care. Indeed, the care received by these patients is for the most part centralized in pediatric clinics or pediatric hospital centers. Having been followed for several years or months in this environment, AYAs mentioned that they had developed a relatively thorough knowledge of the pediatric environment in which they had spent a great deal of time undergoing examinations, consultations and even short, medium and long-term stays with the various health professionals who followed them.

Since staff turnover appeared relatively rare in pediatrics, the young adults reported stability and continuity in the care they received and the appointments they made. The relationship between the care providers dedicated to the follow-up of the adolescent and the young person themself evolved with time. Appointments came to take the form of familiar and trusting relationships, characterized by friendly, productive and informal exchanges. Pediatric healthcare professionals had built a strong and often lasting relationship with young patients living with chronic diseases, developed through the regularity of the care children receive. One young adult expressed that she felt that pediatric care was “a lot more specialized and a bit more intimate” than adult care, as she grew up with the same doctors and care team. She valued the relationship she was able to develop over the years and did not know what to expect with a “set of new doctors” (AYA005).

Thus, on the one hand, AYAs’ perception of the adult care environment was constructed by comparison with the environment they had known until then. Appointments and exchanges with pediatric HCPs served to bring the young adults into the bounded structure of a pediatric service, with specific and identifiable service and care markers. This familiar environment provided a benchmark of what it meant to receive health and social services – all within the same facility with the same team. In addition, time and proximity were dimensions that the youth contrasted strongly between the two settings:

> “*Well, what I think is, like, at […] pediatrics I felt like they really took the time to talk to me and I even had their numbers, and I could call them if ever I had anything to talk*

> *about. So, I felt like it was very, like, one on one, like close interactions and stuff. But then to Adults I felt like it was very rushed. And I didn't really know what was going on or how everything worked, like, to take appointments or stuff like that, and I felt I was less important to them – like, the appointments were very rushed and that's what I remember."* (AYA006)

Young adults reported to be upset by unfamiliarity with the new environment, how it worked, and the feeling of being less important than in pediatric care, from their first appointments with adult care services following their transfer. The standard of pediatric care – that is, the type of care to which they had become accustomed and came to regard as normal – was based on interprofessional collaboration operationalized by multidisciplinary teams that allowed young adults to have appointments with multiple health professionals on the same day at more regular intervals.

The capacity to provide interprofessional care around the patient's convenience was also marked by a difference in patient volume in the two care environments. Pediatric healthcare professionals were proud of the difference between the type of care they provided and that of adult services. On the other hand, pediatric care specialists anticipated an increase in the number of transitions due to the increased volume of adolescents in their institutions. However, they lamented the lack of preparation, anticipation and knowledge on the part of adult healthcare professionals. As one pediatric specialist noted:

> "*Because there are more and more patients coming our way who will graduate when they turn 18, it's coming. And the adult side doesn't seem to want to recognize that or do anything proactively about it. So, they [adult care specialists] may not think that transition is an issue for them. But when all of these patients with strange genetic disorders that they've never heard of, and medical needs that they never managed land on their doorstep, they're going to want help from a generalist, and a team, including nurses [and] social work. You know, that's what it's going to take."* (Ped-HCP007)

Evidently, adult care stakeholders' understanding of pediatric care reflected the adult care culture specificity and specialization. In addition, adult care specialists faced a disruption in their practice with the gradual but steady influx of a new demographic, namely adolescents and young adults with chronic – sometimes complex – conditions that they did not care for 10 years ago. This demographic was to include more complex care patients with multiple chronic conditions, as opposed to conditions that could be characterized, in relative terms, as single-system conditions. Similarly, pediatric providers might not have known how their former patients coped with their care in adult care settings, although they realized the stark difference in care delivery that young people were to potentially face. Despite some shared understanding of cultural differences in care and how they might have influenced the way young people were cared for over the rest of their lives, the three care settings (pediatric, adult, and primary care) were not seen to have developed complementary and joint constitutional pathways for ensuring continuity of care for the AYA population.

Participants in pediatric care emphasized the unique knowledge and expertise they had with AYAs. This knowledge is tied to the structure of pediatric care, allowing for individualized care, and then is seen to cease after transfer to adult care. In pediatrics, patients' needs and expectations were well known and adequately supported both socially and medically. This level of support was not matched in adult care. As a pediatric HCP stated, the difference also lay in the structure of the adult care culture which was seen to be relatively opposed to pediatric multidisciplinary teamwork compared with adult care unidisciplinary work:

> "*[AYAs] have, like, the typical ambulatory care experience, [in adult care services] …. They need nurse practitioners; they need nurse case managers in order not to burn right out. Otherwise, the physician is left with all these tasks. I mean, there needs to be a social worker embedded in that program. There should be a psychologist, a nutritionist; then you can provide good care to these patients*." (Pedes-HCP009)

Pediatric HCPs highlighted critical differences they perceived between their approach to care and their professional culture from the adult system, which characterized the current health system approach at a broad level. This dissonance was discussed as fundamental to experiences, perceptions and outcomes of the operationalization of transitional care. Most pediatric healthcare providers believed that true transition had not been achieved. Instead, despite some efforts in transition clinics or other strategies, only a formal transfer was accomplished. Only a handful of patients were seen to be benefiting from “transition” *per se*. In other words, the notion of transition was a goal not yet put into practice with young adults. Many health HCPs and young adults made the explicit distinction between “transfer” as opposed to “transition”. As AYAs moved to adult care, they entered the dominant healthcare delivery realm.

Different ways of functioning

The fundamental differences between pediatric and adult care influenced how young patients were expected to engage in their care, as well as the provision of continuous care while transitioning. It was evident that service boundaries were not fixed, but were enacted and reinforced interactionally, including by young people themselves who were brought into the prevailing structures of care. As this section shows, AYAs and parents encountered challenges in adjusting to the abrupt implementation of new rules upon transitioning to adult care services. The healthcare system's response to AYAs’ needs and expectations shifted their engagement from a collective responsibility to an individual-focused approach.

Accountability and patient engagement

A transfer of social responsibility

Pediatrics, a collective and systemic responsibility

The transition to adult care is conveyed as marking the assumption of responsibility by young adults for their care. This shift in responsibility is described primarily by pediatric HCPs and young adults and their families as occurring without any real transition, that is, abruptly, at the age of majority. The symbolism of coming of age is questioned, such as by a parent of a young person in adult care:

> “*It's incredible how they think that when [adolescents] turn eighteen all of a sudden, they're adults and everything is different. Like, a while back, it was twenty-one. We could stay until twenty-one. And twenty-one to twenty-two; it's a bit more realistic than*

> *eighteen to nineteen or seventeen to eighteen I find. It's just... [...] I think the transition was better at twenty-one, when it was up to twenty-one. I think it was more realistic... There's not as big of a disparity I find. But, there's nothing we can do about it.*" (PG002)

This abstract and "arbitrary" moment of service change for a client, as some medical specialists described it, is one of the great challenges of the transition to adult care. The disparity from one youth to the next is identified by all stakeholders. While one youth may be able to navigate adult care at age 18 on his own, another may not be able to do so until age 25.

For HCPs on adult wards, care management is a significant burden that falls on patients who are considered adults. Two nurses in adult care (rheumatology and nephrology) acknowledged the difficulty for adolescents to follow up on their care when this has been continually done for them by pediatric HCPs, highlighting the lack of consistency (A-HCP013).

As far as adolescents are concerned, the responsibility for care was initially the responsibility of the pediatric teams who took charge of the care of the adolescents from their entry into the service, which sometimes counted for many years. This team-based responsibility was, therefore, integrated by the families as a logic of care which, when the adolescent blew out his or her 18 candles, changed completely. For the families, the close accompaniment by pediatric teams of patients was appreciated, being perceived to facilitate access to care within a reasonable time frame:

> *"The complex care team did a great job; just the adults' side is really challenging. With complex care... like we would call [the Nurse coordinator]. Everything would be set up for us. We had, like, every six months – everything was done. On the adult side, the neurologist already told us they see us maybe once every two years, once every year, from once every six months. To get a hold of someone – I've been trying to get a hold of endocrinology since January [for 7 months]."* (PG005)

The transition to adult services disrupted the previously regular follow-up schedule maintained under pediatric care. This change caused significant delays for young adults and made them primarily responsible for their own follow-up care.

The primary model of responsibility for pediatric care was described by HCPs as "maternal accompaniment", reflecting a caring approach. For example, one family physician described the change to adult care as: *"quite drastic for some"*, explaining that young adults find transferring in difficult:

> *"[There's a] difference in approach between pediatrics and adult care ...The follow-ups are closer. In general, in pediatrics, the young people are maybe a little more mothered, and then they fall into adult care and then it's up to them to take responsibility for doing their follow-up, taking their medication."* (PCP-HCP019)

One internal medicine specialist explained that one of the biggest challenges for patients and their families in the transition to adult care is the expectations created by pediatric care regarding support – especially multidisciplinary support – for appointments and follow-up:

> *"I actually think ... managing expectations [is a challenge], ... because my sense is that in pedes everything is managed for the parents and the kids. I've got all these nice friendly people to make sure that, you know, diabetics come to appointments and etc etc and all of the multidisciplinary team, things are in place, and suddenly they are expected to do things themselves, book their appointments, turn up to their appointments, take their meds, know when to ask questions. You know, etc, etc."* (A-HCP013)

There was a marked difference between the two services, especially with respect to direct communication and availability of HCPs. For the young adults, the responsibility for their care, including making appointments and following up on their treatment, came on the day they were transferred to the adult services. Young adults link this burden directly to their new adult status. This contrast significantly impacts their overall experience. As one young adult noted in describing the change in role he experienced, in terms of attentiveness both to his needs and clinical results, when he moved to adult care:

> *"Honestly, I think we're lost. Lost ... I mean when I was at Children's [Hospital], I mean, with Dr. [Pediatrician Specialist], we were always backed, we always had contact, [and knew] what was going on. So, we always had to see each other every minute. So, it was really more accurate. But with adults, it's really more about leaving you behind. There is a side that I understand, but there is a side that for me – communication is very, very, very important and there is no real communication [in the adult service]. If you're there, if you're not there, it doesn't matter, it was your job. I just think there's more communication missing. [...] It's really more like, 'We give it to you [the appointment] and if you're not there, it's your problem.' It's stuff like that. It's really more like, 'You have to be there; this is your job; since you're an adult you have responsibilities.' But, like I said, at Children's [Hospital] it's not the same. It's really more of a different universe."* (AYA001)

The shift from one setting to another involved, among other things, a change in social responsibility. Responsibility shifted from the healthcare system, represented by the pediatric care team workers to individuals. Pediatric care workers accompanied patients in a multidisciplinary approach. They guided the family in health and social care, reminding them of their appointments, suggesting that they consult a specific provider based on their needs identified in the discussions. Responsibility shifted to the adolescents themselves as responsible for the consequences of their actions in a new healthcare environment. This environment was characterized by less support and relatively difficult access to adult care. For families, the shift in responsibility was seen to come to them "overnight". For young adults, the assumption of responsibility was a complete change of functioning and environment. Adult care was managed in a more formal environment with new people who had a different approach than they had known before.

The collective responsibility taken by pediatric institutions emphasized valuing of the child and adolescent population without recognizing the progression that occurred to adulthood. The notion of individual responsibility was legitimized in adult settings in which little difference was made to a 20-year-old young adult with complex health needs compared with a 38-year-old adult with an appointment for simpler needs requiring single-system expertise, such as cardiology. Few priorities were thus given to young adults with multidisciplinary care liabilities in a particular environment where individualism was socially valued.

The social boundary between childhood and young adulthood was further demonstrated by the recognition of the needs of children and their parents to be supported by health institutions, and on the other hand to leave the total management of their care to young adults. This transfer was carried out according to a social attribute delimited by age (in the West, the majority age of 18 years, bringing with it a set of new rights and duties) without taking into account individual variations of biological and psychosocial maturity. Collective responsibility showed the capacity of the system to operationalize systemic care according to the needs of a population. Thus, through an organization of human, material, and economic resources, pediatric care was managed collectively for individuals.

The recognition of holistic care and its application in pediatrics, although imperfect, made it possible to evaluate the importance of the resources invested in a privileged population. The resources invested in such a population stopped when the population in question left its category of belonging, which then became part of a larger population with which it did not identify. Youth, who represent the future of populations, were given attention until they reached adulthood. Depending on their social status, young adults would have been more or less equipped to respond to the transfer of responsibility from the institution to the individual. We will see in the next section how young adults face this responsibility and what the main challenges are.

Individual responsibility of the young adult

Young adults associated the need for autonomy with the lack of coordination and responsiveness of the healthcare system. As such, the various intersecting systems of their lives, place in society and health in which they were implicated, acting on and being acted on, were on display. For example, simply having to follow up on their own and relying on their symptom management to meet their needs appealed to some AYAs' desire to exercise their self-care and autonomy skills required by health professionals to avoid potential complications. These abilities were considered individually-held, however, and were the result of a social environment from which the young adult might or might not have benefitted. For example, a family physician told the story of one of their patients who experienced complications of type I diabetes (retinopathy) due to a lack of follow-up with medical specialists caused by family events during their adolescence and adulthood. In addition, because their financial situation did not allow her to be billed for any healthcare expenses, this patient did not complete their follow-ups and was abandoned by the health system.

Thus, the consequences of the lack of individual responsibility for their care were heavy both for the individual and ultimately for society as a whole. Indeed, the health needs of apparent and disabling lesions led to more consultations and related costs than prevention through the regular treatment of patients already living with a controlled pathology.

In other cases, young adults even felt that stabilization or even improvement in their health status was only due to their management and willingness, after trying to move through the adult healthcare system without success. In other words, they believed that they were able to manage the adult health system in spite of rather than because of the adult care system. This was conveyed by one adult who had been transitioning to adult care for more than five years, reflecting on two years of being out of treatment at the time of her transfer to adult care:

> *"I was at [a Cégep – post high school college] and then I dropped out and I started working. Yeah, that's what I did for those years. And then what did I do? I ended up getting better after my friend died because it scared me. I ended up going back to the [clinic] afterwards and it was too intense ... like, when I finally got a spot, it was too intense for what I needed because I was doing really well at the time. So, I felt like they were treating me, like, how I was when I was just turning eighteen, you know, but they had no clue what had happened to me in the last two years while I was waiting, you know? It would've been ideal if I would've obviously gotten a spot right away, but nothing happened. Yeah, I got 100% better on my own."* (AYA010)

The transition of responsibility was not just about self-care or managing the symptoms of illness. Young adults and their parents became progressively aware of the opacity of the adult care organization as they tried to make appointments to see specialists they were used to seeing in pediatrics – often one after the other. A mother of a child living with epilepsy lamented that she had used her own social network to find a neurology specialist for her son:

> *“It is certain that without this network, I don't know what we would have done, and it is the same network or the same person we came to ask for a second referral because the first one had left to [take up] an academic position.”* (PG004)

Even routine examinations, like blood tests or imaging, required regular follow-up for chronic conditions to monitor their progression and, ideally, stabilization, depending on the type of condition. Despite her social and professional network, the mother clarified that her son:

> *“Had seen his neurologist maybe once a year, not even blood work to see if the medication level was ... [appropriate]... He had maybe one or two [electroencephalograms in] ten years and we were in a bind to find ways, solutions on our own.”* (PG004)

The transmission of responsibility was all the more disturbing for young adults and their parents in its temporality and anticipation. Indeed, the symbolism of adulthood and the new responsibilities associated with it, and the symbolism of adult care as being less welcoming than pediatric care, stemmed in part from parents' experiences with adult care services. Changing relationships with adult healthcare professionals in a mode of independence for *“the rest of one's life”* was an additional factor. One young adult who had been transferring to adult care for over a year stated:

> *“... I guess going back to that bias of whether or not adult care is not as welcoming... because I was kept on being told this is going to be more serious and, like, there were some things that worried me because my mom always said she was worried about who I was going to be referred to as a gastroenterologist, because I guess in her experience*

> *maybe not all doctors are the nicest. So, I guess there is that fear of like a 'hit or miss' thing in the serious independence aspect. I guess it was just that. It just seemed there was a lot and, like, especially since you're transitioning to something that's going to last until we die, so that's something too."* (AYA003)

The notion of irreversibility increased the fear of the consequences of a lack of follow-up and, thus, the overload of individual responsibility became more critical. This responsibility, as we have seen, was closely linked to the social and economic capital of the young adult, to the ability to take charge of his or her care, but also to navigate through the organization of adult care services.

Another variable that came into play in terms of responsibility was related to decision-making in care and leadership roles. Indeed, due to the nature of the follow-ups affecting the continuity of care of the young adults, the latter, after having experienced the transfer to adult care, indicated the importance of being able to follow the actions of the HCPs in order to eventually correct them or even to carry out the monitoring of the test results themselves. One young adult who transferred over five years ago reflected on the time taken to transfer to adult care:

> *"I would [use] the word 'destabilizing'. They still try to prepare us, but it's destabilizing, and it's a blow to the reality of the healthcare system. What I mean is that at the Children's Hospital you are used to being taken by the hand. [...] [W]hen I arrived at the adult system and I had an intravenous medication to receive, I remember that there was a nurse who was not too sure of the dose, of what to do. I was really worried that if they didn't give it to me at the right rate and in the right way, I was going to have an allergic reaction; whereas [at the Children's Hospital], I was really alone with my team. They knew how to give me everything, I didn't have that worry. So, it's like adults you have to watch yourself."* (AYA002)

While taking on new responsibilities was anticipated for some young adults, transitioning into adult care proved to be a more intricate experience than it initially appeared to many of them.

One young adult expressed happiness in being able to articulate their case and needs, describing the experience as a significant change. Ultimately, they greatly appreciated the guidance and support they received, likening it to being “held by the hand” (AYA002).

The expectations set by discussions with HCPs in pediatric services or parents helped to somewhat mitigate the harshness of the transfer of responsibility to the individual. However, the reality, shaped by family experiences, demonstrates a shift in the young adult's status, which is still evolving. Additionally, the development of the capacities needed for individual responsibility vary depending on the stage of the person's progression in pediatric care.

A family physician noted that inadequate independence, stemming from the pursuit of accountability, left underprivileged youth without access to healthcare resources. This led to unnecessary visits to the already overcrowded emergency department for issues that could have been prevented with regular, proactive care. Another family physician added:

> *“We say, 'Oh well, it's their choice if they don't want to come to the follow-up; I'm not going to chase after them’. So, I think that's a barrier in adult care compared to child care. And maybe the patient is expecting that because they missed their appointment: ‘Well the nurse will call me in and book another one because that's how it was when I was seventeen and a half years old.’ But now that [they’re] eighteen and [...] in adult care, we don't necessarily do that all the time because I think the volume of patients is so much bigger than in pediatrics, so there's no time to be able to remind adults to be able to do that. So, I think there's a huge loss to follow up. If you look at the numbers of missed appointments from adults versus children, it's massively different because there's no parent [of healthcare professional] to remind them.”* (PCP-HCP026)

Intergroup tensions from the lack of integration of care

The relationships between the stakeholders – that is, between HCPs, and between HCPs and AYAs along with their families, were influenced by the transition trajectory, or degree of access to HCPs. The existing gaps in the transition process from pediatric to adult care services affected the care pathway of AYAs, either from the lack or inappropriateness of interactions. As it was illustrated by a PCP, an AYA who anticipated being reprimanded because they missed an appointment would not come back for the next appointment (PCP-HCP019). The relationships patients-carers changed as new interactions were required with new HCPs. These interactions reflected the clash of cultures and resulted in role adjustments.

Role changes and identity re-evaluations were crucial mechanisms activated by the transition to adult care. These processes allowed stakeholders to progress and sustain care, often extending beyond their formally recognized competencies or designated roles. While the specific mandates of each stakeholder during the transition depended on their status and profession (for HCPs), HCPs often found themselves exceeding these mandates to ensure the necessary care for young adults. They were “filling gaps” in care that the culture of adult care, which its fragmentation and strategic imposition of individual autonomy, created. Such extension of roles was closely linked to the collaborative actions required by other members of the stakeholder groups, all working towards a common goal of optimal care transition.

Both HCPs and families acknowledged that they were going beyond what was conventionally expected of them. This awareness highlighted the fact that each stakeholder possessed a distinct understanding of their initial role, with clear boundaries of inclusion and exclusion, which might not have been mutually understood in intergroup relationships. For instance, a pediatrician might not always have been fully aware of the role limitations of a family physician or an adult specialist, and vice versa, leading to tensions and revealing new fault lines in the process.

By venturing beyond their defined roles, actors entered other spheres that they perceived as compatible with their own expertise, but might not have been recognized or realized by other stakeholders. Action taken beyond professional boundaries shed light on the flaws within the transition process and paved the way for strategies to reduce these shortcomings. The presence of intergroup tensions was seen as an inherent aspect of the stakeholders' primary roles and roles acquired to compensate for deficiencies, resulting in both acknowledgments and confrontations. Each stakeholder believed that they held some of the essential knowledge required for the transition process, and were aware that areas of overlapping knowledge among them existed. In such cases, confrontations could arise when stakeholders from different groups sought to assert their knowledge without necessarily considering the expertise of others.

Confronting expertise and power dynamics

Various confrontations of expertise took place between care professionals, including pediatric, adult and primary care settings, as well as between AYAs and adult care professionals. Pediatric and adult healthcare providers shared an overall goal of stable health status and quality of life for young adults, but had a different approach and philosophy of care, reflecting and reinforcing their relatively bounded environments. Cultural differentiation across the two services was central to first, the care that stakeholders in these two distinct groups expected of each other, and second, the manner in which that care was delivered.

Health professionals in pediatric settings were recognized as the experts in pediatric pathology, both in diagnosis and in the treatment and care approach with children and adolescents. This view was shared by participants across all groups. In this vein, pediatric health professionals reiterated that their approach was somewhat different from that provided by adult services. As one pediatric nurse specialist put it:

> *"We provide more family-centered care. And so, the parents are also involved. And in the adults, it's not. So, it's tricky."* (Pedes-HCP025)

Considered more appropriate to the care of AYAs, the care provided by adult HCPs was seen as less adequate and not appropriate to the young adults' condition during the particular transfer situation. This is because the adult care approach was seen not to take account of all the other transitions that occurred in parallel in the young people's lives. In fact, one pediatric physician specialist noted the lack of training for adult physicians to take over the care of adolescents and young adults with complex needs:

> *"It's very, very difficult to find people who want to take chronic complex patients. There's some people who will, but, you know, we offer to support them. We offer summary documents. We offer to call back if they need help, but I think it's not because they're bad*

> *people. It's because they're not comfortable with these problems. So, you know, they probably don't have the training or the skills. They don't know what to do with them.”* (Pedes-HCP009)

The differences in professional cultures between pediatric and adult care reinforced the boundaries between them, especially since the two groups did not communicate except for the transfer of patient information through chart notes and summaries. Relationships between these two groups were rare, and little information was shared. One pediatric nurse and one pediatric physician mentioned knowing some of the names of the people who would be seeing their patients, but not knowing them or talking to them directly. They mentioned *“not having a relationship with the adult care teams”* (Pedes-HCP008, Pedes-HCP007).

Pediatric HCPs appeared to conceive of their relationship with adult care providers in terms of a disrupted power dynamic in which pediatric HCPs – experts in the care of children and adolescents – were taken away from their mandate to care for patients they knew how to care for. This involved leaving their patients to other HCPs who were less competent than they were in both knowledge of care and approaches, attitudes and behaviors appropriate to this young adult population. Pediatric HCPs had a similar perspective on PCPs, whom they considered to be minimally responsive because of the apparent undersupply of family physicians accessible to the general population, particularly for AYAs.

Pediatric HCPs emphasized that – as with adult care – community resources were limited and not easily accessible, even for adolescents and young adults with acute needs (e.g., for care provided by allied health professionals). In addition, lack of support, coaching and training were mentioned as missing elements of primary care in the community. These gaps were highlighted by pediatric health professionals:

> “*[There is a] lack of the knowledge and skills in the people that truly have the mandate. The government has given [primary care providers] the mandate, and they haven't been able to fulfill it. And there's no, like: who's supervising that? Who's checking it? You know, like, here in the hospital, if I don't do my job, I'm going to have a report written*

> *about me. Right. But if the social worker in the [local government community clinic] doesn't do her job, right, well, you know, we're so desperate to have social workers in the [community clinic]. Right? You know, she's not going to be fired over it. [...] And again, these are good people. Like, what I want to say is, me too, if I was working in a [community clinic], and they got no instruction, if I didn't get any support, if nobody came in, showed me, you know, the rules and things like that, if I got no training, if I got no updates, well, it would be hard for me to do my job also. Right. So, are these resources well available to people? Are they formatted in a way that's easy to understand?"* (Pedes-HCP009)

The problems highlighted by this group of stakeholders were seen as systemic and related to the organization and administration of the healthcare system. In addition, pediatric specialists tended, when possible, to transfer their patients to adult or family physicians in their professional network, in order to ensure continuity in the approach and quality of care for their patients. Adult specialists, on the other hand, were in a state of adjustment with young adults, viewing the population as special, with a developmental phase leading to decreased compliance in particular, for which many adult specialists appeared to have little or no interest. For example, one physician specialist in adult services mentioned that adolescents and young adults were transferred during an unstable period, all at the same legal age of 18, but not at the same level of maturity. They had lost all the support they had received from the pediatric teams up to that point:

> *"Well, we're transitioning them now. It's like they're about to turn 18. You know, it's more than that. It's more than that. It's about … maturity. It's about, you know, preparing them. I think many kids are transitioned, kind of by chronological age, and I'm not sure that's an appropriate [criterion], because they transition and then they fall through the cracks because the only reason that they got to where they are is because of all the supports, which they've lost, right? So, for some kids, it is clear that they're going to fall off the tracks during the transition. Because they're rebelling and they're this and they're that … they're not going to get the support. So, I guess it's just – I don't even know that it ought to be chronologic. It probably should be developmental or something like that. But*

> *I'm not an expert in that piece to know the answer to that. But I would just say for them as for the learners, I would say, usually, it's probably a process that's going to take some time. Don't think it's just like ... six months before the age of 18, we're going to do one, two visits, and then hand you off and write a letter. Do you know what I mean?"* (A-HCP018)

The very act of transferring youth during a period of instability, without the required support, was seen to lead to transfer failures for some young adults. Thus, emphasis was also placed on the conditions of transfer in an environment in which holistic care was not implemented in adult care, based on its highly sub-specialized organization. Specialty adult HCPs supported the perspectives of the HCPs of the pediatric services on their lack of training and specific knowledge of certain pediatric and rare pathologies. Therefore, the approach dependent on pathologies more familiar to adult specialists due to their prevalence in the adult population (e.g., diabetes). In these cases, the expertise among pediatric health professionals, rooted in a "caring" culture, was considered more developed.

The environment of adult services was also identified as a contributing factor to the challenges in serving this population. Issues included a higher volume of patients compared to pediatric services and a lack of resources tailored to the development and maturity of young adults. Adult services typically cater to the general adult population, without considering the nuances of specific stages of adult life. Indeed, adult HCPs positioned themselves as being in a unique situation that did not allow them to achieve the same level of care that the transition of adolescents to their services required. Participants in this group were in a more difficult environment than pediatric care givers, with working conditions less conducive to the type of pediatric care. Lack of time, resources, and staff to develop the multidisciplinary approach in adult services exceeded the efforts that HCPs in adult services could provide.

This stemmed from the fact that for all health professionals, pediatric, primary care and adult, the healthcare system was built around an adult population that excluded adolescents and young adults. The latter found themselves in different services that were not specialized for their category, in addition to the fact that this population is growing with more and more complex conditions. On the other hand, HCPs on adult and primary care wards have particular expectations of other stakeholders regarding the preparation of young adults before transfer. Unmet expectations in the transition process make the transfer of adolescents to adult services more difficult, as it did not correspond to a continuity or logical continuation of their experience in pediatrics. With respect to parents, adult and primary care providers, while understanding their need to be present to monitor their children, deplored the fact that too much presence led to a lack of autonomy for their children, as did the attachment developed with pediatric providers, which made it more difficult for them to transition to their services. This was illustrated in particular by the young adults' scheduling of appointments or absences from their appointments, given that the functioning differs greatly from the more “protective” pediatric model.

The positioning described by adolescents and young adults in adult care depicts a new situation in which they feel less listened to compared to pediatric care. As one young adult who had been in transfer to adult care for over a year mentioned, her feelings were not taken into consideration as much as when she was talking to HCPs in the children's hospital. She compared adult services unfavourably with the amount of time she was given during medical visits, the quality of interaction she was able to have with HCPs, the perceived importance of her condition, and what she could freely express with her pediatric HCPs (AYA006). Young adults lamented the impression adult HCPs had that youth did not know their condition or recognize symptoms that required certain types of care. Adolescents and young adults emphasized the evolution of knowledge related to their experience of illness, which is sometimes more complete and accurate than the more generic knowledge of healthcare professionals, and reflect on the need to respect patients' rights and opinions.

Thus, their experience provides adolescents with expertise about their condition and effective ways to treat their symptoms of complications. The disconnect between the advice of adult HCPs, who are often unaware of the details of their condition, and the perception of relative disinterest in them compromises the trust adolescents have in HCPs. A young adult who was transferred to adult care over five years ago lamented her experience with patient-caregiver collaboration and respect for the patient’s experience and perspective:

> “*My worst experience was when I had swollen eyes and for me that's water retention. It means that I'm losing protein, so my health is not so good. And when I wrote to the nurse who was in charge of me, she told me to go make an appointment with the optometrist. I was, like, "Oh, I have to go get blood tests. So, that means I'm going to keep losing protein. And then she was, like, "Well, you have to go see the optometrist." I was, like, persistent to come in and take my blood work because I know my case. She's a nurse who works in nephrology. So, it really surprised me that, even though I'm the patient – [and] I know my health [and] I say it's fluid retention – I still had to go out to … take a blood test. [...]Yeah, that's right, it's that at some point, I've been doing this since I was nine years old and as for the adult system we don't want to tell them what to do, but we know our body (sic). Maybe it's being more in tune. I know they're in over their heads, but when you have a patient who says, ‘I'm 100 percent sure when I'm retaining water, it's not right,’ [it’s important] to listen to their request a little bit. Finally, I went to do the blood tests and it wasn't going well. So, you don't feel very well taken care of in those situations. And the first doctor I had was also doing her job well, but I was used to clinical appointments where they were checking for water retention – checking things. But here I was faced with a doctor who asked questions, but she didn't touch me during the consultations. And not that [this was a problem* per se*]... We're adults. But, it was just that side of it that made me insecure.”* (AYA002)

A young person who was transferred to adult care over a year ago believed that it was important to be served in French, his native language and the official language of the province, while some health professionals are more comfortable in English, the official language of the country. This attention to the particularity of language – although very specific to Quebec and other provinces or regions sharing the same linguistic issues – is relative to communication between actors and to the fact that this young adult, although able to exchange in English, wished to maintain an environment in which the symbolism of the imposed language did not take place. He also mentioned speaking English with some of the other HCPs in the pediatric settings even though they knew each other, although the primary language of communication had not been imposed by the caregiver.

In the adult wards, a power struggle was perceived to have regularly occurred, particularly through the behaviour of specialist doctors and medical students, who repeatedly demonstrated a lack of consideration to adolescent patients, as conveyed by a young person interviewed:

> *"It's, like ... didn't you read my file? That's the basis of reading my file. I find that in Children's [care] and in Adults' [care] it's really something else. I remember when I was young, when I was 17 or 18 ... no, 17, sometimes we'd come in and they'd be like, 'Hi, how are you?' I'm introducing myself... But like, direct. They make you feel comfortable. Now it's really more like 'Hi Hi, this is my name, I'm a student. Okay, do you give me permission?' I'm like 'Ah... no. 'Scuse me, but no.' It just kind of ruins the mood. It's like I'm an exam or something. I'm like 'no, no'... I don't even [fully] remember, but there was a group of students that came in, like, a group with notes. I'm like 'what are they doing there?' and the physician says like, 'Ah they're taking notes.' I'm like 'No, no. I want them to go away.' They didn't even ask my permission, one, and two, I mean... I'm an example, but when it's like 7 in the morning and you haven't slept well, I'm not tempted to be with [college] students taking notes [for whatever reason]... No, no. You get yourself another patient, not me."* (AYA001)

Detailed knowledge of specific cases by adult services health professionals was seen as a missing element of transition by young adults. Young adults expected their new HCPs to have sufficiently humble and patient-centred attitudes to invest in attending to their changing individual circumstances. Such patient-centred attitudes and behaviors were perceived to better enable adult HCPs to develop a relationship with the young adults.

The recognition of the different stakeholders involved in the transition process models their interactions and the way in which the transition process is experienced, particularly for young adults, is marked by situations involving power dynamics fuelled by imbalances in knowledge, skills and experience. Some stakeholders are unwillingly involved – adult services – while other actors are excluded even though they are involved in the process – primary care services.

The understanding by pediatric and adult services of each other's roles shapes expectations of each other. When these expectations are not met, inter-group tensions arise. Roles are constructed according to the bounded norms of the systems to which they belong, in which the transition to adult care does not correspond to prevailing models. As a result of the confrontations, though often indirect, between groups of actors, the emergence of groups symbolically excluded from the process occurs in response to the way they define themselves and illustrate their roles. With social and organizational changes, primary care is becoming increasingly important in the care transition process. This is particularly significant given its mission to monitor the population, provide access to specialized services, and ensure continuity and quality of care.

Emergence of new groups (Family Physician) – process membership recognition

Primary care providers have a unique position in the healthcare system. Physicians, in particular general practitioners – called family physicians in North America – are seen as the gateway to care for the population and referral to specialty care when needed. As part of the transition to adult care, primary care providers took pride in their knowledge of the population but also of the specializations that can accompany their profession, particularly to facilitate the transition to adult care, or even avoid gaps in the system leaving youth without care during their transfer.

In the interviews, family physicians felt that they were being used as "stopgaps" in the failure to secure continuous transitional care (HCP012, HCP019) by other specialists. The latter were sending their patients to a family physician without considering the integration of care and without considering the intensity of the role of family physicians. One Family Physician said:

> *“[We need] to be integrated into [the transition process], and to be integrated in a respectful way, by people who recognize what we have brought.”* (HCP012)

Additionally, parents acknowledged the importance of maintaining a connection to primary care and their role in liaising with other health system stakeholders, particularly specialized adult HCPs who are less accessible to young people during the transition process. One parent said:

> *"It's really important to have someone who can support us, who can help us out, who is your family doctor, and Dr. [the family doctor] is a young doctor who's probably in his early 30s. So, he's here for normally unless there's an accident of course but, he's [been] here for a long time. He is there maybe for the whole life of [my child]."* (PG003)

The notion of long-term accompaniment places primary care in the transition process in the long term, and not as transient stakeholders, only supporting the process. The above-cited parent considered the integration of family physicians in the transition process of his child as:

> *"A long-term medical strategy for him, not for me. I'm old now, but for him. We have to protect him. We protect him monetarily. We protect him at that level too, but there is nothing that can replace health, and especially not money. So, it's important that he be well supported, that Dr. [the family doctor] be present, that we communicate with Dr. [the family doctor] if we have important things to communicate."* (PG003)

Another parent's strategy was to use their family physician as an intermediary to communicate with adult specialists, as direct contact was not possible. Additionally, this strategy highlighted the importance of coordinated care that required the involvement of a third-party facilitator. Discrepancies in status, experienced family physicians, being regarded as present to plug gaps rather than as highly-skilled specialists, underscored the exclusive organization of health services for adults, posing obstacles to the seamless integration of care.

The quality of support and care for young adults being transferred to adult care also depended on the interest of family physicians, and family physicians conveyed a desire to be included in the process. However, family physicians felt unfairly sidelined, even though their mandate made them key players in ensuring the continuity of care for young adults. The quest for recognition of primary care called into question the interactions between groups of stakeholders, particularly those in the health system. It was in a dynamic of matching the needs of young adults with the skills and knowledge required (both cognitive and behavioural) of family physicians that their membership in the transition process was justified.

