APPLYING CONCEPTUAL FRAMEWORKS TO STUDY HEALTHCARE TRANSITION

THE APPLICATION OF ACCULTURATION THEORY AND THE ICF FRAMEWORK TO STUDY THE TRANSITION PROCESS FROM PEDIATRIC TO ADULT HEALTHCARE GUIDED BY A KNOWLEDGE TRANSLATION APPROACH

By

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LAY ABSTRACT

Today, one in five Canadian children, adolescents, and young adults live with a chronic physical, developmental, behavioural or emotional condition that impact their developmental trajectories. Youth with chronic health conditions (YCHC) and their families find it difficult to go from pediatric to adult healthcare. Although the topic of transition is not new, YCHC and parents continue to experience barriers in the adult system for meeting their needs (e.g. fragmented services, accessibility to available services, and biomedical focus of healthcare to name a few). Moreover, research evidence is not reaching the people who need it most, YCHC and their parents, and they are not benefitting optimally from advances in research. Thus, research is needed to carefully examine the process of transition to better understand the underlying processes, to identify current knowledge gaps, and to facilitate knowledge mobilization. The overall aim of this thesis is on the application of theories (acculturation theory) and frameworks (International Classification of Functioning, Disability, and Health-ICF) to provide a new outlook and lens to unraveling the complexities and underlying processes of transition, which has not been examined before. The Knowledge to Action (KTA) framework is used to inform the research process and stakeholder consultation to facilitate knowledge mobilization. The goal is to ultimately produce meaningful and relevant outcomes for YCHC and those involved in the transition process. YCHC and other stakeholders (parents, healthcare providers, community partners, and policymakers) were consulted throughout all of the components of the thesis ensure their voices and needs were heard. Results from this thesis will bring new insights and knowledge to those involved in transition research and practice.

ABSTRACT

Background Although research in healthcare transition is not novel, youth with chronic health conditions (YCHC) and parents still struggle with this complex process. Currently, there is limited theoretically-driven studies to inform transition research. The key foundation of this thesis is on the integration and application of theories and conceptual frameworks to studying the complexities of the transition process to inform research on a conceptual level. ***Purpose*** Three study objectives were: 1) to gain a better understanding of the experiences of YCHC, parents, and healthcare providers with self-management during the transition process; 2) explore theoretical frameworks to guide research in transition and inform the planning and delivery of holistic transition services that is developmentally appropriate and culturally sensitive; and 3) to identify strategies to facilitate knowledge mobilization in transition**.** ***Methods*** This "sandwich thesis" includes four individual scholarly works (Chapters 2-5) positioned between the introduction (Chapter 1) and the conclusions (Chapter 6). The Knowledge to Action (KTA) framework was used to framed all of my four scholarly works together. Chapter 2 was a qualitative study to examine the collective experiences YCHC, parents, and healthcare providers with self-management during transition. Chapter 3 was a critical appraisal of the literature to explored the potential application of acculturation theory in transition through the use of a clinical vignette. Chapter 4 was a scoping review about the current use of the ICF and transition research and practice. Chapter 5 was a demonstration project with the primary aim of working with youth (i.e. university students with and without a disability) and researchers to identify engagement strategies in research to develop partnerships to facilitate knowledge mobilization. ***Results*** Key findings of Chapter 2: i) the process of self-management is interconnected and interdependent between YCHC, parents, and healthcare providers, and ii) results began to

uncover cultural nuances between pediatric and adult healthcare. Key findings of Chapter 3: i) acculturation theory provides a concrete conceptual framework to guide thinking about the process of change within an individual with a change in culture to another; and ii) acculturation can become a natural framework for health systems practitioners when integrated into clinical practice frameworks. Key findings of Chapter 4: i) the ICF broadens our view on health to include personal and environment factors, and ii) the ICF enhances multidisciplinary communication and collaboration. However, the ICF is not without limitation. Specifically, there are limited descriptions around personal and environmental factors and the underlying processes, defining differences between the domains of activity and participation, and the ICF's static nature which does not address change over time. Key findings of Chapter 5: five engagement strategies: 1) creating a physical or virtual hub with updated information or updating current websites to ensure usability and accessibility (e.g. for course selection), 2) hosting "speed dating" events between students and faculty/researchers to enhance communication and knowledge exchange, 3) hosting monthly lectures/workshops/webinars, 4) capacity building via emailing lists for new opportunities, and 5) peer mentoring to connect stakeholders within the University and Hamilton communities. ***Conclusions*** Synthesis of the knowledge from this thesis contributes to the *thinking* and *doing* of transition research. Specifically, acculturation theory (a social science and psychology theory) and the International Classification of Functioning, Disability, and Health (ICF) (a bio-psycho-social theory) are offered as complementary conceptual frameworks to inform transition research. Stakeholder involvement in transition research is critical in facilitating knowledge mobilization, however, researchers need to consider the challenges of research partnership with YCHC. It is recommended to explore and assess opportunities for YCHC to have experiences starting in childhood and through adolescence;

these experiences can assist in building YCHC's capacity to assume adult roles and

responsibilities for self-management.

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"Never doubt that a small group of committed people can change the world: indeed, it is the only thing that ever has." – Margaret Mead, anthropologist

I dedicate my thesis to all the youth and their families facing adversity and difficulty with transition and access to the care they need and deserve. Thank-you for taking time to share your experiences and stories on transition. I hope my work contributes to building capacity for the need for advocacy towards enhanced collaborations and action in research to voice the needs of youth and parents to assist in improving transition services and making sure youth and families benefit from advances in research –if we work together, change *is* possible. I also want to dedicate this work to my dear cousin who passed away too soon, thank-you for showing me the meaning of courage, tenacity, and resilience in the face of cultural stigma and oppression towards individuals living with chronic illness and disability. You have instilled in me a passion and purpose for my work and given me the privilege of spending my early childhood years by your side. I love you forever and miss you in all the moments of my life.

"My favourite words are possibilities, opportunities and curiosity. I think if you are curious, you create opportunities, and then if you open the doors, you create possibilities."- Mario Testino, photographer and artist

My deepest love and gratitude to my family, whose love, patience, and support has allowed me to complete my studies. To my inspirational parents: Khanh and Nga, for giving me my sense of curiousity and the opportunity to pursue my dreams in Canada. To my wonderful brothers: Khoa and Khang, for always making me laugh, keeping me grounded, and giving me work-life balance. To the love of my life Seong Woo for always believing in me and holding my heart more dearly than your own. My deepest gratitude to my Thesis Committee Member and dearest friend Professor Sue Baptiste for seeing my potential well before I did as a young undergraduate student. Sue's enthusiasm and dedication to teaching has inspired me to return to graduate studies. She has given me the opportunity to be immersed in the field of rehabilitation and

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PREFACE

The overall aim of my thesis is to gain a better understanding of the transition process for youth with chronic health conditions (YCHC) from pediatric to adult healthcare using a unique approach of applying theoretical and knowledge translation (KT) frameworks to guide my "thinking" and "doing". Specifically, the application and integration of acculturation theory and the International Classification of Functioning, Disability, and Health (ICF) conceptual framework has been explored to study the complexities inherent within the transition process. It is important to note that ***healthcare transition*** or ***transition*** refers to the full transition process from pediatric to adult healthcare whereas ***transfer*** refers to the point of transition. The terms ***youth and youth with chronic health conditions are used interchangeably (YCHC)*** refer to adolescent, young adult, teen, transition aged youth, and emerging adult ages 12 to 25 with a wide range of chronic health conditions and youth with developmental disabilities. I studied both YCHC broadly, as well as youth with disabilities and will refer to each population in the various manuscripts/chapters as appropriate. The term ***knowledge mobilization*** refers to knowledge dissemination, application, integration and uptake. A key contribution of my thesis research on transition is that it is guided by the ***Knowledge to Action*** (KTA) framework. The KTA framework provided a methodological guide that weaves all of my four scholarly works together, as it encompasses a step-wise process to knowledge creation and dissemination with stakeholder consultations. The term ***integrated knowledge translation*** (iKT) refers to direct involvement of stakeholders throughout the research process from study conception of application of results. The term ***meaningful partnership*** is used to refer to a mutually beneficial research partnership between researcher and YCHC/other stakeholders where both parties are co-researchers throughout the research process. The term ***stakeholder*** is used as an umbrella term to refer to knowledge users, end users, and consumers which includes YCHC, parents, healthcare providers, community partners, and policymakers. I worked with various stakeholders throughout my thesis and will refer to each population in the various manuscripts/chapters as appropriate.

Each manuscript lays the foundation for the next and is integral to one another. Although my thesis was done in the context of a larger program of transition research at *CanChild* Centre for Childhood Disability Research at McMaster University, the four scholarly studies represent my independent work in which I was principal investigator (PI)**.** In all four scholarly works, I sought input from stakeholders to develop the ideas for each scholarly work (study conception) such as the appropriate design and methodology, data collection, analysis, and interpretation (see Table 1). I initiated the first version of all manuscripts and incorporated revisions based on feedback from my co-authors. As PI, I coordinated all activities and tasks including establishing an inclusive team, organizing and facilitating regular team meetings to discuss all aspects of the study**.** During submission of each manuscript I took responsibility as the corresponding author to peer-reviewed journals for publication throughout the submission and publication process. My co-authors provided valuable feedback which contributed to the refinement of ideas for the study conception, design, analysis, drafting of the manuscript, and read and approved the final submission of each respective manuscript.

My thesis is structured as a "sandwich thesis", which includes my four individual scholarly manuscripts as prepared for peer-reviewed publication (Chapters 2-5). My manuscripts are positioned between the introduction (Chapter 1) and the discussion/conclusions (Chapter 6). Chapter 1 provides the context for my thesis research and the background and rationale for the development of my research objectives and methods. Chapter 6 summarizes and synthesizes all of the knowledge and findings of my series of four scholarly works as described in Chapters 2, 3, 4 and 5 to discuss how these findings address my research objectives, identify key lessons learned and limitations, contributions and impact, as well as identify areas for future research that builds on the findings and learnings of my thesis.

For the first manuscript (Chapter 2) titled "You never transition alone! Learning from the experiences of youth with chronic health conditions, parents and healthcare providers on self-

management", my co-authors were Dana Henderson, Debra Stewart, Oksana Hlyva, Zubin Punthakee and Jan Willem Gorter, all members of the TRACE (Transition to Adulthood with Cyberguide Evaluation 2009-2013) Study Group. In this manuscript, I examine the experiences of YCHC, parents and healthcare providers related to self-management during the transition process; expanding current views on health to include self-management and adaptability. Chapter 2 is a qualitative sub-study of the larger longitudinal TRACE mixed-methods study in which self-management emerged as a prominent theme during data analysis. The concept of self-management appeared to be central in facilitating a smooth process of transitioning from one system of care to another, however, it is rarely studied from the collective perspectives of YCHC, parents and healthcare providers. Similarly, through my interactions and conversations with YCHC, parents and healthcare providers, I have learned about the importance of self-management and partner research to ensure youth' voices and needs are heard. I consulted with YCHC, parents, and healthcare providers as part of the TRACE Study Group to inform the development of a tailored interview guide for each stakeholder group focused on learning more about the concept of self-management during the transition process. From this qualitative work I have learned the importance and impact of a lack of empowerment in promoting self-management during the transition process. Consequently, I have identified gaps in current services, including i) the need for consistency in service provision through collaboration between providers in pediatric and adult healthcare; ii) the need for developmentally appropriate services; and iii) consideration of environmental impacts on youth's experiences. I conclude that a guiding framework that is developmentally appropriate and culturally sensitive could assist in service delivery, facilitate holistic care and fulfill the needs of transitioning youth and their families. The second and third manuscript builds on my findings in the first study, in which I explore existing theoretical frameworks that could be applied in transition research to address these knowledge gaps.

For the second manuscript (Chapter 3) titled "Innovative Practice: Exploring acculturation theory to advance rehabilitation from pediatric to adult *cultures* of care, my co-author was Sue Baptiste. In this manuscript, I explore how an emerging theoretical framework in health called acculturation theory can be applied in transition research to facilitate comprehensive care and service delivery. To my knowledge, acculturation theory has not been applied before to health service provision cultures (specifically rehabilitation services from pediatric to adult healthcare) for YCHC. Based on my learnings in my first qualitative study (Chapter 2) I wanted to further understand the impact of a change in healthcare setting or environment on transitioning youth to facilitate culturally sensitive and developmentally appropriate care. I consulted with rehabilitation experts to create a clinical vignette to demonstrate the potential application of acculturation theory in assisting the planning of transition services for YCHC in a concrete and practical way. Although I found that acculturation theory has great potential to build capacity for the importance of culture by addressing the underlying processes, a major challenge with promoting its use in research and practice is the lack of awareness about the theory among researchers and clinicians involved in transition. Thus, I worked with researchers and clinicians to further explore an established conceptual framework in health called the International Classification of Functioning, Disability, and Health (ICF) as a complementary theoretical framework for acculturation theory (Manuscript 3, Chapter 4).

For the third manuscript (Chapter 4) titled "What lessons are being learned about using the ICF in transition research and practice? A scoping review", my co-authors were Debra Stewart, Peter Rosenbaum, Jan Willem Gorter, Sue Baptiste and Olaf Kraus de Camargo. In this manuscript, I explore how the ICF has been used in transition research and practice. I consulted with researchers, clinicians, and educators who all had experience in using the ICF framework in transition to learn from multiple perspectives. A five-stage methodological framework for scoping studies guided the review process: (1) identify the research question; (2) identify relevant studies; (3) study selection based on inclusion and exclusion criteria; (4) chart the data

extraction in a standardized form; and (5) collate, summarize, and report the findings. Analysis of the nine studies that formed the scoping review revealed that the extent to which the ICF has been used in transition research and practice is primarily at a conceptual level. Two key themes emerged from the analysis on the use of the ICF: 1) the ICF builds capacity for a broad perspective on health by emphasizing the influence of personal and environmental factors, and 2) the ICF promotes communication and collaboration among health professionals through the common language. However, the ICF is not without limitation, one of its weaknesses is that it is static and does not address the dynamic needs of youth over time. Furthermore, the ICF does not explain the underlying processes of person-environment interactions or identify and assess key components of personal and cultural influence (i.e. social elements and skills for adaptability), and unclear differences between activity and participation. Thus, these limitations should be considered prior to use of the ICF. Ideally, it is recommended that the ICF be used in conjunction another theory or framework which can address some of its limitations. In the fourth (and final) manuscript in this thesis (Chapter 5), I pull all of the knowledge and findings of my series of scholarly work as described in Chapters 2,3, and 4 together to conduct a demonstration project to work with youth (i.e. students with disabilities) to determine strategies for engagement in research to facilitate knowledge mobilization.

For the fourth manuscript (Chapter 5) titled "Promoting knowledge mobilization: Reflections on a demonstration project to identify engagement strategies with University students with and without disabilities", my co-authors were Julia Hanes, Jan Willem Gorter, Debra Stewart, and Sue Baptiste. In this manuscript, I describe a demonstration project in which I worked directly with youth (i.e. students with and without disabilities) and researchers as partners to identify strategies for engagement in research (including transition research) to develop research partnerships to facilitate knowledge mobilization. Secondary objectives included: i) enhancing awareness of and access to disability research, services, and resources across campus and within the *CanChild*, McMaster University, and Hamilton communities; and ii) to identify priorities

areas to inform program development at *CanChild* and McMaster University. Results reveal five engagement strategies: 1) creating a physical or virtual hub with updated information or updating current websites to ensure usability and accessibility (e.g. for course selection), 2) hosting "speed dating" events between students and faculty/researchers to enhance communication and knowledge exchange, 3) hosting monthly lectures/workshops/webinars, 4) capacity building via emailing lists for new opportunities, and 5) peer mentoring to connect stakeholders within the University and Hamilton communities. The KTE symposium was also effective in enhancing student's awareness and accessibility to disability research, services, and resources across campus and within the *CanChild*, McMaster University, and Hamilton communities. Lastly, results reveal three priority areas: 1) fostering inclusivity and collaboration by engaging students with a disability in research and by improving accessibility on campus, 2) developing a centralized and user-friendly information hub for knowledge exchange; and 3) creating opportunities for networking and collaboration through hosting of social events to promote engagement between students and faculty/researchers (e.g. a graduate-undergraduate mentorship program) for program development at *CanChild* and McMaster University. Reflections on the demonstration project also offer some powerful observation insights into the challenges of research partnership (i.e. iKT). Specifically, insight and learning relating to direct involvement of youth with disabilities as co-researchers and equal partners in the research process from idea conception to application.

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YCHC- Youth with Chronic Health Conditions

KT- Knowledge Translation

KTA- Knowledge to Action Framework

iKT- Integrated Knowledge Translation

ICF- International Classification of Functioning Disability and Health

CanChild- Centre for Childhood Disability Research

TRACE- Transition to Adulthood with Cyberguide Evaluation

HAHSO- Hamilton Academic Health Sciences Organization

CIHR- Canadian Institutes of Health Research

EACD- European Academy of Childhood Disability

OACRS- Ontario Association of Children's Rehabilitation Services

CAPHC- Canadian Association of Pediatric Health Centres Community of Practice

PCMCH- Provincial Council for Maternal & Child Health

QUERI- Quality Enhancement Research Initiative

CRIO- Collaborative Research and Iinnovation Opportuniities

CHSRF- Canadian Health Services Research Foundation

PCORI- Patient-Centered Outcomes Research Institute

LIFEspan- Living Independently and Fully Engaged

FUMHSU- The Framework for Understanding Mental Health Service Utilization

TIP Model- The Transition to Independence Process model

TSIM- The Transition Service Integration Model

CHAPTER 1

INTRODUCTION TO THE THESIS

"It is the theory which decides what can be observed"

— <u>Albert Einstein</u>

"Do not be afraid of the word 'theory'. Yes, it can sound dauntingly abstract at times, and in the hands of some writers can appear to have precious little to do with the actual, visual world around us. Good theory however, is an awesome thing. [...] But unless we actually use it, it borders on the metaphysical and might as well not be used at all."

— <u>Richard Howells</u>, <u>Visual Culture</u>

"Experience without theory is blind, but theory without experience is mere intellectual play."

— <u>Immanuel Kant</u>

1.1 Theory in transition research through a knowledge translation (KT) approach

The key foundation and contribution of this thesis is in exploring the integration and application of theories and conceptual frameworks to study the complexities of the transition process from pediatric to adult healthcare for youth with chronic health conditions (YCHC). The process of integration and application of theories and conceptual frameworks is informed by an established Knowledge to Action (KTA) framework. The KTA framework also enabled the cognitive process of moving through thinking and framing of the four scholarly works of the thesis, as well as the writing of the thesis. The focus of this thesis is on knowledge creation (dynamic, iterative, and evolving process) as one of the two core components of the KTA framework evidence indicates that a lack of knowledge mobilization is often a *knowledge creation* issue as well *knowledge transfer* (action cycle) (Graham, Tetroe, Pearson, 2014; Straus, Tetroe, & Graham, 2013). Application of the KTA framework facilitated stakeholders (YCHC, parents, health professionals, policymakers, and community members) (see Table 1). Stakeholder consultation was essential to the research process to ensure relevance of outcomes in facilitating knowledge mobilization (Graham et al., 2006; Straus, Tetroe, & Graham, 2013).

My interest in knowledge translation (KT) spawned both the desire and passion to pursue use of the KTA framework. Through my experience and learning during a graduate KT course, I quickly recognized the value of the KTA framework and stakeholder consultation in research. My learnings from this course were solidified through my

interactions with YCHC, parents, and health professionals early in my doctoral studies. I became aware of the disconnection between the needs of YCHC and parents and the research findings due to a lack of knowledge mobilization (Gorter et al., 2015; Nguyen et al., 2016). My experiences and learnings in the KT course prompted me to take a step back to reflect on the value of consulting with YCHC and those involved in transition to inform the creation of meaningful and impactful research (Straus, Tetroe, & Graham, 2013; Graham, Tetroe, Pearson, 2014). Thus, I recognized very early on in my PhD journey that stakeholder consultation is essential and framed my entire thesis research within the KTA framework.

1.2 Cultural lens to studying transition process from pediatric to adult healthcare

Healthcare transition is defined as the purposeful, coordinated and planned movement of youth with chronic conditions from child-centred (pediatric) to adult-oriented (adult) healthcare (Betz 2007; Blum et al. 2003). YCHC and their families often refer to the analogy of "falling off a cliff" to describe their experience with the transition process as they face a multitude of challenges and barriers that impede access to services and supports (Stewart et al., 2014; Barron et al., 2013; Aratani & Cooper, 2012; Lewis et al., 2010). Timely and appropriate intervention and support during transition holds the prospect of benefits that extend to adult life through improved quality of life and better health outcomes. It is important to note that healthcare transition sets the context for the application of the KTA framework and subsequent theory and conceptual framework to guide research on the transition process.

My interest in transition is nurtured by personal experience of "transitioning" between various cultures including immigrating to Canada. In particular, my personal insight into transition processes has been a great driver for my interest in conducting transition research that aims to advance knowledge about life transitions broadly through examining how individuals interact with their environment. I am interested in how an individual's environment shapes their experience as the person both shapes and is shaped by their environment or context (Magasi et al., 2015). From my perspective the term *culture* and *environment* extends beyond ethnicity to include changing environmental contexts such as workplace, healthcare settings, new location, changed accommodation, and social expectations. I have changed cultures many times along my developmental continuum and can relate to the struggles of individuals moving from one culture or environment to the next (i.e. differences in language, societal expectations, values and beliefs, government, socioeconomic status, etc.). Regardless of age, gender and ethnicity, we all experience challenges with life transitions on a daily basis and these transitions are fundamental to human growth and development. It is these life transitions that propel us to redefine ourselves and ultimately enriches our lives. My cultural lens is also informed by my academic experiences as I have moved across research traditions from quantitative to qualitative. Consequently, based on my personal experiences, I have approached this thesis through a cultural and KT lens viewing culture broadly and its implications to pediatric and adult healthcare systems. The thesis development was an organic and emergent process. The components are presented within the document in a reasoned

fashion to illustrate the bridging between them, as well as acknowledging any similarities.

1.3 Knowledge translation defined

Knowledge translation (KT) is a multi-step process that involves collecting, evaluating, summarizing and sharing relevant knowledge on a specific topic with stakeholders (Straus, Tetroe, & Graham, 2013). It is often characterized by complexity as it is a reciprocal process that engages those who develop the knowledge and those who will use it. Many terms have been employed to describe this process including knowledge dissemination, knowledge transfer, implementation science, knowledge exchange, knowledge management, and research utilization (Graham, Tetroe, Pearson, 2014; Tetroe et al., 2008). A systematic review by McKibbon and colleagues identified more than a hundred terms currently used for knowledge translation and exchange (McKibbon et al, 2010). Thus, when examining or reading the literature, it is important to pay attention to the context or discipline in which KT is used to understand its intended purpose. It is also important to mention that the science, research, and practice of KT is advancing at various stages in countries around the world, resulting in varying levels of awareness, understanding, and practices of KT. In the context of this thesis, I used the Canadian Institutes of Health Research (CIHR) definition of knowledge translation as it consists of four distinct elements that fit well with the objectives of my thesis research. The CIHR defines KT as a *"dynamic and iterative process that includes the synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthened the healthcare system"* (CIHR,

2016a). This definition consists of four unique elements that are different from other definitions:

- **Knowledge synthesis** involves interpreting research evidence and knowledge in a way that is applicable to your population of interest**.**

- **Dissemination** tailors the key messages to fit the target audience and maximize awareness and understanding.

- **Knowledge exchange** refers to the multiple types of interactions between knowledge-users and those who conduct the research. These collaborations are encouraged in order to enable shared learning and the use of research findings.

- **Ethically sound application of knowledge** establishes the essential need for ongoing review of current and updated information to ensure congruence between practice and knowledge, plus the application of that knowledge in ethical ways.

(CIHR, 2016a, 2016b; Graham & Tetroe, 2009)

1.4 The significance of knowledge translation

Knowledge implementation is an economic imperative and is one of the most important global challenges for public health in this century. It is also one of the ethical imperatives of our time: delayed implementation of effective practice (more importantly, the continuation of ineffective ones) affects people's health and contributes to the sustainability of the health system. Consequently, clients, patients, communities and other potential partners are not able to benefit optimally from research evidence that could inform best practice. For example, research evidence reveals that 20-25% of patients

receive care that is not needed or potentially harmful, while 30-40% of patients do not receive treatments of proven effectiveness (Grol, 2013). These staggering statistics and pressing dilemma have stimulated national (Canadian Health Services Research Foundation, Canadian Institutes for Health Research-CIHR, and Alberta Innovates: Health Solutions) and international (Patient-Centered Outcomes Research Institute in the United States, and the Academic Health Science Centres in the United Kingdom) funding agencies' efforts to promote partnered research to facilitate effective knowledge mobilization to bridge the "knowledge to action" gap.

1.5 The significance and innovation of the Knowledge to Action (KTA) framework in guiding my thesis research

As previously mentioned, an important contribution of my thesis research is the use of the *Knowledge to Action (KTA) framework* in transition research. The KTA framework is an established and internationally recognized knowledge translation framework endorsed by Canadian Institute of Health Research (CIHR). The KTA framework was deemed appropriate for this research since it is a nonlinear and iterative process (each phase can be influenced by the phase that precedes it and vice versa) requiring ongoing collaboration and consultation among a diverse group of stakeholders (Straus, Tetroe, & Graham, 2013). Another strength that I found with the KTA framework is that it consists of two components: (1) knowledge creation (knowledge inquiry, knowledge synthesis, and creation of knowledge products) and (2) action cycle (knowledge dissemination, application, as well as evaluating and sustaining knowledge) (Graham et al., 2006; Straus, Tetroe, & Graham, 2013). Furthermore, the KTA framework is very practical for

utilization since it outlines clear stages and has been widely used within knowledge translation research; adding to its credibility and rigour. A criticism of the KTA framework is that knowledge is mainly conceptualized as empirically derived (research-based) knowledge (Sudsawad, 2007). In order to address this limitation, my thesis research also included expert opinion and feedback through close partnerships with stakeholders.

