

Exploring the transition of the young person with chronic pain

Andrea Higginson

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School of Nursing

Faculty of Health Sciences

University of Ottawa

Thesis Abstract

Objective: To explore and describe the current transition environment for young people with chronic pain in Canada.

Quantitative study: An online survey of nurses working in the pediatric and adult chronic pain setting was conducted to describe the current clinical practices used in both settings to support transition of young people with chronic pain in Canada.

Qualitative study: Semi-structured interviews were conducted with young people with chronic pain who had recently transitioned from the pediatric setting to the adult healthcare setting to explore their transition experiences.

Conclusions: The findings from these studies suggest that young people with chronic pain have similar transition related needs to other young people with chronic conditions as well as unique challenges. Nurses can have a positive impact on transition outcomes by developing processes and forming networks of clinicians who work with young people with chronic pain in order to improve transition related outcomes.

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Any transition is easier if you believe in yourself and your talent. ~Priyanka Chopra~

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Co-Authorship

1. Paula Forgeron RN, PhD

Associate Professor, School of Nursing, Faculty of Health Sciences University of Ottawa

2. Denise Harrison RN, PhD

Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa

3. Bruce Dick, PhD, R Psych

Professor, Faculties of Medicine and Dentistry & Rehabilitation Medicine, University of Alberta.

Dr. Forgeron was the thesis supervisor. All authors were members of the thesis committee.

All authors were involved with the conception of the study design, the corresponding author was solely responsible for the data collection, and all authors were involved in the analysis and interpretation of data. The corresponding author drafted all the chapters and both manuscripts.

Dr. Forgeron reviewed all first and subsequent drafts. Dr. Harrison and Dr. Dick were involved in the revision of the chapters and both manuscripts intended for submission for publication.

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List of Abbreviations**Abbreviation**

CAPHC	Canadian Association of Paediatric Health Centres
CHEO	Children's Hospital of Eastern Ontario
NP	Nurse Practitioner
PI	Principal Investigator
PF	Paula Forgeron, Thesis Supervisor
REDCap	Research Electronic Data Capture
RN	Registered Nurse

Chapter 1

Introduction

Exploring the Transition of the Adolescent with Chronic Pain

The American Pain Society defines chronic pain as persistent or recurrent pain that lasts longer than three months, or pain that persists beyond the point of tissue (American Pain Society, 2012). One in five Canadian adults suffer from chronic pain (Moulin et al., 2002; Schopflocher et al., 2011). Children are no exception as one in five Canadian children have reported experiencing some form of chronic pain, with an estimated 5-8% of children or teenagers suffering from chronic pain severe enough to interfere with their quality of life (Huguet & Miro, 2008; Ramage-Morin & Gilmore, 2010; King et al, 2011; von Baeyer, 2011). Undertreated chronic pain has a negative impact on all aspects of health-related quality of life including: physical (poor sleep, and activity limitation), emotional (anxiety, and depression), social (peer and family relationships), cognitive function and learning, and role function (absence from school and work) (Stinson et al., 2013). Although the negative health related quality of life outcomes are significant for both adults and young people, young people (children, adolescents, young adults) with chronic pain have the added risk of these negative outcomes compounding the challenges they face during the developmental trajectories related to their age. For example, poor school performance as a result of chronic pain may have life long impact in terms of employment prospects as an adult. Therefore it is imperative that developmentally appropriate care practices are designed to support young people with chronic pain as they go through the various stages of development into adulthood.

A prevalence study conducted in 2007-2008, reported that over 1.5 million Canadians between the ages of 12 to 44 live with chronic pain (Ramage-Morin & Gilmour, 2010). Longitudinal studies provide evidence suggesting that childhood chronic pain predisposes children for the continuation of pain into adulthood as well as the development of new onset

chronic pain in adulthood (Walker, Dengler-Crish, Rippel, & Bruehl, 2010). For example, Jones and colleagues (2011) found a significant positive correlation between the experience of multiple symptoms of pain (headaches and gastrointestinal pain) by age 7 and a 50% increased the risk of developing chronic widespread pain in adulthood. Additionally, 80% of participants reporting chronic pain in childhood indicated that the same pain continued to adulthood (Hassett et al., 2013). Despite advances in treatment it is evident that a significant proportion of adolescents with chronic pain will continue to require health services for pain management into adulthood (Dengler-Crish, Horst, & Walker, 2011; Mulvaney et al., 2006). However, little is known about the best practices in the transition of care from pediatric to adult health care services for young people with chronic pain.

Continued research on pharmacological, psychological, physical, and social interventions is needed for children, adolescents, and young adults with chronic pain, however health systems research is also warranted. Pain research in Canada is grossly under-funded with less than 1% of total funding from Canadian Institutes of Health Research and only 0.25% of total funding for health research going to pain related studies (Lynch et al., 2008). Lack of research includes an understanding of the challenges young people with chronic pain faced when they transition from pediatric to adult health care services.