To act as a point of contact for young adults before, during and after their transfer to adult care, family physicians pointed to the lack of consideration of mental health issues that may arise during the transition process. Primary care is more similar to pediatric care, in terms of an espoused holistic approach, than specialized adult care, which focuses more on specialized organs in relative isolation, family physicians rated their approaches and knowledge of psychosocial factors as helpful to the transition process, but not well recognized. One reason for this was that there was little communication with pediatric and adult care stakeholders, so they lacked a chain of information to follow their patients' process. As mentioned by one family physician:

> *"I think we're kind of like a good role because we usually know the patients quite well, right? We don't just see them for their joint problem. We don't just see them for their sugars. We see them for a lot of things. So, I find we're kind of in a good position to really encompass all of their care. You know, many patients with chronic diseases have a lot of mental health issues because they feel stigmatized. They think their life is much different as a child compared to others. So, it would be kind of nice for me to know I'm not going to be the one prescribing or specialty medications, but to at least know how things were, where they were hospitalised often. Were they in the ICU [intensive care unit]? [...] I don't know. Did they have surgery etc.? So, we would kind of be like a map. You know, we help them kind of get to their next stage without really being the ones who have to prescribe the special medications. And they go to a specialist for that of course, but I think if I knew more kind of their trajectory it would be a lot easier for me to treat them as a whole which we're supposed to do, I think."* (PCP-HCP026)

The lack of understanding of the role family physicians was compounded by the conflict of knowledge and power positions in the healthcare system in caring for adolescents and young adults. The ability of family physicians to take on the coordination of transitional care was limited from their position in the healthcare system. Although care coordination was a perceived role for primary care, its operationalization in the current system excludes or is made more complex for out-of-hospital primary care providers:

> *“The biggest problem is that, while we have become more and more adept at transitioning, [knowing] medical conditions and organ systems, we are not very good at transitioning people, individuals. So, I can find a cardiologist; I can find a nephrologist; I can find a gastroenterologist; but [it’s] very difficult for me to find somebody who will take over the care of that individual looking at their different aspects. And often that's deferred to family medicine in the community, where these young adults are highly complex. [It’s] very difficult for a family doctor to coordinate that care, much of which is hospital based.”* (Pedes-HCP009)

The integration of PCPs into the transition process has not been accompanied by an equivalent increase in their influence within the health system. Although these HCPs play a crucial role, they often lack the parity and collaborative authority seen among specialists, who operate in different cultural settings but with more clearly defined roles. Furthermore, primary care transition coordination challenged the separation of healthcare settings and access among healthcare system stakeholders themselves.

The identity of each group of stakeholders influenced how they perceived the roles and actions of the other actors involved in the transition process. Changes in position were marked by overlapping roles and gave rise to tensions. The prominence of acute care professionals in the adult and general system in the process exposed the power dynamics and the social and symbolic structure of healthcare professions.

Conclusion

In this chapter, we have explored the profound disparity between two distinct healthcare cultures, pediatric care and adult care, and how this dissociation gives rise to a host of complex issues. We delved into the fundamental differences between these two realms, emphasizing the conflict of norms and boundaries that arise when patients transition from the known and included world of pediatrics to the unknown and excluded territory of adult care. Although pediatrics serves as a normal environment for young adults, its functioning diverges significantly from adult care where AYAs are transitioning. Accountability and patient engagement take on new dimensions as young adults transition into a realm of individual responsibility, while the social responsibility for their well-being shifts from the collective and systemic to a more individualized framework.

Social boundaries define the structural and functional differences between pediatric and adult care, while symbolic boundaries represent the cultural distinctions and norms that shape the identities and roles within these healthcare settings. The disparity between these boundaries underscores intergroup tensions and highlights the lack of integration of care, as well as the clash of expertise and power dynamics among stakeholders involved in the transition process. The emergence of new groups, such as family physicians, reflects a recognition of the need to bridge this divide. However, the process of membership recognition remains complex and challenging. In the context of adolescent healthcare, situated between the realms of pediatric and adult healthcare, there exists a notable absence and a distinct lack of functionality for AYAs coping with chronic conditions.

Chapter V. Adolescents' Healthcare Divide: Challenges, Disparities, and Ethical Dilemmas

"I was on my own completely. Like, I think what they expect is that maybe … you [can] have a family doctor to follow you until you can get on to the list [in the adult care setting], but I didn't have a family doctor at the time. I really just did whatever I wanted. It was not very ideal. I didn't want to get better, but I was not well enough to be on my own either you know, but I got worse. That's what happened." (AYA010)

Introduction

This chapter delineates the disparities of standards of care in healthcare provision encountered by adolescents with chronic conditions when they transition to adult care services. Beyond the demonstration of two distinct cultures and *modus operandi*, as the previous chapter documented, this chapter reports how the healthcare structure impeded the simple transfer of AYAs from one service to another through boundary walls sufficiently thick to repel interaction across each other's services. These were two systems displaying virtually no interaction with each other. The end of pediatric care marked the end of a holistic and familiar approach to AYAs and their families, along with the assurance of receiving continuous care that adapts to the evolving health status of the youth. This, in turn, underscores the flaws of the healthcare systems generally that are characterized by systems within systems whose boundary walls are thicker than they are permeable.

The abrupt change between pediatric and adult care manifests as a detrimental gap AYAs faced while transitioning to adult care. The first section of this chapter explains the concept of adolescent healthcare as being "in the void", highlighting the disparities in information sharing between the two main healthcare settings and the lack of integrated care models that bridge the divide between pediatric and adult care. It explores the challenges faced by adolescents due to the multiplicity of transfers and the subsequent interruption of systemic care. Additionally, this section explores ethical considerations, such as the lack of access and responsiveness according to the volume of patients, which further compound the difficulties faced by adolescents seeking appropriate healthcare.

The structure of healthcare has excluded the adolescent and young population from receiving responsive and timely care during an unstable period of time. Therefore, the second section of the chapter presents adolescents as the collateral damage of the clash between pediatric and adult care cultures and systems. It explores the unique challenges faced by adolescents who find themselves caught in the middle of two medical realms, experiencing a non-standard adolescence that is often overlooked. This section investigates how the healthcare system places adolescence outside its scope, resulting in a lack of specialization in adolescent medicine and unmet needs of this vulnerable population.

Adolescent healthcare in the void

The distinction of cultures between pediatric care, which caters to children, and adult care, which serves adults, has highlighted a significant gap, or void, in healthcare provision for adolescents. The transitional period between childhood and adulthood, known as adolescence, has not been adequately addressed by either pediatric or adult healthcare systems. As adolescents transition from pediatric to adult care, they often encounter a lack of dedicated healthcare services that specifically meet their needs at this time of rapid changes that may affect their health.

As young adults mentioned, the transition occurred during an overwhelming period of time with the combination of hospital changes, and often the first years of college (Cégep) or university, which was experienced as a period of destabilization in their lives. This transitional phase was characterized by a sense of being unsettled, as significant changes were encountered, which were not necessarily anticipated or desired by the patients. A young adult who transitioned less than a year prior to the study emphasized that these changes were neither necessary nor welcomed during this critical period of their healthcare journey (AYA002).

Furthermore, young adults expressed the need for clarity regarding the transition from pediatric to adult care, highlighting uncertainty over who to seek guidance from during this interim period. Another young adult emphasized that pediatric to adult transition is not merely a straightforward switch, but rather a longer-term process that requires adequate time and support. This participant found herself without any connection to healthcare services while she was waiting for an adult care specialist (AYA005). Consequently, the healthcare structure dividing adolescent care between pediatric and adult care failed to facilitate the seamless integration of adolescent and young adult healthcare into the broader healthcare system, thereby impeding the continuity and quality of care for young adults seeking chronic care.

The health system built around the adult standard of care

Although the dominant model of healthcare, emerging as a "norm", is the adult system, the primary source in the transition that shapes the standard of healthcare for AYAs and their families was the pediatric setting. This means that young adults are moved to a new paradigm in which they have not yet been socialized. Youth experience several changes as they enter a new phase of their adult life, and they also face a change in expectations from their team or HCPs. AYA participants highlighted the myriad of adaptations they needed to make during their transition to adult care services, encompassing academic adjustments (such as moving from Cégep to university or entering the workforce), career decisions, and changes in social relationships, which was mostly described as "disruptive" (e.g., AYA002).

While the transition from childhood to adulthood is gradual and processual, the transition from pediatrics to adult care is sudden and non-functional. Moreover, to accompany young adult patients, family physicians whose model of care may overlap with that of pediatrics are nevertheless unrecognized by their peers, regardless of the role they may play in facilitating the transition to adult care. Pediatric, adult and primary care HCPs could institutionally collaborate to some extent. The system on which collaboration is based simply requires referrals from pediatric specialists to adult specialists, and from primary care providers to adult care specialists. However, the difference in patient knowledge between HCPs created tension. These tensions manifested themselves in a number of ways, including approaches to care and medicine – namely, comprehensive care versus acute and reactive care – and what is means to care for patients. The discourse of HCPs consistently invoked what is commonly perceived as the standard of care, which revolved around adult care services.

What is considered a transition from pediatric to adult care was really just a one-time handoff, as many nurses, specialist physicians, family physicians and young adults pointed out. Pediatric care was described as caring, reminiscent of the notion of "caring" as sensitive and compassionate regard, by health professionals, and which is often contrasted with adult care. Thus, the cultures – that is, the shared meanings and habits that underpin the service's functioning – of each setting differ in the ways identified by those involved in the transition to adult care. However, the transition from one culture to the other was described as 'not being a real "transition"'; it started with abstract mention of a service transfer, sometimes through warnings from the pediatric HCPs or from the parents of the young adults, as a young adult commented:

> "*I don't remember much, but what I do remember is that from then on they said I had to make my own appointments. If there was a problem, they wouldn't be the ones calling me all the time.*" (AYA009)

In most cases, handover was carried out when the young person or their parents made an appointment with the AYA's new adult care specialist, and then during the first appointment – which would occur weeks, months and sometimes years later. The young individuals perceived the codes of the new environment (e.g., operational procedures such as getting a new card, requesting a prescription renewal, appointment scheduling, and interactions with HCPs) as unfamiliar, causing them to feel out of sync with the environment. The mechanisms that had been learned and assimilated in the pediatric environment were, therefore, questioned and even devalued by the young people themselves. This point is internalized by the young adults themselves who, aware that they have moved into the adult world despite themselves, can no longer act like children. Worse, apparently child-like behaviors would deprive young adults of timely care.

The nature of pediatric care to accompany and support adolescent care is starkly non-existent from the perspective of the adolescents and their parents surveyed. The consequence of waiting for support from adult services would be to put care on hold and be even less assured of needed follow-up. Young adults are ambivalent between the accomplishment of being recognized as an adult and what this new status confers. The consequences of this change in social category, which occurs in an inescapable way, compel young adults to adapt to a new set of rules.

This change in category, which results in social downgrading, happens “overnight” as one young adult described it (AYA010). The notion of transition is thus called into question and even erased from the language of the stakeholders involved in the transition process, as it was deemed inappropriate to the context of the phenomenon. Pediatric, primary, and adult care specialists acknowledged the concept of transition, which involves the notion of progress, development, and continuity over time. However, they recognized that the services provided to AYAs did not adequately reflect or encompass much of this transitional aspect as pediatric care was discontinued.

Pediatric HCPs lamented that there was no overlap between the services. The transition was direct and exclusive in most cases when a transition clinic was not available or set up in the AYAs’ adult care service or unit. Thus, it was well understood by the stakeholders that instead it was a transfer from one service to another, and sometimes a partial transfer in which information was partially or not processed at all. As described by one pediatrician specialist and one nurse coordinator:

> *“There isn't a transition. How about that? The patients that we follow have multiple problems. Who at the Children's [Hospital] are followed by complex care that oversees their appointments? The coordination of the care I mean, [the Nurse coordinator] is like their Fairy Godmother who they can call if they need to reschedule appointment; if they have a question about a medication; if you have a question about moving up an appointment, they're sick, they need to be seen more urgently. Can we call the pharmacy to renew this? […] Like, any question, any problem, any issue [the Nurse coordinator], is there. We have an on-call service 24 hours a day, including weekends where the parents can reach someone to discuss an issue or question, a problem. We will call the emergency room if they need to be seen more urgently to try to smooth their way. We really have a very holistic approach. And we are in very close contact with the neurologists, the respirology cardiologists. [The Nurse Coordinator] has their cell phone*

> *numbers, their emails […] we work so closely as a team to make sure that these kids are looked after. And then they turn 18 and all that disappears."* (Pedes-HCP007)

For the integration of care, the issue of overlapping care appeared repeatedly among all the stakeholder groups as a solution that would then make it possible to progress with inter-service transfer. This aspect of transition was discussed as a real service within the healthcare system, rather than merely an objective that pediatric services should pursue independently of engaging with stakeholders in adult services. This solution of overlapping care was aimed transversely as a method of operationalizing the integration of care for transition, as a beginning of defining what would be involved in implementing continuity of care for this population. Considering identified categories of population, this process would signify the acknowledgment of adolescence as a distinct specialty category in healthcare. Moreover, the intention would be that this recognition would be integrated throughout various layers of the health system, reinforcing its importance and impact.

To compensate for the lack of overlap, specialist pediatricians, working in teams with nurses in particular, have set up events marking the end of pediatric follow-up to symbolize the change of team and services. This acted as a return to the rituals of passage, and as a beacon between one category and another that the young person would experience. However, these "rites of passage" to the adult world were only carried out at the level of pediatric care and were not followed up, repeated or updated in the adult services. These events occurred primarily when a transition clinic was established. Pediatric services offered a graduation to the AYAs as a sign or symbol of an end of the AYAs' care with the team that has followed them since childhood and their diagnosis, and to symbolize a beginning in an uncertain adult world. Rather than symbolizing the commencement of a new status (e.g., child to woman or man, adult to elder), that might be of anthropological interest, this constructed ritual provided a way to mark the end a period of life.

Although the ritual of concluding pediatric care symbolically is intended to prepare to some extent the young person for an end, and therefore for the break in pediatric care, the transfer to the new environment and its norms was perceived by all young people interviewed as an abrupt changed. This was exemplified by a young adult who still wanted to make an appointment with a pediatric specialist immediately after her 18th birthday, because she was unable to obtain follow-up from the adult services. She was told that no appointment could be given to her because she was 18 years old (AYA005). Another young person who experienced her transfer to adult care more than five years prior to the study without a transition clinic or graduation event regretted that she was not prepared for this sudden change that she believed required a degree of maturity (AYA010).

Dealing with an unfamiliar environment was seen to require knowledge, skill and maturity. Despite the importance of cultural adaptation to a new service, even pediatric HCPs’ own knowledge of adult services is developed and maintained in an opaque manner. Cultural representations between services contributed to young people's apprehension about leaving pediatric services. Pediatric services are then delineated by the extent of their expertise and knowledge, but the boundaries are not clearly established. For example, the pediatric nurses put a lot of emphasis on teaching young adults, trying to progressively engage the young person with the idea of transfer. To do this, they introduced concepts such as self-management, symptom recognition, and the ability to ask questions of healthcare professionals in a way that is understood and optimizes the chances of receiving a helpful response. In addition, as a pediatrician specialist indicated, the discourse of physicians and nurses, among others, is intended to focus on the behaviour of adolescents and their assumption of responsibility for the management of their chronic condition. A nephrology nurse described her fear in anticipating the potential disruption of care created by such a shift in clinical cultures, and its deleterious impact on the health of young adults.

Disparities in information sharing

Effective care transitions required seamless information sharing between pediatric and adult care settings. However, the absence of a formalized communication system often resulted in inadequate transfer of essential patient information. HCPs, AYAs and their families highlighted the disparities in information sharing practices, including incomplete medical records, inconsistent documentation standards, lack of information, and challenges in accessing complete historical pediatric health data. Indeed, among HCPs, transferring patients included the transmission of important information about them. The transfer of patient files involved various considerations, encompassing multiple layers of the health system, such as information system management, structure of healthcare network, and knowledge of information transfer by HCPs.

The process of information sharing firstly depended on the hospital's network affiliation, leading to two scenarios. In cases where the pediatric and adult hospitals belonged to the same health network and shared a unified electronic centralized system, the transfer was implicit and streamlined, as the adult care specialist would access the patient information. However, challenges arose when dealing with different electronic medical records systems between hospitals that were not part of the same network, making the transfer more complex and demanding extra efforts for seamless integration. In the latter situation, HCPs had to ensure proper transfer, which was not always done properly, as AYAs and adult care specialists could witness. As one pediatrician specialist shared:

> *"I don't think we do [information sharing] very well. When [the patient is] being transferred from [a pediatric specialty at the hospital] to [the corresponding adult specialty in the affiliated general hospital], it tends to be pretty easy because we have a system set-up. [This is] not to say that it isn't without problems, but it's fairly easy to organize. When you're organizing to go somewhere else, then there are just additional communication issues and so on."* (Pedes-HCP015)

Indeed, as soon as the transfer is made to another healthcare facility outside of the affiliated general hospital, communication between pediatric and adult HCPs was reported to be a rare occurrence. As one nurse coordinator in pediatric care commented:

> *"It's easy because we're in the same place, but you know, [AYAs] can go elsewhere too. There's no communication if you're transferred to the [named a specialty institute outside of the hospitals' site and network], for example. [Their HCPs] don't even know the names of the doctors, or the nurses... You know, there's no connection."* (Pedes-HCP004)

Primary care providers were more often outside the hospitals systems, including the electronic medical record (EMR), and thereby experienced the care coordination barrier of a lack of information. One PCP mentioned the lack of a “synchronous or harmonious medical information system” (PCP-HCP026). Another family physician deplored inadequate shared communication systems:

> “*I try. [But,] again, it's much easier to detangle [the file] when I know the treatment plan; when I know how things work. So, because of the lack of information, often long-term follow-up of these young people is a little more difficult.*” (PCP-HCP002)

Differences in levels of information sharing across services was perceived to depend on the specialty and the adult care facility to which the AYAs were being transferred. Such structured boundaries dividing pediatric and adult services in general, and specific services, prevented the systematization of continuous care for AYAs, making it reliant on dedicated individual health professionals and families stepping outside of their normal patterns of work.

The lack of integrated care models bridging the divide

The experiences of each stakeholder shaped how they attempted to address the gaps of the system to transition AYAs to adult care. However, their experience showed how opacity – that is, not knowing how transition is experienced across one’s boundary – had led to a lack of collaboration between the stakeholders involved in the process of transition to adult care. This opacity was reinforced by the pseudo-category to which adolescents belong, halfway between childhood – recognized by the specializations of pediatrics – and adulthood – recognized by so-called “general” care and its fields of expertise. AYAs represents an in-between that does not ultimately fall into any of the two prevailing categories of systemic legitimacy.

In a hyper-specialized social environment, there is paradoxically a lack of specialization in the care of adolescents that may demonstrate a need for recognition of this part of the population. In addition, the marked difference between pediatrics and adult care represents an adaptational challenge for young people who must then take on a new role with no room for manoeuvre or time to adapt to the new rules and standards to be followed. The management of the care of young adults is then their responsibility. This process is governed by a social structure that evolves in a relatively exclusive linear rigidity. Boundary rigidity is represented by socially established and recognized categories, relatively bounded from each other, for which a clearly accepted set of attributes allows for clear inclusion or exclusion. The linearity of the structure, designed for efficiency to serve the majority of users, precludes the accommodation of various and relatively unpredicted dimensions that the complexity of the adolescent experience invokes. The exclusivity of the structure delimits relatively firmly the boundaries of membership in pediatric and adult care categories, and thus the prerogatives granted to them.

Entities or social groups, such as adolescents, that do not fit into these relatively fixed, linear and exclusive paths risk losing their direct connection to the prevailing system, either temporarily or permanently. Accountability will then be enforceable for individuals rather than the system. In the remainder of this chapter, I define this structure in particular by its dichotomous anchoring between clinical phenomena, non-clinical phenomena, and social care. This structure contributes to an interruption of systemic care and thus to the exclusion of a social group.

One transfer divided into several: the multiplicity of transfers

While the pediatric approach is overtly multidisciplinary, attempting to integrate health and social care by including the family, for example, adult care remains fragmented, operating on the structured separation of health and social care. In addition to this fragmentation, all health professionals interviewed lamented a lack of systemic collaboration between different care groups in the adult and general health sector, particularly between primary care and adult care. The transition from pediatric to adult care alone is a shining example of the separation of clinical and non-clinical health services. Although clinical care is subject to formalized handoff through the act of referral from the pediatric referral caregiver to the potential adult referral caregiver, the nonclinical aspects are not part of this handoff. A pediatric cardiology nurse commented on the very clinical focus of the handoff documents. A young adult who had been transferred for more than five years also reported that her move to adult services meant a reduction in her multidisciplinary care, including less clinical care.

Pediatric healthcare professionals noted the risk of the change in care approach to the quality of care and follow-up for young adults. Particularly for chronic conditions, interprofessional collaboration including paraclinical care – delivered by allied health professions such as nutrition, occupational therapy – and psychosocial care – especially with psychologists and social workers – was particularly effective in operationalizing the holistic approach recommended for this population. HCPs in adult services lamented the lack of such professionals in the adult care setting, and a lower professional-to-patient ratio than in pediatric care.

As such, the model of care used in pediatrics does not transfer to adult care. Young adults are transferred to disjointed care settings, which focus on often siloed – that is, discipline-specific – clinical follow-up. The lack of financial investment is the most glaring impediment to holistic care for young adults, according to one specialized pediatrician:

> *"We know what is good care for people with complexity and chronicity. It's the medical home model. It's that philosophy of care. How we put it into place is not complicated. It just costs money. And an institution has to decide to do it. So, until they decide to do it, we will continue with our status quo, which is fragmented care. No matter what curriculum you put in place, no matter who you put on the pediatric side, no matter how much we prepare these pediatric patients, it's going to be the same outcome."* (Pedes-HCP009)

The medical home model of care, being referred to is a front-line based model of care to enable patients to receive comprehensive health and social services. The model is patient-centered in that it provides a space for centralized care to allow for coordination of generalist and specialty care for the patient himself or herself, including the family, as needed. Care is then composed of clinical, non-clinical, social and culturally appropriate resources for the individual. In other words, the approach tends to integrate care and services by limiting the separation between clinical and social care, thus recognizing the part played by these services in the overall care of the person.

This model was originally developed for primary care in the United States. In Quebec, the family medicine group and university family medicine group model is inadequate for this function. While in pediatric hospitals, nurses emphasize interprofessional collaboration that facilitates links between the various departments, in adult services, nurses find interdepartmental collaboration difficult. The level of difficulty increases when a psychosocial service wants to be added to the person's care. The multitude of specialty layers complicates transfers, which can then leave part of the care interrupted, because it is not available in the adult services. A pediatric specialist indicated that in many cases there was no equivalence between the pediatric care structure and that available to adult care:

> *"There are two levels. First level, many of these patients have a general pediatrician and when it's time to make the switch, well there's no pediatrician. The internists don't always choose to see them, even though I've heard for other patients internists say the case is too complex: 'there are too many problems; it's too hard for us'. So, obviously, if the internists say that, then the family doctors forget about it – the family doctors. Many people don't have a family doctor. So, that's the first level. The second level is the different pediatric subspecialties. So, we'll say that when the patient is followed up on the pediatric side in [pneumonology], in gastroenterology, in immunology; he must be referred to an adult [pneumonologist], or an adult gastroenterologist, etc. Well, that's what we have to do too. We have to make the transition. Not only [should] the pediatrician… do it; the primary care physician at the end of the day [should do it]. It's the specialist physician – but, the subspecialty physician should also make the transition, and in both areas sometimes it's done very well. I'm not saying that it's everyone, but sometimes unfortunately the pediatrician is not able to identify a person who is going to ensure the transition. Who is going to play the role of the orchestra conductor? Who is going to organize everything? And then, sometimes, in subspecialties too this transition doesn't go smoothly."* (Pedes-HCP001)

Indeed, holistic transition would require that each of the specialties must be transferred to its equivalent in adult services. Sometimes, even when, in theory, equivalent services exist, it is the time taken to translate services to adult care that may leave the young adult with partial care. This may happen, for example, when an area is newly developed in pediatric care, or when there is a lack of adult specialists in an area with a low population. One pediatrician further states that the complexity of the case is in some ways correlated with the difficulty of finding an equivalent adult service. Although in theory it would be possible to find adult specialists for much of the pediatric care to be transferred: *"in practice especially the higher the complexity of the case, the less you see people volunteering for the task"* (Pedes-HCP001).

In addition to the lack of services, or reluctance to take on patients, is the lack of time, which is widely acknowledged by the nursing staff, as well as the lack of knowledge and experience with the population in question or the pathology. Thus, the health system does not cover or ensure a complete transfer of pediatric care to adult care. The distinct structure of pediatrics operates in a singular and separate way from adult services, leaving some dimensions of care unable to be transferred. We will see in the next chapter how the different services adjust to try to overcome these mismatches.

Interruption of systemic care

Such transfer failures constitute a disruption of care, in which healthcare services are inadequately provided. Participants across the spectrum – pediatric, adult, and primary care specialists and young adults and their families – lamented the interruption of care and communication that would maintain their connection to the healthcare system. Healthcare professionals highlighted the differences between the types of care that can be considered "portable", as opposed to suspended care. While portable care may transition to adult care, the resumption of care was rarely without a break in services. For one young adult, moving into adult services was like *"the 12 labours of Asterix"* because of the complexity of how services were organized and operated. He said he felt *"left to fend for himself ... in complete autonomy, and [had] to go by himself ... without knowing where to go"* (AYA001).

The feeling of being abandoned, left alone, with the fear of being left to fend for themselves and lacking care are all emotions shared by young adults at the time of transfer to adult care, when the last appointment with HCPs from pediatric services is announced. This transfer period is also destabilizing when young adults see that the challenges they face are not easily overcome. With the lack of communication, one young adult complained that he did not know where to go, who to talk to, and that the instructions he received were vague. Most of the young adults reported a lapse in care, an interruption during which they were not followed by either the pediatric or adult HCPs, foreshadowing an uncertain future.

In addition, the timing of transfer depended primarily on the age of the patient, without necessarily taking into consideration the stability of the patient's condition, or the patient's maturity or ability to manage their care once they arrive at the respective adult ward. The delays in accessing adult care and the regularity of follow-up consultations with specialists are not in keeping with the critical time experienced by young adults when health needs are active and sometimes urgent. Moving to another service far from pediatrics disrupts the young adult's follow-up and was reported to lead to passivity in the delivery of care by the adult care system. The interruption of care during the transfer conflicts with the reported needs and expectations of families. Two parents of adolescents who experienced transfer to adult services spoke of feeling as though they had to "fight" or "beg" for care for their ill child. The gaps in care were associated with the administration and bureaucratic complexity of the rigid healthcare system.

Pediatricians, in particular, pointed to the lack of access to mental healthcare, including inadequate wait times. Although pediatric HCPs made referrals to community resources while waiting for the first appointment with specialized adult services, community resources also have a triage system that does not always take into account the particularities of this population and their needs. This sees young adults remaining on a waiting list for active needs in a physical or mental health situation that sometimes has not completely stabilized. In this vein, access to allied health professionals who would provide continuity with the pediatric service offer is often interrupted in adult services, as one pediatric nurse points out:

> *"On the adult side, you have less, like, psychology, social work, psychiatry. [They] are very poorly accessible. On our side, we have a social worker; we have a psychologist; again, limited time because they have lots of work. But we can access them and speak to them and get their input. And certainly, our social workers are heavily involved with our population. On the adult side, they don't have a social worker dedicated to the transplant program. … I don't know how that happens, but they don't. And so, to get that, you have to send a consult; you have to wait; it has to be triaged. And so – the immediacy of it – because they use a lot of community-based stuff. And that's great. But you need to access it. And, as you know, given this recent time, accessing mental health is very challenging. So, in terms of the allied health, they don't have a nutritionist; we have a nutritionist. So,*

> *it's really the nephrologist and the nurse in this particular clinic, and I think that's similar to a lot of the nephrology and I can speak to nephrology, probably in gastroenterology. They have access to a dietician, nutritionist, but again – the social workers and so forth. I think they're all spending all their time with the seniors on the wards in the inpatients and all the other cases, you know, like, so the Allied Health is a little bit poor access, less accessible on the adult side."* (Pedes-HCP025)

Thus, the fragmentation of care across different departments and subspecialties of departments is equivalent to transferring and therefore maintaining a part of the care while abandoning the global and systemic aspect of the management of the young adult's chronic condition. To mitigate the potentially deleterious effects of this interruption, primary care is targeted. However, a pediatric nurse who coordinated a study on transition to adult care found that many patients did not have family physicians: *"In what we saw, … 60% of the patients we surveyed … had a family physician; we have 40% who did not"* (Pedes-HCP004). She also points out that for one particular patient without a family doctor and without adult care after his 18th birthday:

> *"He had to go to a walk-in clinic, ask for a consultation paper to be referred to the you-know-the-adult specialty... come on! Clearly, there are cases that are not well done, but at least this patient was visibly mature if he was able to take all these steps – which is not the case for everyone, is it?"* (Pedes-HCP004)

Thus, the extent of the young adults' responsibility at the time of their transfer, whether or not it was completed, constitutes a potential loss of the person's continuity in the healthcare system. This undermines his or her health maintenance and is a threat to his or her future as an adult.

The health system structure, made up of branches of specialties that rarely intersect, is tied to each category of a population with a recognized status, and is socially translated by dedicated institutions. As a result, the structure of pediatrics is built according to recognized pediatric clinical conditions, but also according to identified needs and associated resources. For example, we have seen that paramedical resources are proportionally more present in pediatrics than in adult services. The structure of adult services is not aligned with pediatric care, as it is based on the historical model of medicine deployed by system, and developed according to the clinical conditions typically encountered in the adult population. The transition between pediatric and adult care is discontinuous, as we have seen, even though a portion of the pediatric population is in this care structure. The arrival of this population highlights the lack of adjustment of the care system to changing demographics, and the relative exclusion of particular social categories. In the next chapter, I explore how the emergence of this population shifts the ramifications of the structure of the care system, and signs of how the entry of a new category is negotiated in a tightly bounded system.

Ethical considerations: lack of access, responsiveness according to volume

The dearth of access to care represented a prominent ethical concern arising from the gap between pediatric and adult care. Adolescents undergoing the transition to adult care reported experiencing a shift in their healthcare status as a result of the transition. While some adolescents still relied on their parents' insurance coverage, others lacked health insurance altogether, leaving them vulnerable to inadequate coverage for essential health services required to manage their chronic conditions. Additionally, in order to mitigate the void in adolescent healthcare, some young adults who possessed robust health insurance through their parents resorted to seeking private healthcare services to bridge the gap during the transition phase, further exacerbating disparities in access to care between different socioeconomic groups. One parent explained having to engage private services to overcome the lack of services:

> *“So, she was without a [family] doctor, and then we applied a long time ago... We still don't have one. So, we go through the private sector for general care. So, it's not even the family doctor that can really get us back into the system. So, I don't know. I don't know what's going to happen. I imagine, well, we imagine that at the end we'll be referred to somebody. You know, direct her because we're not going to be responsible anymore, but the poor thing has to have her own doctor.”* (PG002)

HCPs underscored the notion of patient volume as a key factor impeding the implementation of tailored services for adolescents transitioning from pediatric care in the adult care settings. to respond to the population’s needs was associated with the ratio of HCPs to patients. Indeed, to explain the resource limitations within adult care settings that hinder the delivery of responsive healthcare services specifically tailored to the unique needs of adolescents, HCPs invoked the notion that the volume of AYA patients is minimal compared to the volume of adult and elderly patients within adult care settings. As one nurse from the adult care setting explained:

> *"It's a numbers game. You're going to put your money where the people are. The people are not at the Children's [hospital]. The people are at the 1200[-strong] Adults' [hospital]. That's the problem. So, if you're looking at a physician like Dr. [Pediatrician Specialist] is okay to see four. The billing over here, they want to see fifteen. It's a numbers game. And they need more. They need more, and if they can't get more from here, what other resources are you going to put into place to make sure that they're getting what they need? And their families. Remember, it's not because they crossed over the hallway that the families are not important."* (A-HCP030)

Adult care settings typically experienced high patient volumes, necessitating the allocation of substantial resources to meet the demands of diverse patient populations. However, this concentration on volume often comes at the expense of adequately addressing the distinct needs of adolescent patients transitioning from pediatric care. The limited availability of specialized resources and expertise catering to the developmental, emotional, and psychological requirements of adolescents within adult care settings posed a significant challenge in delivering responsive healthcare services. A pediatric nurse emphasized the importance of patient volume:

> *"Why? Volume, volume and staff, you know, ratios of staff to patient populations. There's just hundreds more of adults with my population, kidney transplants, hundreds more of, you know, adults with general nephrology issues comparatively to here."* (Pedes-HCP025)

The prevailing gaps in healthcare that left AYAs in a state of uncertainty highlight the inflexible structure of the healthcare system and reveal how transitional categories are often excluded. As a consequence, AYAs find themselves in a situation where they are either treated as children or adults, lost between strongly bounded systems, lacking tailored care for their specific needs as individuals undergoing the transitional phase.

Adolescents as collateral damage of the clash between pediatric and adult care

The “non-standard” adolescence in the blind spot of hyperspecialization

As we have seen in the introductory chapters, adolescents are socially aspiring potentials of whom society has high social and economic expectations. However, young adults who have been diagnosed with a chronic condition are part of a subcategory of youth that has not yet seen the development of a dedicated field. In a social milieu divided and subdivided into specialties, there is a mismatch between one's status and the services offered. AYAs, their parents and health professionals agreed that the period was full of social, psychological and biological challenges, especially for young adults. Thus, the difference between being diagnosed as an adult versus being diagnosed as a child and following one's pathology into adulthood are two very different events. As one parent of a young adult explained, the influence of the diagnosis on her child's life is such that the entire social world has been turned upside down. While, in another case, the neurologist called for a halt to competitive sports to maintain the teen's health, their parent recounted how the news locked her child into entrenchments and mental health issues by losing several groups to which he belonged:

> *“So, it fell on us like a building, and then it was the beginning of a long journey for my boy to fall into depression. We had tried all kinds of things and psychologists to encourage him. His friends were great; they tried to help him. It was the beginning of CEGEP [College]. And then you can imagine the difficulties of dropping your social group, starting a new level of school.”* (PG004)

The young adults mentioned their care as an integral part of their lives without prioritizing it. For example, one young adult who was in school at the time of the interview said that her schooling and work always came first, although she was well aware that her medical condition of kidney failure often interfered with the organization of her life.

In addition to the challenges inherent in this phase of life, the change in one’s familiar and reassuring routine was perceived as threatening to the activities and identities of young adults. Apprehension about changing care settings was often described as a sense of fear and dread caused by the representation of adult care for most youth. For their parents, it was their knowledge – however limited – of the adult healthcare system that fuelled the fear of transitioning to these services, in which they had had experiences. Two family physicians noted that the adult healthcare system was difficult to understand both as a patient and as a healthcare professional. Such examples were often illustrated with a real-life case of the difficulty finding a specialist to refer their patients to. One parent discussed his difficulty in obtaining an appointment for a minor problem, pointing to the organization of adult services. One child spoke of the story his mother had told him about her delivery and the complications associated with the difficult communication with HCPs in the adult world, which differed greatly from the one they had experienced in pediatric care. Thus, prior to transfers to adult care, a discourse of fear and difficulty was stored and expected by the young.

Like the parents of the young adults, an association is made by the young adults themselves between the highly specialized pediatric care and the quality of care received and the relationship with healthcare professionals in the adult care sector. As noted by one young adult who transferred to adult services over a year before the study:

> *“With pediatric care, I found it was a lot more specialized and, like, a bit more intimate I guess, just because I had more time and, like, I grew up kind of with my doctor. So, I got to create a kind of a relation with them and then, like, transitioning [to] a complete set of new doctors – I wasn't sure how it was going to go.”* (AYA005)

Additionally, as a mother of a young adult with epilepsy explained, the health system provided many specialists for children on the one hand and for adults on the other, but there is a lack of specialists for young adults, especially for those with a particular pathology requiring expertise. Thus, the category delineations excluded from the healthcare system those in transition between two categories (adolescent to adult) but also those who did not represent the transitional categories because of their particularities.

Placing adolescence outside the system: “Too old for pediatric care, too young for adult care”

Aware of the social representation of both the child and the adolescent in the Western world, young adults, as well as health professionals, realized the influence of actions related to the care of children – benevolent, with gentleness – on the one hand, and that of adolescents very quickly perceived as adults – with less follow-up and a collective expectation of independence – on the other. In health systems, the adolescent has only recently emerged as a patient category and clinics dedicated to this age group are rare and mostly located in pediatric hospitals. A few pediatricians interested in the issue of transition to adult care have begun to take ownership of adolescent care in order to develop dedicated care for this population, which is situated in the middle of a multitude of specialties. The latter being pediatric or adult care. For example, a family physician working in adolescent care, particularly in mental health, has developed this missing component of the healthcare system with the resources available to him.