The focus of this thesis is on knowledge creation (dynamic, iterative, and evolving process) as one of the two core components of the KTA framework since the knowledge to action gap is often viewed as an issue with *knowledge transfer*, while evidence in knowledge translation research indicates that it is often a *knowledge creation* issue as well (Graham, Tetroe, Pearson, 2014; Straus, Tetroe, & Graham, 2013). Thus, the KTA framework was deemed appropriate and valuable in informing my research to ensure that knowledge is created in consultation with YCHC and other stakeholders to ensure relevance and uptake from the outset. Figure 1 shows how I have used the KTA framework to guide my research while Table 1 summarizes how stakeholders were consulted in each of my four scholarly manuscripts (see Figure 1 and Table 1). My knowledge about stakeholder consultation and engagement was on a steep learning curve throughout my thesis that culminated in the final demonstration project. Consequently, based on my personal and academic experiences, I have approached this thesis through a cultural and KT lens to view culture broadly and its implications to pediatric and adult healthcare systems. The thesis development was an organic and emergent process rather than step by step. The components are presented within the document in a reasoned

fashion to illustrate the bridging between them, as well as acknowledging any similarities. The following sections will discuss how this thesis was framed within the knowledge creation phase of the KTA framework which consisted of three phases: knowledge inquiry, knowledge synthesis, and knowledge products

1.6 Phase 1: Knowledge Inquiry: Approach to assessing transition landscape

As with any research study it is of paramount importance to review the literature to determine the state of the knowledge and build on existing literature and work to avoid overlap. In my review of the literature, I was alarmed to learn from a Transition Report published in *Pediatrics* that widespread implementation of transition evidence to inform the delivery of basic standard of care is not yet realized (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians, Transitions Clinical Report Authoring Group, 2011). Moreover, information is not going to those who need it most, namely YCHC and their families as they still struggle with overcoming the complex transition process.

As a non-clinician in the field of rehabilitation, I bring a neutral and objective perspective as an observer towards developing a scholarly approach to studying such a complex topic as the process of transition. Additional research grounded in theory is needed to examine the underlying processes of person-environment interactions and the impacts of culture on transitioning YCHC. Thus, I saw this as an opportunity to take a step back in my role as a non-clinician with a cultural and KT lens to learn about the processes involved in transition. Rather than focusing on transition outcomes, I was much more interested in

theory integration in transition and in particular, to find a suitable theory or conceptual framework that could be used to link concepts, ideas, behaviours, and processes, relationships, interactions, and transactions of personal and environmental factors. I also found limited information on theory driven studies to inform thinking at a conceptual level during the planning of transition programs, research, and interventions to better understand the underlying processes (Geary & Schumacher, 2012). Through my consultation with stakeholders in various Ministry initiated projects, there was an identified knowledge gap in transition research regarding theory which required further attention and exploration (Randall et al., 2016; Major et al., 2014;). Thus, I took a non-traditional, experiential approach of conducting the research through action and reflection, focusing on the "art" of practice–which is lacking in research - rather than the "science". For the Knowledge Inquiry phase, my intent was to review and build on 'current' knowledge and trends to identify knowledge gaps in transition building on up-to-date reviews (Crowley et al., 2011; Maslow et a., 2011). It is important to note that the evidence of this thesis comes from multiple sources to enrich the research and validate findings. While evidence from the literature and research are important, experiences and input of stakeholder consultation is critical to ensure the relevance of the research to facilitate knowledge mobilization (Bowen & Graham, 2013). Furthermore, theories and conceptual frameworks provide important knowledge to guide thinking in research and practice (Glanz & Bishop, 2010; Glanz, Rimer, & Viswanath, 2008).

1.6.1 The complexity of the transition process from pediatric to adult healthcare

Becoming an adult represents a critical developmental stage for all youth and is often characterized by complexity as it is multifaceted. From my cultural lens, the key issue with "growing up" in North America is the cultural expectation that around age 18, youth are typically expected to become adults and make significant transitions in education, personal, social, and healthcare systems and activity prepare for employment. Youth must address many major life decisions *all at once* with many concurrent developmental transitions underway (i.e. shift to independent living, post-secondary education or the workforce, personal and peer relationships/social network) (Stewart et al., 2014; van Staa et al., 2011; Verhoof et al., 2011). Research evidence reveals that due to medical advances youth with chronic health conditions (YCHC) are surviving well into adulthood and likely require lifelong supports beyond the needs of their typically developing peers (Stewart et al., 2013). YCHC have similar dreams for adult life as other young people and aspire to become contributing members of adult communities (Di Rezze et al., 2015; Cussen, Howie, & Imms, 2012; Maslow et al., 2011). However, their transition processes are compounded by their medical condition and challenged by healthcare transition issues including barriers to accessing culturally sensitive, age-appropriate healthcare services and information that is tailored to their needs and goals) (Taylor & Henninger, 2014; Prior et al. 2014; Hall et al., 2013; Taylor et al. 2012). Though I realize that transition to adulthood is more than just a healthcare transition from the pediatric to the adult system, supporting youth and facilitating healthcare transition services is a major and pressing issue for many countries globally as reported extensively in the literature from various

countries including Canada, United States, Australia, and the United Kingdom as it impacts clinical practice and policy (Islam et al., 2016; Paul et al., 2015; McNamara et al., 2014; Rickwood et al., 2014; Tan et al., 2014; Hamdani et al., 2011; Singh 2010; Schmid, 2010). Thus, determining evidence-based strategies and practices to optimize services for transitioning youth is a priority for healthcare systems internationally.

1.6.2 Current trends and knowledge gaps in transition research

A descriptive review of the literature was conducted to build on current trends and knowledge gaps. First, current trends indicate that there is increasing momentum in the 21st century to expand our views on health and enhance health definitions to include concepts of self-management and adaptability through meaningful partnerships, community engagement, opportunities and experiences (Stewart et al., 2014; Modi et al., 2012; Huber, 2011; Allen et al., 2011; Field & Hoffman, 2011). The emerging focus on self-management has stemmed from a need to expand our views on disability and health. Regardless of diagnosis, the importance of self-management for chronic conditions has garnered attention from researchers and clinicians, which has promoted a re-examination of current views of health and well-being to extend beyond medical diagnosis (McDougall et al., 2016; Wright, K., & McLeod, 2015; Sattoe et al. 2015; Prior et al., 2014). For example, this was evident in an article by Huber and colleagues (2011) who suggested enhancing our current perspective on health and disability to include concepts of self-management and adaptability. Similarly, Modi and colleagues (2012) reveal that the complexity of behaviours and processes that underlie self-management are poorly

understood and require further exploration and research despite previous contributions in this area (Modi et al., 2012). From the findings identified through a recent knowledge synthesis (Gorter et al, 2016) and a Ministry-initiated project (Major et al, 2014), it became apparent that self-management lies not with the youth alone but is a shared process of enablement with those involved in transition. Although current work has examined the concept of self-management, there is limited information regarding the collective perspectives of those involved and this warrants future exploration (Sattoe et al. 2015). In particular, my involvement in the Transition to Adulthood with Cyberguide Evaluation-TRACE study solidified the importance of exploring the concept of self-management (Gorter et al., 2015). The TRACE study took a mixed-methods approach to understanding youth's transition and how current tools and interventions can facilitate their experiences. The TRACE study was funded by an unrestricted grant received from Hamilton Academic Health Sciences Organization (HAHSO); grant number (09-124). I assumed an active role in the qualitative aspect of the study. Analysis of the interviews revealed that self-management was a prominent and consistent theme that emerged among all participants. YCHC, parents, and providers also felt that it was an area in need of attention and further exploration. In particular, to learn from the collective perspectives and interactive experiences of YCHC, parents, and health providers about self-management, which has not been studied previously. I learned from YCHC, parents, and providers in the TRACE study about the importance of collaboration to enable self-management. The emphasis on self-management is also echoed by experts and policymakers through my involvement in Ministry-initiated studies (Gorter et al., 2014;

Randall et al., 2016). From the literature on self-management and my interactions and observations with YCHC, parents and healthcare providers, I concluded that there was a knowledge gap in facilitating a deeper understanding of processes to enable self-management during healthcare transition.

Second, within health, the idea of an ecological approach to care is an emerging trend (Batorowicz et al., 2016). This approach stems from the seminal work of Bronfenbrenner (2005) and Lewin (1936) both of whom are considered foundational theorists bringing attention to the study of environment. The essence of their work has infused the study of healthcare systems including transition as exemplified in several models such as: 1) The Framework for Understanding Mental Health Service Utilization (FUMHSU) (Munson et al., 2012), 2) The Transition to Independence Process (TIP) model (Clarke, 2012; Clarke, 2005), 3) The Transition Service Integration Model (TSIM) (Certo et al., 2003), and 4) a Social-Ecological Model (Schwartz et al., 2011). These models focus on guiding practice in the planning and delivery of services, revealing an increasing trend towards expanding current views on health to promote an ecological and transactional approach that includes consideration of personal and environmental influences. Additionally, an article by Rosenbaum and Gorter (2012) emphasize the significant consideration of all life domains and environments instead of "fixing" the person alone (Rosenbaum & Gorter, 2012).

The Framework for Understanding Mental Health Service Utilization (FUMHSU) describes how different types of youth, or 'users', become involved and if they stay

involved in transition services across time (Munson et al., 2012). The different 'users' are characterized in four ways: continuous, single and multiple gap or discontinuers. There is also a quartet of determinant sets that enables characterization, namely dynamics, mechanisms, context, and intersectoral views. *Dynamics* refers to personal characteristics (e.g. age, life stage, behavioral beliefs); *mechanisms* talk to the user's motivation to engage with services, views of treatment efficacy plus knowledge of care. *Context* considers environments inclusive of family, community and employment. *Intersectoral* views refer to how public institutions and health systems provide needed care across service environments. When determining to which user group individuals belong, this framework stresses the user's perspective, based on developmental changes experienced, undesired effects of treatment, difficulties in accessing treatment, and feedback about service use. The interaction of these elements determines over time the acceptance and relevance of service offerings and resulting impacts on transitions. A limitation of this model is the limited description and insight into individualized factors such as behavioral beliefs, social/normative, imagine/impression, emotion and self-efficacy, in order to understand intention to use the mental health system.

The Transition to Independence Process (TIP) model guides community-based services to support transition-related goals in the community. Seven core competencies for facilitators include: encouraging sharing of thoughts; neutralizing judgmental reactions; using positive eye contact and body language; asking open-ended questions; providing affirmation and descriptive praise; reflecting for understanding; and, offering descriptive assistance as appropriate (Clarke, 2012, Haber et al., 2008). The TIP model employs an

individualized approach to transition and identifies core public services needed to enable youths' self-sufficiency (Clarke, 2005). TIP was designed as a coordination guide for the efforts of health professionals and community agencies within three interacting domains: living conditions; educational opportunities; and, employment and career. Youth engage with transition facilitators about life goals and the provision of non-stigmatizing supports. Meeting this TIP goal of self-sufficiency involves family and key stakeholders as partners with youth in the transition process (Clarke, 2012). While the TIP model is comprehensive, it operates at a systems level of service integration with healthcare transition being a component but not the sole focus. Additional information about processes and behaviours regarding the interactions of these systems are needed in future inquiry.

The Transition Service Integration Model (TSIM) suggests that three specific systems (special education, rehabilitation and developmental disability) work collaboratively to assist youth with moderate to profound intellectual disabilities, in achieving optimal transition outcomes as they move into adulthood (Certo et al., 2003; Luecking & Certo, 2003). The TSIM posits that if the systems function in isolation, youths' needs for transition will not be served adequately. Establishing three distinct service silos is a major contribution to poor health outcomes of this population in adulthood (Certo et al., 2003). Competitive employment and inclusion in the community are the primary outcomes of the TSIM. A "one-stop shop" approach is emphasized as encouragement to engage, at the point of transition from the last year of public school (Certo et al., 2003). The model describes how school-based supports may be integrated with post school employment

supports to gain competitive employment with the clear rehabilitation goal focused on job placement. A community based classroom approach, incorporating community engagement for youth, is organized regularly to promote independence and potentially obtain paid employment. While the TSIM does consider health systems, it is focus on competitive employment and education and not healthcare transition, thus it is the most suitable for application in transition. TSIM is also not ideal for use in transition as it is focused on service integration rather than personal and environmental impacts.

A new social-ecological model entitled the SMART model is used to determine patient readiness for transition to adult care (i.e .patient age, knowledge, and skills) (Schwartz et al., 2011). The goal of this the SMART model is to broaden thinking about health beyond the person. However, within this model, additional details are need to elaborate on the specific processes descriptions around person-environment interactions, particularly cultural influences. The development process was informed by gaining knowledge of related theories, relevant literature expert opinion and some pilot data collected from a questionnaire. SMART encompasses variables identified from the study of youth, parents and service providers that relate positively to intervention. Future research opportunities would involve the development and evaluation of transition measures and interventions. Additionally, the SMART model appears to function at an operational practice level, rather than conceptual level to inform thinking and research. Similarly, an "ecological" orientation to care is also proposed by Wang and colleagues in 2010, which describes how themes and relevant concepts in transition can fit within an ecological approach. The Living Independently and Fully Engaged (LIFEspan) model has also been introduced to

assist in the coordination of care between pediatric and adult pediatric rehabilitation (Kingsnorth et al., 2011). However, the focus of these model requires more emphasis on culture and environmental processes at a conceptual level.

The identified models and frameworks demonstrate that current 'knowledge' or 'evidence' about an ecological approach to healthcare transition. The main focus of these models/frameworks is on specific domains and environmental factors of transition, with the trend towards exploring person-environment interactions, however there is limited 'knowledge' that makes explicit linkages about the concepts within the *process* of transition with all of its complexities and transactions. In particular, I noted that the process of self-management as a cultural expectation within this process has not been addressed, nor have any theories been articulated about these processes to guide our "thinking" on a conceptual level. A paper by Geary and Schumacher (2012) found while there is sufficient empirical evidence in transition research, theoretical foundations are rarely made explicit and should be explored. Betz and colleagues (2014) identified a lack of theory-driven studies in transition, thus theory building in transition is needed to understand its complexities to improve research and practice. Similarly, Stewart (2013) states that theory is important to address areas of limited research evidence to better understand processes involved in transition (i.e. cultural influences) to support practice.

The focus of the identified models/frameworks is primarily at a systems, practice, or operational level and more in the "doing" rather than informing the "thinking" for transition research, Thus, these models provide foundational knowledge and builds

awareness about the components, systems, and factors of the transition process, without fully embracing the concepts inherent in the shifts from pediatric to an adult healthcare culture, the cultural nuances themselves, the associated behaviours and the potential impact on youth in their self-management and adaptability. Furthermore, many of these models are focused on service coordination and integration and not enough emphasis is given to the full process of transition that all youth with chronic health conditions and their families experience. Thus, further research is needed to better understand *the process of how* the environment influences the person and vice versa, and the underlying processes involved in person-environment transactions, in particular during a critical time of change such as healthcare transition with many other life transitions occurring concurrently.

Through this review of current models and frameworks in transition literature, I conclude that although existing models and frameworks provide a sound foundation for identifying components and elements of person and environment to guide the "doing" in practice, additional research is need in applying theories and frameworks to guide the "thinking" about the various transactions during the process of transition (Glanz & Bishop, 2010), Thus, with my interest in theory and a cultural lens, I sought to identify and explore theories and conceptual frameworks that could be applied in healthcare transition to address processes of person-environment interactions and the cultural influences on transitioning YCHC. It is important to note that in the context of this thesis, 'environment' includes changing cultures and contexts. In particular, there is a knowledge gap regarding developmentally appropriate and culturally sensitive

frameworks in guiding the thinking about the complexities of transition processes, which I believe is essential for meaningful research and practice (Grant & Pan, 2011). *Developmentally appropriate care* refers to care that is dynamic and accounts for change over time during a youth's transition process and developmental trajectory. Culture and *culturally sensitive care* refers to the influence of ethnic culture as well as changes in healthcare setting (i.e. pediatric to adult healthcare) on youth's self-management and transition experience.

The third trend in the current literature is the focus on knowledge translation to facilitate knowledge mobilization. The failure to put research findings into action is a major societal issue and contributes to an estimated $200B of wasted research funding because the full potential of research was not materialized (Rottingen et al., 2013; Macleod et al., 2014). As mentioned previously, a Transitions Report published in *Pediatrics* also states a significant lack of widespread implementation of basic standard of care in transition, thus YCHC are not benefiting optimally from advances in research (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians, Transitions Clinical Report Authoring Group, 2011). Additionally, YCHC and parents have expressed interest in being directly involved in the research and dissemination process as they are experts in their lived experience with transition (Price et al., 2011; Kingsnorth et al., 2011; Mawn et al., 2015). For example, during a roundtable discussion with stakeholders that I facilitated for the Ministry of Health and Long Term Care transition project in Ontario, Canada on June 4th, 2013 to discuss healthcare priorities for youth with complex care needs, a parent representative stated,

"listen to us, we deserve to be heard, it's time for ACTION". This statement is honest and powerful as it further validates the importance of youth and stakeholder involvement in research. My interactions with YCHC, parents, policymakers, health professionals in various transition projects and multidisciplinary longitudinal studies has solidified the importance of knowledge mobilization into clinical practice (Gorter et al., 2011; Randall et al., 2016; Major et al., 2014). For example, a representative from the Ministry of Child and Youth Services, offered a key recommendation to focus on enacting processes and concrete strategies for collaboration among researchers with YCHC, parents, and providers to enhance knowledge mobilization for information resources and training in preparation for transition. Based on the evidence in the literature that calls for stakeholder engagement (Sharkey et al., 2016; Cross et al., 2015; Camden et al. 2014; Shikako-Thomas et al. 2013; Stewart et al., 2014) and my interactions with YCHC, parents, policymakers, and community members, I concluded that exploring effective strategies for stakeholder engagement is needed to facilitate knowledge mobilization to address this current "knowledge to action" gap in transition.

1.6.3 My research program and objectives

Based on the knowledge gaps presented above on processes of healthcare transition, I formulated my three thesis objectives as follows:

1) To gain a better understanding of the experiences of YCHC, parents, and healthcare providers with self-management during the transition process;

2) To explore theoretical frameworks to guide research in transition and inform the planning and delivery of holistic transition services that is developmentally appropriate and culturally sensitive (considers the influences of person-environment interactions); and

3) To identify effective strategies to facilitate knowledge mobilization.

1.7 Phase II: Knowledge Synthesis: Conducting research to create and synthesize knowledge to addresss study objectives (Chapters 2-4)

Chapter 2 is a qualitative interpretive phenomenology study to explore self-management from the collective experiences of YCHC, parents and healthcare providers. Results of this study provided new insight about how the experiences of YCHC, parents and service providers are interconnected and interdependent during the self-management process. A key learning was that this study began to uncover critical cultural nuances (unwritten and unspoken behaviours and expectations) between the pediatric and adult systems of care that are not considered currently. This critical finding led to the next piece of scholarly work presented in Chapter 3.

The overall objective of Chapter 3 is to discuss how acculturation theory can be applied in rehabilitation practice to assist YCHC with transition. A critical appraisal of key literature in the development of acculturation theory was conducted. A clinical vignette is used to demonstrate the potential application of acculturation theory in transition. The key findings of Chapter 3 include: i) acculturation theory provides a concrete conceptual framework to guide thinking about the process of change within an individual when

shifting from one culture to another; and ii) acculturation can become a natural framework for health systems practitioners when integrated into clinical practice frameworks. Despite the richness and potential use of acculturation theory in transition, it is not a prominent theory in health. Thus, acculturation needs to be integrated into an existing health framework. This learning led to the exploration of International Classification of Functioning, Disability and Health in Chapter 4.

Chapter 4 explores the current use of the ICF in transition research and practice and to look at important implications or 'lessons learned' for future work. A scoping review was conducted to determine the extent, range, and nature of how the ICF is being used in research and/or practice. A five-stage methodological framework for scoping studies guided the review process. The focus of this scoping review was on "mapping" or gaining insight into the extent in which the ICF has been used in transition research and practice, rather than doing an in-depth systematic review and evaluation. While the ICF broadens our view on health to include personal and environment factors and enhances multidisciplinary communication and collaboration, it is not without limitation.

1.8 Phase III: Knowledge Product: Demonstration project (Chapter 5)

My thinking and learning about stakeholder consultation throughout the thesis culminated in Chapter 5, which describes a demonstration project with a knowledge symposium. The demonstrated project provided an opportunity to learn about strategies for youth engagement in research to facilitate knowledge mobilization and insights into the process of an integrated knowledge translation (iKT) approach. Results reveal five engagement

strategies: 1) creating a physical or virtual hub with updated information or updating current websites to ensure usability and accessibility (e.g. for course selection), 2) hosting "speed dating" events between students and faculty/researchers to enhance communication and knowledge exchange, 3) hosting monthly lectures/workshops/webinars, 4) capacity building via emailing lists for new opportunities, and 5) peer mentoring to connect stakeholders within the University and Hamilton communities. Results also provide valuable insight and reflection into the challenges of stakeholder engagement and the potential application of iKT in guiding "thinking" for research, including balancing power differential within the research partnership among all participating members.

Overall, the potential use of the KTA framework and iKT approach has tremendous value in informing transition research, as the stakeholders are always at the forefront of every phase of the research process; thus assisting to ensure relevance and uptake. A challenge with using the KTA framework is that it is extremely time intensive as each phase represents an iterative process of learning and revisions. Careful consideration of all tasks and phases will assist with meeting deadline and executing all of the various phases. Time invested at the outset in building strong and sound relationships with stakeholders to establish an inclusion team where target populations are co-leading the research as equal partners is also key for success. More importantly, the use of the KTA framework and an iKT approach is applicable to any area of study in the creation of meaningful outcomes to enhance knowledge mobilization.

Please note that the references for Chapter 1 are found at the end of Chapter 6

Figure 1: *Using the Knowledge to Action (KTA) framework to guide my thesis research on transition.*

Knowledge
Inquiry

Chapter 1
The issue of transition from pediatric to adult healthcare

Chapter 2
Qualitative study

Chapter 3
Acculturation Theory

Chapter 4
ICF & Acculturation Theory

Knowledge
Synthesis

Chapter 5
Knowledge Symposium

Knowledge
Product

Chapter 6
Conclusions
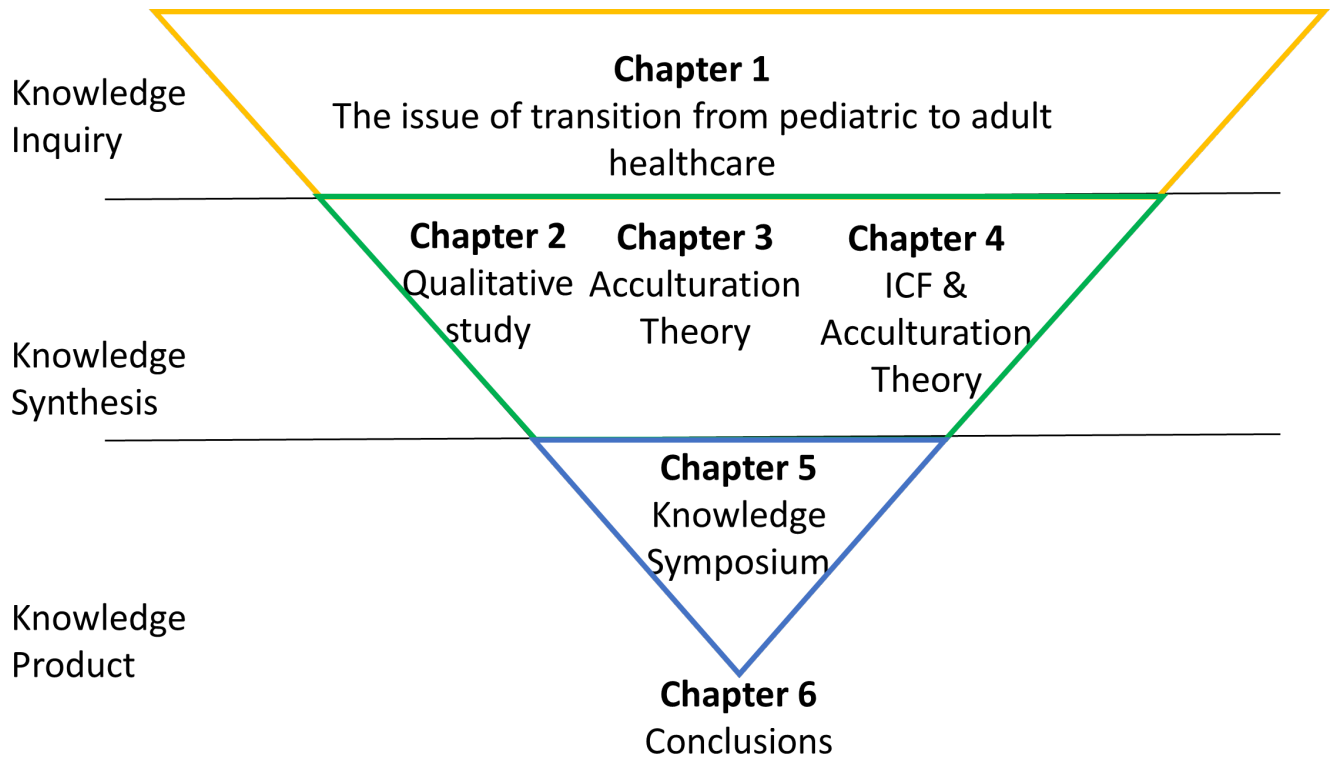
Table 1: *Stakeholder consultation in each of the four scholarly studies in my thesis research*

	Manuscript #1 (Chapter 2: Qualitative Study)	Manuscript #2 (Chapter 3: Acculturation Theory)	Manuscript #3 (Chapter 4: ICF & Acculturation Theory)	Manuscript #4 (Chapter 5: Knowledge Symposium
Purpose	To examine the interactive experiences of youth, parents and healthcare providers related to self-management during transition	To explore how acculturation theory can be applied in rehabilitation services for transitioning youth	To explore how the ICF has been used in transition research and practice and how acculturation theory can enhance its use and application	To convene a knowledge translation and exchange (KTE) symposium for knowledge dissemination
Stakeholder(s)/Target audience	Youth with chronic health conditions, parents, and healthcare providers	Rehabilitation professionals and researchers	Clinical and research experts, educators, policymakers	Youth and students with disabilities, undergraduate and graduate students, educators, community members
Role of stakeholder(s)	Informing development of interview guide questions	Assessing the feasibility, use, and utility of acculturation theory in practice; determine strategies/ methods for the potential application of acculturation in rehabilitation services for transitioning youth	Assessing the feasibility, use, and utility of acculturation and ICF in transition research and practice; determining the unique contributions of acculturation theory and the ICF	Providing feedback on research findings and identifying priority areas for future research
Example of stakeholder(s) consultation	Reviewing and providing feedback (consultations and discussions) on interview guide questions	Providing examples/ strategies of how acculturation theory can be operationalized and applied in rehabilitation services for transition (consultations and discussions	Providing feedback on the practicality of using acculturation theory and the ICF in guiding transition research (consultations and discussions	Roundtable discussions lead by a problem-based approach to address concerns around areas of focus for disability research, accessibility to services and supports, and recommendation for enhancing knowledge uptake
Outcome of stakeholder(s) consultation	Tailored interview guides with relevant and meaningful questions for each stakeholder group	The development and creation of a clinical vignette to illustrate the application of acculturation theory in a very practical and concrete way	Offering acculturation theory and the ICF as complementary theoretical frameworks to address environmental (cultural and contextual) influences on transitioning youth	Improving accessibility to information, resources, and supports though creation of a centralized knowledge hub; Creating opportunities for student engagement in research

CHAPTER TWO

YOU NEVER TRANSITION ALONE! LEARNING FROM THE EXPERIENCES OF

YOUTH WITH CHRONIC HEALTH CONDITIONS, PARENTS, AND

HEALTHCARE PROVIDERS ON SELF-MANAGEMENT

PREFACE TO CHAPTER TWO

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Summary: This manuscript describes a qualitative phenomenology study that I conducted to examine the perspectives and experiences of youth with chronic health conditions (YCHC), parents, and health providers with self-management during the process of a significant healthcare transition. I have deliberately taken an integrated knowledge translation approach (iKT) through partnering with YCHC, parents, and healthcare providers. Whereas other research on transition experiences has been focused upon youth or usually the parents separately, the novelty of this study is that it is among the first to examine youth's interactions with those around them as well as their

environment and its impact on their experience with self-management. I completed this work in the context of a larger, recently completed longitudinal study (Transition to Adulthood with Cyberguide Evaluation 2009-2013- "TRACE"). Results suggest that the experiences of transitioning YCHC, parents, and healthcare providers are interconnected and interdependent in the promotion of self-management. Healthcare providers should be flexible and use a developmentally appropriate approach when working with YCHC and parents in practice. Healthcare providers and parents should work together to enable youth for self-management. I conclude that the findings of my qualitative study only begins to address the gap in understanding the concept of self-management as a significant element within the transition process. Additional research is needed to determine effective strategies to promote and empower youth for self-management. I have identified a need for additional communication and collaboration among providers in pediatric and adult healthcare, as well as with YCHC and parents to uncover cultural nuances and the impacts of a change in healthcare setting on youth's ability to self-manage the condition and needs. Thus, I believe that a guiding framework that is developmentally appropriate and culturally sensitive will assist in promoting consistency in service delivery and fulfill the needs of youth and facilitate holistic care. Most importantly, I learned about the importance of engaging with youth and parents in research from the outset to voice their needs to ensure relevance of the research.