However, as participants across the stakeholder groups mentioned several times, adolescence remains a period of change – not voluntary – with many events in the process or about to be built, such as professional orientation and social network. This period, already marked by change, is even more marked by their diagnosis to manage. The opposition between children and adults is regularly discussed by the different actors. For example, a 21-year-old young adult who was transferred to adult care, primarily in oncology and nephrology, spoke of the more welcoming atmosphere of pediatric care, normalizing this difference, but emphasizing the depersonalization of adult care:

> “*It's normal because they are children. At the Adults' [Hospital, the patient is] an adult. So, they're going to talk to you like a number. At the Children's [Hospital], they will talk to you because you are a child or a teenager. It's normal. You need to get a more familiar atmosphere. You need to feel comfortable. You need to feel confident, but to adults, it's really like I say number one number. You take a number and that's it.”* (AYA001)

This dichotomy between the representation of childhood and adulthood was highlighted by a teenager who described her experience in adult services:

> *"Like, if you're lost, you're not a cute kid anymore. You ask someone and people answer you and [you're seen as] kind of dumb. It's really not the same thing."* (AYA002)

When care is required as the age of 18 years approaches, it is not easy to arrange transitional care. It is common to have the young adult wait for care in adult services when the need was diagnosed before he or she became an adult. However, the adult system does not accept a minor's use of adult care, even within a few months of legal majority. In this case, as one pediatric healthcare professional explains, the youth are in a "void" zone, otherwise in which the required care cannot be delivered to them given their age:

> *"Usually, like, if they're within a few months of becoming 18 [the adult services] say, 'Well, they have to wait until… you know?' By the time we see them, then it's too close… Do you know what I mean? So, as soon as they're like 17, I think it becomes really problematic for them to get help in psychiatry because the pediatric sites think that that's too close for them to be followed because then, soon, they'll be 18, and then the adult sites will say 'well they're not 18' and, so, you have this period where [the patients are] not adequately followed and that's an issue really. That is a real issue. That's something that I've struggled with for years that they fall in that gap, and nobody is kind of like 'Well they're not old enough' or 'They're not young enough'. So, you know some things can't wait … for six months, or whatever. So, I really feel like there needs to be more flexibility in some systems that allow, like, one year or six months or whatever, you know? So that adolescents who need help will be able to have continuous care so that they don't feel like they have to start and then stop and then switch if they are close to being 18."* (Pedes-HCP023)

The 18-year cut-off point occurs while the young person's need is active, and, yet, points to a gap between the organization of the system based on exclusive categorizations. Families move from recognition in a structured environment with which they have been familiar for years, to the uncertainty and unknown of the new environment of the same system that no longer recognizes them.

By the time of transfer, sometimes the young adult no longer has the place that has been reserved for him or her for many years, and for the first time finds himself or herself on a pathway in which he or she is not known and cannot "benefit" from the simplified access that he or she had before the transfer. One mother of a young adult transferred to adult care found that, regardless of the emergencies her son may have had as a complex pediatric patient, he had to go through the same triage methods as other patients whether they have acute or chronic problems, whether they are known to adult services or not. Thus, the degree of prioritization has changed for her and her son:

> "*Losing [the Nurse Coordinator] and the team, I don't have my go-to. You know, if I had anything, and I would email [named Nurse Coordinator], you know? And it's just having that one person that I know is there, like 'Oh [named Nurse Coordinator], this is what's going on, what do you think?' 'Oh, just bring him in.' Because I live close by, it wasn't a problem – like, you know? 'Bring him in this afternoon at one.' I'm like, 'Okay I'll bring him in'. Or 'Bring him an hour; are you free in an hour?' 'Yeah, I'll bring him in an hour.' So, that is what I don't have [anymore]. I don't have someone that is able to say 'Don't go wait in the ER [emergency room / department] for like five hours when he breaks a leg, when you think he broke his leg. Just call.' You know? I call them and then they would arrange the x-ray through them. Whereas now if he breaks a leg, I have to sit in the ER for, like, God knows how many hours. So, it's just that, mainly. And so, with the Duchenne [disease], with the kids that were seen in complex care, there's something in their dossiers. So, when you go to the ER you are not waiting hours. Like, when we're on the Children's [hospital] side, we had a nurse that we will call, and she would advise the ER that we were coming, and we wouldn't have to wait. Like, we would have to wait like if someone's having a heart attack or something. But, you're already pre-triage so you're basically just waiting for the treatment type of thing. That we did that you don't have on the adult side at all."* (PG005)

Patients with complex conditions like Duchenne disease, a severe form of muscular dystrophy, received tailored care that acknowledged their specific needs with their pediatric teams. This specialized approach ensured that their medical history and unique requirements were considered, a service not provided in the adult healthcare system. The role of personalized and specialized care in providing efficient, responsive, and tailored medical services was seen as critical. The transition to adult care, which lacked these resources and coordination, may result in significant challenges and reduced quality of care for patients with complex health conditions.

A lack of specialization in adolescent medicine

Primarily for parents and family physicians, a lack of specialization in adolescent medicine means that the specific needs of this population are not being met. While children's care remains highly specialized, for some young adults it is not possible to find a care team similar to that of pediatric services. This is either because such a team does not collaborate, or because the pediatric specialty does not yet exist on adult wards, due to the novelty of children's longevity beyond the expectations of serious illnesses in the past. For example, for parents of children with complex health needs that cross multiple organ systems, and thus require experts from different departments, as well as experts in complex care, the resources are simply not available in adult care. As one mother of a young adult who has moved to adult care with no specialized resources explained:

> *"It's just that with a diagnosis so severe, ... I don't think my boy would have fallen so far if he had someone who specializes in his disorders...because we had looked for psychologists. But, I think we had tried three, but it's important to have someone who knows the problem. If you're just a psychologist – and I'm not minimizing the education of others – it doesn't mean it's going to help. You have to have a neuropsychiatrist who knows the brain, who decides 'Okay' this is the problem here. So, he or she needs a psychologist who obviously specializes in epilepsy, ADD, or – I don't know what."* (PG004)

The integration of adolescent healthcare into the broader healthcare system remains limited in this setting, with AYAs often excluded from standard healthcare structures and practices. This lack of system integration, with excessively bounded segments, results in missed opportunities to deliver responsive and appropriate care to this population, resulting in an accumulation of unmet needs as they transition into adulthood.

Unmet needs of adolescents

During the transition from pediatric to adult care, adolescents and young adults with chronic conditions encountered several unmet needs that affected their health and well-being. First and foremost, the discontinuity of care posed a significant challenge, as many individuals experience disruptions in medical attention during the transition, which was exacerbated by the lack and difficulty of access to adult care specialists and allied HCPs, such as in psychology, nutrition, and social work. Adolescence is a period of time which encompasses many changes that directly influence one's health. Changes in biological development include menstruations and fluctuating hormone levels, or brain development sometimes leading to reckless behaviour. Changes in personal and social life aspects include identity insecurity, peer group insecurity, nutrition, sleep and physical activity. This is a period when medical attention for adolescents with chronic diseases was essential. Seamless collaboration between pediatric and adult healthcare teams was crucial to establish a comprehensive transition plan, preventing gaps in care and minimizing adverse health events. Moreover, inclusive care, access to accurate and comprehensive information, along with appropriate education regarding a particular patient's chronic condition and self-management strategies, were listed as ways to empower AYAs to take charge of their health.

The psychosocial support needs of this vulnerable population were overlooked during the transition to adult care. Adolescents and young adults with chronic conditions often faced emotional and psychological challenges during the period of uncertainty that transition promises, which tended to exacerbate certain medical conditions they had – such as, high levels of stress, increased glycemia, and lack of emotional support exacerbating eating disorders.

Providing adequate psychosocial support services was mentioned as helping young people to cope with the stress and anxieties of early adulthood, while managing their health condition. AYAs agreed that peer support groups held the potential to play a role in fostering mutual encouragement and understanding from people who lived the same experience, and to whom they could relate, creating a sense of belonging among individuals facing similar challenges. Additionally, the transition which was mainly an abrupt transfer did not allow AYAs to process all the adjustments they needed to make in order to manage their conditions and general health status. As one PCP suggested, the development of autonomy and self-management could be fostered earlier in pediatric care:

> "*Yes, I understand that [adolescent patients in Pediatric care are] seen every two months. But [for some AYAs] it's not realistic and it's not necessary. Sometimes, it may be that the follow-up has been kept too close for too long and, maybe, [the adolescent patient] should have a way of progressing on a care. And I don't know if there are any who are already doing it in certain specialties, but maybe it's worth thinking about as another avenue.*" (PCP-HCP019)

A gradual transition was also requested by AYAs, because they were not ready to take on such a grave responsibility as their care the day they turned 18 years of age. The apparent lack of patience shown by some adult care specialists during the first clinical encounters was seen to make them miss important pieces of information AYAs wanted to share initially (AYA005).

The unmet needs of adolescent patients pertained to non-clinical aspects of care that had a significant impact on the clinical treatment process. Among these aspects, AYAs emphasized the importance of the relationship they built with their new HCPs over time, which influenced the content and manner of their communication. This relationship ultimately affected the HCPs' ability to accurately assess the AYAs' condition and determine if they should receive specific care, such as nutrition support, which a young adult who underwent a kidney transplant believed might impact their chronic condition. Participants noted that their health directly influenced other aspects of their lives, such as school, work, and social interactions, leading them to fear not having a responsive HCP to address their needs, or "*not having the trust and the confidence in each other, and not [feeling] like a close team*" (AYA006).

Eventually, worsening symptoms would bring AYA patients to the emergency department, when they did not have adult care access, or would not feel that they had a relationship or easy access to their HCPs. An adult specialist mentioned:

> “*The other adolescents that we would be getting involved with are people that we've seen in emergency, you know – that have crashed … for whatever reason. So, I've seen a lot of young adolescents, you know, with acute kidney injury. You know, the young girl I talked about with hypertension? … She was someone who crashed into emerge [sic] with hypertensive emergency. And she was, I think, 19 at the time. And, you know – so there's been a couple like that, that have had severe hypertension [that could have been avoided].*” (A-HCP017)

While transitional care is supposed to involve the seamless transfer of patients from pediatric to adult care settings, ensuring continuity of care as individuals age and change services and HCPs, the disconnect between these settings led to disruptions in the transition processes. This compromises patient outcomes and well-being. In order to address the hurdles posed by the health system's structure and the cultural disparities between pediatric and adult care, manifesting in relatively firm boundaries, HCPs devised strategies to overcome the absence of formal adolescent healthcare. This involved adopting informal methods to fill the gap and meet the healthcare needs of adolescents effectively.

Conclusion

In this chapter, the intricate dynamics surrounding adolescent healthcare were examined, highlighting the existence of a void within the healthcare landscape. The challenges faced by AYAs are not merely a clash of two cultures, but an ingrained distinction that makes the appeasement of AYAs’ health needs fundamentally and systemically challenging. We saw the agency of boundaries that impede optimal care. AYAs found themselves caught between a health system primarily constructed around the adult standard of care, leading to a multitude of challenges and disparities.

Social boundaries create a fragmented transition for AYAs, manifesting in disparities in information sharing. The lack of integrated care models that can bridge the gap between pediatric and adult care results in a series of multiple, disjointed transfers. This interruption to systemic care, coupled with ethical concerns related to access and responsiveness due to patient volume, further compounds the challenges faced by adolescents. Symbolic boundaries, on the other hand, represent the cultural and normative distinctions that shape the identities and roles within these healthcare settings that AYAs are compelled to exist within and contend with. The adolescents themselves became collateral damage in the clash between pediatric and adult care, often rendered invisible by a system that fails to acknowledge the “non-standard” nature of adolescence, and places it within a blind spot of hyperspecialization. Adolescents found themselves in a transitional phase, characterized by being considered beyond the scope of pediatric care, yet not fully embraced by adult care. Therefore, this transitional stage lacked the provision of specialized adolescent medicine, leading to unfulfilled healthcare needs.

Hyperspecialization is the enactment of boundaries that are more exclusive than permeable, and its influence is starkly apparent in the mismatch of service structures and client needs. The next chapter addresses the way various stakeholders negotiate their behaviors to compensate for the absence of adolescent healthcare and strive to meet the unique needs of the adolescent population. This examination will shed light on the resourcefulness and adaptive strategies employed by individuals and institutions to address the deficiencies within the healthcare system, with the possibility of informing structures to enhance the quality of care and support provided to adolescents.

Chapter VI. Negotiating Interconnected Networks and Evolving Healthcare Frontiers

"I always tell them, if you have any issues, please call me back. We're always going to be here. So, you know, we tell them that. So, if they have issues, I'll try to reach out to the other services, like I said. But, it is a challenge, because you feel like you are sort of abandoning them. Because you're not too sure who is going to be receiving them on the other end. So, maybe we should go [to the adult care setting], and just, you know, meet the other team and – or ask them to come here or we go there. I don't know. There must be a way that we can make it a little bit smoother, you know, for everybody." (HCP008)

Introduction

The previous chapters have outlined how transition from pediatric to adult care for adolescents with chronic conditions has long been marred by the lack of a dedicated system. The contrasting care cultures of pediatric and adult healthcare, along with their distinct approaches to delivering health and social services, created challenges for adolescents in accessing tailored healthcare while transitioning between these two settings. Inadequacies in complex care requirements have been shown to correspond to the firmness of service boundaries in a society and setting that incentivizes hyperspecialization. This chapter documents responses to try to overcome these challenges. The chapter foregrounds the agency of actors, such as HCPs, and even AYAs and their families, in stitching together threads of untailored care.

This chapter shows that, to compensate for the dearth of systemic adolescent care, healthcare providers sought to establish new norms and effectively develop a parallel healthcare system. This involved the overt expansion of professional boundaries to occupy the voided adolescent healthcare for AYAs transitioning from pediatric to adult care settings, with the aim of eventually meeting their needs. However, while addressing gaps in healthcare delivery, HCPs and AYAs along with their families, experienced various tensions that emerged from their respective roles. The clashes of worldviews between pediatric and adult healthcare cultures led to confrontations involving different areas and types of expertise. These confrontations were not always acknowledged by all stakeholders involved in the transition process. Confrontations of expertise – for example, between experiential expertise of patients and medical expertise of adult care specialists – underscored the critical importance of interdependence among stakeholders and the need for interdisciplinary, inter-service, and inter-organizational collaboration.

Moreover, this interdependence revealed aspects of collaborative work that were previously overlooked, prompting stakeholders to re-evaluate their identities. The dynamic processes involved in working within and around other professionals’ and services’ priorities highlight barriers to a seamless transition and flaws in the healthcare structure. Such processes were a manifestation of professional boundaries, in response to which HCPs expanded their roles to address challenges and improve adolescent healthcare. While the stakeholders shared a common objective of promoting knowledge dissemination, this process was impeded by the absence of formal pathways that would formally recognize adolescent healthcare as a specialized field.

Interdependence of compartmentalized groups

Although pediatric, primary and adult care settings were relatively unrelated in how they operated and how they were managed, they were compelled to interact across services and organizations in patient transfer. Young adults, therefore, depended on the organizations' relationships to enable their transfer, and provide access to healthcare services and specialists. Yet, the organizational relationships were perceived to be based on the authority of unrelated stakeholders to provide access to services, and safe and timely transfer. Health services management, in particular, was perceived as a barrier to adolescent transfer. As an HCP deplored:

> *“For our patients, we have no choice. As far as the administration is concerned, it's clear to me, they can say whatever they want, in their nice speech. People are just numbers. Afterwards, when I tell them that, they get angry and say, ‘Oh my God, how dare you say something like that?’ That's worth zero. Their actions prove that people are numbers. So,*

> *their beautiful feelings – it's very pretty but it's not feelings. You have to make things easier [for patients]. So that's the other level."* (Pedes-HCP001)

Furthermore, the lack of relationships between children's and adult care organizations hindered young people's autonomy in care – that is, their self-management. They faced challenges in acting independently as a result of health professional and health service interactions that were delayed or nonexistent. Consequently, they navigated through an interdependent network riddled with gaps and discontinuities. This was evident in previously observed lack of dedicated and adequate resources. This section underscores the intricate nature of interdependence among transition stakeholders.

AYAs moved from a "caring" and "welcoming" environment to the uncertainty of failing to engage their HCPs as often as they did in Children's services, or getting to know them as they used to know their former HCPs. The uncertainty might manifest itself as simply wondering if they would get along with them at all. The change in relationship was described as no longer being a chosen attachment; instead, adolescents felt compelled to deal with adult healthcare providers (AYA002).

Thus, AYAs focused on ways to make the relationship more functional to allow for the transition to effective adult care. The goal of the relationship was to maintain contact with healthcare services. Another AYA mentioned that she was still hoping to be listened to and expected patience as an important attitude from adult care specialists (AYA005). This required a degree of mutual construction of the relationship as a form of interdependence.

Adult care professionals emphasized self-care and self-management to ensure proper monitoring and adherence to follow-up guidelines. However, this emphasis on independence clashed with the young adults' continued dependence on the care system. Beyond language differences between pediatrics and adult care settings, this raised important questions about how interactions needed to be adjusted during the transition to adult care. The adult care setting expected to see a level of maturity in young adults coming into their services that was not always achieved by some newly transferred patients. Independence was valued by adult care providers and was seen to reflect the young adult's perceived ability to manage their disease:

> *"My most pleasant experience is probably the patient I follow that has a genetic lysosomal storage disease. He is very involved in his care, is very diligent and transparent. Although he has family involvement, he is very independent. I follow him every three months, but know that if there is an issue that arises, he will contact me in a timely manner. It is pleasant to see how he remains positive and has used his maturity and resources to manage his illness."* (A-HCP024)

When the relationship was poorly established and the attitudes of the adult services caregiver was not perceived to allow young adults to express their symptoms, the follow-ups were perceived to be less effective and to endanger adolescent healthcare. In addition, as one young adult mentioned, the lack of communication with the adult specialist about her health status, including her results, impeded her own follow-up and self-care:

> *"I want to know my blood test results, but they wouldn't actually talk about it. Like, apparently for more than a year, I was borderline anemic and they never told me. So, I could have done something before, but then after a year or so, that's when she told me and she was like 'Oh well take vitamin B12.' But, I could have prevented that before, you know?"* (AYA006)

HCPs also discussed the importance of a trusting relationship, which was seen to be facilitated by including parents in a passive and temporary way. Adult and primary care providers also found themselves taking account of the role of parents in some encounters by maintaining boundaries between them and their child, and explaining confidentiality and the new status of young adults in the healthcare system. Initially, parents were almost routinely excluded from their adolescent healthcare. However, when AYAs or parents attempted to communicate to obtain information from HCPs, the interaction was made only possible through another HCP. A parent who had a legal deed representing his child lamented that he went through his family physician to communicate with his son's adult care specialist:

> *“It's hard to get in touch with the specialists... Everything is much more complicated and that's why I asked our family doctor who is a young doctor, Dr. [family doctor], who is the nephew of Dr. [name] who is an oncologist at [Adult Hospital] in Montreal, who is our family doctor. So, I asked [his child's family doctor] to be the link with all of this, because otherwise we don't get any answers. We don't get any letters. I call the nurse who is there. She does not return our calls. I write and she doesn't answer us, and yet we have a notarized paper to represent [our child]. My wife and I legally… can speak for him.”* (PG003)

While the expectations under the symbolism of adulthood and independence are expectations that adult HCPs may have had, the opportunity to achieve the expected level of independence is slowed or even prevented by the withholding of information in the healthcare setting.

Both young adults and parents bemoaned the lack of access to their data to be able to facilitate transfer. The HCPs who received them were the ones who requested this data, expecting it to "sail" with them through their transition (PCP-HCP019, Pedes-HCP001). The adult HCPs’ approach could both make the relationship facilitative and supportive of young adults' care and follow-up, by allowing the young adult to open up to the caregiver and receive more individualized care. It could hinder the relationship to the point where the young adult lost confidence and created insecurity in the healthcare system. For example, adult HCPs recognized the uniqueness of receiving young adults and establishing a trusting relationship during initial appointments. In addition, compared to pediatric care, the care received in adult services was primarily singular, that is, it is delivered by one or two people, namely the physician specialist and the nurse. Because of the nature of the nursing role, it was during nursing care that the relationship could be developed that could then be continued with the specialist physician. In addition, in building rapport with young adults, some adult nurses mentioned using new communication tools to be more easily reached by young adult patients - particularly as pediatric HCPs did, with text messages and direct phone lines, instead of going through a switchboard or automatic voice mail.

The supervision of care by pediatric teams was perceived as obstructing the independence of young adults for HCPs in adult and primary care settings. Young adults bemoaned the need for supervision of care by pediatric teams following transfer when care was no longer to be formally supervised as they moved to adult care at their 18th birthday. The perceived change between the care of AYAs by pediatric teams was the multidisciplinary care approach, which was no longer available, in most cases, in adult care services. The degree of independence required after transfer represented the expectations that the healthcare system had of adults, assuming the ability to manage one's care by navigating different services and understanding how to get the care required. One family physician conveyed this expectation in relating the case of one of his patients:

> *"I think the biggest thing is that in pediatrics they're really good at, you know, giving you a lot of guidance. You know, like, they have groups for you. They have multiple nurses who follow you; doctors who follow you. Your parents are very much involved in your care as well as a child, and then all of a sudden, you turn 18 – in some clinics even before then – and you're left to kind of navigate things by yourself, right? Because now you're an adult and you should know how to deal with your chronic disease or your disease. I don't think there's as many groups, you know? There are nurses, of course, but not as much care for you as you may have had in pediatrics, and it's kind of like an abrupt change, you know? Worse than going from elementary school to high school. It's very abrupt and then all of a sudden, you're meant to figure it out by yourself, and that's what I think most of my patients complain about, and I've seen myself as well. You know, especially chronic diseases. So, that's the biggest [challenge] for sure. The biggest hurdle for them is that."* (PCP-HCP026)

Although independence was targeted as a goal to facilitate young adults' transition to their new specialized services, it was seen as a normal expectation when one reaches adulthood. All HCPs emphasized the arbitrary age of adulthood, that being 18, that triggered transfer to adult care, which was not an indicator of maturity or independence. Moreover, the notion of independence was still qualified by the need for continued care. The relationship of interdependence was thus marked by a type of relationship between AYAs and HCPs, particularly on aspects of relationship-building based on trust.

In this vein, participants from all groups emphasized the possibility for AYAs to choose their healthcare provider, especially if – as the young adults themselves mentioned – these are professionals with whom they must remain in contact throughout their lives. The importance of such relationships was further emphasized by PCPs who, aware of the need for a special long-term connection, required that changes in HCPs be possible at any time for young adults during their transition to adult care, so that the transfer to the new setting is based on relations perceived by AYAs and their families as positive (PCP-HCP002). The weight of the caregiver-patient relationship in the transition to adult care is discussed by all stakeholders in all groups (pediatric, primary, adult care, AYAs and their families). The healthcare system did not allow, or even blocked, any adjustments related to non-clinical aspects, such as interpersonal relationships. Yet, these are significant factors in the transition process. Other skills were also at play in the development of trust between the AYAs and their HCPs. Again, AYAs were compelled to be active advocates in their care. This was exemplified by a young adult who had already successfully changed specialist physicians in adult services, given that the physicians' approaches and the knowledge they demonstrated were perceived to put the young adult's health and follow-up at risk:

> *"Sure, if I could, but... Sure people do the best they can. The first time I had a doctor, well, she's the one who wouldn't touch me during appointments. So, I asked for another doctor. I have a new doctor. He is very nice, but he tends to want to play with the medication. And that's the nurse in the beginning who was difficult because [of] the famous story of my water retention [for which] we went to see an ophthalmologist, and the person works in nephrology. I felt like I was dealing with someone who is there, but he has too much on his shoulders or who is there because he is a good person but doesn't necessarily have nephrology skills. For sure, if I could change, I would choose someone who really has the right knowledge."* (AYA002)

In order to counteract the lack of interpersonal relationships with their HCPs, AYAs also associated the development of their autonomy with nuanced understanding of adult health services, as being key to their experience of transition to adult care. As explained by one young adult who recently started working in a healthcare network with patients:

> *"I think it definitely helps that I have a better understanding of [adult health services]... With the healthcare system, obviously, there are a lot of delays, and sometimes, [while working during holidays in the hospital with patients] we were delayed too. So, I guess it doesn't bother me as much because I understood that sometimes the doctor had to go see another patient, but the other patient had to be put on, like, high level oxygen and stuff. So obviously they're going to be delayed. So, I understand it better. It doesn't bother me as much as it would've before. But yeah, I think I was in a good place to accept adult care more than someone who is really attached and perfectly happy [in pediatric settings]." (*AYA008)

Knowing the health services and system was one way, AYAs or their families could determine if or how to seek to advocate for themselves. However, the very functioning of the organizational structure meant that interactions and communication between the various stakeholders were not taking place. Indeed, the means of communication along with information transfer did sometimes impeded access to some of the information required by certain stakeholders. Adult care specialists and PCPs did not always receive a sufficient quantity or quality of information for optimal care when taking charge of the care of an AYA coming from pediatric care. Adult care providers did not always have access to the electronic medical records, especially when the HCPs were in another facility. Therefore, it was reported that physicians actively compensated for these information gaps by reconstructing a record with the information they were able to gather through requests to pediatric providers or the facility where the young adult was being cared for, and by questioning the young adult. However, adult care providers mentioned that these options did not provide a complete record, because they usually needed to have to understand the full history and background of their new patients.

The interdependence between the HCPs themselves was a product of the very structure of the health system. HCPs, and AYAs and their families, optimized this structure, such as it was. Indeed, because of the segmentation of the different services, care, although complementary, was dispersed through different organizations with distinct functions. HCPs, although autonomous in their respective professions, required the knowledge and information of other HCPs to provide care. In particular, pediatricians needed to reach a specialist physician in adult services in order to make the transfer effective, as did family physicians for specialty referrals. Adult specialists could try to reach the pediatrician for additional information. All HCPs recommended a period of overlap of care between pediatric and adult care between the ages of 18 and 19 to make the notion of continuity of care effective. Various *modus operandi* were used to achieve this, including transition clinics or visits to adult services with the pediatric team and the young adult. Neither compensation nor formal recognition in position descriptions were available for many of these activities. These are described in more detail in the next section.

The process of transitioning to adult care entails the involvement of diverse actors from various institutions, all of whom contribute resources to facilitate the transfer between services. Nonetheless, the experience of moving from one service within an institution – the pediatric hospital – to another service in a different institution – the adult care hospital – brought to light several crucial aspects. These included the notable distance between the stakeholders, the paradoxical interplay of rupture and continuity, and the underlying interdependence that bound all stakeholders together, despite the challenges inherent in the transition process. This interdependence was valued by AYAs and their families as they sought stability in the relationship they had with the healthcare system, i.e. HCPs. AYAs and their families concentrated efforts on maintaining communication with HCPs, because communication provided hope that they would be included in healthcare decisions, and it helped promote a sense of stability while transitioning to adult care.

Seamless communication to maintain the link to the healthcare system and chronic care

Young adults and parents emphasized their need to work directly with a particular person, who thus served as somewhat of a gatekeeper, or “anchor”, to these complex and bureaucratic services. The informal and under-recognized role of such a gatekeeper was seen as ensuring that young adults communicated with someone who is sufficiently integrated into the healthcare setting to maintain a connection to the healthcare system and not start a journey from scratch without access to the HPCs they need. Communication with adult care specialists was difficult when there was no direct contact. Parents explained that their interactions with adult care specialists were diverted, either by using pediatric services or by using family physicians as a conduit to adult specialists. They, therefore, maintained their relationship with pediatric HCPs or initiated a relationship with PCPs, or a new and overtly friendly gatekeeper among the HCPs, to communicate with adult care specialists.

Beyond communication between AYAs and HCPs, actively prompting timely engagement in physical care activities was seen as critical to the transition to adult care, particularly through follow-up of outcomes and communication between HCPs. Parents or guardians saw continuity of care in transition through a maintained connection in the healthcare system that can be made not only through medical appointments but also through regular testing and examination (e.g., blood work, imaging) for monitoring their family member's specific chronic conditions, and preventing potential complications. Considering the lives of adolescents and young adults, which may require flexibility from HCPs to adapt to the pace of follow-up, care engagement required both strategic interaction with adult care and primary care stakeholders, either in direct or indirect form:

> *"I think maintaining engagement in care [is vital]. Now, I say that with reservation because sometimes I have patients who get busier, and they come less often. But it's okay if they miss, as long as they come back and they know they can come back if they need to. I think it's the return, the continued follow-up. And I think that they themselves can see that finally. I have some that miss appointments... When I'm having trouble, I have one … I think … whose … appointment … I've moved … three times. She may have been used to the three months but she has a hard time coming to the six months with me, but it's also that you fall into a period of life, the study embarks, the social life... So, maybe just at some point they realize that they don't need it that often after all. They don't need to see us as often but as long as like there are labs, the blood work is being done, the commitment to care remains there, [it's OK]."* (PCP-HCP019)

Based on their experience with their patients' transitions to adult care, HCPs, particularly pediatric HCPs, anticipated potential loss of follow-up and developed ways to prevent adolescents from remaining out of contact with the healthcare system. They also raised the need for identification of a person of contact during the process. An adult care specialist highlighted the importance of HCPs' communication skills when providing care to AYAs:

> *"[Some adult care specialists] would choose, if they could choose, between 80-year-old versus a 20-year-old or take the 80-year-old because it'll be fast and easy as opposed to a 20-year-old. So, you have to remember when you are referring, [to find] someone who's got good communication skills to refer to."* (HCP014)

In talking about the connection she developed with adult care specialists, a young adult expressed her need to stay connected with "an anchor", or a resource person to turn to and avoid being stuck alone without help:

> *"Yeah, because I knew that, like, if I had some sort of, like, something to hold it like to... like, an anchor, ... it would end up being okay, but it's more, if I'm stuck alone with my thoughts I'll probably leave somewhere."* (AYA008)

While the transition initially involved moving to an adult care specialist, AYAs experienced an additional disconnect in their healthcare when accessing allied health professionals. Indeed, the holistic care approach from pediatric care settings was not being enacted in adult and primary care. Consequently, maintaining a stable support system became more intricate as realistic options for interaction with adult services diminished. On the one hand, health professionals in adult services were entering into a relationship with young adults, and young adults were not known by the HCPs and thus have not yet developed a privileged relationship. On the other hand, the young people lost their privileged contact with the pediatric HCPs, finding themselves without an anchor or a reference person to whom they could turn at any time.

This feeling of 'being lost' and 'left [on] their own' during the transition to adult care was resolved when they were able to identify a person of contact from the healthcare community to be accessible during the transfer period to adult care, and even afterwards, while the relationship between the young adult and the adult care specialist or nurse was being established and secured. The need to maintain a connection with a person or their pediatric team then allowed for the management of issues that might emerge during the transition period, or simply to answer questions that would help them with the management of less acute symptoms. In addition, to formalize this referral contact during transfer to adult care, a dedicated appointment was regularly mentioned by all the stakeholders, such as this young adult:

> *"Just to, kind of like, cut everything off and in between the time that I go to adult care, [I'm asking myself] who do I talk to in this case? Like, do I have to go to a walk-in clinic or what should I do? So, I guess maybe, like, even after turning 18, maybe [it would be good to] have one more appointment after you meet your new doctors and your new team to follow-up with your pediatric team, [to] see if you missed anything that you should discuss, and just to have … them still connected … in case there's a new problem that comes up in between the transition. I think [makes care] more long-term..."* (AYA005)

When contact with HCPs in adult services was discussed, transition stakeholders recognized the lack of multidisciplinarity and, therefore, of allied HCPs' follow-up care. This lack was even more critical when young adults had limited family support or a social network. In addition, for young adults, follow-up appointments with allied HCPs, once they moved to adult care, represented missed opportunities for reminders and updates of information regarding their chronic conditions, their evolution, and their health status, but also for support in certain situations related to the impact of their illness on their employment and their lifestyle.

For example, a young adult in nephrology wanted to change her diet to vegetarianism, but did not know how to do so safely for her situation, and could not remember all the details recommended by the nutritionist she saw at the children's hospital. She reported that despite her requests, she had not been able to access a nutritionist in the adult services and therefore remained unresponsive:

> *"I wrote back to my pediatric nurse because I felt she might be able to respond well. But that's it. Ideally, we lose that nutrition support service [in adult care]. I found that difficult because I have to do it myself. And then I'll have trainers, naturopaths, or whatever, but they'll always tell me, 'Of course I'm not specialized for someone who has a kidney transplant, someone who has a disease, someone who has this medication'. So, it's difficult. It's a follow-up that I think should stay - if not every year, at least every two years to be able to see the nutritionist."* (AYA002)

Some adult services did allow access to allied HCPs, but only in specialized clinics, where only certain clinical conditions were accepted, such as psychiatry and eating disorders clinics. Therefore, the implementation of a multidisciplinary approach was contingent upon the primary specialty of the adult services to which young adults were directed, and consequently, the reliability of multidisciplinarity centered on their primary diagnosis as a chronic condition.

Sustained communication played a pivotal role in mitigating the disruptions during the transition. Nevertheless, its systematic application faced challenges and hinged upon various conditions, including HCPs' willingness to maintain contact with AYAs and their families, the availability of allied HCPs, the level of AYAs' understanding of the healthcare system, and their active involvement in their own care. Beyond establishing a connection, AYAs and their families actively sought stability by maintaining ongoing relationships with the same HCPs as a means of ensuring continuity in their care.

Seeking stability in relationships

The search for a "recurring figure" in the form of an anchor, gatekeeper, or reference person in care was emphasized in relation to the provision of stability in care that is intended to be continuous, especially during this period of changes in HCPs, approaches, services, space and even location. Stability was described by organized and coordinated overlap mechanisms between pediatric and adult care. One young adult mentioned that, despite changes in residents[3], and, therefore, HCPs, having the same person overseeing their care on the long run helped (i.e.

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[3] Residents are medical doctors who are training to be physicians in their specialty.

the patron responsible of their care, who would see them on a regular basis), and other young adults also mentioned the “reassuring” feeling of security they had when the same person was following them through their condition.

In particular, one young adult who had been transferred to adult care for over a year and who previously had the same healthcare professionals in pediatric services, considered that changes in HCPs, especially her physician, affected her negatively, but was balanced by having a continuous pediatric specialist:

> *“I don't know [what] to call them, but they're doctors and they change every two weeks or something. But you see, there's a change. But, that's fine, because it's like they would take your blood pressure, your weight, they would like to ask you questions. But, that's it and then Dr. [Pediatrician Specialist] would come. So, there's the recurrent figure. Well now there's no more recurrent figure.”* (AYA004)

The young adult continuing care gatekeepers were not invested in the relationship and in critical follow-ups of the chronic condition. Instead, they allowed for data collection to be discussed with the recurrent figure in continuing care – in the pediatric setting. The loss of this reference person during the transfer to adult care highlighted the end of a stable recourse, which allowed a “safety net” to be felt in the management of an AYA’s condition. This reference person, also mentioned by the parents as a “go-to person”, gave the AYAs direct access to the healthcare system, a privileged access in an environment in which they were recognized and where their needs could be easily identified and thus met. For young adults, the notion of continuity of care referred essentially to the continuity of communication with a known reference person who recognized the young adult over the long term. Although the regularity of contact may differ from one young adult to another, depending on their needs, their level of maturity to monitor their symptoms in autonomy, or the level of stability of their physical and mental condition, maintaining a connection to the healthcare system through a relationship with an HCP allowed the young person to have a sense of continuity of care.

Other underlying factors were valued for reassuring young adults, such as being able to physically recognize their doctor and nurse. Furthermore, after transfer, maintaining continuity of care was successful when healthcare providers on both pediatric and adult teams used similar strategies. This success was also linked to having expertise in the AYAs' medical condition, akin to the highly specialized pediatric services. As one young adult explained of the new clinic to which she was eventually transferred:

> *"It was good. Everyone was really understanding, I think, because they're more specialized in eating disorders, obviously, because like that's the whole clinic thing. So yeah, they use similar strategies I think, and yeah –. They kind of all say the same thing. They all do therapy. [...] And then my evaluation, it was the same therapist who became my therapist after, so I don't have to reintroduce myself, like, 12 times, and tell different people 12 times because that's what I found so annoying – was always having to tell the same story."* (AYA008)

Having a stable relationship helped maintain a connection to the healthcare system, which can be difficult to access even with active health needs. Maintaining relationships and the continuity they represented also influenced the progress of care by avoiding stagnation with different healthcare professionals. The more meetings that occurred with the same reference person for care, the more the care was perceived to be progressing. To establish such continuity of care within the structure of the health system, intra- and inter-organizational mechanisms were developed by the stakeholders of the different groups.

Parents as "care coordinators"

In the context of pediatric care and the transition to young adulthood, parents also played a crucial role in providing additional support to their children beyond what HCPs and other caregivers could offer. Such parental support was intended to complement the care provided by pediatric professionals. Notably, healthcare providers acknowledged the significance of family support, which, if absent, could lead to serious complications in the health status of young adults (PCP-HCP002). An illustrative example is provided by a mother who maintained an active and involved link with her son's pediatric care. She exhibited a structured and proactive approach to organizing his care and follow-ups. Leveraging her deep understanding of the healthcare system and her son's medical condition, she collaborated with the pediatric care team to ensure continuity of care despite the transition to adult services.

In critical situations, the mother believed that she learned to be able to distinguish what required immediate attention, and became adept at navigating the system to expedite interventions, bypassing the standard procedures that adult patients typically undergo. Even in cases where the healthcare system was designed for individuals with uncomplicated care trajectories, such as those with acute conditions or single-system issues, the mother perceived that her expertise enabled her to overcome potential challenges, such as from delay or interruption of care during the transition. The following situation illustrates how parents sometimes assumed responsibility for coordinating the transition and developed a detailed understanding of the healthcare system. Their active involvement and expertise focused on continuing regular care of their child during this critical phase of transition:

> *"[I was] trying to get a hold of an endocrinologist because [my son] has this calcium infusion, and he broke a bone last September. So, he needs this, and he already has compression fractures in his spine. So, he needs his IV thing. So, I knew he was due in March, and I [started] in January – like, I'm pretty proactive; like, I know the way things are … I've been in the system since he was five. I know what I have to do to get the appointments and all that. So, I did what I was supposed to do, and I still couldn't get through, and that was extremely frustrating because I knew he needed [the calcium infusion] in March, and if it wasn't for [Pediatric Nurse Coordinator] and the team there, he wouldn't have gotten it, because I never got through to endocrinology. And knowing now that he's due for one in August, and that I've been trying since June, and [trying to] get an appointment and I still can't get through to anybody, and still no one calls me back – is my worst nightmare, because I know he needs it. So, like, I already emailed [Pediatric Nurse Coordinator] this weekend and I said, 'you know, could you just give me a hand and have Dr. [Complex Care] call her again?' I said, 'because he needs it'. Now if he hadn't broken a bone maybe I would have been, 'Okay, we can wait a bit*

> *longer,' but, I'm like: 'he broke a bone; he's got the fractures in his back; he needs this'. So, that's my worst transition actually."* (PG005)

Parents developed strategies using their knowledge of the healthcare system and the opportunities that some professional spaces, or gaps, left, to ensure access to care for young adults. For example, one mother explained how she was able to maintain a connection with the pediatric team during the time of transfer with new HCPs from adult services:

> *"… His birthday is in November. So, I made sure I booked it even if his birthday is November 4th, and technically his last appointment with the complex care team was November 3rd, or something. So, I cheated, and I moved it to October instead. So, I got one more time with the team even before because they were mentally preparing me, and I got stuff done that I wanted done – like, I wanted a cardiac [magnetic resonance imaging]. I got it done before he went to the adult side because I knew, like, he was going to be different. So, that was done before we transitioned. So, a lot of the important stuff we got done before he transitioned, like the test he needed done for sure."* (PG005)

In this example, the mother deliberately calculated the time remaining with pediatric care to ensure continued access to care for her child, taking into account the delays in adult services. In explaining her approach, this mother referred to the group of parents she met during her child's follow-up in the complex care services at the children's hospital. Indeed, exchanges of experience between the parents took place on a regular basis at the time of the common meetings of the group of parents of children living with the same complex chronic condition (Duchenne disease).

The conversations of these parents allowed the sharing of strategies for managing the care of the children because some parents were more experienced than others. This group of parents formed a community that was sustained beyond pediatric care. As a result, this mother gained important information about managing her son's transfer to adult care, particularly in managing the delays that represent an interruption of care for these families. During these conversations parents shared "war stories" of transition events relating to the way their child had been transferred from pediatric to adult services for those who had already completed their transfer, what typical barriers they had encountered, what lessons they had learned, and what their successful strategies had been for overcoming challenges. After gathering strategies previously tried successfully by other parents in the community, the in the excerpt above mother had then used some of her own to contribute to the continuous care of her child.

Most of the strategies or methods implemented by the families served as tools to compensate for gaps in the healthcare system. Parents wanted to anticipate as many interruptions in care as they possibly could. They knew they were heading into a system that afforded them considerably less continuity than they had come to expect. Some AYAs sought to achieve greater independence and autonomy in managing their healthcare while leveraging their parents' prior experiences with the healthcare system as a foundation for transitioning to adult services. The involvement of parents in the care of these young adults persisted even after the transfer to adult services, mainly driven by considerations of protection and advocacy.

AYAs reported to be grateful for their parents' involvement in their care even after their transfer to adult services. This involvement was quickly justified by parents, qualifying themselves as being knowledgeable about the healthcare system, rather than being seen to undermine the ability, maturity or independence of their child. One mother who explained her decision to remain very involved with her son's care and medical follow-up felt that close follow-up was part of her “job”, without which the medical and psychosocial outcomes would have been more difficult:

> *“Yeah, and if they don't have a mother like me, it's hard. [...] So, it was my job, and I'm glad I did it. But, for sure, we wouldn't have the same results today that we have if I wasn't at home, and I'm happy with our results. I think it wasn't easy, I think [my son] could have a better quality of life, but we have to continue [to be there for him].”* (PG004)

The perceived need for strong intervention by parents or young adults themselves in the organization of their care – often in tasks and positions beyond their capacity or position in the healthcare system – are discussed by family physicians for whom families are not accompanied. In these circumstances, family physicians sometimes saw themselves as taking on a coordinating role in order to facilitate children's transition, without however having the same impact in the environment as healthcare professionals and other actors recognized in the management of young patients' care. One family physician, in particular (PCP-HCP019), reported to have been regularly asked to explain to parents how the setting to which their child had been transferred worked. They believed that it was important to reduce the surprise effect of the difficulties regularly encountered and the possible disconnection from a whole system on which families depended for the healthcare continuity of the young adult. So, family physicians were relatively diplomatic in explaining challenges AYAs might face transitioning.

Moreover, one nurse explained the difficult reality of the healthcare network for patients who, despite the involvement of a coordinator, perceived many layers to healthcare access:

> *"… So [in cardiology], you have the network, but [even] having the network for all the specialties and within the system, it's [still] a lot of layers."* (Pedes-HCP021)

Parental involvement in the transition to adult care often went beyond the simple accompaniment or family support that is desired by healthcare providers. To avoid the pitfalls that young adults could fall into as they transition from pediatric to adult care, parent participants believed that it was important to develop strategies from their experience and knowledge of the healthcare system to optimize treatment interventions and information-sharing. Such parental engagement was understood by parents to play a crucial role in optimizing healthcare outcomes for their children.

Therefore, the presence of recurring figures or reference persons in the care of transitioning adolescents played a critical role in maintaining stability and continuity during the transition process. These individuals offered a sense of security, facilitated access to the healthcare system, and helped care progress. The development of informal working structures and collaborative approaches further supported transitions between pediatric and adult care settings, which was operationalized through the extension of professional and interpersonal scopes of practice.

Expanding professional boundaries to address barriers to transition under a revised mandate

As we have seen, the mandates of the different stakeholders involved in the transition to adult care were not sufficient to contribute to facilitate a seamless transition between services so bounded that extraordinary efforts were needed to span them. The execution of HCPs' formal roles within the healthcare setting was insufficient to ensure and promote a successful transition. Consequently, the transition stakeholders invoked mechanisms to address the limitations of their roles or the roles of other involved parties. Notably, HCPs in various services had extended their professional boundaries, while parents had assumed a care coordinator role to bridge the gaps in the transition process. This section sheds light on these initiatives aimed at improving the transition experience.

Health professionals and their expanded mandate

The role of health professionals was expanded by themselves to overcome gaps and systemic challenges that may have occurred during transitions with adolescents. Health professionals took on more responsibilities and tasks to ensure that certain actions were in place to avoid delays or problems. In order to compensate for possible interruptions in care or difficulties encountered by families in obtaining answers to their questions, whether regarding care specific to the young adult's illness or regarding community resources or resources complementary to those received in the hospital setting, one nurse, for example, emphasized her availability beyond the end of official pediatric care:

> *"I always tell them, if you have any issues, please call me back. We're always going to be here. So, you know, we tell them that. So, if they have issues, I'll try to reach out to the other services, like I said. But, it is a challenge, because you feel like you are sort of abandoning them – because, like [the pediatrician] said, you're not too sure who is going to be receiving them on the other end. So, maybe we should go to [a clinic], once … you know, meet the other team and – or ask them to come here, or we go there. I don't know. There must be a way that we can make it a little bit … smoother, you know, for everybody."* (Pedes-HCP008)

Therefore, the pediatric specialist sometimes extended her involvement beyond the formal transfer to adult services because, as she pointed out, finding adult specialists willing to take over the comprehensive care provided by the pediatric complex care service was challenging due to its specialized nature and the various HCPs who needed to collaborate across sectors. The concern about the capacity of adult services to deliver high-quality care to transitioning youth was shared by other pediatric professionals, which justified their commitment to continue caring for young adults beyond their designated mandate. In practice, particular pediatric specialists chose to informally follow up with their former patients after transfer. They did so either to offer moral support or to assist these young adults in navigating the resources they required when they faced challenges in accessing them independently, or encountered difficulties with referrals to adult services.

For instance, one young adult who had been transferred to adult care for more than five years acknowledged the support of her pediatric specialist and the ongoing informal communication they maintained, which included occasional updates and brief inquiries. The young adult was well aware of the limitations of the pediatrician's role in her ongoing care (AYA010). In addition to surpassing the usual boundaries in pediatrics, wherein care concludes when the adolescent reaches the age of 18, it was suggested by many HCPs in pediatrics, primary and adult care, that an overlap of services be established. This would serve to guarantee that the AYA patients have receiving HCPs with whom they would have had previous encounters before completing the transfer. This approach was intended to ensure continuity of care and a smoother transition into adult healthcare services for AYAs.

Parents also expressed a desire to extend their connection with the pediatric team, especially when they found themselves without suitable options for their child’s ongoing care. They sought to maintain contact with the familiar pediatric team to facilitate follow-up care. One mother elaborated on her experience, stating that after facing difficulties in securing an appointment with an endocrinologist for her son, who had complex health needs, she made the decision to return to pediatric services. The primary aim was to ensure that her son's required care was promptly and comprehensively addressed during his transition when it was difficult to access adult care services:

> *"… I've been trying to get a hold of endocrinology since January [for 7 months]. I left messages. No one has ever called me back. I spoke with the doctor; maybe she called me back. … [S]he was supposed to call me back with a meeting, but she never did. When you call, it's like a circle. Even if you leave a message, no one calls you back with the message. I actually even went in person to … endocrinology because [my son] needs something done like, for sure in August, and I went in June and, because, technically, the doctor hadn't seen him once, we weren't allowed to do anything. Of course they took my name; 'we're going to call you back', and no one calls you back. So, hopefully – [Pediatric Nurse Coordinator] usually arranges it with the doctor – and [hopefully, the complex care physician] will call the endocrinologist herself and have them call me. But, like in February, he was supposed to get an IV infusion, and we ended up doing it on the children's side because I couldn't get through to anyone on the adult side. It's really disgusting."* (PG005)

Parents-guardians are compelled to rely on hope. As this parent mentioned, the return to pediatric care denotes adult services that appear barely accessible, and not in sync with the current needs of young adults. With her son's timeline of care in mind, the parent also mentioned in the interview that any delay in complex care carried risks for complications of the condition.

Adult specialists and family physicians demonstrated strategies to ensure adequate care and continuity of care, despite operating within an organizational context with limited resources and higher patient volumes compared to pediatric care services. For instance, a nephrology nurse (HCP024) elaborated on the expanded nature of her role when she took over the care of young adults transitioning from pediatric care. Despite the constraints of limited clinical resources, and not having the same ease to access multidisciplinary team members, the nurse made efforts to provide patients with crucial information, and continued teaching self-management techniques initiated by her pediatric colleagues. She also established connections between clinics as required, to ensure that young adults received appropriate healthcare and social services tailored to their individual situations. None of these tasks were necessarily precedented, they were not to be found in their position description, and they certainly were not a basis for a claim to financial compensation.

As has been noted, allied healthcare resources were more limited in adult care compared to pediatric care settings, where adolescents were accustomed to receiving multidisciplinary care. To address this, one pediatric nurse reported to devote personal time to learning about the various services and programs offered by provincial health services for young adults. Furthermore, she remained open to exploring more innovative and creative strategies to improve the care provided to young adults transitioning from pediatric care:

> *"I need to learn about different services/programs/resources and how to access different services for these patients. Given our limited clinic resources, I think coming up with creative ways to be able to continue to care for these patients and linking them to appropriate resources is the key."* (A-HCP024)

One family physician (HCP028) described how he had to work around the health system in order to maintain his specialized adolescent medicine services and provide community-based healthcare to a large proportion of youth per year. This included psychological follow-up, and allowing youth without a family physician to be followed up as a primary care provider and referred as needed. For having done so, he was not the only one to "break the rules" in order to offer services, especially to young adults for whom access to care was more difficult, and whose consequences could be dramatic. The family physician took a path outside the usual health network framework, developing a clinic with a youth outreach program. He asserted that the development of network resources depended on leadership and cross-boundary initiatives to operationalize and sustain, even though as he moved forward, the limitations imposed by the health system slowed the establishment and operationalization of new corridors of care that ultimately compensated for the network's lack of adolescent healthcare.

Crossing professional boundaries was perceived as a viable approach to enhance the transition process to adult care. However, it entailed instances of role overlap, whereby particular specialists assumed responsibilities that fell within the purview of others. Notably, a family physician highlighted the phenomenon of specialists taking over primary care functions, such as addressing general health and lifestyle factors that could impact the monitoring of the patient's pathology and life course. This observation arose while discussing the varying levels of willingness among specialties to collaborate with family physicians, and actively involve them in the patient's follow-up plan. The emphasis on collaboration was attributed to development of a shared approach and common vision of care between the two groups, leading them to be regarded as part of the same collective of HCPs.

> *"On the front line, we see a lot of people with mental health problems. I think psychiatrists have a bit more of a multidisciplinary approach – a team approach. I think they are also quicker. I mean a lot of psychiatrists – even pediatric – when the young person is getting better, they will refer to the primary care physician, whereas endocrinologists, they are the ones who will continue to treat diabetes until the end of time. [For] Type one diabetes – [the patient] doesn't really have a family doctor who manages that. I mean, it can happen in special situations, but, generally, it's always followed by a specialist. Like, if it's hyperthyroidism, or some other fairly benign disease that, once the diagnosis is made, they can follow up. In their minds, they are the treating physician. Then, there are times when we see endocrinologists. I think some pulmonary physicians go a little bit outside their field of expertise to do blood tests [or] discuss contraception. I think there are a lot of young people who don't have a family physician, and they find themselves wanting to cover important things."* (PCP-HCP002)

The transition to adult care necessitated the transcendence of professional boundaries by the stakeholders involved in the process. This entailed going beyond their usual mandates to ensure continuity of care and mitigate the disruptions that often occurred during the transfer period. Sustaining continuity could be achieved by reorganizing the roles of these actors, enabling them to extend beyond their conventional areas of operation. The inherent link between pediatric and adult care in the transition process centered the focus on these two services, often excluding primary care. Nevertheless, some specialties shared commonalities in their care approach with family physicians. By crossing these boundaries, a dual role could be created to address the needs of adolescents and young adults, spanning several specializations that are not inherently integrated with one another.

Organizational learning in light of social boundaries

All the health system modulations presented so far were rooted in a complex and adaptive health system. The actors were parts of this system, acting on and being acted upon. In an increasingly complex world, individuals are subjected to a myriad of influences and forces, many of which operate in ways that are not immediately comprehensible. Despite this apparent opacity, individuals continue to strive, employing their abilities to navigate their environments and fulfill their objectives. It was not mandatory for these individuals to fully grasp all the influences exerted upon them in order to carve out coherent trajectories for their actions. The capacity to achieve intended ends, in this context of complexity, does not necessarily hinge upon a complete understanding of all the factors at play, but rather on resilience, adaptive strategies, and the human capacity for agency and autonomy. This section shows how, in the context of complex adolescent care, adaptations occurred and knowledge was disseminated in the complex and adaptive system that is healthcare. At different levels – individual, organizational and inter-organizational – new information and knowledge was shared and exploited. Different levels of organizational learning started from a common point for various actors in the system – the common goal of making the transition to adult care smooth and seamless, which requires the actors involved in the process to align with each other, by knowing and working around the treatment and temporal priorities of each specialty.

The value of "being on the same page"

Despite varying cultural approaches to care, and the vested professional and personal interests of different stakeholders in overcoming health system challenges, the experiential insights gained from the transition process were underutilized for process improvement. Even when knowledge was generated through initiatives and learning endeavors aimed at optimizing the transition process and yielding positive outcomes, the application of this newfound knowledge was hindered within the organization due to the presence of silos. These silos resulted from structural fragmentation operating at the intra-organizational level in addition to inter-organizational level. Consequently, the steps involved in facilitating the transition, including those identified as beneficial, proved challenging to systematize or disseminate, largely depending on the motivation and willingness of the actors involved in the process.

HCPs collectively expressed the learning that occurred through their engagement in the transition process. The learning process of families can be seen to follow a multi-stage and mutual progression. The following section conceptualizes the learning process as three levels: individual learning, group learning, and organizational learning. Although these levels overlap their distinction serves the heuristic purpose of articulating the work of individuals in relation to systems. Such learning involved the dissemination of knowledge within and across boundaries of health organizations in relation to the transition process.

Individual learning

The individual learning process involved healthcare professionals gaining experiential insights from working with patients aged 14 to 25 years. Healthcare professionals emphasized the importance of long-term longitudinal expertise to comprehend the developmental and evolving needs of adolescents while navigating their transitions within the healthcare system. Understanding the entirety of the adolescent developmental process, including identifying milestones and subtle cues indicative of concerns for young individuals, played a vital role in anticipating young adults' expectations and needs. This process was predominantly characterized as "learning by doing," "learning from work experiences," and "learning from past encounters." If learning means holding something in that can be used again, it often happened that HCPs, AYAs and HCPs re-used successful strategies, and so they and their environments were potentially changed. Formal learning opportunities were provided:

> *"I think [optimal care requires] practicing [knowledge of adolescents], featuring it. Me, I've already done the heart failure clinic where is it heart transplant. Then often the girls of heart failure often had already children, where did we go to see them at the Children's. It has happened that we have had children who were waiting for a heart but who came into the world as adults. Then the parents are there and there are many committees. They talk to each other, both the children of [a pediatric hospital] and the children of the [other pediatric hospital]. I learned some things [such as] how to converse with the parents."* (A-HCP027)

Subsequent learning primarily relied on individual work experiences, with limited emphasis on organizational knowledge dissemination, even during knowledge exchange events organized within the healthcare setting. This adult care emphasized the importance of individual work experiences:

> *"I think just from like, personal experience with it, hearing talks about it. I think more just my experience, to be honest, because I haven't had that many talks on transition. You know, so because it's not a huge topic out there – which probably should be a lot more now. […]. So, I've heard Dr. [Pediatrician specialist] speak a couple times. I've been at the academic half day for our residents. But, you know, … it's otherwise personal experience, and just learning from it."* (A-HCP017)

Furthermore, HCPs emphasized the significance of proactively addressing the transition process for young health professionals, as HCPs reported to have lacked awareness of transition until they began their professional practice. In terms of medical and health science curricula, this lack of knowledge shows the need to equip "the next generation" of health professionals with better knowledge and preparation regarding what to anticipate and how to effectively support adolescents and young adults during their transition to adult care settings. A primary care provider also highlighted the learning process that occurred through individual professional experience:

> *"I think that, over time, … we make mistakes. … The teenager that I told you about who didn't have a good transition … might be blind because of that. I don't think she's going to be blind … because she's going to be taken back. I think that it could have really disastrous consequences. I think that we learn from this kind of case because we look for what we could have done differently. I think that seeing the good cases [where] it went well, for whom it also helps us a lot to the parents and to the children who have the same kind of disease [helps us learn]. But, otherwise [learning from past experiences, from each other and from our environment is] not something that is really taught. It's something that's really more experiential. It's a bit of trial and error and we learn a lot from our patients, the young ones, to see how hard it is. I think that, as a family doctor,*

> *we see so many people with chronic illnesses that we take it for granted, especially when it's a child and we see how life changing it is to have a diagnosis of diabetes or a diagnosis of celiac disease. I think it also makes us a little more attuned to what our patients are telling us and what a mistake it is not to repeat [harmful ways of doing] things so that it goes better."* (PCP-HCP002)

Group learning

However, among numerous healthcare professionals, the incorporation of the transition to adult care as an integrated topic in case-based learning was emphasized, while others proposed alternative strategies to address the knowledge or interest gap. For instance, some suggested incentivizing the involvement of family physicians in the transition process, or maintaining lists of health professionals willing to care for young adults, even with limited knowledge of the young population and pediatric-specific diseases, and a willingness to learn about such conditions. The process of group learning featured both formal and informal collaborations at various levels. Such collaborations were often inspired by "champions" or key individuals who had developed expertise and a strong interest in transition processes for adolescents and young adults.

Additionally, healthcare professionals shared their knowledge through supervising medical students or residents in case-based learning, thereby passing on their individual learning experiences. Formal group learning occurred through exposure to successful evidence-based transition processes at national and international conferences, as well as through presentations and lectures conducted at local hospitals. Working in specific transition clinics also facilitated group learning, as direct or indirect interactions among healthcare professionals and between healthcare professionals and young adults provided valuable role-modeling, insights and experiences. There was sufficient dynamics in the organizational environment to allow healthcare professionals to learn from their more experienced peers, enhancing their understanding of the unique needs and communication styles of adolescents and young adults from diverse backgrounds. This was particularly relevant for adult health professionals who had less prior exposure to this specific patient population.

Both individual and group learning were motivated by the adolescent population and the influence of healthcare professionals acknowledged as "champions," "leaders," or "mentors." All healthcare professional participants interviewed purported to be genuinely interested in transitional care, and linked it to their personal values. Some of these professionals outlined their perceptions and understanding of their roles, defining them in terms of personal values that emphasized continuous learning to enhance their skills and better serve the adolescent patient population. They articulated, in some cases, a “calling” to assist and care for individuals, recognizing the cultural nuances of the population they serve, and customized their care delivery to cater to the specific needs of the patient demographic.

One nurse in adult care conveyed her commitment to continuous learning:

> *“... I [like to think I] pick up everything. Before COVID, there [was] a lot of training in hematology. There are things I don't know. I don't know everything. ... If a doctor explains a new diagnosis or something to me, I'll be like ‘Ah, I'll go look.’ Even in your spare time, [if] it's something that's going to interest you, ... you're going to go look because you have an interest in [it]... But, ... maybe because my personality is a personality that likes to go forward. It's sure that the day I stagnate I'll change, because I think that's how I am personally. But you get what you pay for. I'm picking up everything here. .... And then it's fun because I bring it into my work and often I get to help someone. I get to help my fellow man [sic]. So, that's the fun of it. So, it depends. You have to like what you're doing to be able to do it well, and to make everyone else feel good too.”* (A-HCP027)

Gaps in HCPs’ knowledge were acknowledged, paired with a demonstrated eagerness to address these gaps. HCPs’ motivation to expand their knowledge base was not solely for individual development, but also to better assist others. This pointed to an underlying belief that job satisfaction stemmed from a profound interest and passion for one's vocation.

Organizational learning

Although much learning happens informally, it was difficult to discern overt evidence of the formal integration of learning processes within the hospital setting – organizational learning – and on a broader scale across the network – inter-organizational learning. The apparent absence of institutionalization of the transition process into care routines and protocols was attributed to the prevailing culture within the hospital and the broader medical community. Notably, the culture of adult care, which often emphasized an "organ versus person" approach to healthcare, was perceived to pose challenges in implementing models of care that consider the holistic well-being of the care receiver and their family, including what nurses proudly called "McGill Model" approach to nursing. While some models of care, including the above-mentioned nursing approach, have been increasingly explored and adopted in hospitals and other institutions, their successful implementation remained intricate due to the complex nature of the healthcare environment.

Many participants across various roles and departments were involved in the care provision process within the larger healthcare ecosystem beyond the hospital. Tensions arose from the interplay between individual actions that influenced the environment and the broader social forces shaped by the historical context of medicine, administrative practices, management approaches, and underlying power dynamics. In essence, the challenge lay in aligning and harmonizing various elements within the healthcare system to create a conducive environment for the integration of transitional care practices and the adoption of innovative models of care that prioritize the holistic needs of patients and their families. An adult care specialist reflected:

> *"So, when I was training, did I do Pedes nephro? I'm just trying to think of nephrology if I did. Definitely in my medical school I did, not in internal med. I'm just trying to think: did I do pedes? So long ago. I'm old now. Did I do pedes in my nephrology training? I might not have. At [the university], … they are residents. So, our residents here have combined academic half days with the pedes nephrologist. There used to be a mandatory rotation that the adults did in pedes. So just because they "didn't have enough time to do the stuff",[it stopped]. I do encourage [the residents] to go and do some clinics, and transition clinic in pediatrics. I haven't made it mandatory. But maybe that's something I*

> *should re-look at, to be honest, as a training program perspective, I've kind of gone back and forth and back and forth. Because I've had, again, sometimes, honestly, some mixed reviews about the pedes experience, you know, and I think actually, to be honest, a rotation, which they used to do is not as much bang for their buck, […] I think clinics, you know, GM clinics and their transition clinic, they are better value for their time, you know, [for] my adult residents. So, you've made me think about that a bit more. I'm going to make sure I re-look into that as a clinic. Yeah, I know with Dr. [Pediatrician specialist], though, you know, for what she's gone through, that there has been a little interruption, and I think it's Dr. [Adult physician specialist] who has taken on that a little bit, I think from Dr. [Pediatrician specialist]. So yeah, I'm not sure where that is now – transition to adult – who's doing that on the pedes side."* (A-HCP017)

In the absence of formal institutionalization of transitional care, with its accompanying incentives and mandates, dedicated programs for transition were introduced. In order to allocate sufficient resources and ensure the adoption of evidence-based practices, dedicated programs were seen to be indispensable to address the existing dearth of structures tailored for the care of young adults transitioning to adult care. Such dedicated programs were not only seen to facilitate quality care and patient safety, but also to facilitate a transformative shift in the vision and approach towards transitions to adult care. Advocacy for the institutionalization of transitional care rested on beliefs that it was feasible and sustainable, and would allow for a more comprehensive and effective support system for young adults during their transition to adult care settings.

The process of acquiring knowledge in the context of transitional care encountered several obstacles that had to be overcome. However, where these barriers have been addressed, the mobilization of acquired knowledge has come into question. Healthcare professionals faced challenges in applying evidence-based knowledge, particularly because transitional care was regarded by participants as an informal care process without well-established protocols, unlike the more structured nature of medicine with its protocols. What is worse, care practices were perceived to remain largely unchanged over time, as one adult care specialist stated:

> *“If we accept that the norm is: you go from the velvet gloves to the sharp barbs of the adult side, then no one's going to say, ‘I have a knowledge gap, you know’. ... People [on the adult side] are just going to say, ‘well, that's just the way it is’. So, I think we kind of need to move. We need to shift standards in this regard. But ... I think there's still a big divide between theory and practice. There's a lot of theoretical work, like, you know, that you're probably contributing to, that [is] going to be like: we need to better address [adolescent patients’] issues. And then, ... it's not clear how that is contributing to change on the ground. As a clinician, I have not sensed that, even with the Children's [health services], for example, [re-locating] next to the [general hospital], I have not really sensed any push from them to actually say we need to systematize and make this better, and not make this about being 18, and not make this about, you know, from one day to the next they’re going to transition etc. So, I think we're kind of accepting a bad standard. And, as long as that is a standard that we accept, people aren't going to get on [board – they] are not going to say, ‘we can do better’. I think there's still a big divide between clinical realism around this issue, which is, I think, pervasive on the adult side, and probably the children’s side too. And ... we can do better. And once we accept that we can do better, I think that people will start identifying knowledge gaps and saying, ‘how can we do better?’ But I don't know that we're there yet. I think we're still at a phase where we're accepting these transitions as this is just the way it is.”*(A-HCP018)

Implicitly, this HCP drew attention to the shared culture that can either stagnate or change. To address the primary challenges faced during the transition process, one potential solution emerged in the form of informal bridges, extending care beyond the confines of traditional care structures, starting with transition clinics. This evinced of a wave of efforts aimed at systematizing new care trajectories. Although such care pathways were not formally institutionalized, their initiation was made possible through the leadership and dedication of HCPs. Their proactive approach played a pivotal role in enabling the establishment and implementation of these innovative care models.

Conclusion

In this chapter, the active roles taken to sustain the interdependence of compartmentalized groups within the healthcare system have been explored. It was essential to communicate in a way that actively spanned culturally-enacted professional and organizational boundaries to maintain the link to healthcare for AYAs in need of chronic care. Stakeholders of the transition to adult care were actively seeking stability in their relationships, while often expanding professional boundaries to address barriers to transition. Furthermore, HCPs and the parents acting as coordinators found themselves adapting to new demands and challenges, which highlighted the need for their informal work, compelled by the lack of transition trajectory in health system structures.

All actors learned during their adaptation processes – at least informally by virtue of influence people have on each other, and sometimes formally. The value of “being on the same page” was perceived as an essential factor in the successful transition of care for adolescents and young adults. The next chapter demonstrates how, beyond piecemeal plugging of care gaps, HCPs laid for foundation for more influential structures through their behavior and initiatives. Evidently, however, adolescent healthcare needs its own boundaries – boundaries that foster a unique approach and practice of care, but that facilitate cross-boundary collaboration. The optimization of such structures, and intentional structuring, is shown to be necessary to enable timely and coherent integration of health services for adolescents in transition. In doing this, HCPs role-modelled the systemization and organizational learning that is still lacking in the absence of institutionalization of adolescent healthcare.

Chapter VII. Informal Bridges to Structural Adaptations

"The problem is in the way that our healthcare structures are set up, and in who has the role, the coordination role of leading the transition, and who holds the knowledge and skills in terms of transition, and it's partly medical, but a lot of it is non-medical." (HCP009)

Introduction

This chapter conveys the novel yet informal protocols and guidelines that were tailored specifically for adolescent patients with chronic conditions under particular circumstances. By virtue of their interactional influence in interconnected systems, HCPs were attempting to bridge the disparity between pediatric and adult care, alleviating the burden of transition faced by adolescents with chronic health issues. However, the informal nature of this work raises concerns regarding standardization, consistency, and recognition of the role and voice of AYAs, families and HCPs, and what was required for practical and sustainable solutions within healthcare communities.

Ultimately, the lack of formal recognition as institutionalization of adolescent healthcare doomed transitional care support to accidentality, leaving the responsibility for guiding patients through this critical phase largely unrecognized. The informal work involved in reconciling gaps in adolescent healthcare, undertaken by dedicated HCPs, often went unnoticed within the healthcare system, leading to a disjointed approach to adolescent care. With the absence of a formal framework, healthcare providers had to improvise, making decisions to enable bridges to be built across the boundaries of adolescent patients to adult care services. The informal bridges established by HCPs facilitated the integration of additional responsibilities into their routines. Consequently, this led to a form of adaptive regulation, forging a new but recognizable practice path toward the systematization of adolescent care, which those wishing to facilitate its formal institutionalization could follow and learn from. In implicitly pursuing adaptive regulation, knowledge of the AYAs and HCPs played a pivotal role in facilitating the dissemination of new learning processes and transformative changes.

Informal bridges to compensate for a lack of institutionalization

The perspectives of participants showed that health and social services were structured as silos, with little integration that would facilitate the process of healthcare transition. As a result, continuity of care depended on ways to circumvent the structure of the system – that is, filling in the gaps by building bridges across departmental boundaries. Healthcare providers from different settings described some innovations and "workarounds" to keep young adults in the system and avoid the consequences of discontinuing care, which were putting quality of life and patient safety at risk. Such innovations were necessary in the absence of institutionalization of transitional care – that is, in the absence of formal systems and structures that compel, through the power of the state via its health departments, for example, a degree of standardization and accountability across health services and even systems.

Structural deficiencies in health systems and services influenced how organizations and other sectors operating in or connected to the healthcare system could interact with each other. Thus, at this level, many cultural differences clashed with distinct norms or standards, values and missions, impeding optimal care transition. Whereas at the organizational level, if one considered the organizations involved as separate entities, the transition of healthcare was envisaged, but not institutionalized. Apart from isolated programs dependent on departments or individual HCPs, the transition to adult care remained an organizational rather than a systemic goal.

As indicated by HCPs in the pediatric, primary and adult care settings, the pathway for young adults was left to the preparation they might have received through pediatric services, and the development of their maturity and independence. When asked about institutional documents and guidelines from the healthcare system, HCPs mentioned the lack of updated documents that also depended on the interest of certain teams in specific departments of pediatric or adult care services. One pediatric nurse lamented the lack of available resources that could be provided to families to prepare them for transfer to adult care. The development of initiatives related to certain specialists in certain departments, depended on budgets and interests. Although programs existed, they did not come from institutional guidelines. Such a lack of formalization of healthcare transitional structures was described as leading to a lack of standardization of the process and thus integration of the inherent mechanisms that make up healthcare transition. As a result, HCPs were dependent on the resources available in their departments and did not follow a common or systematic program.

One family physician specializing in infectious diseases overcame system structures that prevented fluidity of relationships between different professionals from different care settings by having developed her network of specialized pediatricians. She maintained links with pediatricians even after her AYA patients were transferred to her services and to adult services, as well as accommodating new patients who were transferred to her services:

> *"Well, just one point: I don't see the parents.... For the first visit [of a new adolescent patient], there are some who will come with the parents because the parent wants to see a little bit how it was going, but then they don't come. ... I think it helps to have organized bridges between the pediatricians who transfer and certain doctors. Basically, I have, ... for example, the pediatrician and some pediatricians who transfer [to] me a lot, who are specialized in [transfer]. Well, I wouldn't mind calling them … texting them and sending emails: 'I have a question', and then sometimes I tell them: 'she didn't show up for her appointment; I just wanted to tell you'. And then … they hear about it and I have the same links with obstetrics – in fact, the ones who follow the pregnant patient at the [Children's hospital], and who is transferred to us after a delivery which was HIV. So, I think it helps because both sides are going to be a little bit more prepared, can prepare the other for where they're going, and I think, already hearing: 'I know her well; it's going to be fine'. Or maybe the pediatrician can also say: 'tell me if it doesn't fit; we'll find someone else' – just that can help. I think visiting the place before can help [with continuous care]... because it's before the follow-up stops at the [Children's Hospital], just to get familiar with the new place. But, I don't think it's done much. But it can be good, I think just to see, because the [adult hospital] can be a little intimidating. I don't know if you've ever been to [the adult hospital]?"* (PCP-HCP019)

HCPs complained that the process was not standardized and was dependent on health centers and services – such as a program having been developed for cardiology or nephrology only. In addition, the progression of the transition was not gradual, as recommended, but seen as rather abrupt. The manner in which transitions were made reflected a lack of documentation and systematization of the process. However, as one pediatrician specialist noted:

> *"... It has to be systematized. But to systematize it you need people who are identified on the other side as having an interest. If people don't have an interest in seeing someone after the age of 18, we're kind of stuck... Well, who do I target, who do I send a summary of the file to, who do I contact? It becomes a little more difficult."* (Pedes-HCP001)

To enable the transition of the young adult, including their data, to adult care, several pathways were described by HCPs, depending on the young adult's situation, namely their diagnosis, the departments in which they were followed, as well as the care provided by the pediatric care department. Such arrangements included the interest of HCPs in developing facilitated pathways for young adults, as well as the professional networks that HCPs might have had to maintain or pathways that needed to be opened to adult care.