2.1 Abstract

Background: Recent evidence suggests that fostering strategies to enable youth with chronic health conditions to work towards gradual self-management of their health is key in successful transition to adult healthcare. To date, there is limited research on self-management promotion for youth. The purpose of this study is to explore self-management from the perspectives of youth, parents, and healthcare providers in transition to adult healthcare. **Methods:** Part of a larger longitudinal transition (TRACE-2009-2013) study, interpretive phenomenology was used to explore the meaning of the lived experiences and perceptions of youth, parents, and healthcare providers about transition to adult healthcare. Purposeful sampling was utilized to select youth with a range of chronic health conditions from the TRACE cohort (spanning 20 diagnoses including developmental disabilities and chronic conditions), their parents and healthcare providers. **Results**: The emerging three themes were: increasing independence of youth; parents as safety nets; and healthcare providers as enablers and collaborators. The findings indicate that the experiences of transitioning youth, parents, and service providers are interconnected and interdependent. **Conclusions**: Results support a dynamic and developmentally appropriate approach when working with transitioning youth and parents in practice. As youth depend on parents and healthcare providers for support in taking charge of their own health, parents and healthcare providers must work together to enable youth for self-management. At a policy level, adequate funding, institutional support, and accreditation incentives, are recommended to allow for designated time for healthcare providers to foster self-management skills in transitioning youth and parents.

2.2 Introduction

Becoming an adult represents a critical developmental stage for all youth as they experience multiple concurrent transitions including leaving high school and beginning post-secondary education, pursuing employment and getting a job, forming new social networks and personal relationships, and moving out of parents' homes to independent living (Nguyen & Gorter, 2014; Gorter et al., 2011). For youth with chronic health conditions this experience is complicated by the additional transition from pediatric services to the adult healthcare system. Healthcare transition is defined as the purposeful, coordinated, and planned movement of youth with chronic conditions from child-centered to adult-oriented healthcare (Blum et al., 2003; Betz, 2007). A review of the literature reveals that healthcare transition can be challenging for youth, families, and healthcare providers and there are negative outcomes in terms of population health, costs and experiences with the healthcare system (Prior et al., 2014; Taylor et al., 2012). The experience of transitioning from a familiar pediatric healthcare setting to an unfamiliar adult setting is often described as a 'falling off a cliff' by youth and parents (Stewart et al., 2014). Thus research to improve transition experiences between these two systems of care is of priority for many professional institutions and organizations in Canada and around the world (American Academy of Pediatrics, 2011; Lugasi et al., 2011; Fletcher-Johnston et al., 2011, While et al., 2004). Effective self-management of one's health is considered essential for everyone, particularly for emerging adults with chronic health conditions (Modi et al., 2012). This consideration is in line with the work of Huber and colleagues (2011) who propose shifting the focus from health, in a strictly medical sense to emphasize the ability to adapt and self-manage in the face of physical, social, and emotional challenges encountered by individuals with chronic disease (Huber et al., 2011). This shift is critical when youth enter adult healthcare services where they are

expected to take on responsibility for their medical needs (McDoungall et al., 2015; Crowley et al., 2011; Kraus De Camargo, 2011; Modi et al., 2011). The importance of self-management for chronic conditions and illnesses has garnered attention from researchers and clinicians, which has promoted for a re-examination of current views of health and well-being to extend beyond medical diagnosis (Sattoe et al., 2015). However, to date, there is limited research on self-management promotion for youth with chronic diseases (Sattoe et al., 2015, Miller at el., 2015).

Research evidence from a recently completed longitudinal study (Transition to Adulthood with Cyberguide Evaluation- "TRACE") suggests that fostering strategies among youth, parents and healthcare providers to empower youth to work towards gradual self-management of their healthcare may be key in facilitating autonomy and successful transitions (Gorter et al., 2015). Although increasingly more research suggests the importance of collaboration among youth, parents, and healthcare providers for self-management and transition planning, few studies have examined all three perspectives to identify strategies to enable these processes. Furthermore, limited description exists about the "how" or strategies to enable self-management and collaboration. The objective of this study is to explore self-management from the perspectives of youth, parents, and healthcare providers involved in the transition to adult healthcare services through an in-depth analysis of the qualitative portion of the larger TRACE study (Gorter et al., 2015). The novel aspect of this study lies in the examination of the experiences of key stakeholder groups in order to learn from each perspective and triangulate the findings regarding self-management promotion from a collaborative perspective.

2.3 Methods

2.3.1 Design

The qualitative method chosen for this study was interpretive phenomenology as it provided the best fit to explore the meaning of the lived experiences and perceptions of youth, parents, and healthcare providers about transition from pediatric to adult services (Creswell, 2015). This approach explored the emergent phenomenon of self-management and ways it relates to the transition process. The study obtained ethics approval from participating institutions (09-124) and informed consent was obtained from all participants prior to enrolment in the study. It is important to note that all participants were enrolled in the larger TRACE study; they were offered two transition supports (transition planning kit and an online mentor) to assist them with transitioning planning, which is not available to all youth.

2.3.2 Sample

Purposeful sampling was utilized to select youth with a range of chronic health conditions from the TRACE cohort (spanning 20 diagnoses including developmental disabilities and chronic conditions), their parents and healthcare providers across 13 clinics at two major pediatric hospitals in Ontario, Canada (Gorter et al., 2015). Purposeful sampling is an approach to recruiting participants who are considered to be champions or experts on the topic of interest in order to provide rich descriptions of their experiences. In this case, individuals who have experienced the transition process were targeted in order to encourage reflection and to identify key lessons (Creswell, 2015). Maximum variation strategy was employed to ensure a range of demographic variables (age and gender), type

of health condition or clinic attended, and experiences. The only exclusion criterion for the qualitative part of the study was inability to answer open-ended questions in English.

2.3.3 Data collection

Four trained professionals conducted telephone interviews during March and April 2012. Semi-structured interviews unique to youth, parents, and healthcare providers were administered after the youth had made the transition into adult healthcare services. Interview questions were focused on eliciting the experiences of youth, parents, and healthcare providers about their roles, expectations, needs and concerns, empowerment, and enabling self-management during the transition process through self-reflection and awareness. Some examples of interview questions for youth, parents, and healthcare providers are included below (please see Appendix A, B, and C for interview guides).

Youth:

- *Can you make any comments yet on how you see yourself changing over time in terms of making decisions about your own health, and directing your own health care?*
- *What would help or support you to make these changes or transitions easier?*

Parents:

- *How do you perceive your role in your youth's care at this stage? In the future?*
- *Can you comment on where you feel your youth is in terms of managing their own medical needs?*

Healthcare providers:

- *How do those other transitions influence their health care?*

   ▪ *What else would help you and your youth with these transitions?*

All interviews were tape recorded and transcribed verbatim for analysis. The interviewers wrote reflection memos after each interview that also became part of the qualitative data for analysis. Member-checking was conducted with participants to verify accuracy of their transcripts and to ensure that their responses to interview questions were captured accurately.

2.3.4 Qualitative analysis

A conventional inductive content analysis process was used for data analysis following the guidelines of Elo & Kyngas (2007). This process involved reviewing transcripts, highlighting key concepts, developing a coding scheme, and comparing coding and analysis for agreement. All four interviewers coded each transcript independently between meeting as a group for discussion and consultation. Agreement of at least three of the four interviewers was considered to be acceptable and any discrepancies or disagreements were discussed among researchers until agreement was reached. Triangulation among researchers enhanced trustworthiness of the results (Creswell, 2015). An audit trail outlining decisions and actions taken in the analysis process was also completed to ensure credibility and reliability (Creswell, 2015).

2.4 Results

A total of eleven youth, seven parents, and seven healthcare providers consented to interviews. Participants enrolled in this study were diverse and represent a range of conditions and experiences. The age range of youth participants enrolled in the study was 18-21. Additional information on participant demographics can be found in Table 1.

<Please insert Table 2 about here>

Three themes emerged from analysis including those related to increasing independence of youth; parents as safety nets; and healthcare providers as enablers and collaborators. Supporting quotes from participants (in italics) are provided to illustrate and validate these sub-themes, with participant type indicated in parentheses after a quote: Y = Youth Participant; P = Parent Participant; HCP = Healthcare Provider Participant.

2.4.1 Theme 1: Youth and increasing independence

The majority of youth participants provided descriptions of the ways in which they felt they were independently managing their health needs. For instance, in discussing what was going well during the healthcare transition, one youth participant reported increased self-management:

> *"Well I am able to kind of manage my health myself now. I find I am able to do my own thing. I learn things when I used to go to the adult clinic and the children's clinic, so I find I am able to use those recommendations still." (Y01)*

Similarly, some youth participants reported that they were attending their appointments with adult healthcare providers alone. For example:

> *"I see myself being more independent all the time. I am pretty independent as it is. I attend most of my appointments by myself, and I already direct my own care pretty well." (Y03)*

Many youth participants reported that they were starting to manage their medical needs independently in preparation for their transition to adult services and that they saw themselves becoming increasingly independent in decision-making and directing their own care in the future.

"I think I've just become more independent, I don't have to rely on my parents at all, which is nice, because there is no middleman. It's just me making my appointments around my schedule. So in a sense it's a lot easier doing that way." (Y11)

The majority of parents reported also that, overall their youth were managing more of their healthcare needs during the transition to adult services, as well as general life transitions.

"She's certainly quite capable of taking care of herself, she medicates herself on a daily basis and she stays on top of things, she's good at telling us when things don't seem right, and if it came right down to it, she and her sister, who insists on being with her, could easily handle going down to [hospital] or going down to [clinic] and, ah, and taking care of things." (P10)

However, despite recognition of their youths' increasing independence, parents described many experiences in which they still provided support, and this became the second theme. Interestingly, healthcare provider participants made no specific comments about increasing independence of youth.

2.4.2 Theme 2: Parents as safety nets

Many parent participants reported willingness on their part to encourage their youth to become more independent and accept more responsibility in terms of managing their medical care.

"At this point, there's really not much that is really required of me because he is full grown. I can just encourage him to stay on track and, you know, not go out every single night. Just keep a general eye over him..." (P02)

Although the majority of parent participants recognized the value of promoting independence in their youth to manage their own medical needs, there were many experiences reported by youth and parent participants that indicated that the youth continue to rely on parents to provide different types and amounts of support (emotional support, transportation, medication and appointment reminders, general reminders for daily social activities, and lending advice for medical and non-medical decisions). For example, many parent participants continued to schedule appointments, drive their youth to medical appointments, or attend appointments with their youth. To illustrate,

"Well when it comes to meds we still have to tell her to take them. She knows she has to take them but it's just like: "Did you take your pills today?" "No I forgot." So we still have to- I have them out in one of those daily- like weekly pill pack things- but we still have to tell her: " Did you take your pills? Take your pills." And when it comes to making appointments we still have to do that." (P15)

The majority of healthcare provider participants recognized the need for balance between the youth gaining independence and the parents embracing the process of "letting go" but still providing a "safety net" to enable their youth to gradually take on adult roles and responsibilities. They acknowledged that this individualized process may vary among youth and parents.

"...it's a time of a lot of change, and there's a time of testing as far as autonomy goes and taking over their own health care and a struggle between where the

parents are and where the kids are. Sometimes the parents are ready for the kids

to move on faster than the kids are, and sometimes the exact opposite is true"

(HCP23)

2.4.3 Theme 3: Healthcare providers as enablers and collaborators

Several healthcare provider participants recognized the importance of the idea of a

gradual, developmentally appropriate transition process rather than a sudden and abrupt

one. For example, one participant stated:

> *"I think that there needs to be more of a transition - that word is a very good*
>
> *word - on the adult side too, that we have to let go but they also have to pick up."*
>
> *(HCP23)*

Despite acknowledgement from many participants that the development of self-

management requires a gradual and balanced approach, some parent participants reported

that the current practices of healthcare providers, particularly in the adult system, did not

reflect this recommended approach. Parents shared experiences of being suddenly shut

out of their youths' medical care once in the adult healthcare system instead of a gradual

transition towards independence for the youth. For example, one parent described a

difficult experience in the adult healthcare system when her son required an emergency

procedure:

> *"He ended up having to go in the surgery while I was not there...I arrived*
>
> *expecting that he would be out of surgery - well I didn't know exactly when he was*
>
> *going in...So there was no information like that... I was left off at this room, where*
>
> *I was to wait for the doctor to come and give me the results or that he was done*
>
> *the operation and how it went. Nobody ever came. I was left in that room to*

wonder about [youth] for so many hours and the whole room emptied and there was no one in the halls..." (P04)

One healthcare provider participant acknowledged that service providers need to be aware of their own expectations for youth self-management, as positive expectations can enable a smooth transition to adult healthcare. An example from a teen clinic supported this idea:

At the end of the appointment, I always give the youth their appointment directly to them, not to the parents...And the next time they know. It's all about expectations...not expecting him to take charge of everything at one time but developmentally appropriate and work towards that.." (HCP21)

Another healthcare provider participant identified a simple strategy that healthcare providers in both pediatric and adult service systems could use to enable youth, and their parents, to transition gradually towards self-management:

"...a lot of times in teen clinic, what we are trying to do is [identify] what are some small steps that teens can start taking on in terms of managing their health care." (HCP09)

In addition to acknowledging an enabling role, several healthcare provider participants also emphasized the importance of collaboration between providers in pediatric and adult healthcare systems to support a gradual and developmentally appropriate transition process. One participant described this as partnerships:

"I think better partnerships with the adult health care providers is something that would make a big difference overall in transition as well." (HCP22)

2.5 Discussion

2.5.1 Key findings

The emerging themes about the development of self-management for transitioning youth with chronic health conditions indicate that the experiences of youth, parents, and service providers are interconnected and interdependent. The role of parents can be analogous to a bridge that connects the youth between services, whereas health care providers' role can be analogous of a navigator that guides parents and youth through the transition process to successfully land in adult services. Our findings suggest that youth depend on their parents and healthcare providers to support them with the self-management of their condition during transition, while parents and healthcare providers depend on each other to support and enable the youth in self-management during transition. Thus, healthcare providers and parents play a crucial role in self-management promotion by enabling youth to take on more responsibilities for their healthcare needs.

The most significant relationship is between youth and parents. The majority of youth reported feeling fairly independent in managing their healthcare needs; however, parents continue to provide significant support 'behind the scenes', including emotional support, transportation, medication and appointment reminders, general reminders for daily social activities, and lending advice for medical and non-medical decisions. Parents contribute to youths' development by thinking about the future and medical needs - a concept that the youth themselves may not yet be reflecting upon (Ellis et al., 2007). While parents recognized the need to gradually encourage their youth to self-manage, they also saw the importance of their role as a safety net for times when youth are in need of support (Chin et al., 2009; Reiss et al., 2005). Research has shown that the role of parents and family characteristics have been linked with self-management. Several studies have shown that

effective self-management is positively influenced by parental involvement in a youth's healthcare and greater levels of family support and relations, while other studies have shown that single-parent families and lower socioeconomic status are associated with decreased self-management (Reed-Knight, 2011; DeLambo et al., 2004). However, in current practice, parents are not involved enough as healthcare providers may not always recognize parents' contributing role in self-management promotion. It is important, therefore, for healthcare providers to foster collaboration with parents to equip them with transition information and resources to enable youth for self-management, before, during, and after the transition to adult healthcare.

To improve preparedness and efficiency of transition planning, healthcare providers need to facilitate collaboration with youth and families. This collaborative process can be accomplished through 1) providing tools and resources that foster knowledge and self-management skills (for example, resources on the gottransition.org website), and 2) providing opportunities (i.e, joint meetings among youth, families, and healthcare providers before, during, and after transition) for youth and families to actively engage and participate in planning their transition in order to ensure an individualized, patient- and family-oriented transition plan tailored to their goals and needs (Major et al., 2014; MaGill-Evans et al., 2005). Collaboration among all stakeholder groups is documented and emphasized in the literature, suggesting that collaboration for service providers should extend beyond just the system itself, to include active collaboration with youth and parents (Miller et al., 2015; Gorter et al., 2015; Barlow et al., 2002). In particular, parents and healthcare provides must work together to gradually enable youth for self-management instead of meeting expectations for immediate and complete autonomy in adult services.

A key finding of this study suggests the need for healthcare providers to adopt a gradual, developmental perspective when working with transitioning youth and parents. It can be challenging, and sometimes unrealistic, for parents and youth to stop navigating the healthcare system together and for youth to assume full responsibility for their medical management at 18, the typical time of transition. It is advisable for adult healthcare providers to become more cognizant of any unrealistic expectations about the patients entering the adult health care system, the role of parents, and medical self-management skills of youth. It is important for healthcare providers in both pediatric and adult services to recognize and take into account the complex and dynamic relationship between youth with chronic health conditions, their parents and the healthcare system. Typically developing adolescents and emerging adults without chronic health conditions are reported to continue to receive support from their parents up to 25 years of age in life domains, such as finances and housing (Gorter et al., 2011; Stewart et al., 2008; Gorter et al., 2014).

As highlighted by the results, for many of the youth, self-management did not mean doing everything on their own. Rather, managing their healthcare needs was and continues to be a gradual process that occurs with a safety net of parents and provider support. Healthcare providers can collaborate with and enable parents and youth to move gradually towards adult healthcare and self-management together so that expectations and goals are met from everyone's perspectives (Fraser, 2007). In that respect, transition readiness measures, such as the STARx Questionnaire and TRANSITION-Q (Cohen et al., 2015; Klassen et al., 2014), may be useful resources for healthcare providers. For example, the 14-item TRANSITION-Q, a self-management skills scale, can help set developmentally appropriate goals for self-management with youth and parents before, during, and after transition as the items are organized in difficulty order: item 1 ("I

answer a doctor's or nurse's questions") being the easiest, to item 14 ("I book my own doctor's appointments") being the hardest skill to achieve (Klassen et al., 2014). This approach will allow youth to take an active role in the planning of their transition while giving them an opportunity to voice their needs and goals.

2.5.2 Study limitations

The experiences of youth and parent participants involved in this study may not be representative of other transitioning youth as they had more opportunities for transition support available to them compared to most youth.

2.5.3 Areas for future research

Currently, there is limited research about self-management of transitioning youth systematically (Sattoe et al., 2015). In particular, we recommend research to learn more about the various factors that influence self-management (such as access to care, communication, and enhancement of family resources to improve self-management) in order to identify effective strategies to support youth and families (Modi et al., 2012; Hsin et al., 2010). Through systematic, longitudinal studies, researchers and clinicians can gain knowledge of trajectories of self-management skills in youth with and without chronic illnesses, identify those who are at risk for unsuccessful transition outcomes and work towards enhancing existing tools or development of innovative, patient-oriented tools for self-management promotion. Furthermore, in current practice clinicians are not mandated to spend designated time to promote self-management for transitioning youth due to challenges with time management and high volume of patient care loads. Thus, it is critical that policies are in place to enforce adequate funding, institutional support, and

accreditation incentives to allow for designated time for pediatric and adult healthcare providers to foster self-management skills in transitioning youth and parents.

2.6 Conclusions

The identified themes about the development of self-management add new insight about the interconnected and interdependent nature of the experiences of youth, parents, and service providers. Results reveal that youth depend on their parents and healthcare providers for support with their needs for self-management while parents and healthcare providers depend on each other to guide and enable youth for self-management in transition to adult healthcare. Furthermore, these findings emphasize the importance of a gradual, developmental perspective when working with transitioning youth and parents. Active engagement and collaboration among youth, parents, and healthcare providers are essential for empowerment of youth for self-management. Researchers and clinicians are encouraged to examine self-management systematically in order to enhance existing tools and solution-based interventions for health promotion, in particular in youth at risk for transition failures.

2.7 Key Messages

- The identified themes about the development of self-management add new insight about how the experiences of youth, parents, and service providers are interconnected and interdependent.
- Fostering strategies among youth, parents and healthcare providers to enable youth to work towards gradual self-management of their healthcare is in facilitating successful transitions.

2.8 Acknowledgements

2.9 Conflict of interest disclosures

None reported.

2.10 Funding support

2.11 Role of the funder/sponsor

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Table 2: *Participant Demographics*

		Youth	Parents	Healthcare Providers
Total # of participants		11	7	7
Gender	Male	5	1	4
	Female	6	6	3
Clinic	Children's Developmental Rehabilitation Program	2	2	2
	Eating Disorders	1	0	0
	Endocrinology	0	0	1
	Epilepsy	3	2	0
	Inflammatory Bowel Disease	2	2	1
	Lipids	2	0	1
	Nephrology	1	1	1
	Spasticity	0	0	1

The following appendices to Chapter 2 summarizes the interview questions used in the qualitative study. Please note that the interview guides for youth (Appendix A), parents (Appendix B), and healthcare providers (Appendix C) were developed as part of the larger TRACE study. Thus, an excerpt of the interview guide with questions pertaining to self-management as specifically developed for Chapter 2 are presented here.

Appendix A: *Youth Interview Guide*

Opening statements: Introductions and brief overview and purpose of study. Welcome and thank-you for participating in this study. Are there any question and concerns about the study before we begin the interview?

- Can you tell me a bit about what's going on in your life right now?
    - Prompts: School? Work? Health? Any other activities?
    - How do you feel about these changes?
    - What about in the future?
    - How have these changes impacted your healthcare transition?

- Can you make any comments yet on how you see yourself changing over time in terms of making decisions about your own health, and directing your own healthcare?

- What would help or support you to make these changes or transitions easier?
    - Prompts: Parents? Clinic staff? Peers with same health care needs? Information from books and the Internet?

- Have you had any visits with your adult doctor?
    - What do you remember?
    - Did you go alone?
    - How did it go overall? (Comfortable asking questions, understood the doctor's advice?)
    - How did you feel?
    - IF NO: Do you any coming up?
        - How are you feeling about the upcoming visits?
        - Do you feel prepared?

- Do you have any thoughts or experiences about transition so far?
    - Have you needed support over this transitioning period?
    - Why do you need support when you are transitioning?
    - What is going well for you?

- Are there any other experiences or comments that you would like to tell us about?

Closing statements: Thank you for your time and your thoughts. We will send the transcript of this interview to you so you can look it over and make sure we have captured everything correctly. It will also give you a chance to add anything else that you may think of afterwards.

Appendix B: Parent Interview Guide

Opening statements: Introductions and brief overview and purpose of study. Welcome and thank-you for participating in this study. Are there any question and concerns about the study before we begin the interview?

- Do you have any thoughts or experiences about transition so far?

- Can you comment on where you feel your child is in terms of managing their own medical needs?

- What else would help you and your child with transition?

- How do you perceive your role in your child's care at this stage? In the future?

- What is your current involvement in your child's medical care?
  - Do you see this changing over time?

- Are there any additional supports you feel you and your child would benefit from?

- Are there any additional concerns or experiences you would like to share with us about your child's transition?

- What else would help make transition easier?

- Are there any other comments, suggestions, or experience with your child's transition in general, that you would like to tell us about?

Closing statements: Thank you for your time and your thoughts. We will send the transcript of this interview to you so you can look it over and make sure we have captured everything correctly. It will also give you a chance to add anything you think of afterwards.

Appendix C: *Healthcare Provider Interview Guide*

Opening statements: Introductions and brief overview and purpose of study. Welcome and thank-you for participating in this study. Are there any question and concerns about the study before we begin the interview?

- What clinic are you from? What is your position in those clinics?

- How do you perceive your role in youth's transition?

- How do other transitions influence healthcare transition?

- How about in terms of parents?
    - What are the biggest challenges you face in dealing with parents specifically?
    - Can you comment on the role that caregivers play in their youth's transition to adult services?

- What are some barriers and facilitators in healthcare transition to adult services?
    - What would help you and youth with transition?
    - What do you find are the biggest challenges in transitioning youth to the adult healthcare services?

- Are there any other experiences, comments, or suggestions that you would like to tell us about?

Closing statements: Thank you for your time and your thoughts. We will send the transcript of this interview over to you so you can look it over and make sure we got everything you said. It will also give you a chance to add anything you think of afterwards.