Transitions of Care Trajectories

The data allow care transitions to be organized into five categories: 1) corridor of care transitions (formal and informal); 2) single-system transitions (with identification of an adult specialist); 3) multi-system transitions (with the absence of some specialists, and, therefore, of some care and a lack of integration); 4) complex care (requiring care from different specialties and community care from different important sectors); 5) orphan transitions, an additional category of transition surfaced from the accounts of HCPs and two young adult patients who encountered a significant disruption in their healthcare continuity due to the lack of suitable adult services that could cater to their specific requirements during the transfer process. Regrettably, no appropriate services were accessible to them at the time of transition. Moreover, HCPs working on pediatric wards expressed distress over comparable scenarios where the specialized pediatric services available to young adults were not replicated on the adult wards, leading to discontinuities in patient care.

Corridor of care transitions were the organized, preconfigured transfer of young adults from a particular pediatric care service that was already linked to the same adult services. This is a specialty that has a known corridor of care in place to facilitate the transition to adult care. The corridor of care was implemented by the HCPs themselves, with or without the support of the organizations. For example, in a urology department, children reaching the age of 18 years followed by pediatric urologists in one pediatric hospital would then be systematically referred to adult urology physicians in another specific hospital. This pathway of care was dependent on the departments, as opposed to the organization or the Quebec health network, and the specialist physicians in the pediatric and adult settings.

“***Single-system***” ***transitions*** are the characterization of the transitions considered by stakeholders in the different groups to be the most facilitating of transition, as it corresponded to the structure of adult care. Thus, when a young adult was followed by a single specialist for a health condition identified by a specialty system, such as pulmonology, without having any other conditions or comorbidities, the transfer was then made to a single specialist, which facilitates the search of the receiving HCPs. This was because it was the same specialty as the one practiced by the pediatrician and the specialty in question, which existed in adult services, could be done more easily. Health professionals agreed that the less complex the condition was considered to be, the easier was the transfer. This is because more health professionals in adult services would be trained to take over the care of the condition and fewer resources would be required to enable the transfer. It is, in fact, a one-time transfer between the pediatric care team – primarily by the pediatric specialist – and the adult care physician. This pathway was for chronic conditions that were by then well-known and considered less complex by adult services, especially since adult services followed a high volume of these conditions, such as high prevalence diabetes and asthma, for example. While this type of transition facilitated the transfer of the patient towards adult care services, it did not diminish the importance of non-clinical aspects of transition care, such as the relationship AYAs may develop with their new HCPs. This was mainly enabling the access to an adult care specialist.

"***Multi-system***" ***transitions*** were transitions for young adults living with a chronic condition that affected multiple systems (more than two). Unlike single-system transitions, these transitions required more than one team – so, multiple physician specialists from adult services. In such cases, the pediatric specialist in the department responsible for coordinating care at the pediatric level arranged the transfer. Some pediatric specialists doing post-transfer follow-ups with young adults requiring transfer to multiple departments found that transfers were reduced to the main department of the condition and that young adults then experienced interruptions in care with other specialties.

Complex care involved many services, including cross-sectoral collaborations. The transition of young adults being followed under what might be called complex care arrangements in the pediatric setting required the same care coordination as multi-system transitions, with care provided in the community. Such involved care arrangements were essential to meet complex health and social service needs. Young adults with complex needs were often technology-dependent and could require tailored services. Thus, pediatric care collaboration engaged more services, professionals and organizations for circumstances definable as complex care than for other transitions. Complex care HCPs, in particular, cited the lack of involvement of social service sectors in the community, and perceived that social service sectors were not fulfilling their mandate to support families. Instead, pediatric HCPs perceived that they were taking on more than their mandate allowed in order to cover the complex needs of families and to continue to accompany them despite the formal transfer. Thus, healthcare professionals favored following these young adults in the hospital environment in which the resources were provided to the family. The HCPs were mostly preoccupied with discussing the resources allowed by a multidisciplinary approach, that is following the culture of care at the pediatric hospital.

"Orphan" transitions are those transitions for which transfer to an adult service was not feasible because the corresponding service did not exist. This was often the case for rare conditions of young adults followed in several departments or with complex care – that multi-system or complex care transition types. These were young adults who – until relatively recently – did not survive the disease into adulthood, and thus were not visible in adult services. However, with medical advances, pediatricians specializing, for example, in complex care or genetic diseases, were transferring more and more young adults with rare and complex diseases to adult care. The trajectories of such patients were thus mostly unknown, and, in such cases, parents usually played a critical role in care coordination.

Such transitions were then inadequate and inappropriate for the young adult. The services to which young adults in such situations would be transferred did not match the active needs of these young adults. To address the pitfalls of “multi-system” and “orphan” transitions in particular, informal means were used by HCPs in different settings. In addition to the conditions inherent in young adults' pathologies, other determinants that influenced the trajectories of young adults, such as family support, education and schooling, were exacerbated the more complex was the young adult’s condition. Thus, the different levels of complexity evident from the participants’ accounts show corresponding differences in the degree of informal bridge-building that fragmented systems required to meet the coordination needs of adolescent patients.

Revisiting professional identity: the confrontation between self-projection and the operationalization of roles

The deficiency of productive interactions and relationships among HCPs across different healthcare settings, as well as between HCPs and AYAs, has led to concerns for HCPs about their dedicated roles in the transition process. Because of the inadequacies of adolescent healthcare, participants believed that drastic action was needed to impose standards on health services. At the individual level, experienced HCPs, who have provided care for young adults, perceived a conflict between the core values of patient-centredness of their profession, and how these values are manifested and operationalized within the healthcare facility.

Pediatric HCPs’ identities and roles in transitioning AYAs to adult care

Pediatric specialists perceived a tension between their professional values and the apparently limited institutional commitment to providing appropriate resources for adolescent transitional care of their work environment. This disjunction perturbed the identities of HCPs, that is, it unsettled their self-concepts of who they are professionally in relation to others. A lack of resources impeded HCPs’ ability to carry out their mandate to provide optimal care that they would envision as healthcare professionals. Some healthcare professional participants perceived a tension between their professional goals and the goals of organization. One pediatrician explained that he felt that his ability to provide optimal care through the creation of a transition program in his specialty upon learning of the lack of successful transfers to adult care:

> *“The [problem is the] establishment too. We had to fight, to find premises, to [justify] the need to do this or that test. So, it's certain that if we don't fight in this system, the door is closed, for everything. So, the basic premise is that the door is closed. After that, it is up to the interested parties to try to open the door, to push the door, because the administration will block everything. Systematically. Systematically, everything that is innovative, everything that improves care, the administration will be against it until proven otherwise. [...]”* (Pedes-HCP001)

Thus, there was a perceived disjunction between hospital administration, on the one hand, and, on the other, the provision of care and development of care services by professionals working on the frontline. This disjunction represented competing visions of how to best serve patients, and was perceived by healthcare professionals as impeding professional care work. While organizational priorities may not always coincide with HCPs’ priorities, HCPs still needed to engage with them. This was necessary to implement care plans that require the use of physical spaces or resources that wouldn't typically be utilized. The difference between the two viewpoints is underscored by a discourse of boundary reinforcement. Here, the HCPs stressed their disassociation from the priorities of their organizational structure. They perceived its operations as not consistently aligning with their expectations for supporting professional patient care. In some cases, they believed it even hinders their ability to provide this care optimally and consistently.

In addition, pediatricians noted the restriction of their mandate to a rigid structure. They reported being willing to go beyond this mandate to finalize care for young adults, and thus promote and facilitate the transition of young adults to adult services. Paradoxically, they also felt that their environment needed to be supervised in order to provide quality care. This ambivalence was partway between their sense of vocation and the sometimes-conflicting demands of the pediatric environment that they perceived as not always supportive of optimal patient care. As pediatric healthcare professionals, they felt they had to live up to the expectations of families, and this required professionalism beyond their clinical training as healthcare professionals. This perceived tension between professional competence, representing their profession, and training emphasized their career as a valid choice.

The identities of health professionals in pediatrics were associated with an espoused desire to provide care to young children and adolescents through a multidisciplinary and holistic approach. However, this common goal was made difficult and limited by the lack of resources associated with the operation of healthcare institutions, and even the healthcare system and politico-economic ecosystems (HCP005). Job cuts or non-renewals of professional positions had led to limitations in the ability of healthcare professionals to work according to the principles aligned with their identities as caring professionals. As one social worker said, healthcare work, with its system-induced pressures and tensions, came to be about managing emergencies, of which transition programs were not a part:

> *"... If you talk about social work resources, there's just not enough hours and not enough people to cover the needs. So, we ended up putting out fires, right? We ended up addressing the urgent needs .... All these wonderful ideas and projects that we have, we just simply don't have the time for .... We don't even have the time for dealing with the urgent crises. So, it becomes a systemic issue, for sure."* (Pedes-HCP005).

The apparent lack of willingness to engage with, and take interest, in adolescent chronic conditions on the part of adult health services was frequently decried in the interviews by pediatricians as well as by adult and family physicians. Pediatricians mentioned the challenge of finding adult specialists who could continue the care of their transitioning patients. They also noted the difficulty in maintaining a connection with specialists or adult healthcare professionals willing to accept new patients. These patients were often seen as more complex due to their age category and conditions specific to pediatric care.

One pediatrician spoke of numerous instances in which identified adult specialists either refused to take over the care of an adult referred by the pediatrician or did not respond to the request at all. The potential reasons cited for refusing to take on these patients were lack of interest in the young adult population, and lack of time. Indeed, the management of this specialist’s patients required more time compared to typical follow-up cases in adult services. The transition to adult care required the transfer of the person – which for pediatricians was more difficult than the transfer of information. Nevertheless, the transfer of information remained a problem when electronic systems did not communicate with each other:

> *"Well, the biggest challenge really is identifying someone to take care of the patients. That is the biggest challenge. Once somebody is identified, the next challenge is getting them the appropriate information. [Given] all the care that happened as a child, you know, if the transition to the [general hospital affiliated to the children's hospital, ... it should be ...] very easy because the file exists in our medical record and it's available. To transition to a hospital site that doesn't share our electronic medical record is challenging because it means that there's an incredible amount of information that needs to be generated by medical records. But that's doable, you know? I will give the patients a list of the relevant information, and we're like, you know: 'these are the things you need from Medical Records'. They sign a form and off they go, and we tell them it's important to always keep a copy with them. So that's doable. It's not easy, but it's doable. But the first challenge is to identify someone to take care of them."* (Pedes-HCP003)

Health professionals highlighted the transition from pediatric to adult care as a domain exemplifying comprehensive care. This included both clinical and non-clinical aspects, alongside the skills and intrinsic motivation necessary to provide quality care to young adults.

In separate interviews, two pediatricians referred to the pediatric hospital logo to emphasize that it does not reflect the reality of their practice. The logo in question was of a pediatric hospital that evokes the symbol of a child (the outline of a small person) surrounded by the symbol of a large person who represents the health professionals and parents. The perceived misalignment between the symbolism of their individual practice and the organization's emphasis resides in the multidisciplinary and holistic approach, and the integration of care, which the organization is seen not to structurally support. One of the pediatricians uses this symbolism to deny the integration of care of pediatric services despite the means that exist:

> *“Well, I’d put the little person beside a big person [instead of the current version]. [In reality] it's not integrated. The means are there [in the health system]. The decision is not being made to spend the money to invest in the process. It's that. All the rest of this is just noise all around the main thing so people can strike task forces. They can write papers. They can build curricula. It's all procrastination to doing the thing that needs to be done.”* (Pedes-HCP009)

The HCPs on pediatric wards perceived that their caring work tends to be undermined by the structures and norms of the healthcare system in which they operate, leading to a tension between the organizational environment and the providers. This tension reinforced the perceived disjunction between hospital administration, on the one hand, and frontline care delivery, on the other.

PCPs’ identities and roles in transitioning AYAs to adult or primary care

For family physicians, defining their role in the transition process presented two major problems. The first was the lack of PCPs in a large metropolis, which for one physician was explained by the organization of the healthcare system for access to the profession depending on the location chosen. The second was the particular interest of PCPs in caring for the young adult population and being specialized in adolescent healthcare. These systemic and individual aspects contributed to the disruption of efforts to further link services and advance the delivery of care for youth moving into adult care. An experienced family physician who opened a youth clinic in primary care underlined:

> *“[Transitional care success depends on] manpower of nurses and space, and you know, like, it's crippling of the whole question of finding a family doctor is a generic problem in Montreal and it complicates [it to have to ask:] "Well, how am I going to find a family doctor who could, you know, [have a] special interest in teenagers?" You just can't find family doctors because the system's paralyzed by the [Quebec system of allocating and selecting for residency positions in family medicine]. In other words, there's no new young doctors for getting a position in Montreal or very few. So, bottom line, it kind of sabotages all kind of rational projects because there's no place.”* (PCP-HCP028)

However, one of the associated hurdles was that PCPs were not systematically included in the transition process. This was due to the lack of communication between the different pediatric and adult care providers, as well as the described lack of PCPs in the area. For example, one family physician mentioned how the information system exacerbated the exclusion of PCPs in the follow-up of AYAs transitioning to adult care when her patients were followed by another hospital that did not share the same electronic patient record system, she was unable to access the patient's information, neither by the adult care specialist:

> *"So, you know I'm lucky enough to work at a hospital where I'm able to see everything that's at that hospital. But at [another general hospital] we don't serve children, right? So, if a child comes from [a pediatric hospital] or the [Children's Hospital], it's very difficult to access their files, ... unless the parent has asked for them. And then it's like you know, 17 pages long or longer than that. So, I'm not going to shuffle through all of that. It would be really nice maybe if there was some sort of summary letter which I think they do give to the adult like the rheumatologist. But, if we could be copied on it as well, [then] I think [it] would make things a bit easier for us to understand how things have gone [in] the child's trajectory in the past."* (Pedes-HCP026)

The lack of inclusion of family physicians, as a group, was highlighted as problematic given the nature of their training and mandate. The group was specifically defined by the characteristics of primary healthcare, charged with covering the needs of the population of all ages, ideally including all parts of the population. Furthermore, the expectation of family medicine has been to consider a range of influential medical and social factors to deliver as holistic care as possible. This means that primary care is expected to encompass the patient's overall context, including their environment, support system, professional and personal circumstances, as well as physical and psychological aspects. In essence, family physicians who were interviewed reported to recognize the importance of both clinical and non-clinical factors that directly or indirectly influence a patient's health status. Non-clinical aspects of the patient's health, including their mental health, and personal support within the healthcare system were not taken into account, even though the family physician recognized a role for them:

> *"What happens is that the family physician is not necessarily in charge of the aspect that is related to his or her illness, but makes sure that everything else that the patient has is taken care of by someone else, or there are other specialists who are taking care of it, or they arrange other care depending on what's going on. So, the young person, for example, may not have any mental health issues while in treatment. Or maybe [they do]. But, it will change the nature of their issues. So, at that point, sometimes, yes, you have to find them someone and help them find care."* (PCP-HCP012)

The notion of transitional care appeared to align well with the mandate of family physicians to actively engage in collaborative efforts with other healthcare groups. However, a crucial barrier to their involvement in the transition process stemmed from the inadequate recognition by these other groups of the value potentially brought forth by including family physicians in the care continuum of their patients, not to mention a range of non-medical personnel and social services in the community. Consequently, the role of family physicians as a potentially significant player in the transition process was constrained. The location of their practice, for example, whether hospital-based or based in community centres not affiliated to a hospital, was seen to potentially influence the degree of their inclusion in the transition process, and therefore on whether or how transition was enabled.

To overcome the lack of integration of family physicians, PCPs observed certain advantages when operating within a hospital setting or specialized clinic that offered primary care services, primarily due to the enhanced ease of communication. This also facilitated more direct collaboration with specialists involved in the care of young adults. By being included in the transitional process, family physicians were better equipped to follow up with AYAs, possessing a deeper understanding of the care plan, and thus ensuring smoother continuity of care:

> *"That's why I think there's a certain advantage to staying in a specialized clinic, even if you're offering primary care. But, if [the patient's] going to be followed up, for example, someone who's in Sept-Îles [a small regional town in Quebec] who's being followed up, well, the infectious disease specialist wouldn't be offering that care, that context. So, in*

> *regions where there are no specialized HIV clinics, the family doctor has to compensate for this aspect or be comfortable with it."* (PCP-HCP019)

HCPs observed that interest in a specific patient demographic often stemmed from personal and professional experiences, as well as the development of attitudes and behaviors that were congruent with the needs of the adolescent and young adult population. PCPs, in particular, noted that, despite their broad mandate to care for diverse populations across varying ages and pathologies, the capacity to provide care for adolescents was perceived as a unique competency, necessitating a distinctive set of skills and knowledge that were often underappreciated in medicine. This was largely attributed to the dearth of training available for this particular demographic, especially when contrasted with the relatively ample resources dedicated to adult, pediatric, or geriatric care. Furthermore, to facilitate communication among the stakeholders involved in the transition process, including their relationships and information exchange, the establishment of a professional network hinged on shared interest. The question of "interest" again underscored continuity of care for complex adolescent patients as workarounds rather than systemically valued and facilitated.

Beyond just practicing family medicine, understanding referral networks required building a professional network. This network needed to include healthcare professionals with a specific interest in adolescent care or PCPs who had developed expertise or specialization in this area. One PCP reported that his network was closely linked to his experiences as a family physician and the contacts he had developed over the course of his career with the healthcare system and other services.

The ability PCPs had to successfully take charge of the care of AYAs during their transition to adult care was portrayed as very much influenced by the field in which the family physician specialized or wished to specialize. To illustrate this point, one family physician emphasized that their profession was based on building long-term relationships with their patients and, thus, for some patients to develop expertise to better support themselves in their medical care (PCP-HCP026). PCPs, although aware of being generalists, did not exclude or contradict the specialization of care required to be provided as generalists. For example, as one family physician who specialized in young adult mental health and substance use disorders noted, this allowed for specialized primary care.

Additionally, when the specific patient population had a negative reputation among some colleagues and healthcare professionals, they were often labeled as "difficult" patients. However, being acknowledged within the specialty network ensured that these patients, who some PCPs or specialists found challenging to manage, received proper care and did not face inadequate treatment. Such recognition within the specialty network increased the likelihood that appropriate and holistic care was provided to complex adolescent patients:

> *"I think just having a doctor who is open to patients transitioning no matter what the medical problem is, I think, ... a lot about the attitude [of the doctor] and not the medical problem. I think that, sometimes, kids who are going to be very used to healthcare have different expectations ... [and] have more expectations actually of healthcare. And you have to understand that. You can't try to fight that, [as if to say]: 'Well, we're going to put it back on because it's not the same as it works.' It's never going to work, and it's disrespectful to what they've been through. I think you just have to accept it and then be comfortable with it. The doctor who isn't [comfortable with it], well, that's never going to be a good match with a patient who is transitioning. That's where I find the natural instinct is to listen. And if there's ... – even [if] in every clinic we identify a little bit [of]:, 'Oh, this person likes addicts,' well, the others are often quite happy to give them to you, and it's going to go better for the addicts with the person who has the interest."* (PCP-HCP019)

Thus, in line with the need for a population focus, family physicians felt that for optimal follow-up of a young adult during transition and beyond, a recognized specialization in adolescent health or even a sub-specialty was required. This would allow for a better understanding of key transition factors that are more often relational and non-clinical in nature. It also allowed for an openness to meeting with parents for a few appointments during the transition to explain and allow them to better understand the transition and what is new and different in the adult system.

Therefore, family physicians valued their identities and skills as generalists through knowledge of diverse patient profiles in a large population, including many sub-populations such as adolescents and young adults. Family physicians also felt that specialization in primary care allowed for better follow-up, recognition of the specific clinical and non-clinical care required for this population, and family medicine to be recognized in the entire transition process, particularly by members of the other stakeholder groups in pediatric and adult care.

Adult HCPs' identities and roles in transition AYAs to their services

HCPs in adult services echoed family physicians' comments about the extent of interest in the population of AYAs with chronic conditions, by adult HCPs. This is because this was not their primary patient population, nor their primary population of interest. Participants in the study echoed the valorization of specialization over generalism that characterizes modern medicine.

However, the population of adolescents with a chronic condition diagnosed in pediatrics is increasing among the group of patients that adult specialists are now expected to follow. Thus, many HCPs in adult care settings have witnessed the rise of dedicated services for young adults transitioning from pediatric care, especially when these services were established by charismatic personalities with an interest, either personal or through research, in young adults coming from pediatric care.

The establishment of transition clinics helped to create interest among other adult specialists in this issue. On the other hand, these services could also be abruptly terminated when the project leader moved or retired, or when the program was unsuccessful, particularly because of the limitations of specialization and lack of inter-group collaboration (i.e. pediatric, primary and adult HCPs):

> *"Many years ago, there was a transition clinic that was a pilot project that we were running through the [general hospital]. And this was, like, in 2011 – 2012, I think, it was finished. So, we kind of attempted to make, like, literally a transition clinic so that patients from the Children's [Hospital] would go to that clinic before being, you know, funneled to the adult system – so that kind of, you know, really piqued my interest in this*

> *kind of age group. But that clinic was a disaster. It didn't work.… It didn't work. [...] The issue with the clinic was that it wasn't really a transition clinic. I mean, we were all adults within an Adult hospital. And we were all adult [specializing clinicians], doctors and nurses, and dietitians. Everybody was [specialized in adult services]. So, I didn't see: how is that as a transition? So philosophically, I had an issue with it as a transition clinic – you know, because I was like schlepping to a hospital that wasn't my hospital, right, you know, once a month, to see these patients. I wasn't familiar with their computer system; their bookkeeping. [It] was very difficult to get in touch with a clinic if I needed to add patients who had to be booked at ... most often once a month, because I was only there once a month. And so, I just felt I wasn't really doing anything that I wouldn't be doing in my usual clinic here at [another general hospital], where I'm more comfortable. And I can see my patients on a weekly basis if I need to."* (A-HCP010)

As a result, adult HCPs reported a wide range of dependence on supportive processes and incentives to improve the transition to their services. Depending on who was involved in the adult care departments, a quality improvement project specifically for young adults may or may not have been initiated and sustained. As one adult physician specialist mentioned, there is some anticipation of the maturity of even the youngest patients when they come to their services. In other words, HCPs assumed that young adults with chronic conditions possessed the same level of autonomy in managing their care as any other adult patients in their service. However, one adult endocrinologist observed that, in cases where this assumption did not hold true, some healthcare providers might have exhibited condescending attitudes towards young adults due to the perception of them being "troublemakers", even though the apparent "trouble" might have stemmed from them not having been adequately prepared for the transition to adult care.

Adult HCPs mentioned as another challenge the handling of the medical condition, which added to the lack of comfort that could interfere with the care relationship to discuss particular topics with such a specific young population. For example, one endocrinologist spoke of her evolving ability to initiate discussions about the personal aspects of young adults' lives, while balancing her tone from one that could be perceived as patronizing and inquisitive – that is, judgmental – to one that was able to be perceived as caring. Her aim was to echo the espoused goal of her profession, which was to accompany the young person in their diabetes treatment and to adjust their medication according to their health circumstances.

Preconceived notions about young adults' lifestyles influenced healthcare providers' interest or lack of interest in them. Some HCPs viewed young adults as difficult adolescents focused on risky behaviors, making them challenging to manage. This was widely portrayed by both family physicians and pediatric specialists, in terms of the difficulty they had in finding the right adult healthcare professional who would be willing to continue healthcare services for their young adult patients. Thus, the image and apprehensions of working with what was considered a difficult population made it difficult to move from one service to another.

In an effort to overcome the effects of such a negative group reputation, some pediatric HCPs developed a specialization in the field of medicine for adolescents and young adults. Such initiatives that the participants reported went beyond individual workarounds for individual patients. The community of HCPs serving adolescents were laying footprints that, interactionally, at micro, meso and macro levels, were able to spread ideas and influence practice to perturb relatively rigid boundaries. Formal recognition was considered to still be a work in progress. As one family physician pointed out, it was important to know scientifically how adolescents developed and its effect on the course of their disease in order to be able to manage it optimally. The way in which adult medicine specialists referred to the difficulties of changing professional views when moving from pediatric to adult care depended on the health of the patient in terms of anticipated complications of the condition in question in adulthood. Adult care specialists, who treated a larger volume of patients living with chronic conditions, were said to focus their care on preventing or treating complications of the specialty condition. As one adult endocrinologist explained:

> *"My sense is [that] at the [pediatric hospital], no matter how long you follow the patients as a pediatric endocrinologist, you rarely see complications from diabetes, because the most time, they've had the diabetes … for 15 years, 17 years max [sic]. Most of the time it is much less than that because they develop it as an adolescent or as a kid and you follow it for 10 years and that's it. So, it's too short [a time] to develop complications. So, my*

> *sense is, sometimes, the complications are not really known to my young patients. They've never appreciated the fact that they can go blind from their diabetes. Not that I'm so brutal with them. I'm not. You know, I'm just saying that, you know, we see those complications because I have had patients who had diabetes for 70 years, okay? And, so, those patients are blind, they're amputated etc. etc. So, my perspective on glycemic control, I think, is different. I really want them to be in good control just because I know what's awaiting them, you know? And they will probably still be my patient when they're 57 and I'm like 100 years old. So, that's a concern to impact them, to impart upon them the importance of why we're targeting something, you know? That is: the complications are real. But, not to scare them, obviously. I spoke to the burdens, you know, but [the intention is] to motivate them to recognize that the numbers mean something. It's not just a number we're treating."* (A-HCP010)

Even routine examinations, such as blood tests or imaging, required regular follow-up to monitor and ideally stabilize chronic conditions, depending on the type of pathology. Regular follow-up appointments, supplemented with effective communication and education, seemed to be the exception rather than the norm.

AYAs' self-identities throughout transition to adult care

The identity negotiation among the young adults themselves was purported to be induced by their change in social role, pushed to become active in their care without having the same "safety net" they enjoyed in the pediatric environment. This new role translated, in particular, into a need for anticipation of quality care, to match the coordination arranged by pediatric HCPs. They were thrown into a system which had interpersonal and health consequences flowing from their compliance with the new culture's expectations of their role-based behaviours. In the pediatric environment, "everything was organized and planned in advance", by allowing them to know what was going to happen in the relatively near future. Such organization was unfavourably compared to adult health services where subsequent appointments were not guaranteed and not scheduled in the near future, since appointments were more distant than pediatric appointments.

One youth's mother stated that, while in pediatrics, appointments were approximately every three to six months – again, depending on the youth's health status and stability – in adult services, appointments were more likely to be every year or two. The anticipation of care allowed young adults to learn the ways of adult care. Pediatric HCPs helped to enable anticipation of care for young adults, particularly by explaining the different stages of the transition. This included actions taken by the pediatricians themselves – such as referral to an adult specialist – as well as actions to be planned by the young adults themselves, sometimes with the help of their families – such as seeking community-based care or complementary care from allied health professionals who would no longer follow them as they did in pediatrics.

For some youth, information about what to expect in adult care had not been communicated to them, and had slowed their transition to adult care. As one young adult mentioned, having a “roadmap” was necessary for preparation and helped to anticipate events that were deleterious to the youth's care. Young adults positioned themselves according to their expectations of adult care in terms of how they understood it with the information they had received up to that point, or how they had experienced it during their transfer and first steps in the adult care setting.

Knowing the standard transfer process would have allowed some young adults to avoid periods of disruption in care. While, for some, transfer was seen as a continuity, for others, the realities of the healthcare system and adult care functioning had made them fearful of transfer. Adapting to changes in the system of care and changes related to young adults' entry into professional or academic life pushed some young adult participants, for better or worse, into the role of emerging adult.

As the young people who were interviewed had experienced many changes in their daily lives in the same short period of time, their social roles and abilities to conform to the new modalities brought on by the changes developed as they adapted to changing circumstances and on the basis of need. As one young adult discussed her adaptations to work and school, in particular how her work status and the new social skills she had to develop in that setting helped her cope with her new status in her new classroom:

> *“No, for me, it's just really … been an adaptation for me to go [to school] because, really I went to* [learn] *welding. So, … really … my adaptation was the fact that I'm … one of the only girls really. Like, at the very beginning, I was with one other girl in my group. But now, I'm … the only girl. So, yes, it's another adaptation [in a little way]. But, since I'm used to everyone in my class, it's not as bad. But, at the very beginning, it was really an anguish for me. I don't know. … The fact that there was another girl … helped me. But, otherwise, I would say that, no, it doesn't necessarily have a link as such. It doesn't necessarily make anything easier. But, I would say that with the work it made it easier for me at school, yes.”* (AYA007)

According to the young adults, the role of explaining the transition process to adult care specialists was mainly performed by nurses. The particular role of these actors involved in the transition process encompassed both care related to the nursing profession (e.g., nursing techniques), and psychosocial support that took into account the specific context of the adolescent. The young adults conveyed that the relationship with the pediatric nurses was a very close one, based on the nurses’ extensive knowledge of the young person’s personalities and habits. Preparation for the transition often fell to the nurses.

So, while the pediatric specialists discussed the procedures for transition to adult care, preparation for the transfer event was discussed in a progressive manner – at least twice explicitly – by the nurses. During interviews, pediatric nurses pointed out the difficulty of preparing an adolescent for adult services, given that the success of the transfer depended on many interdependent variables. These related variously to the individual – including his or her ability to be autonomous and manage his or her own care, for example, by recognizing symptoms. Organizational variables included the resources available in the hospital or clinic to which the young adult was to be transferred. System variables included the distribution of the roles and actions of each of the actors involved in the process of transition to adult care.

Preparation for transition most often involved discussions about the transition itself, the status of the young person's autonomy to make medical appointments, to seek help when needed, and the principles of demonstrating proactivity as a young adult in managing their own care – that is, self-management. In addition, explicit transition discussions were designed to support the young adult in applying strategies to develop self-management skills. The strategies taught by the nurses also included the young adult's communication skills to express their needs and communicate the evolution of their health situation to adult health professionals.

Recognizing the change in the type of consultations that would be had with adult HCPs, the pediatric nurses explicitly shared practical techniques for listing and prioritizing problems to discuss with adult specialists in the often-short time frame of the medical appointment. Although there was evidence that the nurses used to prepare young adults for transfer to their new services, the pediatric nurses lamented the lack of systematization of these discussions – that is, to ensure that such discussions were held reliably, and that all youth benefited from them before the transfer event. The nurses' tug of war with organizational priorities was evident in their desire to do more for young adults, as conveyed in the interviews. The way the nurses described their role in the transition of adolescents to adult care suggested fear that they might fail to share some information or ensure youths' understanding of processes prior to transfer. They feared that, despite their best efforts in their working conditions, some youths would fall through the cracks of the safety net they and their teams were trying to put in place in the face of unsympathetic and unsupportive structures. Thus, between the pediatric nurses' expectations, their ideals and their realities, they found themselves restricted in their actions, and especially in the ability to control the outcomes of the transition.

Young adults felt that they could prepare themselves better when a particular consultation was dedicated to the transition at the end of pediatric care, as if to mark the end of follow-up with the pediatric setting and the beginning of follow-up in adult services. One young adult who was transferred over a year before the study commenced (AYA008) emphasized the importance of receiving guidance from her pediatric healthcare professionals before she stopped seeing them. Scheduling regular meetings to discuss the transfer was seen to be helpful in this regard, as she believed that she had developed a therapeutic attachment to them that was difficult to break. Although her proposal for more counselling before transferring might have seemed to make the separation more difficult, she believed that it made it easier. She mentioned that the end of a therapeutic bond was prepared over several sessions, although she acknowledged that it might have seemed “counterintuitive” to see each other more in preparation for what would be a break-up of sorts (AYA008). Either way, emphasis was placed on dealing explicitly with the phenomenon of breaking with one team and commencing with a new one.

Furthermore, one young adult who transferred more than five years before the study commenced, believed that, on reflection, transition preparation should have begun long before the transfer mechanism occurred. They believed that it should have commenced even before the pediatrician sought out an adult specialist, if the adolescent had begun to have a sense of responsibility for his or her own health, which this young adult visualized at about age 16, two years before transfer age (AYA010). Both a young person who was interviewed, and who had transferred to adult care, and the mother of a young adult who had already transferred more than five years ago, strongly suggested that adolescents and young adults should not be transferred until age 21, which was described as an ideal age for transition, all things being equal (PG002). For example, young adults appreciated being given six months' notice to “avoid the shock of transfer”. Such time preparation time could include discussions, teaching of strategies, simulation, or homework, such as asking the young adult before transfer to go alone to the next appointment with the pediatric team or to prepare a list of questions for their next appointment with the pediatrician. Ultimately, driven by interest in their profession and commitment to the care of adolescents and young adults, healthcare providers tended to expand their own mandates to improve continuity of care, or at least avoid preventable problems that young adults may face. On the other hand, young adults relied on parents and self-care to counteract systemic barriers to continuity of care.

Informal Structures and Unfulfilled Initiatives

The innovations and shared advice among actors constituted new patterns of expectations that emerged and could influence others to change practices. However, success was perceived to have been limited and reliant on fortuitous encounters with benevolent individuals in the absence of formal structural support. The emergence of informal structures within the healthcare system was attributed to the absence of a well-defined transition pathway to adult care, and the limited availability of appropriate transitional programs. Consequently, numerous initiatives were left incomplete or discontinued, resulting in stagnant corridors and non-functional services, leaving young adults waiting for follow-up care in adult facilities. These deficiencies, coupled with the development of *ad hoc* programs by HCPs, highlighted the lack of institutionalization of the transition to adult care.

Passive care versus active disease

HCPs adopted various strategies to address the deficiencies in the healthcare system which hindered or even prevented a smooth transition to adult care for young adults. These strategies aimed to ensure continuous care for the young adults, and facilitate their transition to new services by considering systemic, organizational, and individual barriers. Among these barriers, a primary challenge emerged from the inconsistent processes sometimes faced by young adults, who, despite their age, had to change HCPs during a critical period of physiological and biological changes, which could potentially impact their medical condition.

Furthermore, all stakeholders involved in the transition process acknowledged that the change from pediatric to adult health services occurred while the health needs of young adults remained active, yet unaddressed. As described by an adult care nurse, the status of young adults suddenly became detached from the types of care they received, limiting the possibility that their health conditions would be alleviated or improved during the transition process:

> "*We don't have the resources that the [Children's Hospital] has, and we don't have that easy accessibility either, and I find they're very frustrated because they still have the same issues, and they're [now] on the Adult side. So, nothing changed for them. They still have all the problems that they had over there. But, then, they come here and have even less support. So, you know, they're very frustrated*." (A-HCP030)

The awareness of pediatric, primary and adult care providers about the interruptions to active care triggered the development of initiatives to seek to fill the gaps.

Transition clinics to bridge the gap

The concept of transition clinics was collaboratively envisioned by various stakeholders, including patients and HCPs. The aim of facilitating a successful transition, particularly for AYAs, was well-defined, and emphasized the importance of coordinated communication among

HCPs. The transition clinic model involved bringing together all relevant parties in one location to facilitate the transfer of care and exchange pertinent information concerning post-transition follow-up and adult care services. The intention was to initiate a more comprehensive approach, which was deemed essential for all stakeholders involved. Pediatric HCPs could share crucial information to facilitate the smooth transfer of medical data. Adult or primary care providers could receive the necessary details to assume responsibility for ongoing care. AYA patients and their families could also gain a clearer understanding of the transition process and the functioning of their new healthcare services. While the orchestrated event of transition clinics was perceived as complex, it was deemed feasible by the involved stakeholders. Despite the challenges of devoting time, resources and energy to an activity with little structural support, the recognition of its complexity implied that careful planning and coordination among healthcare professionals and patients were required. Nevertheless, the overall consensus was that the benefits outweighed the challenges, making it a worthwhile endeavor to pursue. As a young adult participant observed:

> *"Well, I mean [it's] not realistic … [now that I] thought about it, if your old doctor and your new doctor would be there with you, like, even if it's on a phone call, and just, like, so you explain because it's easier to explain things if … someone's here with you … introducing the things, and then you complete them. … But, then again, how easy is it to get two doctors from two hospitals on the same schedule for the patients? I don't know. But, that would be amazing, and that would be like giving the patient a glimpse of the adult care, so it doesn't seem too scary. But, if not, like we said before, like, maybe if not … just giving the adult care a big note on what the patient has lived through. But, I don't know [if] they need to be more detailed because, like, there's 1000 charts under the patient's name – so, not just giving them all [of the notes], but just summarizing them or something. And, if not, I think something needs to be worked out for [the adult care specialists]. [...] Something needs to be figured out, and I know it's a complex thing. Like, it's easy to say, but there needs to be something*." (AYA004)

Transition clinics were implemented based on the initiative and capacities of specific pediatric teams.