CHAPTER THREE

INNOVATIVE PRACTICE: EXPLORING ACCULTURATION THEORY

TO ADVANCE REHABILITATION FROM

PEDIATRIC TO ADULT "CULTURES" OF CARE

PREFACE TO CHAPTER THREE

Authors: Tram Nguyen and Sue Baptiste.

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Summary: This manuscript describes a review and critical appraisal of acculturation theory to illustrate its value for application in rehabilitation services from pediatric to adult healthcare to guide research and inform practice. Acculturation theory provides a rich framework involving sub-constructs and strategies to expand upon and explain the challenges faced by individuals or groups when transitioning into a new healthcare setting or "culture". I partnered with stakeholders (primarily rehabilitation professionals, clinicians, and researchers) and sought their input from the onset to assess the feasibility and applicability of acculturation theory as a guiding framework for rehabilitation services from pediatric to adult healthcare. Several consultation meetings (virtual and face-to-face) between myself and stakeholders were held to discuss these important issues. Initials thoughts and reactions were that the acculturation theory was too new and abstract for application and use in rehabilitation and transition. An important element that everyone came to consensus on was distilling the nature of the abstract concepts down to a very practical level for clinicians. Thus, stakeholders were asked to provide feedback on strategies to operationalize the concepts inherent within acculturation theory in everyday practice to facilitate its use by clinicians and researchers. The outcome of this engagement and collaborative work was the development of a clinical scenario or vignette to illustrate the way in which acculturation theory can be used in practice. From

the perspective of stakeholders, the example of the clinical vignette about "Chloe" demonstrated a concrete example of the potential application of acculturation theory in informing comprehensive transition planning, developmentally appropriate, and culturally sensitive care. In this way, acculturation theory encourages a most holistic approach by considering the influences of the environmental not only on a personal level but also on a societal level.

Results of this work reveal that acculturation has potential to create a collaborative context between the interprofessional team, the client/patient and family as they seek to achieve respectful cultural care. This theoretical framework can be used to heighten practitioners' awareness of each individual's unique worldview related to their expectations for care and treatment, and the complexity of transition to adult health care. Principles of client centred care follow a similar trajectory highlighting the importance of partnership, the expertise of the client and family in the complexities of their own lives and the need for understanding the options for care that exist to enable them to make educated decisions and choices to assist YCHC with self-management to build skills for independence and autonomy. Examining youth's overall acculturation processes will add new insight into how transitioning youth interact with those around them and their physical environment and how we can best deliver services and supports to optimize health, opportunities and experiences. For many youth, a change in services is only one of the many challenges faced in achieving independence and autonomy during a critical developmental stage that involves many concurrent transitions. They must learn to adapt to the adult care environment with new services, new customs and possibly the different "jargon" of professionals (Stewart et al., 2009). Their healthcare plan needs to reflect and accommodate for changes in their environment (new educational institution), activities (independent living), and participation (interacting with new peers and social networks),

in addition to personal (peer relationships) and developmental changes (taking on adult roles and responsibilities) that the adolescent is experiencing (move away from home).

3.1 Abstract

Introduction: This perspective paper explores the application of acculturation theory and the inherent concepts and ideas associated with this theory in rehabilitation to provide a framework for interpreting patient circumstances, responses and behaviours as they move from one culture to the next. Traditionally acculturation theory has been use to examine changes in culture in an ethnic or country sense, however, this paper is among the first to apply acculturation theory to the rehabilitation service cultures from pediatric to adult care for youth with chronic health conditions. **Purpose:** The objectives of this paper are threefold: 1) to critically appraise key literature in the development of acculturation theory, 2) to discuss how acculturation theory can be applied in rehabilitation practice through a clinical vignette, and finally 3) to discuss how acculturation theory can advance rehabilitation by enhancing client-centered practice. **Implications for rehabilitation:** Acculturation theory can provide insight into how patients are experiencing a change in healthcare "cultures", in the context of their overarching life circumstances. This, coming from a broader societal perspective can in turn inform an optimal approach to client-centered practice, and the application of rehabilitation-specific team inputs. This theoretical framework can heighten practitioners' awareness of patients' unique worldviews related to their expectations for care and treatment thus reducing fear of diversity to establish positive partnerships between patients and clinicians. **Conclusions:** An understanding of patients' acculturation processes will add new insight into how we can best deliver services and supports to optimize health, opportunities and experiences for youth with chronic conditions.

3.2 Introduction

The field of rehabilitation is often defined as the multi- and inter-disciplinary management of a person's functioning and health in relation to disability, accessibility and participation[1,2]. From the rehabilitation perspective, patients' functioning and health are not only seen in association with the medical diagnosis or condition but also with personal and environmental factors[2,3]. Thus, the environment in which people live plays a central role in shaping their identity. When an individual moves into a new culture, he/she experiences changes in self-identity and behaviour as part of adapting to the new culture, which can in turn impact health outcomes[3,4].

In the context of this paper, culture is defined as changing environmental contexts such as workplace, healthcare settings, new location, changed accommodation, and social expectations. In particular, the focus is on the service provision cultures for transitioning youth with chronic health conditions (including developmental disabilities) from pediatric to adult healthcare. In order to facilitate successful transitions between different health service provision cultures, it is essential for rehabilitation professionals to examine how changes in the "cultures" of care can impact patient health outcomes. In order to communicate most effectively with a patient, rehabilitation professionals need to internalize a detailed appreciation of the context from which the patient comes and how this relates to that of the destination.

Throughout the past two decades, there has been a paradigm shift from the traditional biomedical approach to a more biopsychosocial approach to health and functioning[5,6]. This radical change moves from a focus on diagnosis and cure to one that emphasizes the significance of personal, social, and environmental factors and their impact on health. The concepts of "cultural competence" and "cultural intelligence"[7] are increasingly

viewed as important variables that provide a context for understanding health disparities among patients as they move from one health culture to the next. Although rehabilitation professionals and scholars recognize the influence of cultural changes on health, there is a lack of theoretical frameworks to assist in the application of cultural understanding in practice. An emerging framework for promoting culturally competent practice among rehabilitation professionals and scholars is acculturation theory (see Figure 2)[8]. Acculturation theory examines the psychological and behavourial changes individuals and groups experience when adapting to a new culture[8]. Traditionally acculturation theory has been used to examine changes in culture in the sense of an ethnic group or a specific country; however, this paper is among the first to apply acculturation theory to health service provision cultures and more specifically, how this theory can be applied in rehabilitation to facilitate a more client-centred transition to adult healthcare for youth with chronic health conditions.

Client-centred practice, as applied to adult clinical practice, is first outlined through the work of Rogers (1951)[9]. The essence of practicing in this manner involves flexible, individualized services and the process of enabling clients to solve issues through the provision of information, sharing of experience and expertise and discussion of the implications of decision-making. In addition, client-centred service delivery respects clients and their families, the choices they make and believes that clients and families have the final responsibility about the decisions related to their care[10]. This exemplifies a radical shift in the power relationship between client/patient and health professional. This demands openness, honesty and authenticity from all parties, thus implying that the issue of expertise is shared – the client and family know their own circumstances, goals and preferences and the health professionals can share their knowledge, experience and expertise to inform and advise. From this direct communication stems the formation of

rational and relevant goals and directions for ongoing client-centred service: this service delivery approach respects clients, their families and circles of care, and the choices they make. This approach believes that clients and their families have the final responsibility about the decisions related to their care, assessment and intervention[11,12]. The health professionals' responsibilities are to support, inform, reason and provide information to enable a safe and focused decision to be made[13].

Many youth struggle with transition to adult healthcare since they face numerous barriers in the adult system including access to services, lack of supports and resources, and finding an adult healthcare provider[14-17]. Youth have expressed a need for knowledge, education, and resources to guide them through this difficult transition[17]. Investigating how youth in transition experience these cultures can help professionals design more effective strategies to support youth during this significant transitional process. Thus it is essential to develop knowledge about how acculturation theory can assist rehabilitation professionals in identifying elements that could contribute to an effective client-centered transition program beyond the medical condition. The objectives of this paper are: 1) to critically appraise key literature in the development of acculturation theory, 2) to discuss how acculturation theory can be applied in rehabilitation practice through a clinical vignette (elements of acculturation are discussed and predominant factors identified), and finally 3) to discuss how acculturation theory can advance rehabilitation by enhancing client-centred practice.

3.3 Critical appraisal of key literature in the development of acculturation theory

At the beginning of the twentieth century, there was increased movement of ethnic groups into new societies. This movement prompted anthropologists to examine the impact of cultural contact that resulted from such movement[18]. They coined the term

acculturation to address "a phenomenon which results when groups of individuals having different cultures come into continuous first-hand contact with subsequent changes in the original culture patterns of either or both groups"[19]. Thus in early definitions, acculturation is described as a change in the *culture* of the group. Later, Graves made an important distinction between acculturation as a collective group-level and *psychological acculturation*, which refers to the changes in values, beliefs, and behaviors in individuals as a result of contact with another culture[20]. This distinction is important for two key reasons: 1) it allows researchers to examine the systematic relationships between these two sets of variables; and 2) recognizes that not all individuals undergo the same level of acculturation as that experienced by their group[8,20].

The acculturation process was first conceptualized as unidirectional which assumes that immigrants lose all aspects of their old culture (home/heritage culture) and acquire the traits of the new (host/dominate culture); this is referred to more commonly as assimilation[21]. Within unidirectional acculturation models, old culture maintenance and new culture adaptation are conceptualized as polar opposites along a single unidirectional continuum[21]. A major criticism of this model by many researchers and scholars is that it assumes that there has to be loss of all aspects of the heritage culture to adapt successfully to the dominant; thus, this precludes any possibility of high adherence to both the dominant and heritage cultures[22-25]. As a result, acculturation theorists developed the bidirectional acculturation model which assumes that individuals retain or lose an old culture while learning independently about or rejecting a new one[26-29]. Berry's bidirectional acculturation model is the most accepted and frequently used within acculturation research[8]. According to Berry's model, acculturating individuals face two important issues: 1) *cultural maintenance/enculturation* or the extent in which they will retain their old culture and 2) *contact and participation/acculturation* or the extent in

which they adapt to the new culture[8]. The result is four different types of acculturation strategies including *assimilation* (reject old culture, accept new culture); *separation* (accept old culture, reject new culture); *integration* (accept old culture, accept new culture); and *marginalization* (reject old culture, reject new culture)[8]. Berry posits also that integration should be the preferred acculturation strategy since it incorporates both the old and new culture[8]. However, integration is often difficult to engender since it is a two way process, involving both a commitment from individuals from the old culture to adapt to life in the new, as well as adaptation of individuals from the new culture to accept and support people from the old[8]. Despite the plethora of literature on acculturation theory, ideas related to acculturation have not yet been applied noticeably to rehabilitation services and health system research[30]. It is important to reiterate that in the context of this paper, culture is defined more broadly to include transitions that occur throughout the rehabilitation process, from pediatric to adult care services.

3.3.1 Berry's acculturation framework

Of all those contributing to the discussion of acculturation, Berry's focus on reciprocity, considering the need for mutual integration involving the domestic and immigrant groups, reflects and relates well to the philosophy of rehabilitation. Berry describes the acculturation process as the cultural, psychological, and behavioural changes that individuals experience when they make the transition into a new culture[8]. Elements that can influence an individual's acculturation process may be cultural, psychological, language-based, personality-based, social, economic, and political[8]. An outline of Berry's framework (see Figure 2) offers a well-organized depiction of the complex processes of acculturation. The framework leads the reader through the multiple interfaces involved in interpreting human effort through an acculturation lens.

Components at the level of the societal group (e.g. society of origin, group elements, settlement society) are foundational to establishing a recognition of the person-level components (e.g. age, gender, readiness for transitioning, personality traits); the inclusion of moderating factors (e.g. time frame of acculturation process, support, coping methods, societal attitudes) provides the contextual detail that enables and constrains the process itself over time.

< Please insert Figure 2 about here>

Berry posited that all of the factors inherent within his framework are of equal importance and no one factor is more significant than the other[8]. This way of thinking, although not perhaps conscious, is foundational and second nature to those engaged in rehabilitation service delivery. The rehabilitation philosophy reinforces the importance of bringing what can and should be brought from the pre-trauma, pre-illness "self" to the process of creating the post-trauma, post-illness "self" as it evolves over time. Thus, this worldview is clearly congruent with the approach to acculturation as espoused by Berry. There is a recognizable relationship here where the two-way connection is made between the patient's support system members and their expectations for the patient's future, based on what they knew before, and the patient him/herself. The negotiation has to take place between what the patient sees as his/her desired future after he/she has experienced the losses, the growth and the change resulting from his/her rehabilitation program.

Institutional transition in rehabilitation service cultures from pediatric to adult care for youth with chronic health conditions can be complex and often requires an integrated effort from pediatric, adolescent and adult healthcare communities[31,32]. The term culture is used to describe these two health care settings as they offer different environments of care (i.e. ease of access to services, types of services, resources and supports, frequency

of service, financial support, and numbers/types of health care providers)[33]. The

transition to adult care for youth with chronic conditions is characterized by complexity

as many conditions impact a person through social, economic and environmental factors.

Well-documented strategies for facilitating seamless transitions within the literature

include[33,34]:

- Consistency and collaboration needed across all systems on a range of issues from defining the age range of youth and related services, to addressing the needs of youth with multiple conditions requiring diverse services and supports and developing meaningful outcome measures.

- Collaboration needed to provide person-centred planning at important transition points, and this involves useful, relevant, individualized, and tailored information for youth and families to help them make informed decisions for the future.

- Adopting a holistic perspective and multi-disciplinary team approach to transitional care to examine all life domains involved with the transition process beyond the health condition

- Enablement of youth to work towards self-advocacy, self-determination, and self-management in their health care, assuming adult roles, and independent living

For the purpose of this paper, we wish to demonstrate how sub-constructs and strategies

inherent in acculturation theory can be applied to rehabilitation practice to enhance

transitional care for youth with chronic conditions. We define the *acculturation process*

as an individual's process of learning about and adopting adult health care cultural norms

(i.e., values, beliefs, and behaviors) while retaining particular desired norms developed

during engagement with pediatric services. In Canada, all youth are transferred to adult

services once they reach the age of eighteen. This difficult transition is often associated with poor health outcomes since the adult service culture differ greatly from that of the pediatric culture of care[35]. The pediatric culture is often more integrated and supportive of patient needs while the adult culture is more segregated and encourages, perhaps even expects, independence. It is important to recognize that a shift in the culture of care is only one aspect of an individuals' transition process. There are multiple transitions that could occur in a young person's developmental trajectory into adulthood[35-38]. A key transition is that of leaving one's childhood home and setting up an independent household. Related to this is the acquisition of adult roles that are inherent within this initial step to adulthood – the movement from child to youth to young adult. The change from high school senior to first year university student introduces multiple challenges and new experiences. Being faced with this naturally intricate life change is difficult enough, without having to cope with particular accommodations due to disability, thus the overall challenges become exponentially greater and more complex. Other transitions frequently include: developing a deep personal relationship with an important 'other'; completing a degree; moving on to graduate school; becoming employed, and participating within the community. The importance of this view centres upon the manner in which rehabilitation professionals are able to support and facilitate this complex transition by identifying and applying concepts from acculturation theory. Berry's acculturation framework has been shown to be useful in providing insights related to health outcomes for youth with chronic conditions[39]. Specifically in relation to rehabilitation, studies have illustrated relationships between the level of acculturation and the use of health care services in areas of general health and mental health, assessment and treatment adherence[40-42]. Berry's acculturation framework can assist rehabilitation professionals in supporting seamless transitions by identifying patients' unique goals and expectations (values and

beliefs) for care and personal well-being. This will encourage communication and collaboration with patients to develop culturally appropriate and individualized healthcare plans. Through this collaboration, youth will feel empowered to self-manage their health by taking an active role in their healthcare plan. By incorporating this acculturation framework into clinical reasoning and critical thinking, rehabilitation professionals will be assimilating societal, client-based and treatment-based elements into a multifaceted approach to working with patients and families. The following clinical vignette provides an example of how Berry's acculturation framework may assist the rehabilitation team in facilitating comprehensive and culturally competent care for transitioning youth with chronic health conditions. The importance of perceiving "culture" within a complex matrix should not be underestimated; in this client scenario, cultural domains include the potentially competing cultures of: pediatric/adult health care systems; independent living/family home; high school/university; social familiarity/strangeness. Elements of acculturation and predominant factors will be identified and discussed.

3.4 Application of acculturation theory in rehabilitation practice

3.4.1 Clinical vignette

> *Chloe is an outgoing 18-year-old living with a chronic illness. She is approaching graduation and is looking forward to starting university in the coming year. Despite her excitement, she feels overwhelmed with the needed changes in her life involving her move to adult health care services in a new city. She experiences occasional pressure sore problems and is waiting for a new wheelchair and cushion to be ordered.*

3.4.2 Contextual points

With advances in medical technology and healthcare, an increasing number of youth with chronic health conditions are now surviving into adulthood[43]. Timely and appropriate intervention and support during transition holds the prospect of benefits that extend to adult life through prevention of morbidity and improved quality of life[44]. Rehabilitation professionals play an important role in this complex transition. They are central to developing sensitive, coordinated services that will bridge from child and youth services into the adult health care culture.

Currently, there is a lack of literature in rehabilitation that examines the impact of the changes in these service cultures on an individual's health and wellbeing. Thus, it is essential to develop knowledge in this area to advance rehabilitation practice. Embracing a consistent framework at this stage of need recognition would provide a substantial foundation for a common understanding of system strengths and weaknesses. The differences between the child and youth health care system and the adult system require understanding and explicating in detail. The personal approaches of the child and youth system are natural extensions of the philosophy of mother and child nurturance. Once the status of adult is reached, the need for consistency in relationships coupled with ready access and caring seems to be disregarded. Health care becomes yet another business arena, where one faces a quagmire of ethical dilemmas and 'bottom line' concerns. Regardless of intention or values, there remains little time for creating and maintaining person/client-centred systems at a level of connectedness experienced within the child and youth systems.

3.4.3 Predominant elements of acculturation theory according to Berry's framework

There are three key transitions within this scenario: i) moving to independent living, ii) becoming a university student and iii) transitioning into adult services – all three of these require a cultural shift. According to Berry's framework, some predominate elements of acculturation theory that apply to Chloe in all three transitions include: financial concerns, changes in healthcare needs and service cultures, a loss of social network, accessibility, behavioral and psychological changes, and changes in family relationships. A key area of relevance of the acculturation model to rehabilitation service delivery lies within the need for rehabilitation health professionals to become intimately acquainted with the differences between child and adult health care service contexts. It is not enough to state simply that it is different; it is critical to be engaged with the patient/client and family in understanding differences, developing strategies for coping with the differences and also in preparing for the transition itself. Perhaps introductions and contacts to the accepting services by the departing services could prove of benefit; even if this were contained solely within the rehabilitation environments at both ends, it would be an invaluable link for the patient/client providing a sense of familiarity, however minimal, upon arrival in the new culture.

Berry's acculturation framework has been interpreted through the information provided within Chloe's story (see Figure 3). Examples of each domain and element are given, including examples of rehabilitation inputs as appropriate. For a rich interpretation of Chloe's scenario using Berry's model, referencing back to the narrative related to each section will be helpful to the reader; further insights can be gleaned through personal reflection of known rehabilitative inputs in circumstances such as those highlighted in the scenario.

< Please insert Figure 3 about here>

Moving to independent living: while Chloe has been living in her parental home, she resides in the basement of the house in a custom-fitted apartment and manages her self-care, as well as readying herself for leaving the house each day to attend high school. She has found a suitable apartment in the university town, but will have to add household shopping to her weekly routine. In addition, she needs to make arrangements for help to do the heavy cleaning probably twice a month. She is physically fit through a steady routine of playing wheelchair tennis and basketball. Chloe will need to make the connections for these recreational pastimes once she is settled in; there are other priorities for now. Members of the rehabilitation team could provide valuable input related to recreational options available within the new community to which Chloe can refer once she is ready to consider this component of her life. *Becoming a university student*: Chloe is planning to move ten days before term begins so she has time to set up banking, plus re-connect face-to-face with the University Financial Officer and Registrar about fees and course details. She has also made plans to set up accommodations for her studies as well as living arrangements through Student Services. All of these tasks involve a major change in the amount of planning required and can be expected to be exhausting particularly upon arrival. Pre-planning can be facilitated by rehabilitation staff providing support for problem-solving and decision making relative to the new community. Social links on campus will be pursued as Chloe learns more about what is available. While it is imperative that the rehabilitation team respects Chloe's desired level of independence, the offer of resource lists, contacts and an ear for listening can be given without it being construed as 'treatment' (if this is indeed a concern). *Transitioning into adult services*: This will require getting to know the local community; but, when choosing her program, Chloe wisely reviewed health service options in the communities she was considering.

Consequently, she has made appointments to see a new rehabilitation physician, working from a clinic, where she expects other health services will be available. Despite the pre-planning and orderly fashion with which Chloe has approached these major life changes, she remains nervous and overwhelmed by the amount of changes and challenges. Her parents are supportive but are equally concerned about the number of challenges facing their daughter. In facilitating Chloe's transitions to new living accommodation, new study environment, new social context and new health care supports, all members of the team need to work together, communicating effectively with each other and Chloe to create a tailored healthcare plan that best reflects her needs and goals for these transitions. The identification of a case manager/system navigator or key contact for Chloe in planning and operationalizing her discharge and in commencing her transition would help in minimizing potential duplication as well as enabling the client-centred values of the treatment environment. Acculturation theory can help clinicians become more client-centred by embracing partnership, reinforcing clearly the expertise of the patient and family in understanding and translating the complexities of their own lives and the need for understanding the options for care and services that exist to enable them to make educated decisions and choices. Thus acculturation theory can facilitate culturally competent care by encouraging professionals to examine multiple aspects of a patients' transition experience beyond their medical condition, beyond being engaged with the patient from a client centred perspective and embracing the societal implications of multiple transitions through an acculturation view. When the application of acculturation theory is paired with a client-centred approach by the rehabilitation team, the richness of potential and opportunity can become realized.

3.5 Discussion and implications for rehabilitation practice

Youth and their families, including their health care providers find it difficult to navigate transition into adult health care due to barriers in the adult system and little communication and coordination across the two settings[45,46]. For many youth, the move to adult care is only one of the multiple challenges faced in achieving independence and autonomy. As the adolescent moves from pediatric to adult care, they experience changes in environments or "cultures". They must learn to adapt to the adult care environment with new services, new customs and possibly different terminology as utilized by professionals. Acculturation theory can become a vehicle, a framework, a scaffold for creating a collaborative context between the multidisciplinary rehabilitation team, the young adult and their family to achieve culturally competent care. This theoretical framework can be used to heighten practitioners' awareness of each individual's unique worldview related to their expectations for care and treatment, and the complexity of transition to adult health care. In the preceding paragraphs, there have been multiple references to elements of the transition from child health care systems to adult that can be framed in the language of acculturation. There first has to be a fundamental acceptance that cultures exist everywhere, that culture is something that permeates all components of living. The notions of entering a new clinic or hospital can present a young adult like Chloe with an overwhelming number of cultural challenges and concerns (new providers, roles and expectations, adjustment to new environment of care). While Chloe is becoming acquainted with new rehabilitation professionals, she is carrying with her the memories of how things were done in the pediatric system. For her, this was how it should be done; this was a system and a place where it worked. Therefore, changes in routines and habitual patterns due to a shift in the culture of care can cause confusion and frustration for patients. What then, can be selected from how rehabilitation assessment

and intervention were accomplished previously that had proven to be gratifying and supportive to Chloe and that can be retained. And similarly, what of the unknown can be introduced that will intersect with the familiar in order to create a seamless transition into the new rehabilitation reality. Using this approach and integrating this thinking results in a culturally competent and intelligent application of some of the core elements of acculturation theory.

Everyone is unique and thus making decisions based on assumptions and generalizations is both unethical and unprofessional[47]. It is critical that rehabilitation care teams embrace the essence of a client-centred approach to client-therapist partnerships. Many rehabilitation professionals declare that this is their approach to their practice and many model a declared philosophy of partnership and respect for those with whom they work; this is a good place from which to begin an enhanced understanding. Principles and values of client-centered clinical practice become central to unraveling dilemmas inherent in the acculturation process. The literature is clear that client-centred care does have positive impacts on client/patient satisfaction and impressions of processes of care[48]. There are many ways that rehabilitation health professionals and teams can embrace the foundational principles of client-centred care and acculturation in addressing the complexity of transitions for youth with chronic conditions to the adult health care context. Starting with the most important concerns for the client will ensure a positive beginning to building good rapport and a mutually respectful relationship. By working with the client in determining priorities for assessment and intervention, perceptions of where the problems reside will become clear; the multiple interfaces at which acculturation theory becomes active go way beyond simply a health care system and model of care. As one can see from Berry's model, core elements encompass every facet of day-to-day life from finances to communication, from the workplace to the

neighbourhood coffee shop. Rehabilitation professionals would do well to expand their sphere of attention and integrate an appreciation of the client in situ doing what is a priority for him or her. Assuming that clients will follow instructions given by health professionals just because they have the expertise is becoming a rare event. Consumerism is expanding visibly with more and more clients and families arriving at the office or clinic well prepared and educated about their health circumstances. Rehabilitation professionals would do well to see this as a gift. This is a situation where mutual expertise, knowledge and experience can be shared and applied in discussion between the professional and the client and his/her family. To internalize this approach individually and systemically can result in saving time, using scarce resources optimally as well as establishing a positive rehabilitation environment with successful outcomes.

The integration of acculturation and the core concepts and ideas associated with client-centred practice, can provide a reassuring framework for rehabilitation professionals when interpreting client circumstances, responses and behaviours[49]. This approach can reduce degrees of discomfort or fear concerning diversity, thus encouraging healthy curiosity. Acculturation can become a natural theoretical 'fit' for health system practitioners when superimposed upon or integrated into varied clinical practice frameworks such as rehabilitation. Basic principles of client-centred care in health and social systems are foundational to a respectful human society.

Similarly, these principles and values are consistent with the very foundation of the theoretical framework of acculturation as espoused by Berry (1997). Respect for patients and their families, and the choices they make, is a central tenet, recognizing their ultimate responsibility for decisions about their health, wellbeing and life. Provision of information, physical comfort, and emotional support is central. Facilitation of a patient's

participation in all aspects of service should be valued and enabled through an emphasis on person-centered communication and flexible, individualized service delivery. In order to communicate effectively with a patient, rehabilitation professionals need to understand the context from which the patient is coming and how this relates to the context to which the patient is going. Acculturation theory can provide insight into how patients are experiencing a change in environments, which can in turn inform client-centred practice.