The overwhelming nature of the experience of transition for young adults included the abrupt change in care settings and care team. The development of transitional clinics included specific measures to seek to redress the negative experiences of transition. This included dedicated spaces to receive young people during their transfer to adult care. Such dedicated spaces allowed young adults to become accustomed to the new approaches used in adult services, and thus to be gradually included in the adult care setting. The transitional clinics was reported to help build trust between the adult HCPs and the young adults, with the presence of the pediatric HCPs, who were the recurring reassuring figures for the young adults and parents.

Transition clinics were most often located in the pediatric ward setting, and sometimes in the adult ward. Although the Children's Hospital and the Adult Hospital shared common spaces that connected them with physical bridges, HCPs rarely physically crossed over to meet with specialists on either team. The transition clinics represented this bridge between the pediatric and adult services, and were designed to bring together the specialists involved in the care of young adults being transferred, and thus to share information about the transfer, as way of helping to facilitate the transition.

The clinics were dedicated to young adults between the ages of 18 and 25 – that is, when they could no longer be followed by pediatric specialists. Thus, as a way of maintaining the link with this population leaving their services, pediatric HCPs continued their follow-ups through transition clinics. Transition clinics and programs recognized the trade-off of leaving pediatric services at age 18 by offering a continuum of health services with a multidisciplinary and inclusive approach, in contrast to the adult services alone to which young adults would be transferred.

For parents, the transition clinics or programs allowed for longer follow-up with pediatric HCPs. Particularly for complex care, the transition programs allowed young adults to be transferred, depending on their conditions, to the same adult physician specialist who had developed the skills and abilities to take over the complex care of those children. The transition clinics were a reassuring way for parents to have access to a reference person they could contact according to their children's needs, during the transition, and to continue to be guided by the appropriate services. This was important for parents, because the resources in community services were, for the most part, not adapted to young adults, especially when they had complex health and social service needs. As one mother described it, these coordination services would ensure that appointments with health services were maintained:

> *"And [it's so valuable] having a go-to person to call, just having someone to call when something is not going right, and they can say, 'Okay, no. This is something worthwhile, this is something you go to the [emergency department] for.' Even, basically, like, just having a transition person, maybe to see them twice. Or, even if they can see you every two years – but, have a person in charge of that and then … [the Pediatric Nurse] … organizes all the doctors... Like I said, even if it's only twice a year, they get together and they see all these kids at the same time. Let's say they do a blitz of a week of them all, or, like they did it at the Children's [Hospital] every Friday, every last Friday or every first Friday of the month [...], and then all your appointments are set up that day. That would be perfect."* (PG005)

For HCPs in pediatric settings, most transition clinics or programs remained informal, depending on the networks developed by the HCPs in charge of the clinic in question. Based on their knowledge and experience, HCPs developed transition pathways that sometimes left many follow-up tasks to parents. To prepare young adults for transfer, pediatric HCPs administered questionnaires to assess young adults' readiness, based on evidence from the scientific literature or internal research or quality improvement projects. Even the degree of patients' readiness remained haphazard, and HCPs often reported a lack of time to prepare young adults for transfer. They also felt that, despite preparation on pediatric wards, the transition to adult wards remained a challenge for young adults. Although the age of readiness was estimated by most pediatric HCPs to be between 16 and 18 years, implementation, that followed the practices that were developed in the transition clinic, was rare. HCPs complained that there were insufficient resources, staff and budget to allow transition clinics to function reliably for all young adults identified for transfer to adult services.

Adult HCPs saw the transition clinic as providing a safety net intervention where young adults were prepared for transfer, in a familiar environment with people from the regular care team. Given the informal nature of the clinics – as an adjunct to HCPs' other formally sanctioned tasks – the feasibility and sustainability of the transition clinics depended primarily on protected time to attend the clinic, resources, and an evidence-based approach. Indeed, the lack of systematization in the conduct of the clinic prevented consistent assessment of outcomes in the different situations of young adults' transfers. To make the clinics effective, HCPs emphasized the need for information sharing, the systematic and regular participation of HCPs from the adult services, training to promote relevant skills in dealing with a young adult population, and the establishment of a schedule for regular appointments with new patients during the transfer period to create a bond and foster a climate of trust.

Pediatric HCPs continued to make time available to work in the transition clinic or transition programs to maintain a connection with young adults and to anticipate possible interruptions in care. However, and sometimes the clinics were held without an adult physician specialist. Pediatric HCPs found it difficult to sustain the transition clinics and programs when adult HCPs' involvement was limited. Buy-in from adult specialists was difficult, as one pediatric nurse noted:

> "*I think the other big hurdle is getting physician buy-in – again, in my population. … We're re-evaluating our program right now. And what we've realized is that we have probably too many people [with fingers] in the pie. And it makes for a difficult situation, because then no one really has … full buy-in. Some of the very best working transition clinics … have one adult physician who really buys-in, [and] one pediatric physician who really buys-in, and they do the clinic jointly, and then they, you know, slowly transition over. But when, on my side, it's one of six physicians who may be assigned to that patient, but they don't see them for years, … and they don't have time to come and say 'hello', because they have 800 other patients to contend with, … [that's] a bit challenging. And I think we're trying to see if we can get one physician who might buy in a little bit more, and then … communicate, and then also [get] one nurse instead of three on the adult side. So, then, everything is a little bit more cohesive. And I think that's what's important,*

> *because everybody works in a different way. And for me, I have one nurse that does one thing, one nurse that does another thing, and another nurse [who] does another thing, and one physician [who] does one thing, [and] another physician [who] does another thing. And so, then, I'm trying, and so, it's hard for me to teach, because everybody's a little different. And so, if we have one system and [one] way [the transitional processes work] – [that is], one physicians' way, one nurses' way, then that's easier. We're trying to see if we can get that. I'm not sure."* (Pedes-HCP025)

The story, here, beyond individual effort, is the reliance of transition clinics on chance and luck, and the whim and fancy of individuals. For HCPs in adult settings, programs depended on the interests and leadership of the physician specialists involved. Attempts to involve them in transitional programs or clinics could be derailed when organizational and departmental leaders were not or no longer involved – such as when a leader who made the clinic possible retired. The transition clinics or programs were primarily run by HCPs on pediatric wards, in part because AYAs were still considered to be closer to pediatrics than adulthood and, hence, adult service. Given the nature of these programs, as an added workload for adult HCPs and the presence of pediatric HCPs who are familiar with this population, the clinics tended to be managed solely by pediatrics. As one adult specialty nurse involved in a transition program explained:

> *"It's out of control. ... You're bringing [the young adult patients in] in a time. So, of course, if [the Pediatric Nurse] is there, and [the Pediatrician Specialist] is there, you're kind of like, 'Okay, let them do it; I've got to get this done. I've got four or five [kidney] rejections. I'm trying to do all the protocols.' So, it's not fair. It's not getting the time that it wants. Definitely not. You're seeing [transition] as a burden instead of it being properly incorporated into your workload versus if it was on a Tuesday with the normal flow of the clinic, [which would mean that] it would get the time and attention it deserves. So, now, as a program, we know we are missing another [coordinator]. We were two coordinators. Now we are three coordinators. ... We're going to be four coordinators. So, the work is going to get better, but to be interested in this patient population we need to be compassionate."* (A-HCP030)

The fact that the clinic was not “properly incorporated into [their] workload” exemplifies the lack of institutionalization of adolescent care. For primary care providers, while they were not involved in transition clinics or programs in most cases, communication with other HCPs would allow for the transfer of information and thus optimize continuity of care through informed follow-ups. For family physicians, too little information was passed on to them as young adults were transferred from one setting to another. Information exchange was seen to be essential for the management of the young adult patient by primary care providers, to understand the care received by the young adult and to tailor care and possible further communication with other specialists in adult services. During the transition, family physicians reported receiving almost no progress notes or changes in treatment plans from adult services.

Primary care providers were rarely integrated into the transitional programs, although they saw themselves as supportive and connected to the healthcare system, and could help link young adults to resources as needed, especially when these resources were not available in adult services. Primary care providers were concerned about the lack of knowledge about the role family physicians could play in the transition to adult care and beyond. For example, one family physician specializing in adolescent medicine explained:

> *“But, the adult specialist had an approach that was completely different. When the kid came to that place to get care, it didn't work at all. But, fortunately, what had already happened was that he had already come to me for the physical aspect. So, at that point, what had happened was that I was helping them find other places to go to get their mental health treatment, which undid, in fact, all the work that the pediatricians had done, but offered what the kid needed at that point. So, yes, [the care worked] because I already have those contacts that are established.”* (PCP-HCP012)

Finally, for young adults, transition clinics were not common and were not offered in all departments. While [young adult patients] expected continuity in the care they received in the pediatric setting, the existing bridges were seen as extensions of pediatric care, so that pediatric HCPs remained available to compensate for the lack of access to care in adult services. However, once the transfer occurred, young adults were still disconnected from the healthcare system. The transfer was completed when the transition clinic or program ended, or when the young adults were only followed by adult services. This transition was still perceived as abrupt and happening ‘overnight’. One young adult compared the scheduling of appointments in adult services unfavourably to that experienced while in the transition clinic:

> *“We had communications [in the transition clinic] to say, 'Look there's the clinic at 11:00... With her it was all said. It's ‘At such and such a time you're going to take your blood test, and at such and such a time it's your clinic, and I'm going to examine [you] and I'm going to talk to you.’ That's all. Or if, for example, I had to have, for example, I don't know, an X-ray, for example, after the clinic already had a follow-up [with me], [I get] direct follow-up in three months or six months, and [they’ll] send [my] file there, so that they can make an appointment for [me]. It's already all done. [In adult care], sometimes I get a call to say, ‘Look, this is your appointment.’ It's really ... it's not done right. [...] Sometimes appointments are made but you don't know when they're going to call you. You don't know. You have to wait. Sometimes you cross your fingers. You don't know. The other time they called me maybe around a month and a half [ago] and I was like, ‘did you have that appointment? I don't even remember that appointment’. Business as usual.”*(AYA001)

Ultimately, a significant challenge for transitional clinics and programs was the lack of overlap between pediatric HCPs and adult services. It turned out that transition clinics and programs, while initiating bridges between services, were mostly established as extensions of pediatric services – with the same multidisciplinary approach and HCPs – rather than a combination of both pediatric and adult services. For all those involved in the transition, the effective continuation of pediatric services that characterized transition clinics meant to bypass the arbitrary legal age of transfer to adult care. The implementation of transition clinics or programs aimed at transitioning patients to adult care did not ensure a systematic approach to the transition pathways. However, transition clinics and programs served as a crucial foundation for standardizing the transition process, bringing attention to particular challenges in the system, particularly the inflexible boundary between pediatric and adult care settings. In terms of documents, practice memory and conferences sharing transition clinic “best practices”, there are many footprints HCPs have been laying for if and when health systems finally institutionalize healthcare for adolescents with chronic conditions.

Promoting standards in an unstandardized system

In the meantime, AYAs with chronic conditions rely on local experiments and individual benevolence. Among pediatric HCPs, the absence of standardized procedures impeded the prompt referral of young adults to adult services, resulting in delays in the initial encounter between the young adult and the specialist physician. Moreover, the lack of universally established guidelines for transition across all settings placed a heavy reliance on the knowledge, abilities and goodwill of HCPs and families. Consequently, the preparation for transition was not gradual, as desired, and the transition process often went undocumented, indicating the potential for failure or slowdown in the transition process, not to mention missed opportunities for organizational learning.

Ways to standardize the transition process were often emphasized to ensure that young adults do not lose their connection to the healthcare system and thus maintain follow-up care. Healthcare professionals cited a variety of reasons that pathways should be standardized in formal ways – particularly at the institutional level – based on the organization of the healthcare system. To counteract the effects of the rigid structure requiring automatic transfer of 18-year-old adolescents and young adults to adult services, some healthcare professionals used the structure's means to maintain connectivity with young patients. Questioning the arbitration of age 18 as a reason for transfer, one pediatrician continued to see them in a facility other than the pediatric hospital, where she was allowed to follow young adults aged 18 to 25 (the age of young adults who are followed in hospital transition clinics). The development of the transition clinic was a testament to the importance of the relationship and trust between the young adults and the HCPs:

> *"Well, I've had two patients who I transferred, and they weren't sure if it clicked. And they actually came back to me when they found out I [was seeing] 18 to 25 [year olds]. So that was kind of like, 'okay, now what do I do? What do I tell their doctor?' Because they're coming back to me. But, she was very open. And I said, 'look, I'm going to keep them, since I opened transition … and I'll send them back to you when they turn 24-25'.*

> *Actually, no, I've had three who have [come to me between 18-25]. So, who found out that I'm doing transition and came back? So, that's a little awkward, because, you know, … I have one patient right now I'm really trying to transition that I'm struggling with. So, [it's] very interesting. She actually lives very far [away and] turned 18 during the pandemic. I've done phone appointments with her, but I'm trying to get her to see an adult doctor in [her town], because she lives up north, like, near [named town] like, in a reserve. So, I found someone. So, after, like, contacting people, I finally found the name of someone; booked her to see that adult doctor because she actually was pregnant. So, I was like, 'I don't have the expertise; you need to see this doctor'. She decided to terminate the pregnancy, missed her appointment with the adult doctor, and now came back to see me a couple of weeks ago, and I'm like, 'you need an adult doctor at this point. So, like, there's bigger issues, and you live too far from me to be doing this'. So … I gave [her] … another referral for that doctor. But the thing is, I don't know if she doesn't follow through if that doctor will say, 'too bad, so sad'. And so, I just don't want this girl to slip through the cracks. So, I'm struggling with that one, because she's not in town. … This one is a challenging one."* (Pedes-HCP022)

Difficulties in ensuring continuity of care included when patients return to pediatrics HCPs after an unsuccessful transition to adult services. HCPs then struggled with their own means to ensure that patients did not fall into the cracks. While making such detailed arrangements, spending such time and communicating so regularly, the pediatrician was seeking to manage perceptions of potentially being seen to impinge on and overtake the care of another physician. Such are the communicative, identity and social workarounds that need to be made in the face of limited formal legitimacy of transition roles and structures.

Systematic monitoring of transition to adult care using indicators

The potential risk of leaving young adults with interrupted medical care, especially when they required follow-ups, prompted HCPs to maintain their involvement while referring the patients to adult care specialists. A notable challenge, reported by HCPs, was establishing a systematic approach to ensure a smooth handover, wherein the AYA patients were seen by adult care specialists, and effective communication channels were established between the involved parties, before the interruption of pediatric care services. The idea of developing a systematic approach for transitional care frequently emerged in the discourse of HCPs. The recurring theme was the need for a structured, standardized procedures to improve transition care processes. As one HCP from a pediatric setting remarked:

> *"If there was a more systematic way of doing it, if there was a set of documents that the hospital had approved, that we could give to families to, you know, to start like, 'okay, at 13, 14, … fill this in', like, to get the child to start thinking about 'what are the medications? What are my medical needs?' [it would be great]. … Like, [it would be great if there was] a set of transition workbooks for families and patients … the hospital could provide, if there was a list of like checklists, phone numbers, things that we should be organizing."* (Pedes-HCP007)

Formal institutionalization requires legal-governmental formalization. In its absence, individuals and individual services can do their best to ensure that transitional care for adolescents and young adults receives attention at clinical and contextual levels. Participants were optimistic that moves towards systematization of the transition to adult care, through the multiple incentives of formal governmental institutionalization, would realize programmed follow-up according to benchmarks that would allow the different actors to react according to the identification of particular standardized indicators. Although participants in different roles all agreed on the importance of medical and clinical follow-up, they all placed greater emphasis on the importance of follow-up relating to elements of the social, organizational and structures that would ensure that young adults remained in health services, and thus ensured the best possible prospect of successful transitions with the fewest possible complications.

However, participants reported that few tools had been used to monitor the transition pathway of young adults and, as indicated by HCPs in mainly pediatric and adult services, their use was limited, and did not enable the assessment of their interventions. Transition indicators were sought from participants because they were a concrete tool in the interviews to access stakeholders' priorities for dimensions to be encompassed through institutionalization, not to mention to serve as applicable service indicators in the future. Indicators were identified by all stakeholders. The indicators incorporated the perspective of all transition stakeholders for each phase of the transition (i.e., before, during, and after transfer). The indicators for young adults covered monitoring of clinical, social, and organizational elements related to the young adults' clinical and social circumstances.

The clinical aspects included tests and results that allowed HCPs to assess the stability of the young adults' health status prior to their transfer. To this extent, a set of tests related to the condition was considered important prior to transfer, particularly in order to determine the most recent baseline data for transfer. Specific indicators to monitor transitional care for adolescents and young adults to monitor were seen to centre on information-sharing, including the occurrence of transition conversations and ownership of information, which were considered to be at odds with the current structure and norms of healthcare institutions. Indeed, many HCPs noted that conversations about transition, despite its critical importance, were not documented in the same way as other clinical information, because it was outside the scope of formally recognized clinical care.

Indeed, ownership of the information was raised by the various stakeholders, especially parents and young adults, because finding information about young adults' outcomes was a difficult task. Young adults, although active in their care and understanding of their symptoms, were regularly blocked from accessing their health data, which almost contradicted what was asked or expected of them in adult services. AYAs frequently experienced challenges adapting to the prevailing culture of "no news, good news" that they encountered in these adult services. This culture was particularly evident in the context of diagnostic tests and waiting for results. For example, a young adult patient undergoing a series of medical tests might find themselves anxious and confused due to the lack of immediate feedback, a stark contrast to the more communicative approach often found in pediatric care. The transition to a healthcare environment where silence is typically interpreted as a positive outcome, presented a notable challenge for these young adults, requiring them to adjust their expectations and understandings of healthcare communications. In addition, knowledge of the healthcare system was emphasized by all stakeholders, with the paradox that the system was too complex to be understood, even by healthcare professionals themselves.

Health professionals monitored several key indicators, with a focus on quality of care, clinical outcomes, and patient trajectories. These aspects were primarily identified by the HCPs themselves. However, stakeholders and particularly young adults highlighted other crucial elements. One of these was the importance of coordination. This notably included establishing a point of contact for AYAs. The identification of a specialist physician and their team within adult services was a critical part of this process. Furthermore, stakeholders underscored the value of HCPs' knowledge and skills, especially when transitioning from pediatric to adult care. Lastly, information and communication practices played a significant role. This involved maintaining clear and consistent charting between services and between pediatric and adult care teams. Young adults and parents also cited the ability of HCPs to identify appropriate resources for young adults, as well as the communication skills of healthcare professionals toward the adolescent population, as indicators to monitor for successful transition to adult care.

The above priorities to inform indicators can be shaped into monitoring markers for an "ideal" transition. The notion of a successful transition was evoked by the stakeholders through the nomination of such items relating to spheres much broader than the biomedical sphere. It was noted, moreover, that follow-up required recognition by institutions to invest formal resources in clinics and programs to facilitate the transition process. It was reported as needing to come from legal-governmental sanction and resources. On the pediatric side, the follow-up of young adults was relatively routine, and the strategies for managing their care were developed and tested. However, the lack of structure, resources and institutional anchors was lacking in the pathways of young adult transfers, as explained by a pediatric nurse:

> *"I think the biggest thing is time, time to allow for [transition-type] clinics to happen on the government side. And on the Adult system side it's not. I'm sure that Adult physicians would love to be able to deal with this. It's just that they don't have the ability, clinic space, time – all that stuff. I don't think there's anything more I can add. God knows, you can talk about it forever. But, you know, I know the tools that are being developed [including] all the tricks to help [young adults] take medications."* (Pedes-HCP025)

Significant challenges faced in transitioning from pediatric to adult healthcare systems included the lack of time, resources, and clinic space within the adult system to handle the unique needs of transitioning AYAs effectively. Despite the desire of adult physicians to manage this transition smoothly, the constraints of the current system inhibited this process. However, there is an acknowledgment of ongoing efforts to develop tools and strategies to assist AYAs, more actions were required to ensure a seamless transition of care for AYAs moving from pediatric to adult healthcare services.

Conclusion

This chapter explored the multifaceted landscape of transitions in adolescent and young adult healthcare disentangling the roles of informal bridges, which have emerged as crucial compensatory mechanisms in the absence of institutionalization. The attempt to institute care transition trajectories across barely porous boundaries contributed to the revaluation of professional identities and the interplay between self-projection and the practical realization of one's role in the processes of transition to adult care. The unique identities and roles of healthcare providers at different stages of the transition process were presented, from pediatric healthcare professionals guiding AYAs to adult care, to the pivotal roles played by primary care physicians and specialists in the transition process. Additionally, self-identities of AYAs were shown to evolve as they moved to adulthood with new social roles.

The presence of informal structures and, at times, the underwhelming fulfillment of transitional initiatives were conveyed. The chapter outlined informal health corridors created by HCPs in a non-responsive healthcare structure aimed to overcome the systemic “passive care with an active disease” that represented the transition to adult care services for AYAs with chronic and active – sometimes not-even-stable – conditions. Such structural challenges highlighted the importance of transition clinics as essential tools to bridge the gap between children’s and adults’ health services, and to facilitate smoother transitions across them. Priorities for standardization through institutionalization in the transition process and the systematic monitoring of transitions were illuminated by soliciting from participants the nature and requirements of key indicators of successful transition for adolescents and young adults.

The next chapter discusses the findings from the four findings chapters. From the detailed analysis of the main stakeholders of adolescent transition to adult care, these findings – informed by social theory of symbolic boundaries – offer a roadmap for understanding missing opportunities for holistic care to enhance the healthcare transition experience for AYAs. Recommendations emerged from these findings, and will be presented in the following chapter, providing insights into how this vulnerable population can be better supported, and ensure a more seamless and effective transition to adult care.

Chapter VIII. Discussion

Introduction

This dissertation opened up understanding of the meanings that inform and flow from efforts to transcend the rigid boundaries of health services for adolescents. Health services were shown sadly to misalign in a persistently structural manner with the multi-faceted realities and complex needs of adolescents – a massive demographic – especially for those with chronic conditions, who are thus subject to even greater vulnerability.

Adolescent healthcare is received and delivered in the face of a healthcare structure devoted either to pediatric or to adult services, inspired by modernity's defining preoccupation with "progress" through specialization, neo-liberalism's cultural dominance that places value according to profits of production owners, and western society's bipolar affection with exclusive categories of childhood promise and adult productivity. Most research on adolescent healthcare has tended to focus linearly either on single conditions, on de-contextualized aspects of the pathway, or on the evaluation of interventions to improve adolescent care (Cassidy et al., 2022; Colver et al., 2018; Dimitropoulos et al., 2019). Suboptimal adolescent healthcare reflects a deficiency in complexity-informed frameworks.

Contributions of the dissertation

In response to previous research on adolescent healthcare, this dissertation asked the following questions: *How is the transition from pediatric to adult care understood to operate across different stakeholder groups? What are the processes activated to improve the operationalization of the transition? What learning is generated and mobilized?* By drawing on complexity-informed sociological theory of symbolic and social boundaries, the research aimed to elucidate how shared perspectives and behaviors delineate distinct groups, offering a foundation upon which more nuanced and effective healthcare services for adolescents can be constructed. The research delved deeply into the perspectives and operational dynamics of various stakeholders in adolescent care, particularly regarding the distinctions between pediatric and adult care and the corresponding responses to these distinctions, to understand the intricate web of influences and interpretations surrounding care. The research shed light on the linear biomedical approach to adolescent health and underscore the complex requirements for effective AYA care.

This research engaged qualitative methods that flowed from a constructivist and sociological notion of symbolic and social boundaries. A perspective from boundaries holds that definable systems cultures can only emerge and change through the permeability of boundary walls, and the strength of the boundary walls determines the distinctiveness, and hence capacity for exclusivity, of the cultures within them (Bourdieu, 2001; Lamont et al., 2015). The findings showed that the degree of permeability of service boundaries created agential opportunities for patients, family members and HCPs to improve transitional care, at least in individual cases. A boundary perspective showed adolescent care not only in terms of service shortfalls, but showed connections between conceptions of human development and in particular adolescence, and meaning-making around the processes of negotiation of idealized and individualized care in relation to structures of varying degrees of firmness and boundedness.

The findings showed that overt solutions and workarounds to solve specific and immediate problems created emulatable strategies for colleagues who witness such improvision (Vryan et al., 2003; Vygotsky & Cole, 1978). As such, the symbolic interaction among HCPs occurred as new informal practice standards – that is, the consequently amended expectations for “good practice” or “patient-centred care”. Culture and behavior are changed by evolving expectations HCPs have of each other of practices and standards to be met if others wish to be accepted in a community of practice rather than isolated.

The contribution of individual patients, family members and HCPs to agentially optimizing the permeability of service boundaries were not only one-off acts. They provided footprints, as practice precedents, which others could follow. Nevertheless, the research showed that such agency was no match for the relative thickness of the boundary walls to reinforce fragmented practice structures, in the absence of systemic intervention (institutionalization) to incentivize integrated care for young adults. Beyond unproblematized invocations for services and professionals to collaborate, this research showed the importance and roles of boundaries. Indeed, what was learned about boundary-work in healthcare was that boundaries are not only able to be spanned, but that collaboration occurs within boundaries, and indeed requires boundaries and involves their expansion.

While most research to date has focused on exploring an individual level of integration of care — notably collaboration between healthcare professionals — little research had looked at how all the stakeholders involved in integration of care organize and influence care pathways towards integration. In order to empirically represent the tandem of integration and hyperspecialization of care, this research used the archetypal transition of care, as an extreme case study (Yin, 2009), the transition to adult care. This process represents the complexity of integration of care, with the involvement of many stakeholders, from different services, specialties and organizations. This qualitative study based on a socioconstructivist approach, and an interpretive paradigm therefore elaborated on the mechanisms of the transition from pediatric to adult care, including health professionals from three distinct organizational structures (pediatric, adult, and primary care), as well as young adults and parents of young adults who have been transferred to care for adults.

The research bore witness to ethical dilemmas, such as limited access and responsiveness, that further compound the challenges for adolescents seeking appropriate healthcare, and for disempowered HCPs to help them to the degree that they would like. This study underscores the urgent need for systemic changes to address the inadequacies in healthcare provision for adolescents transitioning to adult care, aiming to ensure continuity of care and meet the unique needs of this vulnerable population.

The findings imply that the navigation of established boundaries directly shapes how those boundaries are negotiated, consequently impacting their fluidity. Moreover, these navigated boundaries play a crucial role in reconciling any discontinuities, thereby influencing the negotiation of transitions to adult care and the boundaries involved. Figure 6 shows the links between the stages and mechanisms described.

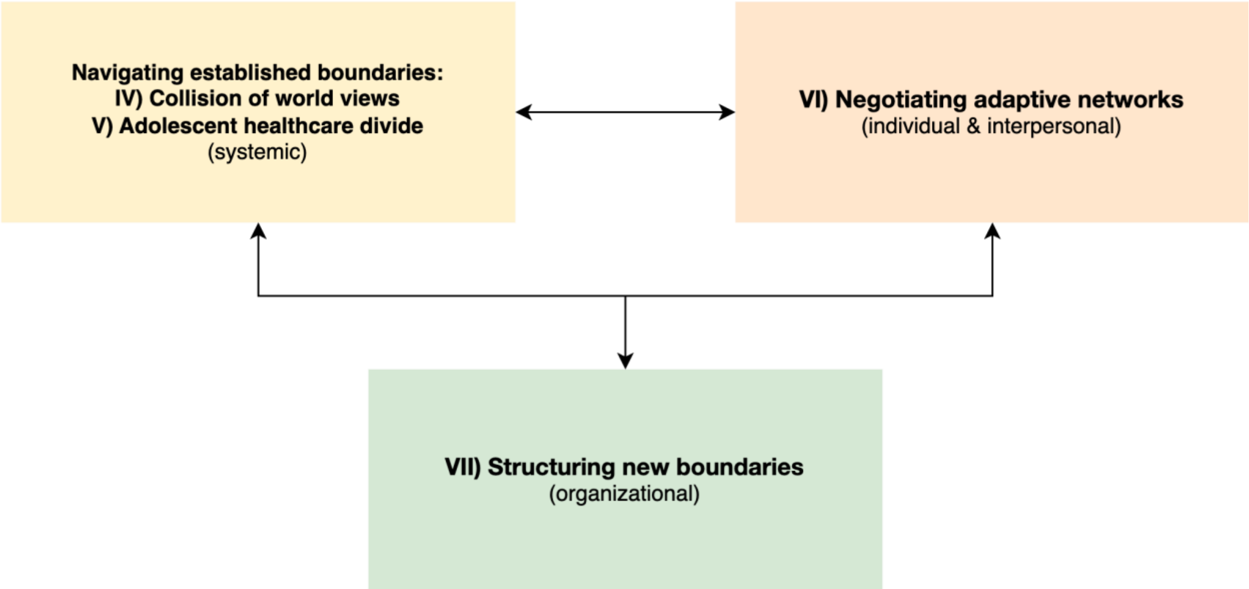

Figure 6 Structure and connection of the findings

The dissertation explored, firstly, two main mechanisms for understanding how stakeholders in the process of transition to adult care interact; namely, by highlighting the boundaries established in the healthcare system and across healthcare services, and by the means used by stakeholders to modify the boundaries impeding the process. Secondly, it elaborated the mechanisms developed by the stakeholders to improve this process and reconcile discontinuities, allowing for easier trajectories for patients transferred to adult care. The broad processes towards inappropriate AYA care are indicated in Figure 7.

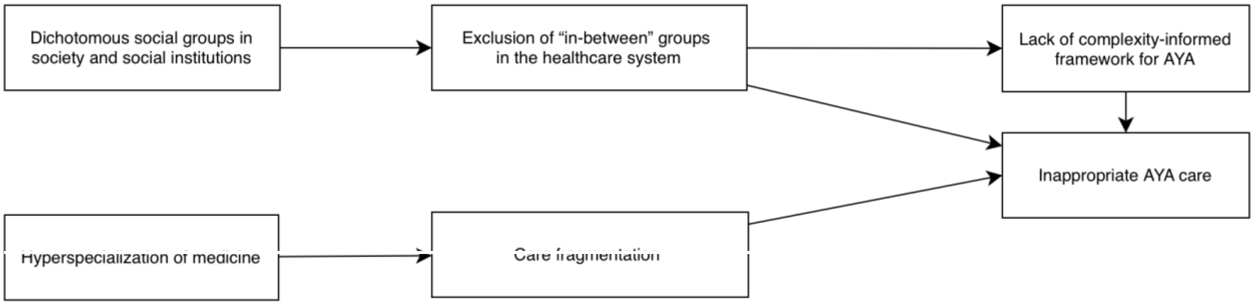

Figure 7 Processes of AYA transitional care

Figure 8 illustrates the interaction of dimensions that influence the transition to adult care. At the individual level, both to compensate for the pitfalls of the system and the lack of continuity of care inherent in the symbolic boundaries between pediatric and adult care, on the one hand, the agency of young adults and the advocacy promoted by the parents of young adults who are transferred to adult care are the mechanisms that come into play in the transition pathway. On the other hand, healthcare professionals extend their professional boundaries to both fulfill the mandate of services that do not exist in the system or services that do not fulfill their mandate in the transition pathway resulting in interruptions of care for young adults; and to fulfill their vocation that is not fully reflected in the care setting in which they work. HCPs' role and professional identity adjustments are influenced by the personal interests and caregiving skills of young adults. These individual mechanisms lead to the development of informal ways of transitioning to adult care at the organizational level, particularly in pediatric settings, through the leadership of certain leaders. The knowledge mobilized in each organization diffuses very little among the organizations' teams, which, at the inter-organizational level, fails to disseminate the resources and skills acquired to assist the transition to adult care. Thus, between organizations, boundaries are reinforced by the distinction in organizational and professional cultures and their respective norms regarding the care provided to young adults. In effect, care is provided without distinction between young adult and adult amalgam populations. These different mechanisms operate within a structural framework of fragmented healthcare and social services that makes it difficult to access certain services for different populations. Each mechanism interacts by influencing and being influenced by the mechanisms of the other levels.

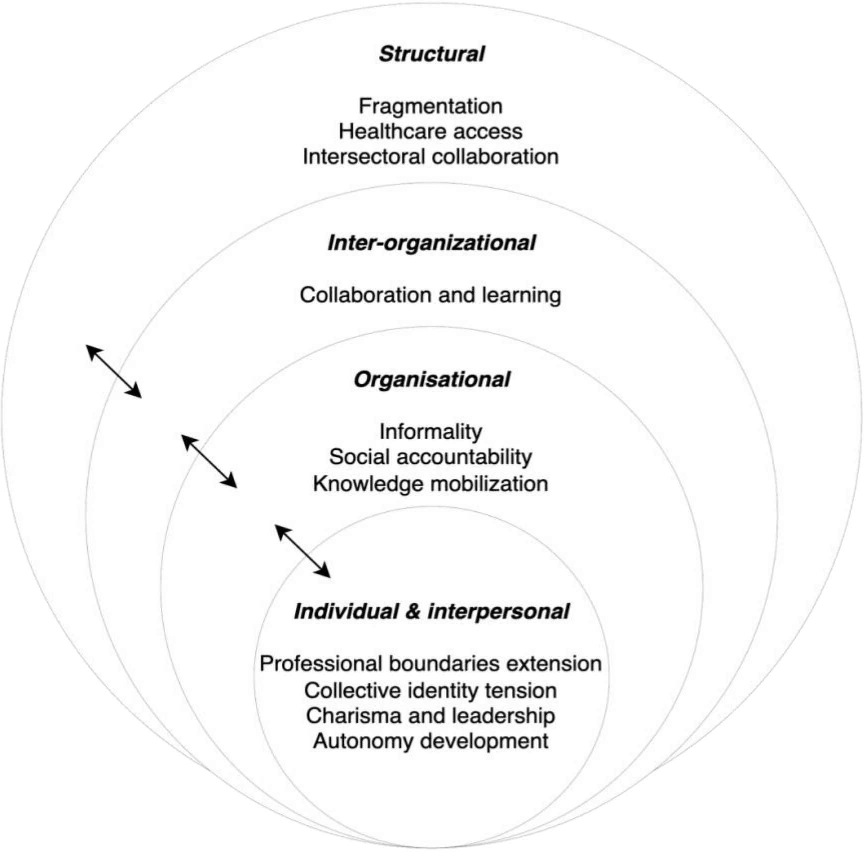

Figure 8 The interrelated structural, inter-organizational, organizational, and individual dimensions of transition to adult care

In light of the symbolic and social boundaries, the transition to adult care occurs through three main mechanisms located at three levels that influence each other. At the systemic level, the transition takes place in compartmentalized and opaque environments, which do not easily allow the knowledge and norms of other environments to infiltrate, even though collaboration is necessary, because it is inherent in the process of transitioning from services in one organization to services in another organization. Previous research has highlighted the impact of service fragmentation and the unique pediatric approach (Toulany et al., 2022). Furthermore, this has been reflected in research where focus within each disease group is advancing within its own separate sphere (Bihari et al., 2022; Cleverley et al., 2020; Gray et al., 2018; Robinson et al., 2022). This study found that health professionals in the pediatric setting have a perception and thus an experience of the professional culture of pediatric care that is distinct from, and sometimes even opposed to, the professional culture of adult care. These distinctions lead to clashes of expertise and, through power relations, to a lack of recognition, and thus of legitimacy, with respect to other groups involved in the transition to adult care, such as family physicians – PCPs – and young adults themselves and their parents. To counteract the professional and institutional boundaries that impede the transition to adult care, health system stakeholders develop informal pathways to standardize the pathway of young adults to adult services. Transition monitoring occurs in the pathway in a siloed manner and inter-organizational knowledge exchange is limited. As conveyed in the following section, the silos in the healthcare transitions of AYAs reflect disempowering interpretations of childhood and adolescence.

Understanding childhood and adolescence

The sociology of adolescence critiques discourses that adolescents manifest deficits in need of "fixing". Such a perspective assumes adolescence to be a developmental problem to be managed, perpetuating stereotypes of irresponsibility and susceptibility to external influences (Lesko, 2012). The assumption of adolescence as a problem not only dismisses adolescents' competencies. It also reinforces structural inequalities by reproducing symbolic violence, where adolescent voices and perspectives are marginalized in favor of adult-centric interpretations of their needs (Bourdieu, 2001).