3.6 Conclusions

In order to facilitate culturally competent practice, it is recommended that rehabilitation professionals consider the context from which a patient is departing and the fresh context ahead. This paper focused on an exploration of change in the service provision cultures for youth with chronic health conditions as they move from pediatric to adult health care. An understanding of patients' acculturation processes will add new insight into how we can best deliver services and supports to optimize health, opportunities and experiences for this population of youth. When working with patients in different service provision cultures, a lack of confidence tends to result in a search for recipes or protocols to enable the therapeutic process and provide the therapist with a sense of security. This strategy is not congruent with the notions inherent within client-centred care and the philosophy of rehabilitation overall. Acculturation theory can become a natural worldview for health professionals when it becomes integrated into clinical practice frameworks such as rehabilitation. This theoretical framework can be used to heighten practitioners' awareness of each individual's unique worldview related to their expectations for care and treatment, thus reducing fear of diversity to establish positive partnerships between patients and clinicians. This paper is seen as a cornerstone by the authors for moving

ahead with a program of study related to acculturation theory; its application in healthcare will be one of the key foci.

3.7 Acknowledgements

3.8 Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

3.9 References

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Figure 2: *Berry's Acculturation Framework*
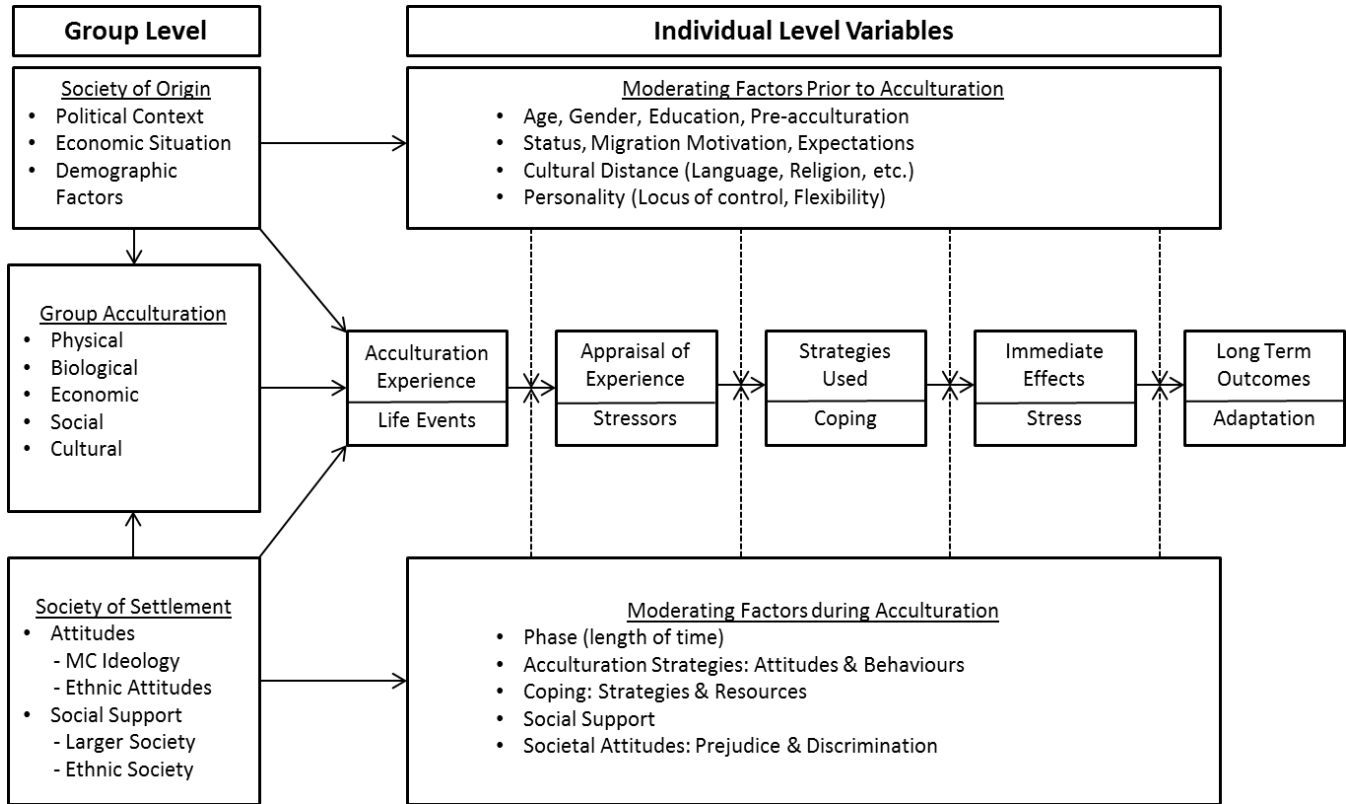
Figure 3: Application of Berry's Acculturation Framework to Clinical Vignette (Chlöe)

Group Level	Individual Level Variables				
Society of Origin Pediatric health care: • Well integrated • Consistent, supportive provision of care	**Moderating Factors Prior to Acculturation** • 18 year old young woman, who uses a wheelchair due to chronic illness • Moving to independent living in new town • Becoming university student with accessibility and accommodations issues • Transitioning into adult health care: finding new physician at a clinic with rehab team				
Group Acculturation • Youth with wide range of chronic conditions including developmental disabilities • Complex process of transition	**Acculturation Experience** Leaving home, acquiring adult roles including student, adult health care recipient	**Appraisal of Experience** Challenges related to accessibility, transportation, and access to services	**Strategies Used** Booked appointment with MD, has connection with university re: accommodation, registration, and finances	**Immediate Effects** Feelings of nervousness and being overwhelmed	**Long Term Outcomes** Adapting to new lifestyle involving participation in the community of campus & town, self-management of health care
Society of Settlement Adult health care: • Lack of communication • Fragmented services	**Moderating Factors during Acculturation** • Established sound relationships with new healthcare providers, university resources, social network • Advocates for cultural sensitivity and diversity through active engagement in campus association for students with disabilities				

CHAPTER FOUR

WHAT ARE THE LESSONS BEING LEARNED ABOUT USING THE ICF IN

TRANSITION RESEARCH AND PRACTICE? A SCOPING REVIEW

PREFACE TO CHAPTER FOUR

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Summary: Although the findings of Chapter 3 indicate that acculturation theory has strong potential to facilitate healthcare transition, the stakeholders within the study (i.e. YCHC, parents, health professionals) prompted me to consider the challenges associated with promoting its use in research and practice due to the lack of awareness about the theory among researchers and clinicians involved in healthcare transition. The stakeholders suggested that an approach to overcoming this challenge is to use acculturation theory in conjunction with an existing theory in healthcare. This critical and important feedback prompted the exploration of the International Classification of Functioning, Disability and Health (ICF) as a complementary framework to bring acculturation theory to the forefront of healthcare transition. Given my experience and knowledge about the ICF through teaching in a graduate level course about the ICF, the ICF could provide a fit for use with acculturation theory (Nguyen et al., 2016b; Nguyen & Gorter, 2014). The ICF is an internationally recognized framework and classification system endorsed by the World Health Organization and used around the world. Thus, the next step was to review the literature on how the ICF has been used in transition research and practice.

This manuscript describes a scoping review to learn about the extent in which the International Classification of Functioning, Disability and Health (ICF) has been used in transition research and practice. In contrast to systematic reviews, a scoping review was chosen as the aim of the review was to explore current use of the ICF in transition

research and practice for youth with chronic health conditions (YCHC) to inform thinking about its strengths and limitations for future work. The focus of the scoping review was not on evaluation of the quality of existing studies or methodologies; thus all relevant studies that met inclusion criteria were included. A total of nine articles form the current scoping review. Results from analysis of the nine included studies included this scoping review reveal two key themes on the current use of the ICF: 1) the ICF builds capacity for a broad perspective on health by emphasizing the influence of personal and environmental factors, and 2) the ICF promotes communication and collaboration among health professionals through the common language. However, the ICF is not without limitation, one of its weaknesses is that it is static and does not address the dynamic needs of youth over time. Furthermore, the ICF does not explain the underlying processes of person-environment interactions or identify and assess key components of personal and cultural influence (i.e. social elements and skills for adaptability), and unclear differences between activity and participation. Thus, these limitations should be considered prior to use of the ICF. Ideally, it is recommended that the ICF be used in conjunction another theory or framework which can address some of its limitations.

4.1 Abstract

Background Since the introduction of the International Classification of Functioning, Disability and Health (ICF) in 2001 by the World Health Organization, there has been growing momentum for a paradigm shift in how we view health to include personal and environmental influences**.** This paper describes a scoping review which aims to explore the current use of the ICF in transition research and practice for youth with chronic health conditions (YCHC) and to inform thinking about its strengths and limitations for future work. ***Methods*** A scoping review was conducted to determine how the ICF is being used in transition research and/or practice (clinical practice, any area of health care practice, community practice, assessment or intervention) for YCHC. A five-stage methodological framework for scoping studies guided the review process: (1) identify the research question; (2) identify relevant studies; (3) study selection based on inclusion and exclusion criteria; (4) chart the data extraction in a standardized form; and (5) collate, summarize, and report the findings. Searches were conducted using the following databases: Medline, CINAHL, HealthSTAR, PsycINFO and Embase. All databases were searched using a combination of the following key words: 'transitions', 'ICF', 'ICF-CY', 'youth/adolescents with chronic health conditions', 'youth/adolescent with disabilities'. Final inclusion criteria: (1) published between January 2001 and December 2015; (2) published in the English language; (3) sample included youth with chronic health conditions aged 12–25 years old; and (4) report described utilization of the ICF in facilitating transitions for youth with chronic health conditions. ***Results*** Results from analysis of the selected nine studies reveal that the extent to which the ICF has been used in transition research and practice is primarily at a conceptual level. Two key themes emerged from the analysis of the use of the ICF: 1) the ICF builds capacity for appreciation of a broad perspective on health by emphasizing the influence of personal

and environmental factors, and 2) the ICF promotes communication and collaboration among health professionals through a common language. However, some limitations include: limited descriptions around personal and environmental factors and the underlying processes, unclear differences between the domains of activity and participation, and the ICF's static nature that does not address change over time. ***Conclusions*** Despite the strengths of the ICF and proposed use in transition research and practice, its limitations should also be considered. It is recommended that the ICF be used in conjunction with another theory or framework to address the identified limitations.

4.2 Introduction

In 2001, the World Health Organization (WHO) introduced the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) and subsequently a child and youth version (ICF-CY) (WHO, 2007), propelling a paradigm shift in how we view health (see Figure 4). The concepts inherent within the ICF have nurtured new ways of thinking about health and healthcare practice by researchers and clinicians alike (Rosenbaum & Stewart, 2004). Specifically, the ICF has informed the field of childhood disability research and practice through "new ways of formulating ideas about children, child development, social-ecological forces in the lives of children with chronic conditions and their families, and 'points of entry' for professionals to be helpful." (Rosenbaum & Gorter, 2012, p.1). For example, Rosenbaum and Gorter (2012) have created a set of ideas, rooted in the ICF domains, called 'F-words' in child neurodisability – function, family, fitness, fun, friends and future – in hopes of encouraging people to take a holistic, patient-oriented and lifecourse approach to care by utilizing these concepts in clinical practice, service, research and advocacy for child and youth with disabilities and their families. Additionally, a paper by Nguyen and Gorter (2014) explored the potential use of the ICF domains and framework as a tool to guide practice to support adolescents with chronic health conditions during their transitions to adulthood and their families. The Nguyen & Gorter (2014) paper was a commentary to raise awareness on the potential application of the ICF in transition. Specifically, how the ICF could guide the planning of three phases of the transition journey: the preparation, the journey itself, and the landings in the adult world (Stewart et al. 2009). This scoping review will build on the knowledge gap identified in this commentary and will formally explore how researchers and clinicians actually have used the ICF in transition research and practice for youth with chronic health conditions (YCHC), including developmental disabilities.

Specifically, this paper describes a scoping review that aims to explore the current use of the ICF in transition research and practice for YCHC to inform thinking about its strengths and limitations for future work.

< Please insert Figure 4 about here>

4.3 Methods

Scoping reviews are becoming an increasingly common approach for "mapping", a process of summarizing research evidence in a specific field of interest to convey breadth and depth (Arksey & O'Malley, 2005). A scoping review was conducted to determine the extent, range, and nature of how the ICF and ICF-CY are being used in research and/or practice (clinical practice, any area of health care practice, community practice, assessment or intervention) relating to transitions to adulthood for youth with chronic health conditions and their families. Arksey and O'Malley's (2005) five-stage methodological framework for scoping studies guided the review process: (1) identify the research question; (2) identify relevant studies; (3) study selection based on inclusion and exclusion criteria; (4) chart the data extraction in a standardized form; and (5) collate, summarize, and report the findings. In contrast to systematic reviews, a scoping review was chosen since the aim of the review was not on assessment or evaluation of the quality of existing studies or methodologies; thus all relevant studies that met inclusion criteria were included in this review. The focus of this scoping review was on "mapping" or gaining insight into the extent in which the ICF has been used in transition research and practice, rather than doing an in-depth critical analysis. Furthermore, the focus was not on the evaluation of the studies as this could have limit the scope of the search.

4.3.1 Step 1: Identifying the research question

The scoping research question was "How has the ICF been used in transition research and practice for YCHC?"

4.3.2 Step 2: Identifying relevant studies

Under the guidance of a librarian, the primary author searched the academic literature through the following databases: Medline, CINAHL, HealthSTAR, PsycINFO and Embase. All databases were searched using a combination of the following key words: 'transitions', 'ICF', 'ICF-CY', 'youth/adolescents with chronic health conditions', 'youth/adolescent with disabilities'. Key words were slightly modified and tailored to adapt to the requirements of each database to ensure accuracy and efficiency of searches through consultation with a librarian.

4.3.3 Step 3: Study selection

The final selection of peer-reviewed articles was based on the following inclusion criteria: (1) published between January 2001 and December 2015; (2) published in the English language; (3) sample included youth with chronic health conditions aged 12–25 years old; and (4) report described utilization of the ICF in facilitating transitions for youth with chronic health conditions. In addition, the reference lists of the articles included in the review were explored for further papers potentially relevant to the research question.

4.3.4 Step 4: Data charting and extraction

A data extraction template was created using Microsoft Office Excel to organize the extracted information according to the following categories: authors, publication date,

country of origin, sample, purpose, how the ICF was utilized (e.g., conceptual framework, classification system), and key findings about using the ICF within transitions research or practice. The lead author extracted data from all of the included articles before sending to additional team members for verification. Three team members (DS, PR, and JWG) reviewed the charted data independently before meeting as a group to discuss any disagreements, suggestions, or differences; the necessary revisions were completed. Consensus was achieved on the final data extraction table through several group discussions and consultations.

4.3.5 Step 5: Collating, summarizing, and reporting the findings

An iterative approach was used among three team members (DS, PR, and JWG) to review and synthesize the extracted data. Thematic analysis of the key findings of included studies elucidate key themes related to current use of the ICF. Results of the process of analysis informed thinking about important implications or 'lessons learned' for future work.

4.4 Results

4.4.1 Search results and findings

The initial search using the keywords in all databases yielded 1416 articles (see Figure 5). The search was then limited by population age (youth aged 12-25); and time of publication (January 2001- December 2015), reducing the number to 273 articles. The lead author reviewed the titles and abstracts of all 273 articles using the inclusion criteria and removed all duplicates, yielding 14 articles for full text review. Five articles were excluded after group consultation. A total of nine articles form the current scoping review including three reviews, one knowledge synthesis, one commentary, two survey research

studies, one qualitative study, and one systems research study. The studies in this scoping review originated from Canada (five), the United States (two), the United Kingdom (one) and Australia (one). Table 3 provides a summary of the included articles and findings.

< Please insert Table 3 about here>

< Please insert Figure 5 about here>

4.4.2 Key themes about current use of the ICF from analysis of the included studies

Two key themes emerged from thematic analysis of the nine included studies regarding current use of the ICF in transition research and practice (see Table 3):

- Enhancing communication and collaboration between professionals, and between professionals and their patients; and
- Promoting a broad and holistic perspective on health and a comprehensive approach to healthcare service and delivery over the youth's developmental process or lifespan.

4.4.2.1 Communication and collaboration

Since transition to adulthood of youth with chronic health conditions typically requires support from multiple health professionals, the common language and structure of the ICF framework can be key in providing consistency and transparency for outlining treatment plans and documenting clinical decisions among professionals. The majority of the included studies utilized the ICF's conceptual framework (rather than the WHO's coding and classification system) to enhance consistency in the description of health conditions and communication among team members. Foley and colleagues (2012) also discusses the importance of the ICF conceptual framework in providing a common

language for information sharing, and framing transition research to identify gaps. A challenge with the planning and delivery of transition services is that multiple professionals and service sectors are involved different levels of care, thus is critical for communication to remain clear as youth move from one provider to the next. The issue arises when messages or recommendations get lost in translation professional jargon and language. Thus, the ICF's common language is critical in facilitating discussion among a diverse group of providers in healthcare teams to discuss the development, planning and execution of interventions and service delivery in an orderly and clear manner according to the five life domains. Additionally, Kraus de Camargo (2011) suggests that the universal framework of the ICF can provide a transdisciplinary and coordinated approach to support the transition process by promoting more integration and collaboration among the health, education, and social welfare systems of care.

4.4.2.2 Broad perspective on health

Foley and colleagues (2012) recognized that the ICF is currently being used to facilitate a broad perspective on health through consideration of personal and environmental factors on health. A patient's health condition is only one aspect of a person's overall health and well-being, thus this should be reflected in their healthcare plan. A knowledge synthesis by Gorter and colleagues (2014) found that developmental outcomes are determined by the processes of relationships, opportunities, and experiences that arise from person-environment interactions for transitioning youth regardless of the underlying disability or health condition (Gorter et al., 2015; Major et al., 2013). Healthcare plans then should not only focus on 'fixing' the health condition but also should focus on the development of the person. Therefore, transition to adulthood encompasses much more than 'just' healthcare transition or transfer from pediatric to adult care settings (Rosenbaum &

Gorter, 2011). Transitions for young people with chronic conditions are critical developmental processes and may influence several life domains, such as social interactions, school, employment, and community life. Liptak and colleagues (2010) also discuss the importance of using the ICF framework to guide the holistic planning and delivery of transition intervention that considers the needs of youth in various life domains beyond the medical condition. This approach builds capacity for equal recognition of personal and environmental influences on health and the importance of engagement and participation in social and personal activities in promoting health and quality of life (McDoungall et al., 2015).

Included articles by Rosenbaum and Stewart (2007) and Van Naarden Braun and colleagues (2006) suggest that adoption of the concepts of the ICF will expand the scope of developmental services through emphasis on activities and participation in society, as well as the acquisition of adult roles. By using this approach, there is acknowledgement of the role of both personal and environmental elements as legitimate components of intervention programs. The two studies by King and colleagues (2005, 2006) emphasized the importance of an ecological approach an attention to personal and environmental factors of the ICF framework that extends beyond health to include a variety of developmental transitions including education, social activities and peer supports, and community participation and engagement for transitions to adulthood.

4.5 Discussion

4.5.1 Strengths of the ICF

All of the included studies utilized the ICF's conceptual framework, without empirical data about how the framework was applied or used to understand transition processes or person-environment influences. Results of this scoping review indicate that the ICF has been used to promote communication and collaboration between health professionals, as well as between professionals and their patients which is consistent with the broader literature (Dempsey & Skarakis-Doyle, 2010). More importantly, a noteworthy finding is that the ICF facilitates a broad perspective about health through consideration of person and environment influences on youths' transition experience. Additionally, there is a focus on 'interdependence' (recognizing that youth need supports and resources at various stages and transitions in their lifetime) rather than 'independence' (focusing on individual skills and autonomy) (Stewart, 2014; Stewart, 2009). Such an approach broadens our scope from pediatric to adult age range and from the field of disability to all chronic health conditions (encouraging a non-categorical approach to care).

Consideration of person-environment interactions allows for a more holistic outlook to healthcare as a youth's living environment impacts their development process and ultimately transition experience and outcome (Magasi et al., 2015). For example, Magasi and colleagues (2015) reported on the importance of the reciprocal or transactional relationship between person and environment. In other words, the person both shapes and is shaped by their environment or context, thus the focus should not be on either the person alone or their environments (Magasi et al., 2015). The ICF's promotion of a broad perspective begins to address calls from funding agencies for consideration of a more holistic perspective towards transition planning and service delivery, given the multiple

concurrent transitions that occurs during transition (i.e. the move to independent living and the move to post-move to secondary education) (Singh, 2009, McGorry et al., 2013). Particularly, the five life domains of the ICF builds capacity to address the needs of transitioning youth beyond their medical condition (Liptak et al., 2010).

4.5.2 Limitations of the ICF

Despite the strengths and richness of the universally accepted ICF conceptual framework in enhancing how we view health, it is not without limitation. There is limited description and detail regarding personal and environmental factors and the underlying processes/interactions behind these factors as represented by the bidirectional arrows in the ICF conceptual model (WHO, 2001). While the ICF provides a useful guide and taxonomy for clinicians and researchers to identify biological and environmental influences it does not provide clarity around the processes or conceptualization of the relationship within and between factors in the environments over time. For YCHC, the environmental domains can include physical (accessibility), social (societal attitudes), cultural, institutional, services and legislation (policy, infrastructure support, and administrative processes) (Stewart et al., 2014). An understanding of youths' interactions with their environments and underlying processes can assist in formulating effective transition plans and identifying targets for interventions and strategies to address their needs, goals, and concerns. Furthermore, the ICF lacks description around the reciprocal relationships between environmental factors at the individual, community and societal levels.

There is also evidence that further clarification is needed to distinguish between the activity and participation domains of the ICF (Jette et al., 2007). For example, results from a study conducted by Jette and colleagues (2007) revealed that clear distinctions

between activity and participation sub-domains of the ICF could not be identified upon analysis. Thus, a consideration for future research on the development of the ICF is to provide additional information to further define personal, environmental, activity, and participation domains to give researchers clarity and option when mapping or developing transition programs and interventions based on the ICF. As the impact of chronic illness and disabilities is lifelong (Overbeek et al., 2010), another limitation of the ICF is that it is static in nature. This static nature can be problematic when studying transition as a lifecourse approach is encouraged to meet the dynamic and changing needs of youth over time in their developmental trajectory. Thus, additional research is required to examine the element of change over time in order to address the developmental and dynamic needs of transitioning YCHC.

4.5.3 Recommendations

Overall, the key lessons learned from this scoping review are; 1) the ICF broadens our perspective on health through consideration of the five domains in the ICF to frame transition research; 2) the common language of the ICF can enhance communication and collaboration in the planning and delivery of transition interventions; and 3) to consider the limitations of the ICF. The limitations of the ICF include: i) limited descriptions around personal and environmental factors and the underlying processes, ii) a lack of distinction between the domains of activity and participation, and iii) the ICF's static nature which does not address change over time, which is essential for addressing the dynamic needs of YCHC. A key recommendation is to explore complementary theories to address some of the limitations of the ICF, as this would provide researchers and clinicians with options or a 'bundle' of theories that provide comprehensive guidance and direction when studying and providing services for healthcare transitions. As no one

theory will be perfect in addressing such a complex issue as transition, it is also important to consider the use of multiple theories to utilize the strengths of each and moderate the limitations.

4.6 Conclusions

While the findings of this scoping review suggest that the ICF has been used to broaden our perspective on health (bringing awareness to the influences of personal and environmental interactions) as well as enhance interactions between professionals, it is not without limitations. Specifically, additional research is need to explore the interactions and process between personal and environmental factors and differences between activity and participation. While the ICF provides a useful guide and taxonomy for clinicians and researchers to identify biological and environmental influences it does not provide clarity regarding the conceptualization of the relationship within and between factors in the environments over time. An understanding of youths' interactions with their environments and underlying processes can assist in formulating effective transition plans and identifying targets for interventions and strategies to address their needs, goals, and concerns. In order for the ICF to be used effectively in transition, these limitations need to be addressed through consideration of alternative theories (e.g. acculturation theory) which can moderate its limitations. Lastly, additional research is needed to advance knowledge towards developing empirically based evidence for use of the ICF beyond a conceptual application.

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Figure 4: Diagram of the International Classification of Functioning, Disability and Health (ICF) Conceptual Framework. The five life domains of body structures/functions, activities, participation, environmental factors, and personal factors are presented. Bidirectional arrows represent the interactions among the different domains, reflecting the ongoing influence of environmental factors on body functions, activities, and participation, and vice versa (World Health Organization, 2001).
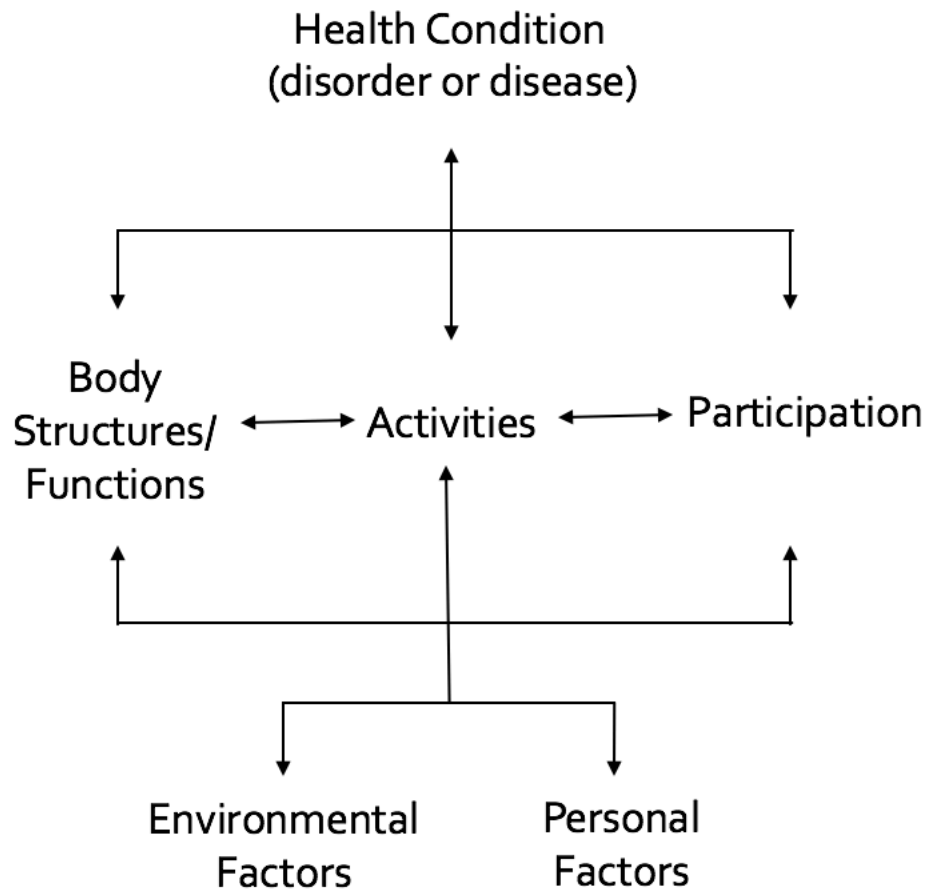
Figure 5: *Flow chart of search and study selection*
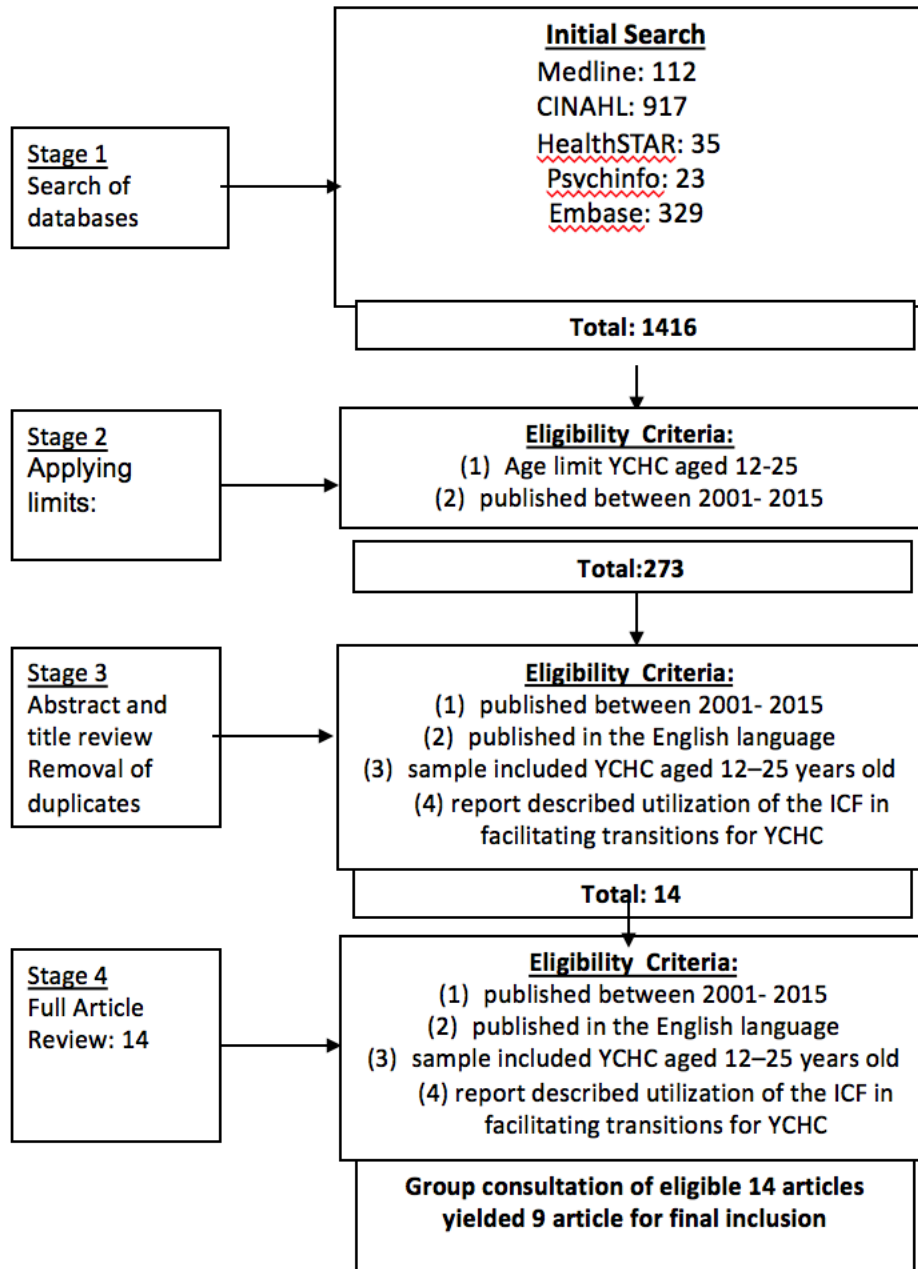
Table 3: *Summary of the research studies included in scoping review and data extraction.*

Author(s), date, country	Sample	Purpose	How the ICF was utilized (conceptual framework or classification system)	Key findings about using the ICF within transitions research or practice
Foley et al, 2012 Australia [1] Review	Young adults with intellectual disability	To describe the literature on transition for youth with an intellectual disability and to identify knowledge gaps	Conceptual framework	• The ICF promotes a broad and holistic view of health that extends beyond the diagnosis to include the impact of environmental and personal factors that may influence an individual's ability to participate in life activities • The ICF provides a common language for information sharing • The ICF can help frame transition research and identify gaps
Gorter et al., 2014 Canada [2] Knowledge Synthesis	Youth with childhood-onset disabilities	To provide a synthesis of available knowledge about the developmental trajectories of youth with childhood-onset disabilities with a focus on mental health and psychosocial outcomes.	Conceptual framework	• The ICF emphasizes the relationship between the biopsychosocial elements of a person and their participation in everyday activities and experiences in their environment, recognizing the important interaction between person and environment • Healthcare plans should reflect the processes of relationships, opportunities, and experiences that arise from person-environment interactions, leading to developmental outcomes over the life course
Jeglinsky et al, 2012 Finland [3] Qualitative Research	Children and adolescents with cerebral palsy	To explore the practices and approaches involved in rehabilitation planning for children with cerebral palsy	Conceptual framework	• The ICF-CY provides an overarching framework and common language to enhance communication and collaboration between various rehabilitation professionals (i.e documenting clinical decisions and in communicating within a multidisciplinary team) as well as between professionals and their clients (children and families) • The ICF-CY framework could optimize collaborative goal setting and structure both the procedures and documentation of the rehabilitation plans and goals
King et al, 2005 Canada [4] Review	Youth with disabilities; emotional or behavioral disorders, learning disabilities, developmental disabilities, and chronic physical health conditions	The primary aim is to provide a framework or model describing existing transition approaches and strategies	Conceptual framework	• Transitions may occur with respect to several life domains, such as friendships, school, work, and community. Adult roles therefore reflect broad expansion of health as endorsed by the ICF to encompass problems people may experience in engaging in life situations (person-environment interactions)

King et al, 2006 Canada [5] Review	Youth with disabilities; emotional or behavioral disorders, learning disabilities, developmental disabilities, and chronic physical health conditions	To review the effectiveness of the 10 main strategies used to provide transition education and planning services for youth with disabilities	Conceptual framework	• There is an increasing trend for interventions to focus more on participation, which appears to be related to growing awareness of the importance of participation experiences for positive outcomes for children, and to the ICF's conceptualization of disability as encompassing participation restrictions. • Integrated and comprehensive transition services should address skill instruction and self-awareness; provide customized informational, emotional, and instrumental supports to meet the needs of youth and families; provide direct opportunities and experiences for skill development; and address the welcoming nature of community activities and settings.
Kraus de Camargo, 2011 Canada [6] Systems Research	Adolescents with complex health conditions	To examine the transition process within different systems of care by applying the classifying principles of the ICF	Conceptual framework	• The common language of the ICF framework could enhance communication and collaboration between systems (health, education, and social systems) involved in the transition process • The ICF could assist in identifying various needs and factors that impact functioning of patients in distinct environments and can guide transdisciplinary processes to provide holistic care across the lifespan of youth
Liptak et al, 2010 US [7] Survey Research	Youth and young adults with spina bifida	To describe outcomes and to identify factors that affect social participation among youth and young adults with spina bifida.	Conceptual framework	• Future health planning and interventions to improve outcomes in adults with spina bifida will need to address factors in all life domains beyond just the patient's health condition as endorsed by the ICF
Rosenbaum and Stewart, 2007 Canada [8] Commentary	Children and youth with developmental disabilities	To offer the ICF as a framework for understanding disability and guiding transition to adulthood	Conceptual framework	• Through adoption of the concepts of the ICF, the scope of developmental services is beginning to expand; moving beyond concerns with "body structures and functions," professionals are promoting function through an emphasis on activity and participation in society, and acknowledging the role of personal factors and environmental factors as legitimate components of intervention programs. • Recent evidence also supports the need to focus efforts on altering the environment to reduce barriers and build supports

Van Naarden Braun et al, 2006, US [9] Survey Research	Young adults with developmental disabilities	To examine the relationship between childhood impairment and the acquisition of normative adult social roles in transition to adulthood	Conceptual framework	• The ICF provides a multi-dimensional conceptual framework for examining the acquisition of adult social roles within the domain of participation defined as involvement in life situations ranging from major life areas (e.g., education, employment, economic self-sufficiency) to community, social, and civic life (e.g., recreation and leisure, religion, political life) • Through application of the ICF, this study underscores the need to examine impairment by type and severity in order to capture the vast differences in functioning and acquiring adult social roles

CHAPTER FIVE

PROMOTING KNOWLEDGE MOBILIZATION: REFLECTIONS ON A
DEMONSTRATION PROJECT TO IDENTIFY ENGAGEMENT STRATEGIES WITH
UNIVERSITY STUDENTS WITH AND WITHOUT DISABILITIES

PREFACE TO CHAPTER FIVE

Title: Promoting knowledge mobilization: Reflections on a demonstration project to identify engagement strategies with University students with and without disabilities

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Summary: This manuscript describes a demonstration project in which I worked directly with University students with and without disabilities (SWWD) and researchers as co-researchers to identify strategies for engagement in research (including research in transition). Results of this demonstration project will assist in developing meaningful research partnerships to facilitate knowledge mobilization. The demonstration project consisted of four phases in the development and execution of a knowledge translation and exchange (KTE) symposium: 1) stablishing an inclusive research team, 2) convening a knowledge translation and exchange symposium (activities/strategies), 3) sampling and recruitment, and 4) evaluation and analysis. An integrated knowledge translation (iKT) approach guided the "thinking" in consulting with SWWD and researchers as partners following the principles of direct stakeholder engagement and equalizing partnership throughout the research process. The KTE symposium provided an opportunity for SWWD for face-to-face interactions with researchers, which is essential for relationship

building to develop research partnerships. Although SWWD and researchers are the primary target populations in this project and paper, other stakeholders included educators and community members in order to facilitate rich discussions from multiple perspectives. Although facilitators introduced research in healthcare transition as a point of discussion, the scope of the symposium included research in general.

The primary objective of the demonstration project was to identify engagement strategies to develop research partnerships between students with disabilities and researchers at McMaster University. Secondary objectives included: i) enhancing awareness of and access to disability research, services, and resources across campus and within *CanChild*, McMaster University, and Hamilton communities; and ii) to identify priorities to inform program development at *CanChild* and McMaster University.

Results reveal five engagement strategies: 1) creating a physical or virtual hub with updated information or updating current websites to ensure usability and accessibility (e.g. for course selection), 2) hosting "speed dating" events between students and faculty/researchers to enhance communication and knowledge exchange, 3) hosting monthly lectures/workshops/webinars, 4) capacity building via emailing lists for new opportunities, and 5) peer mentoring to connect stakeholders within the University and Hamilton communities. The demonstration project was also effective in enhancing students' awareness and accessibility to disability research, services, and resources across campus and within *CanChild*, McMaster University, and Hamilton communities. Lastly, results reveal three priority areas: 1) fostering inclusivity and collaboration by engaging students with a disability in research and by improving accessibility on campus, 2) developing a centralized and user-friendly information hub for knowledge exchange; and 3) creating opportunities for networking and collaboration through hosting of social events to promote engagement between students and faculty/researchers (e.g. a graduate-

undergraduate mentorship program) for program development at *CanChild* and McMaster University. Reflection on the demonstration project offers some powerful observational insights into the challenges of research partnership (i.e. iKT); specifically, insights relating to direct involvement of youth with disabilities as co-researchers and equal partners in the research process from idea conception to application.

5.1 Abstract

Background The realization that target populations, as youth with disabilities, are often not included in research has prompted the current focus on engagement to develop research partnerships. The purpose of this paper is to describe a demonstration project with a primary objective of identifying engagement strategies to develop research partnerships between student with and without disabilities (SWWD) and researchers at McMaster University. Secondary objectives included: i) enhancing awareness of and access to disability research, services, and resources across campus and within *CanChild* Centre for Childhood Disability Research, McMaster University, and Hamilton communities; and ii) identifying priorities to inform program development at *CanChild* and McMaster University. ***Methods*** The demonstration project consisted of four phases in the development and execution of a knowledge translation and exchange (KTE) symposium: 1) stablishing an inclusive research team, 2) convening a knowledge translation and exchange symposium (activities/strategies), 3) sampling and recruitment, and 4) evaluation and analysis. An integrated knowledge translation (iKT) approach guided the "thinking" in consulting with SWWD and researchers as partners following the principles of direct stakeholder engagement and equalizing partnership throughout the research process. The demonstration project was held at McMaster University in a joint collaboration with *CanChild*, McMaster University, and Hamilton communities. Thirteen participants attended the KTE symposium. Although SWWD (n=7) and researchers were the primary target populations in this project and paper, other stakeholders included educators and community members facilitating rich discussions from multiple perspectives. ***Results*** Results reveal five engagement strategies: 1) creating a physical or virtual hub with updated information or updating current websites to ensure usability and accessibility (e.g. for course selection), 2) hosting "speed dating" events between students

and faculty/researchers to enhance communication and knowledge exchange, 3) hosting monthly lectures/workshops/webinars, 4) capacity building via emailing lists for new opportunities, and 5) peer mentoring to connect stakeholders within the University and Hamilton communities. Students' awareness and accessibility to disability research, services, and resources across campus and within the *CanChild*, McMaster University, and Hamilton communities also improved. Three priority areas for program development: 1) fostering inclusivity and collaboration by engaging students with a disability in research and by improving accessibility on campus, 2) developing a centralized and user-friendly information hub for knowledge exchange; and 3) creating opportunities for networking and collaboration through hosting of social events to promote engagement between students and faculty/researchers (e.g. a graduate-undergraduate mentorship program) for program development at *CanChild* and McMaster University. Reflection on the demonstration project also offer some powerful observation insights into the challenges of research partnership (i.e. iKT). ***Conclusions*** This demonstration project offers a variety of strategies for engagement in research as suggested by SWWD and researchers. They also found that the KTE symposium was effective in increasing their awareness of and access to disability research and resources. Lastly, priority areas for program development were identified. Therefore, results provide a starting point and learning opportunity for working with SWWD to enhance research partnerships to facilitate knowledge mobilization. Future research is needed to evaluate the effectiveness of the proposed strategies identified in this project.

5.2 Introduction

Today's research climate emphasizes a need for effective knowledge mobilization or dissemination to bridge the "knowledge-to-practice" gap (Macleod et al., 2014, Martin et al., 2013; Rottingen et al., 2013; WHO, 2006). Traditional approaches to knowledge (end-of-grant) typically include publications and conference presentations to share and communicate research findings. These approaches often target scientific communities and not necessarily populations such as clients, patients, communities and other potential partners who may benefit from research evidence that could inform best practice. Furthermore, traditional approaches often engage stakeholders almost exclusively at the end of the research process (Andrews et al., 2016; Bowen & Graham, 2013). There is increasing evidence that knowledge mobilization is bidirectional between creators of knowledge (researchers) and the people that use the knowledge (Kitson et al., 2013; Straus et al., 2013, Straus et al., 2011; Tetroe, 2011). There is also evidence supporting the value of engaging stakeholders (youth, parents, healthcare providers) in research to facilitate knowledge mobilization in rehabilitation and disability research (Sharkey et al., 2016; Cross et al., 2015; Camden et al. 2014; Shikako-Thomas et al. 2013; Stewart et al., 2014).

This realization has garnered national and international attention, promoting global funding agencies to support efforts for partnered research to facilitate effective knowledge mobilization (CIHR 2016a, 2016b; CRIO, 2016; PCORI, 2016; QUERI, 2016; D'Andreta et al., 2013; Soper et al., 2013; Fisk et al., 2011; CHSRF, 2010). In particular, an integrated knowledge translation (iKT) approach has become internationally recognized in the promotion of stakeholder engagement from idea conception to application with researcher and stakeholders as co-researchers (Graham et

al., 2014; Graham et al., 2006). iKT is defined as *"a way of approaching research to increase the chances that the results will be applicable to the population under study. It is a paradigm shift that focuses on engagement with end users and the context in which they work. Essentially it is a collaborative way of conducting research that involves researchers and knowledge-users, sometimes from multiple communities (e.g. clinicians, managers, policy makers, patients) working together as partners in the research process."* (Graham, Tetroe, Pearson, 2014, p.11).

Although the value and use of iKT is gaining awareness and momentum among researchers and clinicians, a challenge is to identify strategies (in this case SWWD) to address the *"how"* of youth engagement. The purpose of this paper is to describe a demonstration project with a primary objective of identifying engagement strategies to develop research partnerships between students with disabilities and researchers at McMaster University. Secondary objectives included: i) enhancing awareness of and access to disability research, services, and resources across campus and within *CanChild*, McMaster University, and Hamilton communities; and ii) identifying priorities to inform program development at *CanChild* and McMaster University.

5.3 Methods

This demonstration project utilized an opportunity offered through the *Forward with Integrity* Initiative in 2015 to develop student and researcher partnerships within the McMaster University and Hamilton communities. This demonstration project represents a joint collaboration between the *CanChild*, McMaster University and Hamilton communities. The demonstration project consisted of four phases in the development and execution of a knowledge translation and exchange (KTE) symposium: 1) establishing an inclusive research team, 2) convening a knowledge translation and exchange symposium

(activities/strategies), 3) sampling and recruitment, and 4) evaluation and analysis (Fraker & Rangarajan, 2009). An integrated knowledge translation (iKT) approach guided TN's "thinking" in working and consulting with SWWD and researchers as partners following the principles of direct stakeholder engagement and equalizing partnership throughout the research process (Graham et al., 2014). iKT was deemed appropriate as it combines two research paradigms, namely knowledge transfer (biomedical paradigm) and participatory research (engagement paradigm), by engaging stakeholders in the research process (CIHR, 2016b; Graham & Tetroe, 2009; Tetroe, Graham, & Scott, 2011). Partnering with SWWD was imperative as TN stroved to ensure this project reflected their voices and needs for engagement. It is worthy to note that this project was not a formal application of iKT and the goal was not to execute and conduct all aspects required of iKT (processes, tasks, activities, and evaluations).

This demonstration project was developed as a learning opportunity for TN's experiential learning through reflection and action regarding the potential value, challenges and points for consideration of using iKT. Thus the focus was not on the application of all aspects of iKT. This demonstration project occurred over the course of one year (June 2015-May 2016 with a symposium on November 22, 2015 at McMaster University), fitting the timeline provided by the FWI Initiative at McMaster University.

5.3.1 Phase 1: Establishing an inclusive research team

The core research team included the principle investigator/ project coordinator (TN), research assistant (JH), four researchers (JWG, PR, DS, BP), and a young adult with a disability (MF). TN is a PhD candidate studying healthcare transition and knowledge translation at the School of Rehabilitation Science (SRS) and the *CanChild* Centre for Childhood Disability Research at McMaster University. The research assistant for the

project is an undergraduate student at *CanChild* (JH) who has a childhood-onset physical disability. JH was selected as the research assistant as she had a good understanding of childhood disability and youth needs through her many connections at McMaster University as well as Hamilton communities. JH is a community advisor and teaching assistant, which provided valuable insight for creating a diverse and inclusive research team. JWG, PR, DS, BP are researchers in transition and childhood disability. MF is also a PhD candidate in SRS and *CanChild* who is an active young adult with a disability within McMaster and Hamilton communities. Core research team members worked together as co-researchers in the development and execution of all phases of the project and contributed to team meetings and discussions (face-to-face and teleconference) and offered insight and direction for data collection and analysis.

5.3.2 Phase 2: Convening a knowledge translation and exchange symposium (activities/strategies)

The idea of the KTE symposium stemmed from engagement with students with disabilities as it provided an opportunity for face-to-face interactions with researchers, which is essential for building strong partnerships. An interactive half-day KTE symposium was held in at McMaster University on November 22, 2015 (see Appendix D). The KTE symposium was structured as a half-day roundtable facilitated discussion with students with disabilities and researchers. A problem-based or self-directed learning (PBL) approach was employed to facilitate participant discussion and engagement (Savery, 2006). This is a globally recognized approach to learning developed by and characteristic of the Faculty of Health Sciences at McMaster University. A PBL approach empowers learners to apply knowledge, skills and experiences to a defined problem or issue in order to uncover a viable solution, or set of solutions. PBL was selected as the

approach for the symposium because it aligns well with an iKT approach which is participant focused. Facilitators (JH & TN) of the symposium were familiar with the approach and techniques used to employ problem based-learning. Participants were divided into four small groups and encouraged to independently brainstorm solutions to address each of the three objectives of the demonstration project before engaging in small group discussions. The small groups were purposely organized to include at least one representative from each stakeholder group to facilitate discussion from multiple perspectives. Once all of the small groups had a chance to discuss the three objectives, everyone came together in a large group discussion to reach agreement on the final suggestions for each objective. It was important to note that student attendance at the symposium was greater than any other stakeholder group as students were considered to be the primary stakeholders.

5.3.3 Phase 3: Sampling and recruitment

Given the scope and funding of the demonstration project, only a small number of participants could participate in the symposium (up to 15). Based on these restrictions, purposive sampling was deemed appropriate to ensure a representative and diverse group of participants and allow for rich discussions from multiple perspectives. Purposive sampling was also employed to ensure SWWD represented the majority of participants as they were the focus of this project. Other stakeholders recruited to participate in the KTE symposium included educators and community representatives in facilitating rich discussions from multiple perspectives. JH and TN led the recruitment with key informants from within McMaster and Hamilton communities. Recruitment strategies included emails and networking with key informants, often targeted to hard to reach or marginalized populations. JH and TN reached out to students with and without

disabilities, researchers/faculty and staff across various departments within McMaster University to engage interested researchers and educators. Community preventatives such as the director of McMaster's student accessibility services, and directors of accessible sport programs were asked to participate. JH used her connections within McMaster and within Hamilton communities to recruit student leaders across campus including those with roles in Student Accessibility Services, the McMaster Students Union, Residence life and representatives from various faculties including Kinesiology, Geography, Engineering, Health Sciences, Life Sciences, Humanities and Social Sciences.

5.3.4 Phase 4: Evaluation and analysis

Pre and post symposium survey questionnaires consisting of both Likert scale and open-ended questions were emailed to all participants to provide feedback on the symposium (see Appendix E & F). Survey questions were designed the questions to capture insight into participants' previous experience and exposure with disability research as well as their perceptions and expectations before and after about the symposium. The surveys also inquired into participants' perspective of the symposium as a meaningful format for discussion, engagement, and knowledge dissemination. A brief, online pre-symposium questionnaire was administered at the time of symposium registration to establish participant demographics and a baseline of participants' awareness and access to of existing resources, supports, and information about disability research, services, and resources across campus and within *CanChild*, McMaster, and Hamilton communities. The pre-symposium questionnaire also inquired about what supports participants believe should be implemented to facilitate engagement and access to information, resources and supports. Following the conclusion of the symposium, post symposium survey questionnaires were administered in person at the end of the symposium to seek feedback

on i) structure and content; ii) impact and effectiveness; and iii) areas of strength (i.e. what participants liked about the symposium) and weakness (i.e. areas for improvement in the planning of future events).

Basic descriptive statistics was performed on the results of the pre and post symposium questionnaire. For the open-ended questions, salient themes and distinctive quotes were identified. Member-checking was completed to ensure accuracy of participant responses and feedback. Brief synopses and key messages from the symposium was also sent to all participants within two weeks for final feedback. JH and TN analyzed all surveys independently before meeting with the core and extended team to discuss and validate the results. Data from the symposium discussions were recorded and analyzed alongside individual feedback given in the surveys.

5.4 Ethical considerations

Ethics approval review was waived by the institutional Research Ethics Board.

5.5 Results

5.5.1 Pre-symposium results

Thirteen participants attended the symposium (see Figure 8) including: two students with disabilities, five students without disabilities, three researchers/faculty members, two clinician-scientists, one a distinctive community member with a disability who plays an important role in the university's accommodations and accessibility office. Many participants had dual roles with varying levels of research experience. Participants were divided into four small groups and stakeholders were purposefully selected and assigned

to each group to ensure a diversity within the groups allowed for rich discussions through multiple perspectives.

5.5.2 Symposium results

Achieving the primary objective: Participants came to consensus on five strategies for engagement: 1) creating a physical or virtual hub with updated information or updating current websites to ensure usability and accessibility (e.g. for course selection), 2) hosting "speed dating" events between students and faculty/researchers to enhance communication and knowledge exchange, 3) hosting monthly lectures/workshops/webinars, 4) capacity building via emailing lists for new opportunities, and 5) peer mentoring to connect stakeholders within the University and Hamilton communities.

Participants, particularly students with disabilities, stressed the importance of improving accessibility to information, services, and supports. One student participant with a disability suggested establishing a centralized knowledge hub (physical location on campus or online virtual hub) for information exchange. All participants felt that creating a centralized hub connecting services and support within McMaster and Hamilton communities would enhance communication and dissemination of information between those with shared interests. Participants were in agreement that the hub should be created in partnership with students with disabilities to ensure the content is up-to-date and format of information is tailored to their needs. Participants were also in agreement regarding a need to create opportunities for student engagement in research through enhancing networking with researchers/faculty to promote collaboration. All student participants felt a lack of opportunity to engage with faculty and researchers.

Achieving the secondary objectives: Overall, results of the pre-symposium and post-symposium assessment Likert survey responses indicated that the demonstration project was effective and impactful in enhancing stakeholders' awareness of services and supports on campus and within Hamilton communities; this was indicated by the majority of responses of pre- and post-symposium surveys from "fair" to "good" (see Figure 6 and 7). Participants identified three priority areas for program development: 1) fostering inclusivity and collaboration by engaging students with a disability in research and by improving accessibility on campus, 2) developing a centralized and user-friendly information hub for knowledge exchange; and 3) creating opportunities for networking and collaboration through hosting of social events to promote engagement between students and faculty/researchers (e.g. a graduate-undergraduate mentorship program).