Future studies of adolescent healthcare must engage critical perspectives that challenge disempowering assumptions by addressing intersectionality in advocacy for the discursive inclusion of adolescent voices (Lesko, 2012). As such, attention must be paid to inclusion of those from marginalized groups, to expose and dismantle the ways structural inequalities are reproduced in health settings (Crenshaw, 1994). By questioning the adult-centered nature of much research and practice, such moves will involve recognizing adolescents as active agents with diverse experiences, rather than passive recipients of care. Critique of the power dynamics inherent in health settings must reconceptualize adolescence as a socially constructed and contextually shaped life stage, rather than as a universal condition.

As suggested in literature on the sociology of childhood, children should not merely be seen as "adults-in-the-making," but as individuals with their own rights and capabilities (Kosher & Ben-Arieh, 2019). This shift in perspective is crucial for fostering an understanding of children's roles in decision-making processes, particularly in care settings where their voices are often marginalized. Furthermore, the recognition of children as "social actors" underscores their ability to make choices that impact their lives, challenging the adult-child binary that often positions adults as the sole decision-makers (Yılmaz, 2021).

The concept of children's agency is not merely theoretical; it has practical implications for how care settings are structured and how decisions are made. It is essential to incorporate children's perspectives in healthcare decisions, as their participation can lead to improved outcomes and experiences (Coyne & Gallagher, 2011). Children who actively participate in their treatment decisions experience reduced anxiety and a greater sense of value (Quaye et al., 2019). Moreover, the involvement of children in decision-making processes is associated with enhanced cooperation with healthcare procedures and improved perceptions of care services (Quaye et al., 2019).

Despite the clear benefits of involving children in decision-making, barriers remain. Research indicates that many parents and professionals may not fully support children's participation, often viewing it through a lens of protection rather than empowerment (Coyne & Härder, 2011). This dichotomy can lead to tokenistic practices where children's input is solicited but not genuinely considered (Miller, 2009). Therefore, it is essential to foster environments that not only encourage children's participation but also ensure that their contributions are valued and acted upon. This paradigm shift is essential for promoting children's rights and ensuring that they are acknowledged as active agents in their own lives. The following section shows that the promotion of empowering discourses is far from reality, evident in the specific mechanisms of AYA healthcare transitions and their implications.

Different trajectories of transition to adult care

This research answered the call for more comprehensive research that includes diverse perspectives to fully understand the transition process and the care trajectories (Brandon et al., 2019). The research shed light on four distinct trajectories that underscore the constraining elements of the transition process. The presence of different specialties within the pediatric setting such as eating disorders or complex care, juxtaposed with their absence in the adult setting, can lead to what is termed as “orphan transfers”. These transfers occur when young adults are transitioned into adult care without the continuity of specialized services they require, resulting in disjointed care experiences. This phenomenon highlights the impact of symbolic and social boundaries on the continuity of care and underscores the importance of bridging these boundaries to ensure seamless transitions for young adults with complex health needs.

The pathways involve adaptations of the healthcare system to capture the needs that each pathway demands and to provide the resources. The four transitional pathways raise the need for coordination of different services, and the gradation of their complexity is reminiscent of the readiness stage of care integration. Based on the care pathways, the identification of missing resources provides a better understanding of patients' pathways through the healthcare system (Nuemi et al., 2013). In the case of transition to adult care, coordination between organizations and collaboration between pediatric, adult and primary care health professionals are at the heart of two-tiered pathways. In all pathways, collaboration among physician specialists is limited by lack of inter-organizational coordination, and for “multi-system” and complex care transitions, interprofessional collaboration is required within and across organizations. Various collaborations exist between and across specialties, which are primarily involved in the pediatric setting. Pediatric care stakeholders finalize the transfer to adult care through the primary pediatric care specialist. In transitional trajectories, the chronicity of young adult illness highlights continuities and discontinuities related to expert and lay knowledge (Bury, 1982). Figure 9 represents the stakeholder groups involved in the transition process from pediatric to adult care.

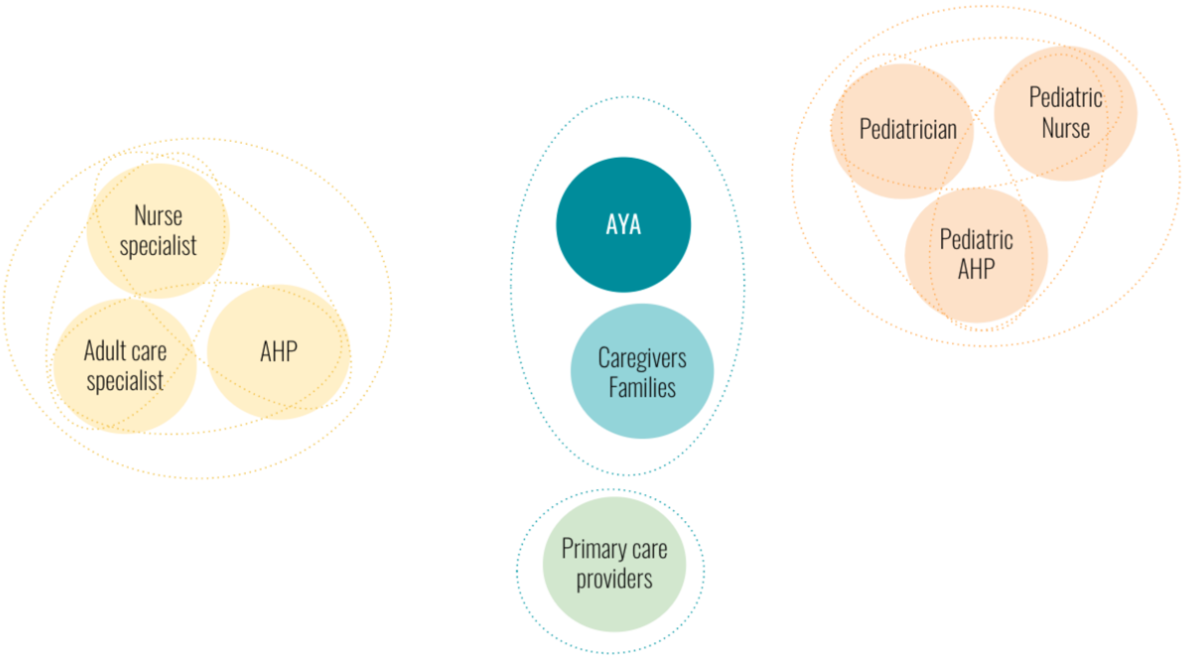

Figure 9 Stakeholders groups involved in the transition to adult care in the healthcare system

The main groups are represented in Figure 9, although I acknowledge the participation of related groups present in the process in an advisory capacity or for transitions requiring stakeholders from other sectors – notably when community services are required for young adults with medical complexities requiring home care and individualized school follow-up. The way I represent the groups has influenced their analyses. At the center of the transition is the adolescent who is both in a group that I have tried to define in this chapter, and who is also connected to his or her family (I am considering here the role of the family, thus the adolescent's developmental environment). These two stakeholders (adolescents and their parents or guardians) represent a stakeholder group composed of two entities. On the right is the pediatric community, composed primarily of pediatric specialists, pediatric nurses, and allied health professionals. Although this group of stakeholders represents a milieu, many intra-group boundaries exist. The same is true for the adult care setting, which is composed of physician specialists, adult care nurses, and allied health professionals. Finally, the primary care setting, although often overlooked in transitions of care involving specialties, is represented here by family physicians who are the primary care providers. It should be noted that this argument is evolving as primary care is changing and its organizational structure is undergoing reforms that are transforming the primary care environment, which is not addressed in this work.

The transition to adult care: a structural disorganization

Neoliberal capitalism profoundly reshapes social and symbolic boundaries. It emphasizes market contributions, individualization, and the accumulation of various forms of capital, as conceptualized by Bourdieu (Bourdieu, 1979; Brown, 2019).

Partitioned experiences of transition

The current study found that based on what is expected by the group to which they belong, this situation creates expectations of one group on another, or on the contrary creates little or no inclusion of other groups. For example, pediatric HCPs, although aware of shared standards with primary care, did little to include family physicians in the transition to adult care for youth.

While integration of care requires organizational capacities for collaboration, cooperation and coordination (Castañer & Oliveira, 2020), depending on the level of implementation, it is highly dependent on the means and possibilities of communication between the different stakeholders involved in the transition to adult care for the same young person. The sharing of values and norms between the stakeholders influences the type of interaction that will take place, particularly induced by professional and social boundaries. The organizational structure is then established as the spatial anchor of the inter-organizational boundaries through which the stakeholders involved in the care of the same patient must cross. The opacity of the roles and responsibilities of the other stakeholders indicates a clear separation between organizations. This separation emphasizes both the lack of integration of inter-organizational care, and the division of populations in the health system that sometimes considers children and adolescents, sometimes considers adults (Bowker & Star, 1999). The many recent changes in the organization of the healthcare system in Quebec are not seen to have addressed this split between services for children and for adults. Although mergers of healthcare institutions have allowed some rapprochement between organizations, and sometimes even physical rapprochement, research shows that even these organizational changes do not stimulate improvements in the practices of professionals (Beaulieu et al., 2020).

Multiple transfers

Multiple stakeholders in the transition process complicate the delivery of integrated care (Liberati et al., 2016). Interestingly, this research found that multiple transfers take place in parallel, leading to a disorganization of care that occurs within a rigid structure. Transfers of services are centralized on the medical transfers of the main specialty of the AYAs' condition. While pediatric care operates in a multidisciplinary model, multidisciplinary follow-up in adult services does not occur. This finding is aligned with current research looking at the challenges in transition to adult care (Toulany et al., 2022). In addition, while the medical follow-up of the specialty provides some of the stability of the young adult's health status, the lack of multidisciplinary follow-up runs counter to the notion of integration of care, as care is incomplete. Research has shown that lack of coordination affects healthcare utilization, which reduces the effectiveness of healthcare (Agha et al., 2020; Persson et al., 2022). Furthermore, with the lack of access to health resources, young adults are left without follow-up at a time when their needs are active. Connectivity with the healthcare system, or the ability to maintain a direct link to healthcare services, is shown here to be central to the transition to adult care.

Transition brings a disruption of systemic care. The transition to the age of maturity considered as the arbitrary and institutionalized transition to adulthood (age 18) engages a transfer of responsibility to the individual compared to the collective and social responsibility that was induced by care in the pediatric ward. Thus, the shift to adult care marks a change in accountability that occurs at a time when care is no longer appropriate for the young adult. Accompanied by a graduation ritual in some transition clinics or pediatric wards to mark the end of care event in the pediatric setting, the transfer to adult care is accompanied by a discharge from multidisciplinary follow-ups, motivated by the social age of maturity and the civic prerogatives attached to it. The capacity for independence that is granted to AYAs by the simple fact of reaching "the age of majority", is directly translated in their trajectory of care, while the discourse around a citizenship of adolescents and young adults is still nebulous and gives account of its polysemic, normative character from which many intrinsic tensions arise (Gaudet, 2018). This work demonstrates, however, that this still-vague social group expresses a social belonging that does not yet fall under the status of an adult. In spite of this distinction of belonging, this mixed state is not recognized in the health system.

Importantly, the evolution of accountability in transitional care is less discussed in the current literature. However, it should be noted that accountability cannot be separated from knowledge and ownership of information. Indeed, to enable accountability, that is, responsibility for one's action or inaction in a specific context, one must understand the scope of one's actions in order to understand the consequences. In the transition of care, adolescents and young adults can take ownership of their care management through knowledge of their illness, signs and symptoms, and information about their healthcare. Self-management is hindered by the opacity of timely access to their own medical records. Although empowerment evokes independence, structural conditions block young adults' agency to play their new social role.

Conflicting standards

Pediatrics is the first continuing care environment that young adults will have experienced from the time of their diagnosis until their transfer to adult care. This familiar environment becomes the benchmark that young adults will have for quality and expectations of care. Exposure to this environment for young adults with long-term health needs builds the constitution of what is considered normal for young adults. While pediatric HCPs have valued the expertise of young adults that was gradually built during their follow-ups in the pediatric setting, their transition to adult care challenges their knowledge. Increased knowledge of the pediatric setting by adult HCPs allows for an understanding of where young adults are coming from, their expectations of their transfer and follow-up care in the new setting, as well as an understanding of the responsibility issues that come from a different normal setting than adult care.

A dissonance between the operationalization of health services between pediatric and adult care stems from fundamental differences between the professional culture of the two settings. The lack of relationship resulting from the loss of relationship with the healthcare team has deleterious effects on the follow-up of AYAs. Much research has shown the importance of including parents and young adults in transition preparation and handoffs (Crawford et al., 2021). Young adults and their parents become unknown to and excluded from the healthcare system when they come from a background where they were known and included. The adult care environment, now more future-oriented – especially in regard to the complications of medical conditions – focuses on the condition itself and less on the relationship with young adults to create a long-term partnership.

Between recognition and confrontation of expertise

The conflict of norms leads to adjustments of the stakeholders involved in the same transition process in order to compensate for the normative upheavals induced by the passage between two organizational cultures and several professional cultures, which will then mutate in an attempt to build bridges that do not formally exist in the system. Different clinical groups manage conflict either by collaborating, compromising, avoiding, competing and accommodating (Özkan Tuncay et al., 2018). Depending on the groups of stakeholders, certain interactions and behaviors are legitimized by the stakeholders of the dominant groups or, on the contrary, invalidated. Thus, in order to go beyond the boundaries separating the care settings and facilitate the transition between these settings, an explicit negotiation of roles must be carried out in an attempt to overlap the environments, compensate for the lack of collaboration and cooperation between the stakeholders and make the transition less difficult for young adults and parents.

Negotiation of roles

Role negotiation serves as a modifying intervention in response to the ramifications of the structure of the system of care that, to a great extent, excludes the young adult population in the healthcare system. These findings showed that stakeholders negotiate their identities and thus their roles in the process of transitioning to adult care to override the caesuras between services. In this sense, young adults, for example, understand the implication of their transfer due to coming of age. The mismatch in HCPs' vision of collective identity triggers a role negotiation that reaches the expectations of the profession by the professionals themselves but also reaches the expectations of young adults and parents. This negotiation takes place through a combative discourse towards the organization, notably through the recognition of role restrictions imposed by the rigidity of the organizational structure. Expectations – without the knowledge of each other's roles and responsibilities – form the role negotiation of the stakeholders involved in the transition to adult care. This structure, which excludes the young adult population on the one hand, does not formally incorporate the means to bridge the system discontinuities created by the exclusion of young adults from the care system.

Extensions of professional boundaries and collective identity

Health professionals, then, extend their mandates to enable continuity of care for young adults, overlapping with the roles and responsibilities of other stakeholders considered inactive or less legitimate by the dominant stakeholder groups, namely, pediatric and adult care specialists. The extension of their boundaries was seen as mechanisms to compensate for gaps in their own roles within the healthcare system or gaps in the roles of other stakeholders in the transition to adult care. Moreover, while role overlaps arise from these spillovers, they also arise from the demands of young adults and parents. The extension of professional boundaries represents a way for young adults and parents to reclaim vested healthcare rights in a familiar environment where power dynamics interfere little (if at all) with access to care received. To avoid disruption of care, parents become care coordinators to make the various transfers possible, primarily with the help of pediatric HCPs. This duplication of roles between parents and pediatric HCPs is done in partnership, thus opposing the lack of relationship between parents and adult HCPs. Parents, in reality, have little access to adult HCPs, which reinforces the exclusion of young adults as a recognized category in adult services (i.e., the reference services of the health system), and also materializes the downgrading of parents in the health system with respect to the care of their children.

Young adults become experts in their own health through exposure to pediatric follow-up and teaching of HCPs to young adults. It is well-recognized that patient engagement in their care can lead to various positive outcomes, including enhanced care processes and improved quality of life (Bombard et al., 2018). The evolution of their status as patient-actors aims to make young adults independent and thus to reach their adult status. However, their knowledge and agency development are challenged when they transfer to adult care. Sharing their knowledge with adult HCPs is hindered by a new power dynamic. Issues of power in group interactions related to knowledge and the recognition of that knowledge (whether scientific, experiential) intervene as pitfalls in the transition as young adults begin to define themselves as competent and knowledgeable about their condition and needs, sometimes in opposition to adult HCPs. For the AYAs, knowledge of the person is emphasized over medical knowledge, which becomes less imperative in light of the experiential knowledge gains that young adults have been able to develop during their follow-up in pediatric settings. These differences in the recognition and legitimacy of knowledge lead to a hierarchy of knowledge and to confrontations of expertise between the different stakeholders involved in the transition to adult care. The engagement of young adults in their care with adult health professionals depends on the relationship established between the two stakeholders and thus on the recognition of legitimacy that the stakeholders develop towards each other.

Lack of recognition and confrontation of expertise

The lack of recognition of particular stakeholders in the transition to adult care hinders the continuity of care. The necessary recognition of expertise is part of the mechanism for revisiting collective identities induced by the process of transition to adult care. The interactions between the stakeholders during the transfer allowed the stakeholders to understand the expectations that particular stakeholders have of the interactions in question. In this way, the inter-stakeholder relationship is either disrupted or strengthened to lead the transition to adult care. In addition, interactions between particular stakeholders can inform role overflows of other stakeholders fueling inter-group relationships under tension when one group has its role restricted by the actions of stakeholders from other groups. These tensions thus emanate from the understanding and operationalization of socially and symbolically prescribed roles compared to or related to roles acquired through negotiation and extension of professional boundaries. While stakeholders see themselves as members of the adult transition process, the recognition of other legitimate members according to the structure of the healthcare system materializes membership in the process and by extension inclusion in the process.

Various confrontations of expertise thus take place. Adult HCPs may also question the care provided by pediatric HCPs, particularly through dosage adjustments considered inappropriate by young adults. The tension that arises between the legitimacy given by the young adult to his or her treatment from pediatric care, on the one hand, and the legitimacy of the physician's role in managing the patient's treatment, on the other, actually pits three sets of expertise against each other: those of the pediatric HCPs, those of the adult HCPs, and those of the young adults themselves. Young adults are not recognized for their expertise by adult caregivers and question the role of adult HCPs in their care after transfer. The binary construction of childhood and adulthood within WEIRD societies has profound implications for healthcare transitions.

Recognizing children as active agents in their care and fostering collaborative relationships between pediatric and adult healthcare providers are essential steps toward improving the transition experience for young adults. By addressing these cultural and systemic barriers, healthcare systems can better support the needs of emerging adults, ultimately leading to improved health outcomes and patient satisfaction.

On the one hand, the lack of recognition of a group that considers itself legitimate and considered legitimate by the main group, creates tension and polarization of expertise. On the other hand, HCPs lacking legitimacy in the eyes of other stakeholders strengthen their position by basing their legitimacy according to their skills and perceived social usefulness. Legitimacy is based on normative principles of rationality and reinforces or questions the qualification of situation, of social and professional positioning (Guéguen, 2014). The question of the legitimacy of the professions in the transition to adult care highlights the distribution of the roles of health professionals and their respective environments according to the status of the patient, which is based on social categories derived from medicine. This implies an exploration of the structure of healthcare according to the social evolution of collective identities and less according to medical classifications.

While adult HCPs are involved by default according to system structure, primary care health professionals are excluded from the adult care transition pathway. System structure does not interact with the recognition of a population by a group of HCPs. The exclusion of primary care providers occurs in a changing context in which primary care faces several issues specific to the primary care mandate. The mandate of family physicians, as representatives of primary care, is to provide access to primary care, in other words, access to the healthcare system. In addition, family physicians are mandated to monitor populations for referrals to specialty care, represented by pediatric and adult care physicians. However, collaboration between HCPs is limited when a patient falls within a specialty. In this situation, the specialist becomes the primary physician treating the patient's condition. It is then that the recognition of generalist medicine, even as comprehensive medicine, is reduced by the cessation or quality of information transfer from specialists to generalists. Although healthcare access is a cross-cutting health system issue, the failure of the primary care system to meet the basic needs of the population acts as a catalyst for the exclusion of primary care providers in the transition to adult care. The condition under which the mandate can or cannot be fulfilled in the healthcare system according to institutional guidelines influences the interactions between healthcare stakeholders. In this case, family physicians are identifying mechanisms to overcome this hierarchy of social recognition of professions to assert their membership in the transition to care process for adults.

The inclusion and exclusion of groups of stakeholders according to the stages of the transition process to adult care makes it possible to foresee the involvement of stronger markers in the roles and responsibilities of each group of stakeholders. Indeed, although professional boundaries are involved in the complexity of the necessary inter-stakeholder collaboration in the integration of care, they are indispensable in the functioning of complex systems such as the health system (Nancarrow & Borthwick, 2005). The imposition and operationalization of professional norms assists in the division of labour and thus the advancement of the organizational mission. Interactions within the organization reveal the degree of adherence to professional norms and their effects on processes.

Emergence of new groups

The emergence of the young adult population induces shifts in the roles and responsibilities of the various stakeholders involved in the transition to adult care. The arrival of this growing population tends to restructure the system by means of redefining collective identity and overcoming professional and cultural boundaries. These mechanisms occur more in the context of a hierarchy of roles between groups of stakeholders, of which pediatric specialists and adult specialists are the main groups considered at the inter-organizational level of the transition to adult care. Expert patients and family physicians thus emerge as active members of the transition to adult care, through the mechanisms of transformation of their group's collective identities. Their involvement in the transition process and their location on the margins of other groups that confront the structural norms of adult care influence the emergent response of these groups. Primary care boundaries induce general practice that fits the primary care mandate based on population need. Yet the literature demonstrates the preventive effects of involving primary care providers in the continuum of care for populations such as adolescents (Toulany et al., 2019). The value of including family physicians in the transition to adult care stems from the proximity to the approach and models of care of pediatric settings, which are the settings normalized by young adults for healthcare. Valuing the profession is more relative, however, to the ability to add specializations in order to gain new social recognition of the profession, both with patients and with other health professionals in other specialties and fields (pediatric and adult care).

The hyperspecialization of professions and medicine leads to the re-mapping of health services with respect to emerging populations whose emergence is linked to new pathologies (through medical advances for rare genetic pathologies, for example, or through medicalization or depathologization, for gender transition issues, for example), or to a social group recognized as such (for example, young adults). In this vein, the specialization of care — which influences the nature of the health system and contributes to the difficulty of integrating care — is also a source of solutions to overcome the exclusion of certain groups. The different mechanisms of identity negotiation lead to the development of informal compensatory ways to transform the organizational structure and allow for the inclusion of young adults as specialized healthcare, recognizing the particularity of the needs of this population.

Informal work to compensate for the lack of institutionalization

Recognition of the interdependence between the stakeholders of the transition

Adult services are structured for patients independent of continuing care, whereas young adults have an interdependent relationship with services and HCPs over the long term. Indeed, the act of independence is relative to the young people's adult status, which is then relative to their development and maturity to understand the impact of their treatment and care. Such independence is only possible through interdependencies with HCPs in different settings and thus with the healthcare system. Independence is part of the expectations of adult HCPs for young adults, but this notion does not include the ongoing, long-term relationship that is necessary for young adults in their individual care. A contradiction between the independence and social status of the young adult reinforces the individual accountability of care to the young adult while minimizing the more collective accountability of the healthcare system. Thus, the interdependence of stakeholders runs counter to the promotion of independence that is fostered in the healthcare system, primarily in adult care. The discourse of healthcare professionals that emphasizes patient empowerment – that is, individual empowerment as opposed to collective responsibility – reinforces the normalization of these expectations for young adults, who are nonetheless dissociated from the adult status that is associated with this competence.

The degree of family involvement in transitional care impacted the young adult's ability to manage their care. These findings align with existing literature, which highlights the co-construction of care management between young people and their families (Spray & Hunleth, 2023). The identification of a person in the health system who provides a link to the health system is represented by primary care. However, the practical translation of this structure is difficult to achieve when young adults did not have an assigned family physician, at which time the referral person was part of pediatric care. In cases where the family physician was following the young adult, then based on his or her knowledge and network, a sense of connectivity with the healthcare system through the family physician was possible. In any case, information sharing is one of the mechanisms that can influence the continuity of care linking stakeholders in the same network (Burns et al., 2022). It reduces the impact of lack of collaboration on continuity of care, understood here as the coordination of care. However, the possibility of information transfer is largely dependent on structural and institutionalized circumstances.

Informality in the transition to adult care

Healthcare professionals establish specific transition pathways, such as through transition clinics, to build bridges between formally linked services. Indicators for monitoring the transition to adult care were identified as both clinical and non-clinical aspects that were perceived to influence the transition. Informality and lack of institutionalization again raise the question of the legitimacy of young adult care and the development of specialization in this area.

On the other hand, the space created by informal ways of working can be seen as reflective spaces for collective experiences among professionals that could not be realized in normalized work contexts. The transformative potential that could be induced by these spaces lies outside the normal work context (Lunkka et al., 2022). However, the development of transition programs and clinics is the work of health professionals perceived as leaders in their sector. Adult HCPs, while recognizing the particularity of the young adult population, consider the shift to adult care as an evolution in the prevailing approach to clinical care, whereas pediatricians (and family physicians) name the particularity of young adults as requiring a specific care pathway. Despite the interest in and enthusiasm for the young adult population, especially on the part of charismatic clinical leaders, organizational constraints (patient volume versus team and staff presence for formal and institutionalized care programs) were seen as impeding the participation of adult HCPs in transition programs.

Incomplete stages of interorganizational learning in the transition to adult care

The mechanisms of the stakeholders are derived from the sharing of knowledge at several levels: individual, team, organizational and inter-organizational. All of the mechanisms involved in the process of transition to adult care stem from the circulation of knowledge and the diffusion of resources. The health system is complex and adaptive, and changes according to the interactions that occur within its organizations. The interactions are based on the needs of the system to function. Functioning based on increasingly complex specializations requires knowledge sharing to enable the integration of care. Thus, the flow of knowledge within and between organizations reflects the difficulty of integrating care, particularly in light of contextual and institutional constraints on young people's transition to adult care.

Experiential, collective, organizational learning

Learning for health professionals occurs primarily on an individual basis and according to one's experience. This is the first level of learning for inter-organizational knowledge sharing. This type of learning, however, is related to what the stakeholder sees as consistent with those beliefs and values (Boerner, 2016). Beyond the experiential and the individual, formal knowledge related to the transition to adult care from the collective emanates mainly from the pediatric specialists and is transmitted to pediatric nurses who participate in the informal work, considering this knowledge then translated and incorporated into their practice. They thus follow a hierarchy rooted in the health system, allowing the application of certain elements mainly in a *top-down* flow. Collective knowledge exchange occurs according to the interest of pediatric specialists who either generate the new knowledge or absorb formal, codified knowledge from organizations outside the system (e.g., from local, national, or international scientific conferences or research groups). At the organizational level, little knowledge exchange and dissemination is seen to occur, making it difficult to share resources and duplicate services needed in the transition to adult care. This means that there is little expansion of the organizational exchange stage that accompanies individual learning. There is little evidence of diffusion of knowledge generated in one service to other services, which may in turn develop other knowledge that is maintained in silos.

Inter-organizational learning

Knowledge transfer and resource-sharing between organizations allows for inter-professional and inter-organizational collaboration. From the study of the mechanisms of transition to adult care, little evidence was seen of inter-organizational learning to allow for knowledge exchange between the groups of stakeholders in the complex yet adaptive health system. The extension of the professional boundaries of healthcare providers and parents leads to an extension of the symbolic and social boundaries of young adults' status. As the system moves through the interactions of its stakeholders, boundary distortions are emergent and operate in an informal context. The diffusion of resources between organizations in the system that can initiate stronger inclusion of new norms is difficult to achieve within and between organizations. The slowing of knowledge dissemination to anchor mechanisms beyond the pediatric sphere is influenced by a lack of specialization and recognition of the young adult category in the healthcare system.

To allow for the boundary overlap induced by the transition to adult care, interorganizational learning is expected, yet it was incomplete in the settings of this study. Owing to institutional constraints, there was relatively little flow of information and exchange of resources across the boundary between the pediatric and adult care sectors. It is indeed more difficult to transfer and circulate tacit or informal knowledge than formalized, codified knowledge. The type of knowledge that enables informal mechanisms is more complex to extract and materialize in formal processes (Kogut & Zander, 1996; Williamson, 1985). The capacity of an organization to disseminate and absorb knowledge is a determinant of its learning efficiency (Boerner, 2016; Griliches, 1991).

These notions related to the mechanisms of knowledge sharing with the intention of inter-organizational collaboration allow us to draw the steps to improve the transition to adult care.

While informal mechanisms are difficult to translate into explicit data that can become formalized, the documentation of even informal processes makes it possible to transform the knowledge generated by this process into explicit knowledge that becomes formal. In this vein, the monitoring of programs, their development and their effectiveness would make it possible to identify knowledge that is more easily transferable to the organizations in the system with which the collaboration is targeted. From this transfer, a systematization process can then be envisaged. Systematization of transitional care evaluation integrating clinical and non-clinical care would then prevent young adults from falling through the cracks and losing connection to the healthcare system. While adolescent medicine is included in pediatric care, young adult health is an emerging specialization, as are its standards. Informal work and knowledge mobilization across organizations are helping to shift the boundaries. The findings of this research demonstrate the importance of combining the voices and perspectives of stakeholders involved in the process.

Limitations

The research was undertaken in a single health system, comprising a children's hospital, an adult hospital, and primary care settings. Given the association between the children's and adult hospitals, there might be limitations of the transferability to other settings. Nevertheless, the research focused on broad issues of research, and had broad resonance with the literature. Therefore, the findings ought to be transferable to public urban acute care systems, the extent of transferability awaiting further research in other settings.

This work was carried out in an urban context in which organizational structures involved the presence of separate children's hospitals, adult hospitals, and primary care facilities. Although access to some structures was shown to be difficult in this context, transitions to adult care in rural and remote areas have more marked limitations depending on the resources available to the population, involving other complementary sectors of the health sector, such as transportation. Studies focused on these contexts could, therefore, provide a better understanding of the issues related to the organization of structures and the resulting interactions.

More stakeholders were identified as directly or indirectly influencing the transition to adult care. For example, in addition to health system organizations, stakeholders in other systems may influence young people's transition to adult care. In particular, the school or employment setting of young adults, through the willingness of these organizations to facilitate access to health services through freed-up time and insurance benefits. In addition, administrators of healthcare organizations (e.g., hospitals and clinics) as well as policy makers were identified as having decision-making power to enable the transformation of informal transitional programs and clinics into institutional elements, integrated into the organizational culture. These stakeholders were not consulted in this research as it focused on stakeholders directly involved in the transition pathway of young adults to their new services, especially looking at the healthcare system, without including other system that may be indirectly involved in the transition of AYAs, such as education, work, and finance.

Future research should involve such additional stakeholders identified in this work to help identify the levers of these other systems involved in the transition pathway. This research does, however, incorporate a diversity of voices, including the inclusion of young adults with chronic and complex healthcare needs, as well as the interdisciplinarity of care teams from different settings, particularly the pediatric setting. The development of the study also stems from a collaborative effort between researchers, clinicians, patient representatives and medical residents.

Theoretical benefits

Qualitative research plays a crucial role in understanding the experiences, perspectives, behaviours, and patterns involving the AYAs transition process' stakeholders. The transferability of findings from such research is essential in informing healthcare practices and policies to better support young people during this critical period of their lives. In doing so, theory plays a crucial role in bolstering the transferability of research findings by furnishing a conceptual framework that facilitates the extrapolation and application of insights across various contexts (Crotty, 1998). Theoretical foundation not only lends depth to research but also provides a lens through which phenomena can be transferred to other settings. By anchoring this research in the symbolic and social boundaries theory, the underlying mechanisms and dynamics inherent in the AYAs' transition to adult care process were elucidated. This theoretical grounding enabled discernment of key variables, relationships, and processes, thereby enhancing the potential for findings to possess relevance and applicability beyond the immediate research context.

Furthermore, theory-driven inquiry fosters systematic exploration, nurturing the accumulation of knowledge and facilitating cross-study comparisons. Understanding the commonalities and variations in experiences can inform the development of more tailored and effective support programs and interventions. Understanding of meanings and processes are crucial for intervention, beyond studies of outcomes, important though such work is. Drawing on the theory of symbolic and social boundaries, this research was able to illuminate the underlying elements of care coordination between services and organizations within the same system and the emergence of the integration of young adult care into the system by allowing for an understanding of the mechanisms influencing the transition of care. The symbolic and social boundary theory guiding this research was then complemented by concepts of inter-organizational learning to better understand the evolution of boundaries through learning, considering healthcare as a complex adaptive system. The engagement of a boundary perspective also enabled the study to position the phenomenon of transition to adult care as a case to highlight the informal work, the stages of inter-organizational learning and the immobilization of knowledge, and thus the lack of institutionalization of young adult care.

Conclusion

This research has shown that healthcare systems should be organized in ways that transcend reliance on the individual goodwill of social agents, instead embedding collective responsibility at the structural level. The current dissonance between the social accountability mission of healthcare—improving population health—and practices that exclude or socially downgrade unrecognized or marginalized populations highlights a critical need for systemic reform. This exclusion underscores the paradox of healthcare: its mandate to improve health is often constrained by the ideologies and conflicting neoliberal priorities that shape its operations, such as market-driven imperatives or resource limitations. As Foucault’s concept of governmentality illuminates, social systems function as a tool of both care and control, shaping populations according to prevailing political and economic logics (Foucault, 1990b, 2003). Healthcare is no exception. To fulfill its mission effectively, healthcare must move beyond the promoted individualization of responsibility to a model based on collective accountability. This shift would enable healthcare to address systemic inequities and better align its practices with its stated goal of advancing health for all. By prioritizing inclusivity and equity, healthcare can better fulfill its role as a cornerstone of societal well-being.

The growing neoliberalization of healthcare reflects broader cultural and economic transformations that disproportionately shift responsibility for structural inequities onto marginalized groups, including adolescents, individuals with disabilities, women, and people of color (Ahlberg et al., 2019; Baru & Mohan, 2018; Sakellariou & Rotarou, 2017). This shift not only obscures the systemic nature of healthcare disparities but also reinforces mechanisms of blame and exclusion (Charmaz, 2020). At the same time, adults are not immune to these systemic challenges, which similarly disempower and infantilize them. Such realities underscore the urgent need for systemic interventions that institutionalize collaborative care models and elevate the role of primary care and family medicine. To address the unique needs of adolescents with chronic conditions, primary care professionals require robust support systems to develop the expertise necessary to manage these conditions, which often extend into adulthood due to improved post-childhood survival rates (Allen et al., 2022; Chafe et al., 2019). Such support structures must also work to dismantle oppressive social reproduction, challenge ageist assumptions, and promote the empowerment of children and adolescents as full citizens within society.

The perspective of symbolic and social boundaries has highlighted the development of informal work in a formal environment framed by norms and regulations at different levels that exclude particular groups. The exclusion of certain groups of people who can no longer receive adequate care in the health system constitutes social disorganization. Such disorganization itself modifies the structural boundaries of the health system, notably by providing space and developing alternative paths to conventional ones. The lack of integration of care allowing the linkage between services from different organizations can be explained by the stagnation of knowledge at the service level constituting a failure of the transfer of knowledge across organizational and inter-organizational boundaries.

The findings of this research can inform policy makers in the processes of institutionalization of transition services to adult care, including consideration of transition trajectories, for example, by indicating the development of transition corridors. The findings also confirm the need for health system policies to invest in information-sharing processes in order to foster care coordination. In addition, these findings can guide educators in fostering adolescent health competencies through various means, such as systematic and mandatory pediatric rotations during medical residency, or the development of case studies on transition to adult care in health professional curricula across specialties and professions (e.g., through the development of interprofessional teams in the development of transition plans to adult care). Finally, through the findings, healthcare professionals and service managers will be able to systematically evaluate the transition process (at each phase) to track indicators of transition success. Future research is needed to validate any emerging multi-perspective assessment tool, as well as to undertake ongoing research of informal healthcare service delivery, improvement and learning.

Chapter IX. Conclusion

Introduction

To conclude this work, the main findings will be aligned as specific implications for research, policy and practice. The recommendations that emerge from this work stem from the theoretical foundation that guided this research. Indeed, the use of a socio-constructivist approach and an interpretive paradigm to investigate the transition from pediatric to adult care gives the findings a capacity for transferability to other similar contexts. Furthermore, the analysis of the transition to adult care phenomenon in light of symbolic and social boundaries will have enabled identification the meanings and processes implicated in the coordination and continuity of chronic care across several organizations, services, and with several stakeholders.