5.5.3 Post-symposium results

5.5.3.1 Structure and content

Participants enjoyed the symposium content and structure as they felt the small and large group discussions, as well as the problem-based approach fostered extensive discussion and collaboration between faculty and students. Participants also felt that the material presented and discussed at the symposium increased their awareness and knowledge about supports for disability research (see Figure 7). One student participant stated *"I really like the idea of brainstorming on your own, as a group, plus then as a big group - great structure!"*

5.5.3.2 Impact and effectiveness

Student participants expressed appreciation not only for the invitation to be involved but also the concern about their needs, which they found to be effective and impactful. One

student participant cited the symposium as an eye opening experience stating *"It was very eye-opening and interesting to listen to the voices of people from different backgrounds with a common interest of disability research."* Another student felt that the symposium was effective in facilitating awareness: *"I got a chance to hear about these issues that I was not aware of and learned a lot of what's available.".*

5.5.3.3 Areas of strength and weakness

Participants enjoyed the multidisciplinary approach to learning; they appreciated the diversity in perspectives. One student participant stated *"My peers came from a variety of backgrounds and from other programs, the discussion may be very rich with information when individuals with a common interest in disability research convene together".* Another student stated *"[I enjoyed] having discussions with faculty members, other undergraduate and graduate students and students with disabilities. Everyone came from a diverse background that allowed me to learn from their perspectives.* Participants had several suggestions to improve the structure and format of the symposium to increase its effectiveness including selecting a date that is at a less stressful time for students, providing concrete information about how the data from the symposium will be used and having the opportunity to read about the topics ahead of time. One participant also suggested an important topic to be discussed *"There seemed to be a huge focus on research despite briefly discussing services as well. I think it would be great to add a greater focus on how to bridge disability research with services/social supports."*

5.6 Discussion/Conclusions

This demonstration project has addressed the primary objective set at the outset of the study: five strategies for engagement were identified between SWWD and researchers.

Moreover, secondary objectives were addressed among all participants such as increased awareness of and access to disability research, services, and resources across campus and within *CanChild*, McMaster University, and Hamilton communities; and, three priority areas were identified to inform program development at *CanChild* and McMaster University.

Results from the demonstration project are consistent with the current evidence indicating the need to include stakeholders in research to promote knowledge mobilization (Corring et al., 2016; Rycroft-Malone et al., 2013; Jagosh et al., 2012). This was accomplished by providing an opportunity for SWWD to voice their needs at an interactive symposium with researchers using a multidisciplinary and problem-based approach. The symposium encouraged active participation and discussion. Reflections on the stakeholder consultations revealed that the value of an iKT approach is related to the promotion of direct stakeholder involvement in the research process as equal partners.

This demonstration project also provided a learning opportunity for youth engagement (i.e. students with disabilities) to ignite and to enhance research partnerships. At the symposium TN observed a process leading to strengthening the synergy between SWWD and researchers, which could ultimately facilitate knowledge mobilization, an unplanned insight gained through the symposium process. Results of this demonstration project also offered TN opportunities for reflection about the value and challenges of iKT from researchers' as well as youth's perspectives. In the following paragraphs TN will share some specific insights and learnings, which could be applicable to any researcher interested in partnering with youth and any youth interested in getting involved in research. While the core principle of iKT regarding direct involvement of stakeholders as equal partners in the research process (from idea conception to knowledge mobilization)

may appear straightforward, however, when put into action, it can be extremely challenging to execute as many factors are at play (Graham, Tetroe, Pearson, 2014). For example, iKT is not simply about stakeholder consultation or bringing researchers and stakeholders together in one room. The challenge lies in balancing power differential to achieve meaningful partnership where all parties involved feel they have an equal role and knowledge to impart. From my interactions and personal communication with youth in this study as a researcher, TN learned that some youth did not feel as knowledgeable or experienced as researchers and thus felt that they did not have anything to offer. Some SWWD did not perceive themselves as equal partners or experts. From a youth perspective, they were sometimes surprised to be referred to as experts. Thus, TN found it very difficult to work towards empowering youth to feel confident, to speak candidly, and to recognize that they are experts in their lived experiences through a unique lens and insight into the topic of study. Another key learning was that iKT is a time intensive process. Time investment at the outset of any research study with stakeholders can assist in building strong relationships for partnerships where stakeholders feel that they are in a safe and supported environment to speak openly and candidly with the research team.

One of the most challenging aspects of iKT for a researcher is assessing (whether formally or informally) researchers' and youth's satisfaction regarding roles and expectations. In this study, TN was left wondering if research team members were satisfied with their role and involvement in the project as co-researchers. Building in process assessment for all members of the research team or partnership would be helpful in determining satisfaction.

Additionally, TN struggled with balancing her role as PI and researcher to meet the needs of all parties involved. TN found it very hard to ensure consensus among members of the

core research team, balancing my views and objectives as a researcher and lending voice to youth. For example, as PI, TN needed to fulfill duties such as meeting study deadlines and funding mandates, which may not be a key concern for youth, researchers, and other stakeholders. Also, TN found it challenging to select a symposium date, as the date had to accommodate a variety of different schedules while at the same time meet the deadline of the study. In the end, we had to select a date that worked for the majority of participants, which may not necessarily meet the needs of all youth and may appear to side more with the researchers' needs. Similarly, there were challenges and discussions around research approaches and scientific rigour, particularly for youth to grasp their role and input. Furthermore, youth suggestions were often new and non-traditional approaches which took time in order for researchers to develop a formalized approach and build in rigour.

Upon reflection of this demonstration project, a few important lessons learned also emerged based on TN's observations that she would recommend for future development of any research partnerships between researchers and stakeholders (Straus, Tetroe, & Graham, 2013; Graham, Tetroe, Pearson, 2014). First, research partnerships are not just about bringing researchers and stakeholders together. There is a need for attention and focus on the importance of establishing mutually beneficial partnerships. Mutually beneficial partnerships means that everyone involved in the research has equal weight with their input and expertise is recognized by all team members (Flicker et al., 2008). This is particularly important to empower YCHC and parents to speak candidly about their experiences, learnings, and suggestions in a team of researchers and clinicians where they may not feel the most comfortable or at ease in expressing themselves. Additionally, in order to facilitate communication among team members it is important at the study outset to clearly define roles, tasks, time commitment, and expectations for a better understanding of all parties involved and work together on any issues that may

arise so that all members feel valued. This in turn will assist with promoting knowledge mobilization and sustainability of outcomes as all members are invested in the research and recognize the significance and value of their role and contribution.

Second, researchers are encouraged to think "outside the box" when it comes to stakeholder consultation and knowledge mobilization, enhancing traditional approaches (i.e. publications, conference presentations) with non-traditional approaches by listening to suggestions of stakeholders. This demonstration project is an example of executing an idea suggested by one youth who stated that it is "more fun to get together and talk" instead of simply completing a survey. A key learning for engagement is to use venues for interaction and discussion between researchers and stakeholders (i.e. interactive face-to-face symposiums are beneficial). For example, a suggested engagement strategy by youth is to conduct a "speed-dating" event for students and researchers. TN would have never thought of this approach, however, youth were extremely excited and motivated to participate and get involved to connect with researchers in this way as it provided a more relaxed and fun environment.

Lastly, there is a need to create opportunities for youth engagement and youth-led studies as youth felt that this was currently lacking (Suleimanm, Soleimanpour, & London, 2006). Researchers should consider creating affordable and sustainable platforms that support networking with youth. Some suggestions are offered in this study such as regular meetings for knowledge exchange (i.e. research rounds, webinars, networking meetings) can assist in creating points of contact for between youth and researchers. A critical learning is that almost all of the youth who attended the symposium communicated that a major challenge of connecting with researchers is that they felt intimidated and are unsure of how to make the connection or how start the conversation.

Thus, providing opportunities for engagement truly bidirectional, and place high value on the input of key stakeholders allows for fruitful discussion and will assist youth in reaching out to researchers and vice versa.

5.7 Limitations

As mentioned above, there was a plethora of challenges and limitations in this project namely related to direct stakeholder involvement throughout the research process and equalizing power differential among core team members. Use of the iKT approach required great time investment at the outset of the study and more time could have been beneficial for everyone. Time investment is needed to build strong relationships with stakeholders in order to facilitate candid conversations and mutual respect in expertise between researches and stakeholders on the research team. Furthermore, the tasks involved should be taken into consideration in depth prior to the use of this approach. Another limitation of this demonstration project is that the scope of the project was restrained by the location being solely on McMaster Campus; additional time and funding would allow for recruitment of additional stakeholders, in particular more students with disabilities, parents, as well as community members.

5.8 Direction for future research

Further research is needed to fully apply all of the elements and processes related to the "doing" of iKT. Researchers are encouraged to consider the findings of this study together with existing resources to inform future research (e.g. Involving People in Research, 2016). A future study can work towards developing additional tools and resources to formally assess researchers' and stakeholders' needs, roles, and expectations to enhance research partnerships; thereby, resulting in more relevant, useful and timely

research that can be more quickly moved into practice and policy. A better understanding of the underlying partnering process and variables that impact partnerships would be helpful in defining the roles and expectations for researchers and stakeholders.

The results of experiential learning from this demonstration project has informed the plans for developing a knowledge hub for youth and research within the *CanChild* website. It is important to note that students should be active members in overseeing the development (content and format) of this knowledge hub. The idea is that this hub will create a contact point for students, faculty and community members to connect with each other to facilitate communication and knowledge exchange to cultivate shared interests among stakeholders. This work will also contribute to the establishment of a youth network to inform disability research and program development.

5.9 Funding

5.10 Acknowledgements

5.11 References

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Appendix D: *Forward with Integrity Symposium Agenda-Sunday November 22, 2015, 12-*

4pm

TIME	ACTIVITY
12:00-12:30	**Introduction** • Lunch and networking • Welcome and introductions

12:30-2:00	**Presentation**
	Overview of Project
	1. Purpose of Forward with Integrity Initiative/Project
	  • Inspire innovation among students and faculty in research and practice to impact patient care and intellectual communities.
	  • Enhance student experience and community engagement
	  • Promote interdisciplinary collaboration
	2. Small group format discussions to identify priorities for research, education, and services on campus for students with disabilities
	  • Identify available resources and supports within McMaster and Hamilton communities for disability research/services: What supports are you aware of on campus or within the community for disability research/services and Compile a list, barriers, and challenges
	  • Connecting students with faculty: Brainstorm strategies to connect student and faculty (e.g. what can be implemented to enhance communication and collaboration for example- monthly workshops/webinars, mentorship, physical or virtual hub). Determine preferred method of communication and engagement
	  • Identify 3 key recommendations or top areas of concern to bring forward to the University to enhance students and community engagement and experiences

2:00-2:15	**Break**
2:15-3:30	**Experiential Session** • Each small group will present their learning • Large group sharing
3:30-4:00	**Let's Vote!** • Collectively discuss/vote as a large group to identity priority areas • Recap of the day; Thank-you and wrap-up; Feedback survey

Appendix E: Pre-symposium Survey Questionnaire

1. Name and Department
2. What is your role(s) within McMaster University and/or in the Hamilton community?
3. From your perspective, what are the barriers to connecting students and faculty with a common interest in disability research?
4. From your perspective, what were/are your primary challenges in accessing information, resources and supports to pursue your interest in disability research?
5. How would you rate your knowledge of available services, resources and information on campus and within the community to enable students to pursue education or research in disability?
    i. Excellent
    ii. Good
    iii. Fair
    iv. Poor
6. From your perspective, what supports and resources can be implemented to assist students in connecting with faculty and resources to better understand career paths or explore interests in disability research?
7. What are you hoping to learn from this Knowledge Symposium?
8. How would you rate the ease of access of information in communicating with students or faculty of liked interest in disability research?
    i. Excellent
    ii. Good
    iii. Fair
    iv. Poor

Appendix F: *Post-symposium Survey Questionnaire*

1. How effective was the symposium in achieving the objectives of:

a. Awareness and Availability of Services and Supports for Disability Research on campus
   i.   Excellent
   ii. Good
   iii. Fair
   iv. Poor
b. Determining strategies to connect student and faculty with shared interests and in the community
   i.   Excellent
   ii. Good
   iii. Fair
   iv. Poor

2. What aspects of this symposium did you find the most beneficial?

3. What aspects of this symposium would you add or change?

4. What are the top three concerns or issues that you would like the university to be aware of in regards to provision and access of information and supports to access disability research and services?

5. Would you want to see events like this in the future?

6. Would you recommend this event to your peers? Why?

7. Additional comments or thoughts.

Figure 6: Results of Pre-symposium assessment Likert survey responses.
Each participant completed the form prior to attending the symposium allowing the research team to establish a baseline. Most participants rated their ease of accessing information and ability to connect with students or interested faculty as fair. Similarly, participants rated their knowledge of available resources as services predominantly as good or fair.
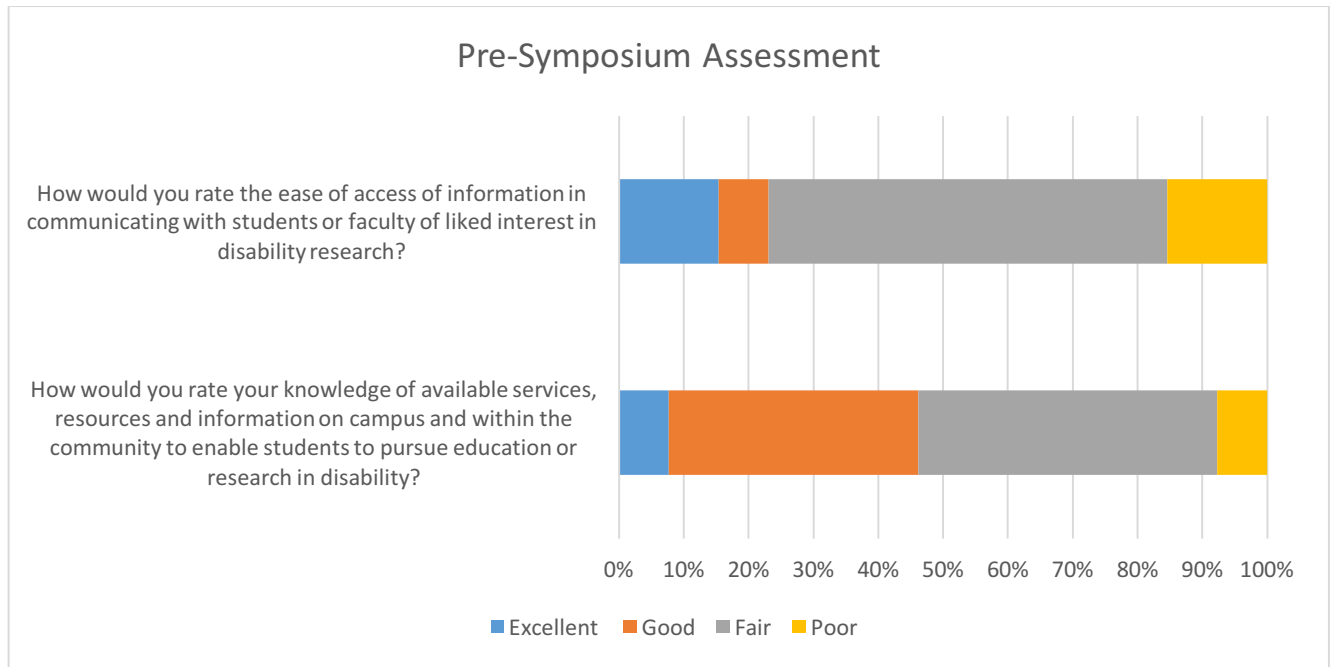
Figure 7: *Results of Post-symposium assessment Likert survey responses.*
Each participant completed the form following the symposium allowing the research team to gauge effectiveness of the symposium. All participants rated the effectiveness of the symposium as good or excellent in the domains or awareness of available resources and determining strategies to connect students and faculty.
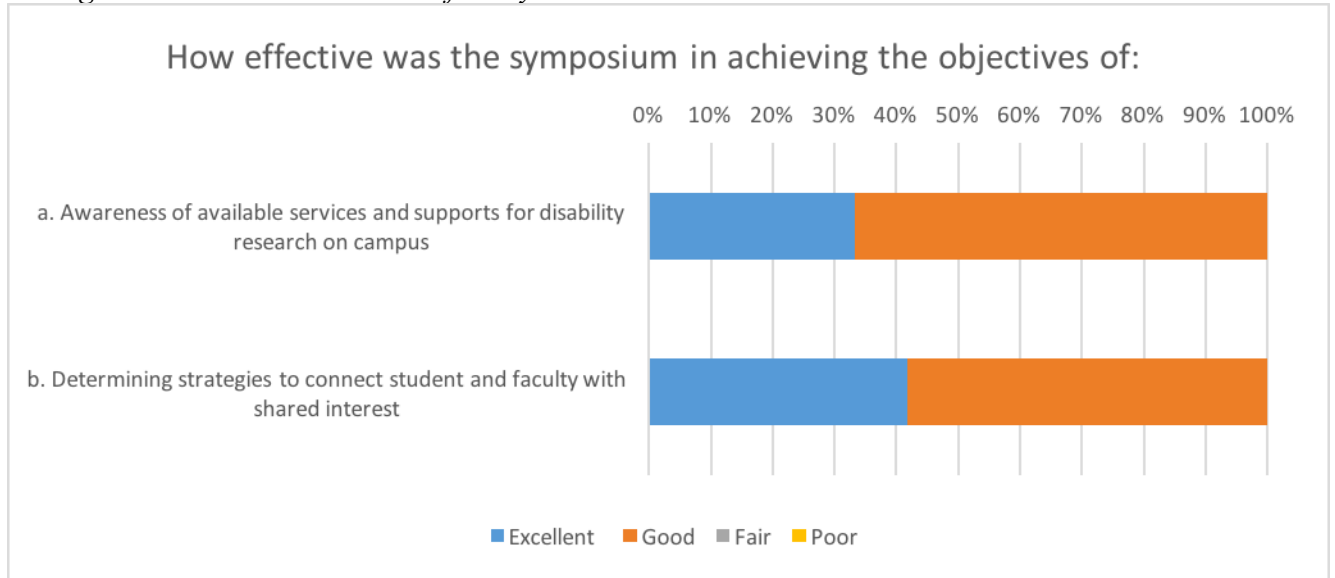
Figure 8: Participant demographics (n=13 with some participants in dual roles)
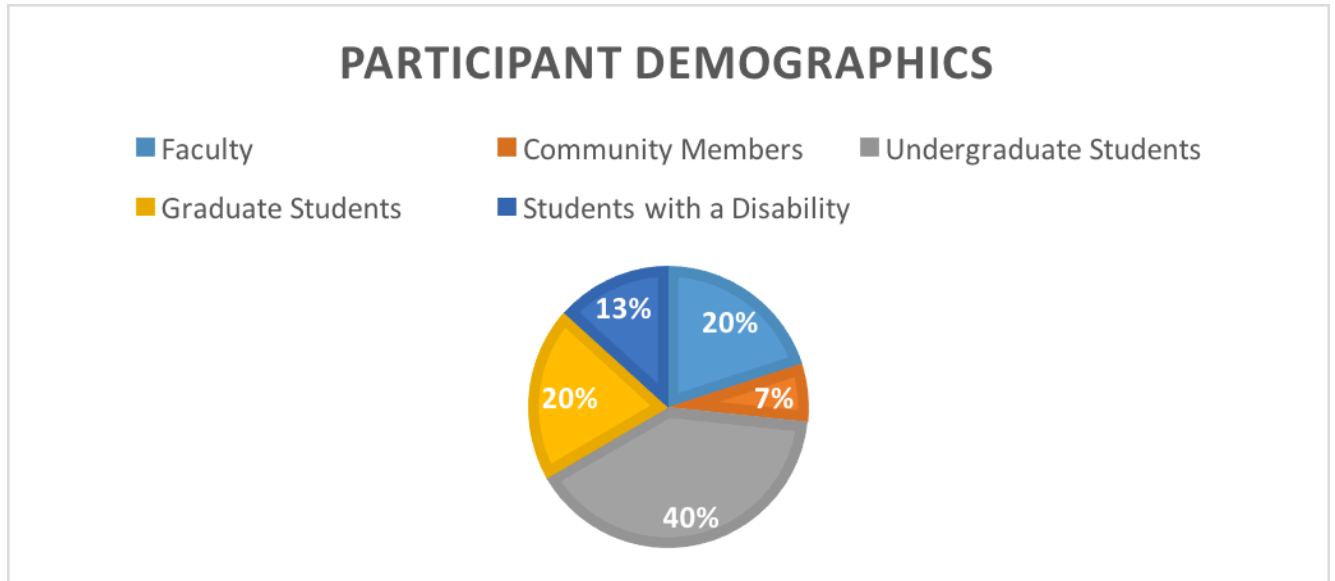
CHAPTER SIX

CONCLUSIONS

6.1 Addressing the study objectives

After completing and synthesizing the findings of the four scholarly manuscripts in my thesis, in this final chapter I return to review the objectives at the outset of my thesis as defined in chapter 1.4. The following sections will discuss the extent to which my work has addressed the knowledge gaps that I had identified and suggest areas in need of further exploration. It is worthy to note that a significant aspect of these key findings represent new learnings which stemmed from my experiential learning, reflections, observations, and interactions with stakeholders (YCHC, parents, healthcare providers, researchers, policymakers, community partners) throughout the four scholarly works in my thesis.

6.1.1 Objective 1: To gain a better understanding of the interactive experiences of youth with chronic health conditions (YCHC), parents, and healthcare providers with self-management during the process of transition.

How my thesis work addressed objective 1: To address the first objective, I worked directly with YCHC, parents, and healthcare providers to learn about the collective perspectives and interactive experiences with self-management during the transition (Chapter 2). I sought feedback from YCHC, parents, and healthcare providers in developing the interview guides to ensure the questions and prompts were relevant and reflected the needs of each stakeholder group. Upon reflection, I learned the value of consulting with stakeholders to allow for active participation, which YCHC and parents appreciated to help them voice their needs and concerns for research. A key learning from working with YCHC and parents is that time investment is needed at the outset (study conception) to establish clear roles, expectations, and commitments for the study to enhance synergy between all team members.

In regards to advancing knowledge about the process of self-management, a clear and resounding message that I elicited from the qualitative study reported in Chapter 2 and my interactions with YCHC, parents and healthcare providers is that fostering collaboration between all stakeholders, particularly between professionals in the pediatric and adult healthcare, is in empowering YCHC to self-management. The three stakeholder groups all identified an apparent divide between the pediatric and adult healthcare settings (Nguyen et al., 2016a). This concern is consistent with emerging evidence in transition regarding differences between healthcare settings (McLaren et al., 2013: Singh, 2010). In pediatric healthcare, although there may be variations between centres, parents lead the decision-making and youth are "cared" for in a one-stop-shop facility (Lamb & Murphy, 2013; While et al., 2016). On the other hand, in adult healthcare, youth are suddenly expected to become "adults" and take charge of making decisions regarding their healthcare with limited parental participation (Murcott, 2014). The abrupt change often happens overnight on the eve of youth's 18th birthday (common age cut-off for pediatric).

All stakeholders (YCHC, parents, and healthcare providers) felt that many of these differences in expectations were cultural in nature, meaning they were unwritten and unspoken ways of thinking and doing within a particular system culture of care and practice. Consistent with previous work, the findings of this study also found that compounding the drastic shift in roles and expectations between healthcare settings are the multiple concurrent developmental transitions (i.e. independent living, post-secondary education, etc.) that parents felt impacted their youth's ability to self-manage and access to care (Stewart et al., 2014; Embrett et al., 2015). Parents in my qualitative study emphasized that their child's self-management of healthcare needs is only one aspect of

the overall developmental trajectory and transition process. This finding is important and is consistent with the current push for self-management supports to include and examination of factors beyond the youth's medical condition such as the influences of personal, social, and environmental factors. For example, a study by Sattoe and colleagues (2015) concluded that "conceptualizations of self-management support often remained unclear and content focuses predominantly on the medical domain, neglecting psycho-social challenges for chronically ill young people" (Sattoe et al., 2015, p.704). These findings align well with contemporary views on health to focus on the importance of self-management and adaptability (Huber et al., 2011). Thus, it is important to build on these findings to further explore personal as well as environmental impacts on self-management processes.

YCHC also experience a cultural shift during transition from pediatric to adult healthcare (Lamb & Murphy, 2013; Lindgren et al., 2013). The concept of culture is an excellent example of person-environment interactions at work but it is just beginning to receive attention in research and practice. The identified differences between healthcare settings resonates with current research. Findings of a recent systematic review by Mulvale and colleagues (2016) found that pediatric and adult healthcare systems operate under different philosophies which professional need to consider with working with youth. Pediatric services were described in the literature as nurturing and family oriented (involving families and taking a developmental approach) while adult services were perceived as having a clinical/diagnosis-focus with emphasis on client autonomy and individual responsibility (Singh, 2009; McLaren et al., 2013). Thus, a key strategy to enhancing youth's self-management skills is to facilitate communication and collaboration between services to better understand roles and expectations. Thus, there is a need to focus on environmental (home, social, societal, and community) impacts and

the influence of changing healthcare settings or "cultures" of care and not the youth in isolation in transition planning and service delivery to promote self-management.

A significant observation and learning was that not all YCHC perceive their parents as a source of support for self-management during transition. Some youth prefer the support of friends and peers rather than parental or family involvement. As youth become adults they sometimes leave care and do seek adult services since they equate adulthood and with independence and autonomy (Goodkind, Schelbe, & Shook, 2011). Parents are sometimes perceived as a barrier to enabling YCHC for self-management as parents find it hard to *let go* (Gorter et al., 2015; Nguyen et al., 2016a). Results of a recent study by While and colleagues (2016) also suggest that healthcare providers in transition programs should work to promote self-management of youth with cystic fibrosis, congenital heart disease and diabetes by discouraging parent overprotection. This sentiment was also expressed by a youth representative during a stakeholder meeting for the Ministry of Health and Long Term Care. This finding is consistent with a paper by Lindgren and colleagues (2013) which suggests that that some youth with mental health disorders prefer not to have family involvement in adult services, while youth who were well supported by parents in pediatric services suddenly feel alone. Thus, it is important for healthcare providers to work together with both YCHC and parents to assess their transition readiness. Healthcare providers can work to assess parents' feelings towards the f transfer between services. For example, a study by Suris and colleagues (2016) indicated that parents experience easy transfers when they feel ready and there is adequate coordination between teams in both systems.