In this work, therefore, I explored the evolution of the social groups involved in the phenomenon of transition of care for adolescents living with a chronic condition. This dissertation highlighted the tensions that exist in the navigation of the healthcare system established according to a hyperspecialization of professions and sectors, the role negotiations of the stakeholders in the transition process and the informal means adopted to reconcile the discontinuities of the healthcare system interfering in the transition process. The establishment of social groups through the creation of boundaries, whether symbolic or social, influences the social structure while contributing to its disorganization. In the healthcare system, the boundaries that make up the system and that have been presented in this work have highlighted the overlapping issues necessary for continuity of care.

This work has shown the different stages of emergence of new social boundaries propelled by the arrival of a new group in a system. The health system that does not have a space dedicated to adolescents and young adults sees its structure disrupted by the emergence of this undefined group, which is in-between the main and recognized category of population, i.e. children and adults. Thus, the stakeholders, after renegotiating their role and position in the system, create new spaces to provide specialized care to this new group. However, in doing so, limitations in the dissemination of informal knowledge and skills impeded the integration of various stakeholders from different organizations. The lack of sharing of resources and knowledge across the boundaries of a service's multidisciplinary teams thus limits the coordination and continuity of care across the organizational structure, and thus at the inter-organizational level.

This work offers an original reading of the transition to adult care. While this recent field is often studied from a perspective that is comparatively interdisciplinary, the contribution of an inclusive vision of the stakeholders called upon to interact in the transition process makes it possible to broaden the scope of the findings and implications. The sociological approach – focused on the mechanisms of this phenomenon – highlighted the multi-level influences that contribute to the interactions of the stakeholders hindering or facilitating the transition to adult care. In fact, to compensate for the theoretical gap in this field, the application of an analytical grid including symbolic and social boundaries will have allowed to account for the multi-dimensional aspects. The findings allowed for the recognition of the issues and the workings by including them in this analysis of the transition of care to give a more complete overview of the phenomenon. This input brings out practical applications for the different stakeholders in the process. In addition, this dissertation provides a reading of inter-personal, inter-professional and inter-organizational collaboration mechanisms. Finally, the findings allow us to appreciate the contribution of the theory of symbolic and social boundaries in the study of adolescent healthcare, and collaborative work in healthcare more broadly.

Application of the findings

The findings highlight social and professional challenges. The structure of the healthcare system tends to exclude social groups that are not legitimized by its norms. This work focused on transition mechanisms that require continuity of care including the necessary coordination of care and collaboration between and within organizations and the professionals and other stakeholders involved. This section outlines potential practical applications of the findings for every stakeholder group engaged in the transition care process of adolescents and young adults.

For patients and parents/guardians

Young adults are an emerging population in healthcare. Still poorly understood and integrated, findings point to their abrupt transition that does not take into consideration young adult development. The shift in responsibility occurs during the transition to adult care, including the new status of the young adult reaching age 18. The conflation of the symbolism of age of majority and adult status prevails in the healthcare system. Preparing young adults for their transition is an important part of the process, beyond a readiness questionnaire. In addition, a better understanding of the mechanisms involved in the transition to adult care contributes to the preparation of adolescents and young adults' transition process to new healthcare services. The different trajectories as well as the transition tracking indicators allow for monitoring of the transition and the elements that influence its course.

Recommendations for practice and *research* – Patients and parents/guardians

One-year overlapping follow-up:

- For AYAs transitioning from pediatrics to adult care settings, allow for an overlapping follow-up by pediatrics care services throughout the 18th year of age.
- *Investigation of the effectiveness of extended follow-up period in terms of health outcomes, patient satisfaction, cost and continuity of care.*
- *Qualitative research methods such as interviews or focus groups will give voice to the perspectives of AYAs, parents, and healthcare providers regarding the importance and feasibility of overlapping follow-up care.*

Self- management learning:

- Prepare AYAs for self-management using pedagogical tools adapted to different level of maturity, such as serious games.
- *Evaluating the effectiveness of serious games in enhancing health literacy, promoting self-management skills, and improving engagement among AYAs.*
- *Comparative studies assessing the impact of game-based learning versus traditional patient education on health outcomes and healthcare utilization among AYAs would*

provide empirical evidence to support the integration of such tools into transitional care programs.

- *Qualitative research, including participant observation or focus groups, would explore AYAs' experiences with serious games, their preferences for different types of educational interventions, and perceived barriers to engagement, to inform the development of future game-based learning tools.*

Continuous Tracking Indicators for Seamless Transition in Healthcare:

- Implement systematic tracking indicators throughout the transition process, starting before the transfer between services and continuing after transfer is completed.
- *Longitudinal studies tracking AYAs' healthcare experiences and health status before, during, and after the transition process could provide valuable insights into the benefits and challenges to improving transitional care performance indicators.*
- *Collaboration with healthcare organizations to implement and evaluate tracking systems in real-world settings could enhance the generalizability and applicability of research findings to clinical practice.*
- *Assess the tracking indicator tools presented in this research, tailored to different stages of the transition process, considering factors such as patient demographics, clinical characteristics, and healthcare system variables.*
- *Longitudinal studies utilizing these tracking indicators could assess the impact of transitional care interventions on various outcomes, such as healthcare utilization, continuity of care, and patient satisfaction.*
- *Mixed-methods research designs integrating quantitative tracking data with qualitative insights from stakeholders could provide a constructivist understanding of the transition experience and identify areas for improvement in transitional care practices.*

For healthcare professionals and educators

Conflicting norms among the different organizations demonstrated, among other things, a lack of knowledge of professional roles and responsibilities among the stakeholders. Greater visibility of the roles and responsibilities of the stakeholders involved in the adult care transition pathways would clarify the common goal and allow for the perception of the added value of broader collaboration, particularly with the inclusion of primary care providers in the process.

These findings provide an opportunity to reorient the preparation and training of health professionals to follow cases of transition to adult care, on the one hand, and to better understand the specific needs of young adults, which differ from the needs of children and adults, on the other. Greater recognition of the expertise of different professionals may help better identify, as a basis for mitigating, the power dynamics between the different stakeholders involved in the transition. Difficulties in getting buy-in from stakeholders in the development of transition programs and clinics – particularly adult care providers in transition clinics developed in pediatric settings – raises the need for co-leadership to enable the inclusion of adult care providers in the development of these means to achieve inter-organizational collaboration and coordination of transition care.

Finally, the findings show the importance of interest and specialization for adolescents and young adults in facilitating both knowledge transfer, collaboration, interpersonal relationships with young adults, adherence to adult care transition clinics and programs, and informal network development. All of these elements can be strengthened by fostering communities of practice that bring together the stakeholders who are directly or indirectly involved in the adolescent transition care process. The array of stakeholders involved in this process underscores the complexity of transitioning to adult care, encompassing diverse professions, specialties, and care sectors such as young adults, parents, healthcare professionals, educators, students, policy makers, and researchers.

Recommendations for practice and *research* – <u>Healthcare professionals and educators</u>

Enhanced visibility of stakeholder roles and responsibilities:

- Develop clear documentation outlining the ideal roles and responsibilities of stakeholders involved in adult care transition pathways.
- Implement regular meetings or workshops to educate stakeholders about each other's roles and how they do and can contribute to the transition process.

- Utilize visual aids or infographics to simplify complex organizational structures and roles.
    - *Conduct a systematic review of stakeholders' roles and responsibilities to inform the development of best practice guidelines.*

Co-leadership for transition program development:

- Develop and implement co-leadership models that involve both pediatric and adult care providers in the development of transition programs and clinics.
- Facilitate joint decision-making processes to ensure the inclusion of perspectives from both pediatric and adult care settings.
- Provide training on collaborative leadership approaches to professionals involved in transition program development.
    - *Evaluate the effectiveness of co-leadership models in fostering collaboration between pediatric and adult care providers.*
    - *Assess the impact of co-leadership on the development, implementation, and outcomes of transition programs.*

Communities of practice for knowledge transfer and collaboration:

- Foster communities of practice comprising stakeholders involved in adolescent transition care.
- Facilitate knowledge sharing, collaboration, and network development within this community. Organize regular meetings, seminars, or online forums to encourage interaction and exchange of best practices.
    - *Examine the influence of community of practice initiatives on knowledge transfer, collaboration, and interpersonal relationships among stakeholders.*
    - *Measure the effectiveness of communities of practice in improving adherence to transition clinics and programs, as well as in facilitating informal network development.*

For organizations

Care trajectories and indicators that emerged from this study can in a practical way guide more formal transition to adult care interventions by ensuring the availability of resources and the integration of stakeholders from other organizations. As this study showed, formal institutionalization is the indispensable structural intervention and influence that is needed to support health service boundary-cross in the direction of aligning with the complexity of AYAs' needs. The extension of professional boundaries and the development of informal means to enable transition to adult care can act as avenues for the production and dissemination of new knowledge. Formalizing knowledge to facilitate its exchange and dissemination beyond the organizational structure is necessary and can thus enhance inter-organizational learning and by extension inter-organizational collaboration.

Recommendations for practice and *research* – <u>Organizations</u>

Care trajectories and follow-up indicators:

- Implement and sustainably resource an adolescent care service, and a transitional care clinic.
- Incorporate identified care trajectories and follow-up indicators into the development of formal transition to adult care interventions.
- Ensure that resources are allocated based on these trajectories to adequately support transition processes.
- Involve stakeholders from various organizations to provide comprehensive support and continuity of care.
- ▪ *Explore ethnographically the factors that influence the way HCPs, AYAs and families respond to institutional structures in relation to transition, and their innovations and workarounds to improve transitional care.*
- ▪ *Investigate the effectiveness of formal transition to adult care interventions guided by care trajectories and follow-up indicators. Assess outcomes such as patient satisfaction, continuity of care, and health outcomes to determine the impact of these interventions.*

Inter-organizational collaboration:

- Encourage joint initiatives and projects that involve stakeholders from different organizations.
- Foster a culture of cooperation through shared training programs or cross-organizational events.
- ▪ *Investigate how power dynamics affect decision-making, collaboration, and the overall success of transition programs.*

Knowledge exchange and dissemination:

- Establish formal mechanisms for documenting and sharing transition-related knowledge across organizations.
- Develop standardized protocols or guidelines to facilitate the exchange of information and best practices.
- Implement training programs to ensure stakeholders are equipped with the necessary skills to participate in knowledge exchange activities.
  - *Investigate how formalized knowledge exchange processes enhance inter-organizational learning.*
  - *Measure the impact of knowledge formalization on improving collaboration and coordination between organizations involved in transitional care.*
  - *Assess the long-term effects of knowledge exchange and dissemination initiatives on inter-organizational collaboration.*
  - *Explore how efforts to foster sustained collaboration relate to improved transition experiences and outcomes for patients.*

For the healthcare network

Orphaned trajectories hinder the transition to adult care and restrict continuous care provision, necessitating a redefinition of services to include linkages between pediatric, adult, and community care. This change is essential to ensure continuity of care for young adults beyond their transfer from pediatric services. The implementation of clinics and programs requires inter-organizational buy-in and formal structural interventions. The agency of strong formal interventions would be needed to begin to rebalance power in favour of AYAs by expanding the learning and change capacities of service and professional boundaries. This work has highlighted the organizational constraints related to the management of resources in the network, which impede optimal involvement of relevant stakeholders. In addition to the concepts and recommendations presented so far, the advancement of information systems, particularly for the exchange of patient data, is a central element of continuity of care and deserves the attention of policy makers in health system networks.

Recommendations for practice and *research* – <u>Healthcare network</u>

Redefinition of services for continuity of care:

- Collaborate with stakeholders to redefine services that facilitate linkages between pediatric, adult, and primary and community care.
- Develop complexity-informed integrated care models that ensure seamless transition and continuity of care for young adults beyond the transfer process.
- Implement protocols or pathways to address orphaned trajectories and provide necessary support for those who fall through the gaps.
- *Investigate the influence of redefined services on the continuity of care for young adults transitioning from pediatric to adult care settings.*
- *Assess patient outcomes, satisfaction levels, and healthcare utilization patterns under the new service models.*

Inter-organizational buy-in:

- Address organizational constraints by fostering learning collaboratives to share local innovations, open communication, negotiating resource allocation, and establishing shared goals and objectives across organizations.
- Develop partnerships and alliances to leverage resources and expertise across organizations.
- *Evaluate the effect of strategies aimed at securing inter-organizational buy-in for transition clinics and programs.*
- *Explore barriers and facilitators to collaboration and cross-service learning, to identify best practices for overcoming organizational constraints and build collaborative capacity.*

Advance information systems for data exchange:

- Advocate for the advancement of information systems to facilitate the exchange of patient data between pediatric and adult care settings.
- Invest in interoperable electronic health record systems that allow for seamless transfer of patient information.

- Collaborate with policymakers to prioritize the development and implementation of information systems that support continuity of care.
    - *Investigate how enhanced information systems influence continuity of care across care transitions.*
    - *Measure the impact of improved data exchange on care coordination, patient safety, and healthcare quality.*

Conclusion

In view of the findings of this work, important mechanisms influencing the transition to adult care have been put forward and interpreted in relation to previous research. The formal and implicit organizational structures that underpin these mechanisms are rooted in hyperspecialization. The integration of care is idealized as a model of the development of healthcare services in health systems to respond to the segmentation of care that hyperspecialization involves. This sociological examination of the transition to adult care, which represents the complexity of integration of care, with the involvement of multiple professions, services, and organizations, at a time when the population is moving from a well-defined category to a fuzzy one, contributes to the current literature on adolescent care and healthcare interdisciplinarity and interprofessionalism.

This research brought together the voices of the various stakeholders involved in the complex process of transition to adult care. Engaging in interdisciplinary development, this work paves the way for future work to strengthen interprofessional and interdisciplinary collaborations. This work examined the mechanisms employed by stakeholders involved in the transition to adult care using symbolic and social boundary theory. This sociological framework was able to highlight complex mechanisms interacting at different micro, meso and macro levels that reveal conflicts of norms between health structures creating shifts in social responsibilities; transformations of stakeholders' roles that evoke a crossing of professional boundaries and the tensions inherent in this crossing; informal work that highlights the emergence of specialized care for young adults; a limit in knowledge dissemination at the organizational and inter-organizational levels that hinders inter-organizational collaboration and by extension the continuity of care. The demonstration of the interactional, rather than fixed, character of professional and service boundaries highlighted the importance of structural interventions to optimize inter- and intra-boundary learning capacity, to better service adolescents and other marginalized and vulnerable populations.

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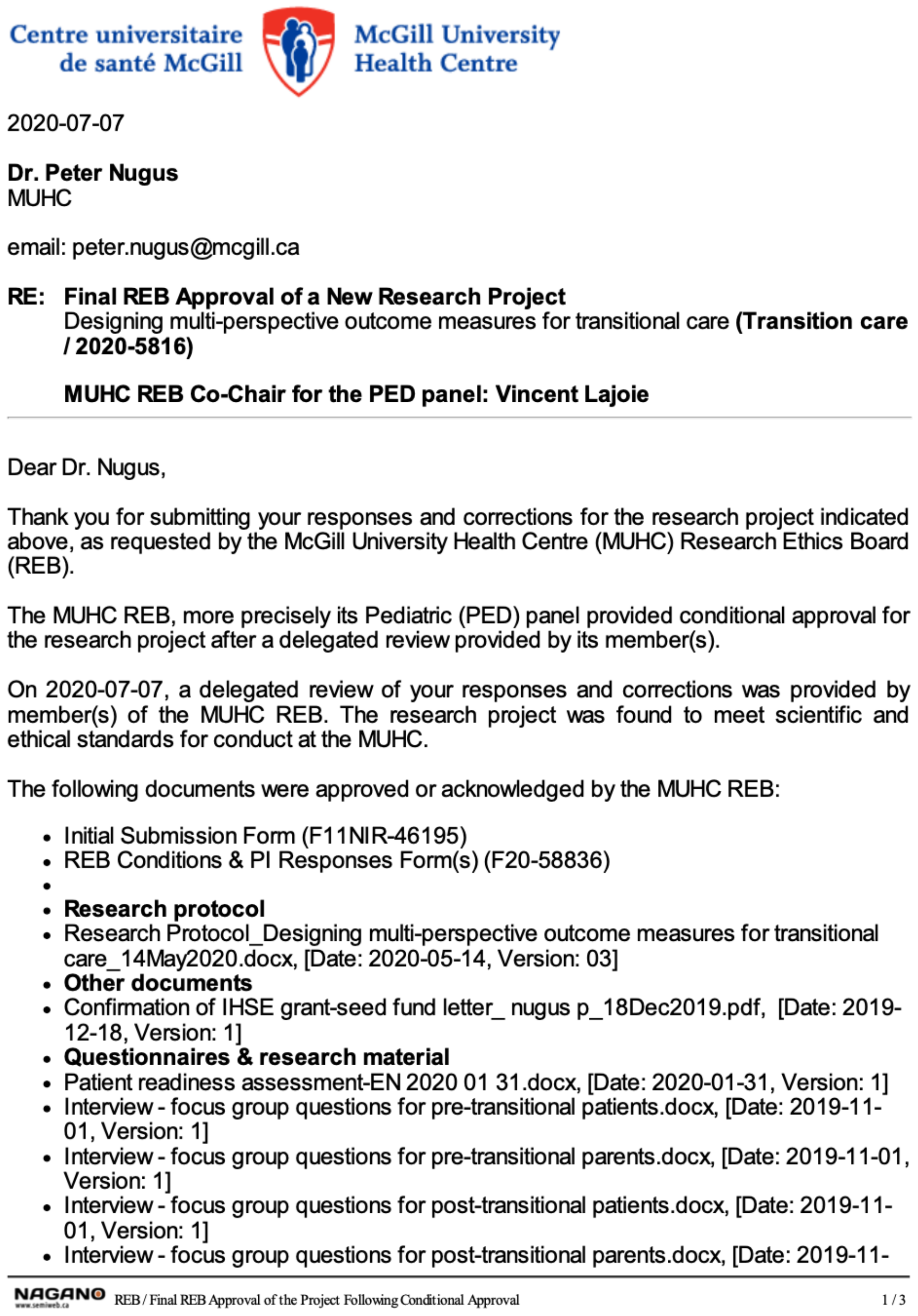
Appendices

A. Letter of approval from the MUHC Research Ethics Board



Centre universitaire
de santé McGill
McGill University
Health Centre

2020-07-07

Dr. Peter Nugus
MUHC

email: peter.nugus@mcgill.ca

RE: Final REB Approval of a New Research Project
Designing multi-perspective outcome measures for transitional care **(Transition care / 2020-5816)**

MUHC REB Co-Chair for the PED panel: Vincent Lajoie

Dear Dr. Nugus,

Thank you for submitting your responses and corrections for the research project indicated above, as requested by the McGill University Health Centre (MUHC) Research Ethics Board (REB).

The MUHC REB, more precisely its Pediatric (PED) panel provided conditional approval for the research project after a delegated review provided by its member(s).

On 2020-07-07, a delegated review of your responses and corrections was provided by member(s) of the MUHC REB. The research project was found to meet scientific and ethical standards for conduct at the MUHC.

The following documents were approved or acknowledged by the MUHC REB:

- Initial Submission Form (F11NIR-46195)
- REB Conditions & PI Responses Form(s) (F20-58836)
-
- **Research protocol**
- Research Protocol_Designing multi-perspective outcome measures for transitional care_14May2020.docx, [Date: 2020-05-14, Version: 03]
- **Other documents**
- Confirmation of IHSE grant-seed fund letter_ nugus p_18Dec2019.pdf, [Date: 2019-12-18, Version: 1]
- **Questionnaires & research material**
- Patient readiness assessment-EN 2020 01 31.docx, [Date: 2020-01-31, Version: 1]
- Interview - focus group questions for pre-transitional patients.docx, [Date: 2019-11-01, Version: 1]
- Interview - focus group questions for pre-transitional parents.docx, [Date: 2019-11-01, Version: 1]
- Interview - focus group questions for post-transitional patients.docx, [Date: 2019-11-01, Version: 1]
- Interview - focus group questions for post-transitional parents.docx, [Date: 2019-11-

01, Version: 1]

- Interview - focus group questions for health professionals.docx, [Date: 2019-11-01, Version: 1]
- **Approval of the Department / Division Head**
- Dr. Shevell_Approval of department head template_v2018-03-02 2.pdf, [Date: 2020-05-14]
- **Approval of the Department / Division Head**
- Approval of Departmental Chair_MMC-PN.pdf, [Date: 2020-05-22]
- **Information & consent form**
- ICF HCP REB review_14May2020_REBapproved.docx, [Date: 2020-05-14, Version: 03]
- ICF PARENTS_GUARDIANS_14May2020_REBapproved.docx, [Date: 2020-05-14, Version: 03]
- FIC Professionels de la santé_14mai2020_REBapproved.docx, [Date: 2020-05-14, Version: 01]
- FIC Parents ou tuteurs_14mai2020_REBapproved.docx, [Date: 2020-05-14, Version: 01]

This will be reported to the MUHC REB and will be entered accordingly into the minutes of the next PED meeting. Please be advised that you may only initiate the study after all required reviews and decisions are received and documented and you have received the MUHC authorization letter.

The approval of the research project is valid until 2021-07-06.

All research involving human subjects requires review at recurring intervals. To comply with the regulation for continuing review of at least once per year, it is the responsibility of the investigator to submit an *Annual Renewal Submission Form* (F9) to the REB prior to expiry. Please be advised that should be protocol reach its expiry before a Continuing review has been submitted, the data collected after the expiry date may not be considered valid. However, should the research conclude for any reason prior to approval expiry, you are required to submit a *Completion (End of Study) Report* (F10) to the board once the data analysis is complete to give an account of the study findings and publication status.

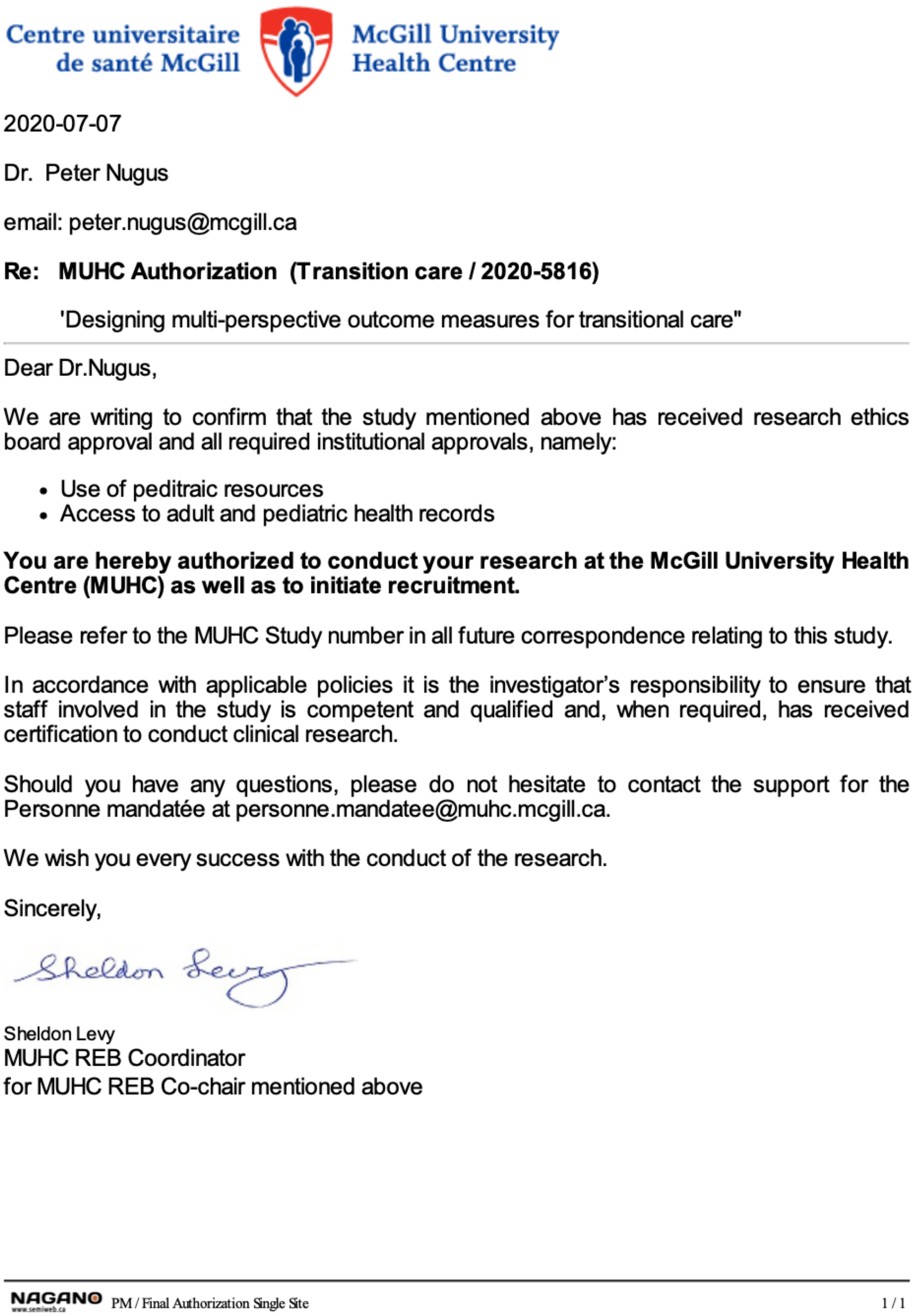
Furthermore, should any revision to the project or other development occur prior to the next continuing review, you must advise the REB without delay. Regulation does not permit initiation of a proposed study modification prior to its approval by the REB.

The MUHC REB is registered and works under the published guidelines of the *Tri-Council Policy Statement 2*, in compliance with the *Plan d'action ministériel en éthique de la recherche et en intégrité scientifique* (MSSS, 1998) and the *Food and Drugs Act* (2001.06.07), acting in conformity with standards set forth in the (US) *Code of Federal Regulations* governing human subjects research and functioning in a manner consistent with internationally accepted principles of good clinical practice.

We trust this will prove satisfactory to you. Thank you for your consideration in this matter.

Best Regards,

Ms. Elizabeth Craven, Coordinator, MUHC REB
MUHC REB Coordinator
for MUHC Co-chair mentioned above



Centre universitaire de santé McGill
McGill University Health Centre

2020-07-07

Dr. Peter Nugus

email: peter.nugus@mcgill.ca

Re: MUHC Authorization (Transition care / 2020-5816)

'Designing multi-perspective outcome measures for transitional care"

Dear Dr.Nugus,

We are writing to confirm that the study mentioned above has received research ethics board approval and all required institutional approvals, namely:

- Use of peditraic resources
- Access to adult and pediatric health records

You are hereby authorized to conduct your research at the McGill University Health Centre (MUHC) as well as to initiate recruitment.

Please refer to the MUHC Study number in all future correspondence relating to this study.

In accordance with applicable policies it is the investigator’s responsibility to ensure that staff involved in the study is competent and qualified and, when required, has received certification to conduct clinical research.

Should you have any questions, please do not hesitate to contact the support for the Personne mandatée at personne.mandatee@muhc.mcgill.ca.

We wish you every success with the conduct of the research.

Sincerely,

Sheldon Levy

Sheldon Levy
MUHC REB Coordinator
for MUHC REB Co-chair mentioned above

B. Interview Guide for Young Adults

Interview questions for post-transitional <u>patients*.</u>

*(This Guide is provisional and will be modified, as appropriate throughout the study)

Interview questions <u>for post-transition patients*.</u>

***(This guide is provisional and will be modified as appropriate throughout the study)**

Thank you very much for participating in our study. We were wondering if you could please read this consent form and, if you are willing to participate, please sign it.

Thank you very much for participating in our study. We were wondering if you could read this consent form and, if you are willing to participate, please sign it.

1. How have you found your experience of transition from pediatric to adult services?
   How have you found your experience of transition from pediatric to adult services?
      Why? Please explain. Tell me more....
      Why is this? Can you explain, tell me more?

2. What was your worst experience of transitioning from pediatric to adult care?
   What was your worst experience of transitioning from pediatric to adult care?
      Why? Please explain. Tell me more....
      Why is this? Can you explain, tell me more?

3. What were you most afraid of before you transitioned?
   What were you most afraid of before you transitioned?

4. What was your best experience?
   What was your best experience?
      Why? Please explain. Tell me more....
      Why is this? Can you explain, tell me more?

5. What do you wish would have happened differently?

   What do you wish had happened differently?

6. What advice would you give to other patients about making the transition?

   What advice would you give to other patients about making the transition?

7. How could this advice best be passed on to others?

   How could this advice best be passed on to others?

8. Who do you talk to about your health challenges?

   To whom do you talk about your health challenges?

   Who would you like to talk to?

   Who would you like to talk to?

   Would you like to meet and talk with others in your situation?

   Would you like to meet and talk with others in your situation?

   How would you like to do this? Eg. online? Meeting in the hospital? Meeting somewhere else?

   How would you like this to be done? Eg. Online? Meeting in the hospital? Meeting somewhere else?

9. What advice would you give to medical students/healthcare professionals about managing transition of care?

   What advice would you give to medical students/healthcare professionals about managing transition of care?

10. What would a successful transition to adult care look like to you?

    What would a successful transition to adult care look like to you?

11. What would a bad transition to adult care look like to you?

    What would a bad transition to adult care look like to you?

Prompt: What do you recommend as outcome indicators for successful transition to adult care?

What do you recommend as outcome indicators for successful transition to adult care?

12. Do you have any other thoughts or comments?

    Do you have any comments or are there any points we haven't covered that you would like to add?

Interview questions for pre-transitional patients*.

*(This Guide is provisional and will be modified, as appropriate throughout the study)

Interview questions for pre-transition patients

***(This guide is provisional and will be modified as appropriate throughout the study)**

1. What comes into your mind when you think about moving from pediatric to adult care?
   What comes into your mind when you think about moving from pediatric to adult care?

2. When did people start talking to you about transition?
   When did people start talking to you about transition?

3. What were you told?
   What have you been told?

4. What do you think will happen?
   What do you think will happen?

5. Have you done anything so far to get ready for transition? If so, what?
   Have you done anything so far to prepare for the transition? If so, what?

6. What do you hope will happen when you transfer to adult care?
   What do you hope will happen when you transition to adult care?

7. What are your worries or fears?
   What are your concerns or fears?

8. What help do you think you and your parents need to be ready for adult care? Any specific information?

What help do you think you and your parents need to be ready for adult care? Specific information?

9. How ready do you feel?

   How ready do you feel?

   Prompt: What might help you feel more ready?

   ***Elaboration*: What would help you feel more prepared?**

10. What help or information have you had from your nurses and doctors to help with transition?

    What help or information did you receive from your nurses and doctors to help with the transition?

11. Is there anything else you would like to have help before transition?

    Is there anything else you'd like to have help with before the transition?

12. What would a successful transition to adult care look like to you?

    What would a successful transition to adult care look like for you?

13. What would a bad transition to adult care look like to you?

    What would a poor transition to adult care look like for you?

    Prompt: What do you recommend as outcome indicators for successful transition to adult care?

    ***Elaboration*: What do you recommend as outcome indicators for successful transition to adult care?**

14. Do you have any other thoughts or comments?

    Do you have any comments or are there any points we haven't covered that you would like to add?

C. Interview Guide for Parents

Interview questions for parents/guardians*.

*(This Guide is provisional and will be modified, as appropriate throughout the study)

Interview Questions for Parent/Guardians*.

***(This guide is provisional and will be modified as appropriate throughout the study)**

Thank you very much for participating in our study. We were wondering if you could please read this consent form and, if you are willing to participate, please sign it.

Thank you very much for participating in our study. We were wondering if you could read this consent form and, if you are willing to participate, please sign it.

1. How have you found your experience of transition from pediatric to adult services?
   How did you find the experience of transitioning from pediatric to adult care?
      Why? Please explain. Tell me more....
      Why is this? Could you explain?

2. What was your worst experience of transitioning from pediatric to adult care?
   What was the worst experience/worst moment of this transition?
      Why? Please explain. Tell me more....
      Why is this? Could you explain?

3. What were you most afraid of pre-transition?
   What was the most frightening thing to you before the transfer to adult care?

4. What was your best experience?
   What would be the best experience/time?
      Why? Please explain. Tell me more....
      Why is this? Could you explain?

5. What would you like to have been done differently?

Would you have liked something different to happen?

6. What advice would you give to parents of children about making the transition?
   What advice would you give to parents of youth who are being transferred to adult care?

7. How could this advice best be passed on to others?
   How could we give this advice? Through what means?

8. Who do you talk to about your child's health challenges?
   Who do you talk to about your child's health challenges?
   - Who would you like to talk to?
     Who would you like to talk to?
   - Would you like to meet and talk with others in your situation?
     Would you like to meet and talk with others in your situation?
   - How would you like to do this? Eg. online? Meeting in the hospital? Meeting somewhere else?
     How would you like this to be done? Eg. online? Meeting in the hospital? Somewhere else?

9. What advice would you give to medical students/healthcare professionals about managing transition to adult care?
   What advice would you give to medical students who are going to be following youth who are going to be transferred to adult care?

10. What would a successful transition to adult care look like to you?
    What would a successful transition look like to you?

11. What would a bad transition to adult care look like to you?
    What do you think is a failed transition?

Prompt: What do you recommend as outcome indicators for successful transition to adult care?

Are there any indicators that should be monitored for a successful transition? Which ones?

12. Do you have any other thoughts or comments?

    Do you have any comments or are there any points we haven't covered that you would like to add?

D. Interview Guide for Health Professionals

Interview for health professionals*.
*(This Guide is provisional and will be modified, as appropriate throughout the study)

Interview Questions for Health Professionals
***(This guide is provisional and will be modified as appropriate throughout the study)**

Thank you very much for participating in our study. We were wondering if you could please read this consent form and, if you are willing to participate, please sign it.

Thank you very much for participating in our study. We were wondering if you could read this consent form and, if you are willing to participate, please sign it.

1. What do you think is the biggest challenge patients and their families face in transition to adult care?
   What do you think is the biggest challenge patients and their families face in transition to adult care?

2. What is the biggest challenge for you as a health professional?
   - How is it different for different patients? By specialty? Patient age-group? Condition? Etc.

   What is the biggest challenge for you as a healthcare professional?
   - **How is it different for different patients? By specialty? Patient age group? Condition? Etc**.

3. What was your most challenging experience in the transition of patients from pediatric to adolescent care?
   - Why? Please explain. Tell me more...

   What has been your most challenging experience in transitioning patients from pediatric to adolescent care?
   - **Why is this? Can you please explain. Tell me more...**

4. What was your most pleasant experience?
   - Why? Please explain.

   What was your most enjoyable experience?
   - **Why is this? Please explain. Tell me more....**

5. What advice would you give to parents of patients who are about to make the transition?
   What advice would you give to parents of patients who are about to make the

transition?

6. What advice would you give to medical students or other healthcare professionals about managing patient transition?
   What advice would you give to medical students or other healthcare professionals about managing patient transition?

7. What have you learned about healthcare transition from pediatric to adult care?
   What have you learned about healthcare transition from pediatric to adult care?

8. How did you learn this?
   How did you learn this?

9. What do you still need to know?
   What do you still need to know?

10. How would you like education to be delivered?
    - Conference? Webinars? Meetings?
    - What topics should be delivered?

    How would you like to see education provided?
    - **A conference? Webinars? Meetings?**
    - **What topics should be addressed?**

11. How do we educate health professionals about the importance of transitions, and how to manage them in the best interests of patients?
    - How do you get people to know they need to know something?

    How do we educate healthcare professionals about the importance of transitions and how to manage them in the best interest of patients?
    - **How do you let people know that they need to know something?**

12. What do you wish you'd known as a medical student/healthcare professional student or earlier in your career that you didn't?
    What would you like to know as a medical student/healthcare professional student or earlier in your career that you didn't?

13. What would a successful transition to adult care look like to you?
    What would a successful transition to adult care look like to you?

14. What would a bad transition to adult care look like to you?
    What would a bad transition to adult care look like to you?

15. What do you recommend as outcome indicators for successful transition to adult care?
    What do you recommend as outcome indicators for successful transition to adult care?

16. Do you have any other thoughts or comments?
    Would you like to add anything or do you have any comments?