Healthcare professionals and parents need to recognize the importance of gradually enabling youth to take on adult roles and responsibilities for self-management by building

youth's confidence and autonomy (Gorter et al., 2015). Healthcare professionals can use the *shared* management model coupled with goal setting activities to work with parents towards a gradually shifting responsibilities to youth (Gall, C., Kingsnorth, S., & Healy, H. (2006). Parents can work together with youth to set appointments and to take their medications on time instead of telling them when their appointments are and when to take their medications. Healthcare professionals can use transition readiness measures (i.e. STARx Questionnaire and TRANSITION-Q) to assess youth's readiness (Cohen et al., 2015; Klassen et al., 2014). Specifically, the TRANSITION-Q can assist YCHC to set developmentally appropriate goals for self-management before, during, and after transition, allowing youth to take an active role in the planning of their transition by voicing their needs and goals. Assessing readiness of YCHC will also enable clinicians, researchers, as well as policymakers to better understand *what* type of supports and more importantly, *who* should be involved to best assist YCHC with self-management by asking youth directly. Additional strategies for fostering knowledge and development of self-management skills among YCHC, their families and other key stakeholders involved in their transition process can be found in the recently released best practice guidelines by the Canadian Association of Paediatric Health Centres Community of Practice as well as a report released by the Provincial Council of Maternal and Child Health Ontario (PCMCH, 2016; CAPHC, 2016).

Based on learnings and observations on self-management, I conclude that the use of a consistent guiding theory or framework in transition may assist researchers and practitioners by informing their thinking, actions, and behaviours. Furthermore, to gain insight into cultural nuances and the impacts of changing environments on processes involved in transition, including process of to enable self-management when working with YCHC and parents. Chapter 3 and 4 explore the potential application of

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acculturation theory and the International Classification of Functioning, Disability, and Health (Berry, 1997; WHO, 2001) which will be discussed in the next following sections.

Areas in need of further exploration: My work on self-management provides a starting point for advancing knowledge about our understanding of the transition process. The current emphasis on self-management and adaptability in the literature (McDougall et al., 2016; Camden et al., 2015; Huber, 2011) highlights a much bigger issue. This highlights the need for additional research on youth empowerment in the context of a holistic, lifecourse approach to care provision for the management of chronic illness and disability. More attention should be given to opportunities for YCHC's community engagement and their experiences in everyday activities, instead of a sole focus on their healthcare condition alone (Nguyen & Gorter, 2014; Stewart et al., 2014). Further research exploration is also needed to develop evidence-based tools, interventions and strategies that are sensitive to differences between pediatric and adult healthcare settings to equip healthcare providers and parents with tailored resources to enable YCHC with self-management during any transition process they experience. It is also worthwhile to explore and assess opportunities for YCHC to have experiences starting in childhood and through adolescence; these experiences can assist in building YCHC's capacity to assume adult roles and responsibilities for self-management (McPherson et al., 2016).

6.1.2 Objective 2: To explore theoretical frameworks to guide research in transition and inform the planning and delivery of holistic transition services that is developmentally appropriate and culturally sensitive (considers the influences of person-environment interactions).

How my thesis work addressed objective 2: To address the second objective, I worked with stakeholders including primarily rehabilitation professionals (occupational

therapists, physiotherapists), educators, and researchers to identify existing theoretical frameworks that could be applicable in transition (Chapters 3 & 4). This work builds on the findings of my qualitative study (Chapter 2) to better understand the influence of changing healthcare environments on YCHC and their ability to self-manage during the transition process. The next step is to explore theoretical frameworks that may assist in guiding researchers' and professionals' thinking to further explore and uncover critical cultural nuances between two systems of care that are not considered currently (unspoken and unwritten expectations for behaviour, being independent from parents, taking on adult roles and responsibilities, and self-management of health condition) involved with a change in healthcare setting

Through a review of the literature, coupled with consultations with stakeholders, I identified two theoretical frameworks, acculturation theory and the ICF, and started to explore their potential use and application in transition. More importantly, the following sections will discuss how these two theoretical frameworks can be used in combination and complement each other to guide transition planning and service delivery to inform research and practice. I arrived at this conclusion based on the findings of Chapters 3 and 4. The findings from Chapter 3 suggest acculturation theory can become a natural framework for healthcare professionals when integrated into clinical practice frameworks. However, since acculturation theory has not been readily applied in transition research, it has to be used in combination with an existing prominent healthcare framework to bring it to the forefront of researchers and clinician's awareness for effective integration in research and practice. Thus, in Chapter 4, the ICF was explored as it is a universally recognized classification and health framework endorsed by the World Health Organization (WHO, 2001). Results of a scoping review suggest that while the ICF has been used in transition to promote a broad perspective to health and to enhance

communication and collaboration among professionals through its common language and conceptual framework, it is not without limitations. Thus, acculturation can be used to address the limitations of the ICF, while ICF will assist in building its capacity for acculturation theory transition research. There are some key reasons why these frameworks are complementary (see Figure 9).

Acculturation theory and its inherent concepts can continue to broaden our understanding of the processes underlying of person-environment interactions by describing the psychological and behavioural changes that may occur when an individual or group move from one culture to the next (Berry, 1997; Demes & Geeraert, 2014). While the ICF brings awareness to the influences of personal and environmental factors on health, acculturation theory can begin to describe the processes, relationships, and interactions of these factors over time. This thinking is consistent with contemporary perspectives on health to redefine the concept of "health as the ability to adapt and to self manage and to be identified and characterized for the three domains of health: physical, mental, and social" (Huber et al., 2011, p.2). Specifically, acculturation theory can equip clinicians with a reassuring and concrete framework upon which to rely in interpreting patient circumstances, responses and behaviours when moving between cultures (Berry, 1997; Nguyen and Baptiste, 2014).

Acculturation theory can assist in advancing our understanding of the emotional and psychological elements and processes that youth undergo when they transition to adulthood over time, which is often missed in the 'technical' aspects of a transfer from a pediatric healthcare professional to his or her adult counterpart. In this way, acculturation theory can assist in understanding the issues and challenges associated with many

transitions over the youth's lifecourse to better understand the relationships between the five domains (areas in between the bidirectional arrows) of the ICF framework. Healthcare professionals can also use acculturation scales to assess youths' adaptation, cultural distance, and orientation to determine their experiences with transition before, during and after transition to adult healthcare to gain a better understanding of their needs, goals, expectations (Demes & Geeraert, 2014; Berry, Phinney, Sam & Vedder, 2006). It is important to note that these scales may need to be adapted and tailored to meet the needs of transitioning YCHC, parents, and providers but could provide a good starting point for tool development in transition.

Acculturation theory can also enhance the use and implementation of the ICF framework, reaching beyond the ICF's current static and 'cross-sectional' nature reflecting the analytic-deductive thinking typical in healthcare and in the field of medicine (Rosenbaum & Gorter, 2012). Two key contributing aspects of acculturation theory are the element of time (to address the dynamic needs of transitioning youth) as well as societal impacts at a group level and not just individual level as described in the ICF. It is noteworthy to mention that acculturation theory and ICF are not mutually exclusive, but rather are complementary theoretical frameworks. The ICF broadens our knowledge of health through examining personal and environmental influences influences, while acculturation theory begins to describe the processes underlying an individual's interaction with changing environments (physical, social, cultural, and institutional) – a perspective that is lacking in the ICF.

Through this work, I identified a key issue that may be impeding holistic care. The current approach to care and services in transition, as well as transition research, is

predominately operational and often focuses on identifying a specific issue and accompanying solution. This approach is static and only addresses youth's physical ability and condition in the "here and now" instead of a dynamic approach that considers change over time, environmental influences, and changing needs (Hamdani et al., 2014; Sheehan et al., 2015; Zhou et al., 2016). Furthermore, current services in healthcare are in silos with a lack of communication and collaboration between pediatric and adult healthcare (Mulvale et al., 2016); thus a common theoretical framework may help overcome the gap and guide transition research and change in practice. A theory could disentangle the complexity of the transition to inform our understanding of processes to assist YCHC with self-management during the process of transition. Theories can also broaden awareness of issues, generate questions, and identify knowledge gaps in transition research to advance our understanding and approaches to care.

Areas in need of further exploration: My work on cultural impact in healthcare transition builds capacity for the need to broaden current perspectives and approaches to transition services to include a transactional and transdisciplinary approach to address social, cultural, and other environmental influences on transitioning YCHC's ability to self-manage. These results are consistent with the current focus on cultural influences on health (Friesen et al., 2015; Mancini et al., 2016; Anderson et al., 2014). Although this work begins to identify a comprehensive approach and components that may be missing in transition services, further exploration and empirical evidence is needed to determine the effectiveness and applicability of these theoretical frameworks. Additionally, training and education for YCHC, parents, and healthcare providers, and identifying effective approaches and strategies that explicitly integrate these frameworks into research and practice is also worthy of further examination.

6.1.3 Objective 3: To identify strategies to facilitate knowledge uptake and integration of transition evidence in research and practice.

How my thesis work addressed objective 3: To address the third objective, I worked directly with youth (i.e. students with and without disabilities) and other stakeholders (i.e. researchers/faculty and community members) on a demonstration project to identify strategies for youth engagement to facilitate knowledge mobilization (Chapter 5). This project identified five engagement strategies: 1) creating a physical or virtual hub with updated information or updating current websites to ensure usability and accessibility (e.g. for course selection), 2) hosting "speed dating" events between students and faculty/researchers to enhance communication and knowledge exchange, 3) hosting monthly lectures/workshops/webinars, 4) capacity building via emailing lists for new opportunities, and 5) peer mentoring to connect stakeholders within the University and Hamilton communities. Results also provide valuable insight and reflection into the challenges of stakeholder engagement and the potential use of integrated knowledge translation (iKT) in guiding "thinking" for research, including balancing power differential within the research partnership among all participating members. Specifically, investment in relationship building among YCHC, communities, and partners is critical for building meaningful partnerships. Engaging YCHC in knowledge creation and mobilization is essential in meeting their needs and concerns for self-management and research (CAPHC, 2016; McDougall et al. 2016; Stewart et al., 2014).

An important reflection is that direct stakeholder engagement as co-researchers in research due to challenges in balancing power differentials. A possible strategy to manage this problem is to establish an open dialogue between researchers and YCHC. A study by Flicker and colleagues (2008) found that authentic youth participation requires

transparent and open dialogue between researchers and youth to facilitate power sharing and management of roles and expectations. It is important for researchers to focus on providing opportunities for youth-led projects in which youth are co-researchers to allow youth to take an active role in voicing their needs (Suleimanm, Soleimanpour, & London, 2006). Such opportunities will enable youth to develop skill sets that have relevance and applicability across life domains. In this way, youth can make more informed decisions around managing their needs and healthcare plans. The significance of stakeholder participation in research is also endorsed by the World Health Organization which has outline that youth and community participation health in the development of programs is essential (WHO, 2006).

Areas in need of further exploration: My work on youth engagement and using an iKT approach to guide thinking is an opportunity for learning as there are many challenges associated with executing this approach. it is very hard to conduct all of the required aspects inherent in iKT. My approach to stakeholder consultation throughout my research represents my learning curve and development of iKT which culminated in Chapter 5 detailing the demonstration project. The demonstrated project provided an opportunity to learn and consolidate knowledge about strategies for youth engagement in research to facilitate knowledge mobilization. Although my work brings attention to stakeholder consultation and strategies for engagement, additional research is needed to formally assess the effectiveness of the identified strategies and build evidence for iKT to apply this approach more fully and systematically. To date, the partnering process inherent in iKT has seldom been critically assessed nor systematically studied. Thus, TN's proposed postdoctoral research is the first to systematically examine the partnering process between researchers and transitioning youth with disabilities from pediatric to adult

healthcare as an entry point to provide new insight into research partnerships and to identify best practices and appropriate conditions for partnering to achieve the greatest impact on research use; advancing the science of iKT. Moreover, a better understanding of research/youth needs will enhance research partnerships thereby resulting is more relevant, useful and timely research that can be more quickly moved into practice and policy.

Further exploration is also needed to explore and develop opportunities for engagement that are truly bidirectional, and place high value on the input of key stakeholders through fruitful discussions and meaningful research. This creates a culture of partnership rather than a linear, unidirectional, involvement of stakeholders. For example, engaging in discussions that shape inquiry builds respect and trust between partners while building understanding of lived experiences from a mutual base.

6.2 Main contributions and impact

The findings of my thesis research advances knowledge and understanding about the process of transition through contributions to current *thinking* (using theoretical frameworks to connect research to theory) and may help in guiding use of the KTA framework. My thesis work contributes to building capacity for researchers and clinicians to integrate theory in practice in order to better understand the transition process (Palisano et al., 2016). Being guided by theoretical frameworks in research can assist in organizing thoughts and concepts to address the "why" of actions, processes, concepts, activities, and interventions that are being studied (Lerner & Castellino, 2002). More importantly, my thesis work offers two theoretical frameworks that give new insight into the transition process by unearthing cultural nuances involved during a change in

healthcare settings. Youth and families have expressed a lack of attention to cultural impacts and the differences in expectations and environments between pediatric and adult healthcare settings. The contribution of my work is that it has demonstrated, in a very concrete way, the blending of a social science theory (acculturation theory) with a biopsychosocial theory (ICF) in health (best of both worlds) to tailor and adapt theories for everyday use in transition research. The novelty of using acculturation theory and the ICF to guide transition research is that it reflects an upcoming paradigm shift in how we view transition. For example, these theories can broaden our perspective on health and the scope of research and to examine the "bigger picture" by including concepts of environmental and cultural influences (Chapters 3 & 4). Furthermore, these theoretical frameworks could provide a guide to assist with enhancing communication and collaboration between professionals in pediatric and adult healthcare to begin discussions around addressing the disparities between services. The integration and use of theories explicitly in transition will assist in guiding researchers away from just addressing the current operational approach (solution driven) of transitioning youth from one system to another, towards a systematic approach, grounded in theory and hypotheses to better understand the complexities of healthcare transition. This systematic approach and shift in thinking has shown to have an impact by its implementation in some research programs and keynote presentations by experts in transition research (Palisano et al., 2016). This work has also shown impact as these ideas has resonated with other scholars within research communities, extending beyond health, through an invitation to write a book chapter on the significance of cultural sensitivity within a sociological resource text (Nguyen & Baptiste, 2014).

My thesis also contributes to the *doing* or method of using the Knowledge to Action (KTA) framework to guide the research process and inform stakeholder consultations. It is important to clarify that the KTA framework helped to frame the research in the thinking of activities and tasks conducted as some components were applied (i.e. stakeholder consultation), as well as the writing of this thesis. Researchers can build on this work to apply the framework fully to include the *action phase* as this thesis focused on the *knowledge creation phase*. My thesis research also brings attention to the significance of stakeholder consultation in research to ensure meaningful and impactful research evidence/outcomes and enhanced knowledge mobilization. Bringing awareness to the need to consider the needs of stakeholders rather than researchers and institutions alone to prevent the "ivory tower" effect. Specifically, the demonstration project within my thesis (Chapter 5) provides a learning opportunity focusing on youth engagement in knowledge mobilization using principles of iKT with direct involvement of youth as co-researchers in research to guide thinking. My work is impactful as it begins to establish an open dialogue between researchers and YCHC to gain new insight and a thorough understanding of the transition process to identify knowledge and service gaps. An open dialogue between researchers and YCHC is critical in identifying appropriate or missing components for interventions and service delivery, as well as formulating ideas for future research collaboratively to address current issues and challenges associated with transition. Again, this approach has shown to have an impact as it has been implemented in some research programs. Engaging youth in research from the outset is also anticipated to assist in their readiness for transition as they have an active role in the process and can better identify and manage their needs.

6.3 Lessons learned and limitations

My key lessons learned relate to applying theories in research and practice and executing the principles inherent in knowledge translation and qualitative methodologies to better understand healthcare transition processes. This learning has implications for transition research and practice, which will assist other researchers with shared interests to conduct similar projects.

Grounding transition research in theory is essential for advancing our understanding and thinking of processes and behaviours for research and practice. Furthermore, to allow for concepts to be organized and connected to explain actions and behaviours (Townsend & Polatajko, 2007; Kielhofner, 2008). A critical insight is that theory can be a powerful tool in assisting researchers and providers in thinking about in building the capacity among assist YCHC to think about their actions and behaviors as there are concrete elements and factors in which to articulate their thoughts (Geary & Schumacher, 2012; Betz et al., 2014). The KTA can assist YCHC and parents to identify their roles and expectations for involvement in research, where they would like to be involved and the associated tasks more clearly. An important point worth noting is that it can be extremely challenging to complete all of the steps and phases of the KTA as it is very time intensive. When I first learned about the KTA framework, I anticipated to complete all the steps and phases in the entire framework including the *action phase*. However, I quickly learned from talking to experts in the field that only a few steps are tackle at a time as it is meant to be an ongoing process of development, evaluation, and sustainability. My research focused on the knowledge creation phase and additional research is need to complete the action phase. Additionally, the introduction of acculturation theory and the ICF as complementary theories can assist health professionals to begin examining the processes

underlying person-environment interactions and change over time to meet the dynamic needs of youth.

My thesis work provides a starting point for using theory to better understand and explain the transition process. This is accomplished by bringing awareness to the importance of culturally sensitive care that is reflective of the needs of YCHC and impacts of changing environments on health. A key lesson learned is there is so much great research that has been done and is ongoing, thus it is important to build on existing knowledge and avoid the idea that we have to "re-invent the wheel" to provide the perfect solution (or in this case theory) that will work for everything. In my opinion it is the added insight and efforts for collaboration that are most impactful. This insight has implications for scientific communities as it has sparked conversations around a new notion of 'theoretical knowledge translation' as I have adapted and tailored a social science theory for use in healthcare. I have enhanced the practicality of an abstract theory that is relatively unknown by combining it with an internationally recognized framework endorsed by the World Health Organization. The use of theory to guide transition research may assist in identifying factors that influence the process to address why transition "doesn't work". Another lesson learned is that transition research and practice can benefit greatly from a transactional, lifecourse, non-categorical, and transdisciplinary approach to care through sound partnerships with YCHC and other stakeholders (Bethell et al., 2014; Hamdani et al., 2014; Halfon et al., 2014). A transactional approach to care refers to the need to address not only the person in isolation, but identify strategies to improve the 'fit' between the person and the environment. This promotes more attention to the whole 'process' of transition rather than elements or factors separately. Exploring person-environment interactions is also important as cultural nuances between healthcare settings and the lived environment impacts transition experiences and access to care. Thus, both

person and environment capacity must be addressed. Acculturation and the ICF can be used to provide structure and guidance to build capacity for person-environment interactions.

Additionally, healthcare transition is one aspect of the lifecourse for YCHC; needs for services and supports do not cease once youth turn 18 years old (Halfon et al. 2014). An integrated continuum of care should be promoted instead of age-based services that are driven by non-negotiable age cut offs. This learning supports a 'non-categorical' approach. Instead of working in the silos of different service systems, each thinking the population served has unique and special needs. Communication and collaboration among professionals in pediatric and adult healthcare settings, YCHC, and parents is needed to determine the common experiences, challenges, and strategies to facilitate youth's management of their healthcare needs. This will enable the evolution of a transdisciplinary approach and interwoven process that eases transition from pediatric to adult healthcare. This focuses on learning from one another and building knowledge in more meaningful and efficient ways. In particular, professionals from pediatric and adult healthcare settings and parents must work together to enable YCHC's voice in participating and collaborating in the development of self-management processes and skills. Within healthcare transition research, YCHC and parents should be given the opportunity to lead collaborative activities whenever possible and desired. It is only when YCHC, parents, and healthcare providers work together, youth's self-management of their healthcare needs can be experienced in a more gradual, age-appropriate, and client-centred manner.

A critical lesson learned is the use of knowledge translation frameworks (KTA) and processes of stakeholder consultation (i.e. iKT) is time intensive. There are a few key

points worthy of consideration based on my experience and reflection, as no approach is without limitations. Effective knowledge translation requires time to establish meaningful partnerships with YCHC and stakeholders; this is an iterative and ongoing process. Time investment from the outset of research is needed to build trust and mutual understanding and appreciation for individual expertise so that YCHC are involved in the study's conception. Thus, a limitation of my work is that I could have invested additional time at the outset of each of my four scholarly works to build stronger relationships with YCHC and stakeholders. Establishing strong partnerships will assist in defining clear expectations, roles, and time commitment for researchers, YCHC, and other stakeholders involved in the research. Furthermore, investing additional time, funding, training and education for researchers and stakeholders, and gaining institutional support was critical for successful stakeholder engagement and knowledge mobilization. Another limitation of this work is that my learning of stakeholder consultation developed as a learning curve over the course of my thesis work and I was only able to start applying some of the principles and aspects if an integrated knowledge (iKT) towards the end of my thesis in the demonstration project. Thus, I learned through a process of reflection and action to consult with stakeholders.

From my experience and observation of working with consulting with YCHC in research, one of the greatest challenges I encountered was balancing power differential among members, particularly between researchers and YCHC. For example, I observed that YCHC sometimes felt intimidated or uncomfortable discussing specific issues/concerns in the presence of their healthcare providers. Thus, an important lesson learned is that partnered research is not simply about bringing stakeholders together in one place. The real challenge is ensuring that everyone is working on an equal and level playing field

where they feel supported and safe to speak candidly on any particular issue. Additionally, I found it challenging to balance the demands of the study and the needs of youth. For example, managing funding mandates, timelines and administrative tasks to meet the needs of the study while at the same time ensuring youth's voices and priorities are heard. Thus, this is another limitation of my work on partnering with YCHC as I did not assess formally how youth felt about their contribution and role in the research. A later study in my postdoctoral research program will examine and assess researcher-stakeholder partnerships in more detail.

Through my experience with qualitative research, I have learned the importance of addressing the "why" to better understand everyday experiences and rationales behind actions and decisions of YCHC-a critical component that is lacking in quantitative research. I believe that qualitative methods are of utmost value when working with YCHC as this approach provides an opportunity for youth to voice their needs and concerns. Qualitative research can provide an effective strategy for assessing the impact as the feedback comes directly from YCHC and provides strong and powerful evidence. A limitation of my work is that my qualitative study was confined to one site and was cross sectional. Given additional time, I would have liked to conduct interviews at multiple research sites and clinics with YCHC, parents, and providers pre-transition, during transition, and post-transition, to learn about their experiences with self-management and change over time.

6.4 Future research

Future research can build on this thesis to frame new research within an established knowledge translation framework (KTA) to consult with stakeholders in knowledge creation and mobilization. Our knowledge about the complexities of healthcare

transitions has increased a great deal. It is now time for research that focuses on establishing meaningful partnerships for knowledge mobilization and experiences. Future work is also need to formally assess stakeholder and researcher partnerships. This thesis work provides a starting point for using iKT, demonstrating its potential use in guiding "thinking" rather than "doing". Thus, additional research is required to build evidence for the use of iKT, specifically, to   apply all aspects of iKT more fully and systematically.

Future research should formally assess the application of acculturation theory and the ICF to guide transition practices between pediatric and adult health systems. This can be accomplished through demonstration projects that will help us learn more about researcher and youth participation, and about roles in research, and what works and does not work during transition. The findings of my thesis support the need for action for knowledge mobilization through youth-led studies that involve open dialogues among researchers, parents, health providers and authorities, community partners, and policy makers. It is also worthwhile to explore and assess effective opportunities for youth to have experiences starting in childhood and through adolescence; these experiences can assist in building youth's capacity to assume adult roles and responsibilities for self-management (McPherson et al., 2016). Experiences also enable the people around the young person to build their capacities to support and include them in all aspects of community life.

For instance, a future study can take a mixed-methods design, applying both qualitative and quantitative methods to identify systematically and assess specific components of effective research partnerships to studying the identified areas for further exploration as identified previously. The quantitative aspect could include formal assessments of research partnerships between professionals in pediatric and adult healthcare, as well as

with youth and parents (i.e. roles, expectations, and satisfaction in research partnership), effectiveness of transition tools and interventions (i.e. use and utility) to promote self-management, and the use of acculturative scales to assess youth's personal, social, and environmental influences on youth's ability to self-manage and adaptability to changing healthcare settings during transition pre-, during, and post transition to gain insight into their adaptive processes. The qualitative aspect can include interviews to explore the impact of research partnerships (i.e. identify best practices, barriers and facilitator) and the impact of tools and interventions for self-management. Quantitative findings help us consider *what* are the the best tools or interventions to use to promote self-management and *when* to use them while qualitative findings can assist in informing *how* and *why* we should use them. Using both research paradigms will also yield results that justify the value of partnered research, while building evidence for its use in communities, academic settings, public health institutions and beyond. Research evidence has shown that advocacy for the creation of local and regional policies to impact change in transition services is essential, thus policymakers are an important stakeholder group for inclusion in future studies.

In summary, additional information and education can enhance everyone's capacity to support the transition process if it is meaningful and developed in partnership with youth and families in order to reflect their needs. A great deal of "education" can take place through experiences ('learning through doing') if the people involved in the experience take the time to reflect on the 'lessons learned' and build their capacity for future experiences.

Figure 9: *Acculturation theory and the ICF as complementary theoretical frameworks to guide holistic transition planning and service delivery*
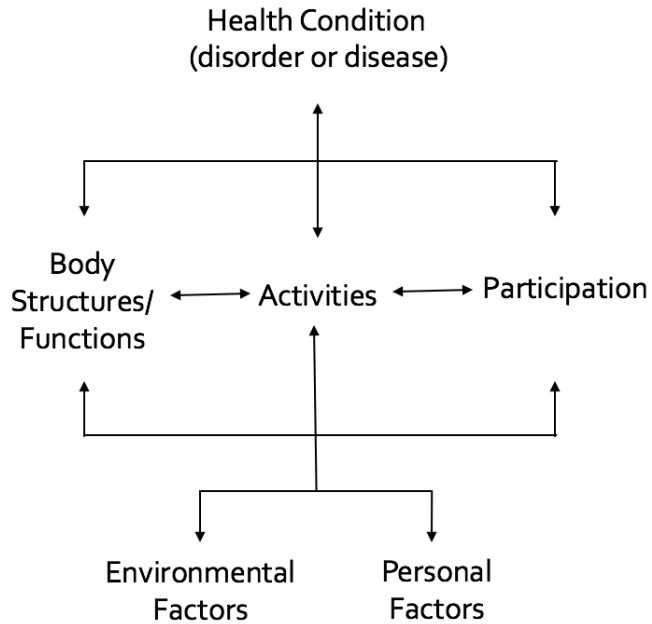
Complementary acculturation theory elements to the ICF framework:

1. Group & Individual Level
2. Concrete strategies and factors to behind process underlying behaviours and environmental influences
3. Dynamic and address change over time

6.5 References

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