The research that has been conducted on the transition process from pediatric to adult health care services for many chronic conditions suggests gaps in care and loss to follow-up as a result of a poor transition process (Lugasi, Acille, & Stevenson, 2011). There are multiple factors that contribute to negative transition experiences. One of significance is the adolescent or young person's developmental stage, as the level of executive functioning skills (organizational management, planning, self-regulating, and inhibition) required to undertake self-management

tasks are not fully developed in the brain until mid-to-late twenties (Casey, Getz, & Galvan, 2008). Studies examining the self-management practices of adolescents with chronic pain have indicated that it is important to work with both parents and adolescents to support these adolescents to assume increase pain and disease management activities and to identify specific family and parental practises that promote autonomy and effective pain self-management (Palermo, Valrie, & Karlson, 2014). However, a study to examine the pediatric to adult healthcare setting transition needs of this specific population has not been conducted.

An interprofessional approach to chronic pain management is advocated as the most effective approach to work with children and adolescents to treat chronic pain (Simons, Logan, Chastain, & Cerullo, 2010). This model integrates medical, physical, and psychological interventions (Simons et al., 2010). Specific interprofessional pain treatment recommendations generally involve beginning or changing a medication regimen (medical), increasing activity tolerance through physical therapy (physical), and learning new cognitive-behavioural approaches to pain coping (psychology) (Simons et al., 2010). The interprofessional model of care is also the optimal standard of treatment for chronic pain in the adult healthcare system, however many adults encounter barriers to accessing an integrated treatment approach to chronic pain in Canada. This means that an adolescent with chronic pain in Canada seeking care at one of the pediatric chronic pain clinics would be treated by the prescribed interprofessional approach only to be transitioned into a system that may no longer provide the approach to care that they are accustomed to and require.

Current provincial and territorial health system arrangements do not support chronic pain management for all Canadians (Wilson, Lavis, & Ellen, 2015). In a survey study conducted in 2006 of the Canadian chronic pain treatment facilities, 136 clinics were found across Canada,

however only 120 met the inclusion criteria. Inclusion criteria for the study was that the clinic needed to be advertised to offer interprofessional services for the diagnosis and management of patients with chronic pain, having a minimum of three different healthcare disciplines (including at least one medical specialty) and available in the same facility (Peng et al., 2007). Of these 120 clinics, 98% of them were found in urban centres and major metropolis centres (Peng et al., 2007). Considering that there are limited interprofessional clinics in Canada, it is likely that the approach to care experienced by most young people with chronic pain who access care in a pediatric chronic pain clinic may be significantly different when they are transitioned to the adult healthcare system. In addition, the inadequate number of adult interprofessional pain clinics may result in many young people being transitioned to the care of their family physician who may have minimal contact with other clinicians with chronic pain management expertise.

Some family practices may entail an interprofessional care team, which includes other professionals such as nurses, dietitians, pharmacists, and social workers. However, these teams typically do not include team members with special expertise in chronic pain management (Lavis & Boyko, 2009). Thus, it is not surprising that these care teams are challenged in meeting the needs of the adults with chronic pain (Lavis & Boyko, 2009). In general, general practitioners are faced with the challenges of prevalent mental health disorders and inaccessibility to consulting services, such as psychology. Physicians have identified an inability to access the mental health services for their patients, regardless of their insurance status (Peachy, Hicks, & Adams, 2013). This is troubling as private physiotherapy and psychology services are associated with significant costs and those unable to afford such costs or lack coverage through a third-party payer may have to forego effective programs, services, and medications (Lavis & Boyko, 2009). Therefore when

non-physician services for young people are no longer provided under the adult provincial health care plans compared to pediatric services gaps in their chronic pain management are likely.

The STOP-PAIN project conducted by Choinière and colleagues (2010) was a two-fold study, first examining the biopsychosocial portrait of patients on waitlists for treatment at multidisciplinary pain treatment clinics. Secondly, the project identified the economic burden of chronic pain on patients and families. Quality of life was measured using the SF-36 version 2 (Ware, Kosinski, & Dewey, 2001). Participants with chronic pain on the waitlist reported lower quality of life scores than those with other chronic illnesses. Physical, social, and psychological functioning was reported to be remarkably lower compared to the rest of the Canadian population without pain and also those reporting chronic illness (Choinière et al., 2010). The symptomology of chronic pain that contribute to lower quality of life scores may be quantitatively and qualitatively different than for adolescents and young adults with other chronic illnesses and require unique processes and practices in supporting their transition from pediatric to adult healthcare settings.

Chronic pain may have a negative impact on developmental trajectories as children and adolescents with chronic pain experience significant disruption to their activities of daily living such as going to school or socializing with friends (Caes, Vervoot, Eccleston, Vandenhende, & Goubert, 2011). The continued impact of chronic pain on young people as they become adults may contribute to poor employment opportunities and their ability to secure social support. Chronic pain also affects an adolescent's relationship within the family and may contribute to disruptive family functioning. Poor family functioning is associated with greater disability in youth with chronic pain (Finley, MacLaren-Chorney, & Campbell, 2014). Given that parents have an important role in the development of the adolescent's decision-making skills, especially

in times of stress, poorer family functioning may negatively impact a parents ability to support their young person's ability to navigate the adult healthcare environment.

Transition of adolescents and young adults with chronic conditions from pediatric health services to adult health care has been shown to induce anxiety and uncertainty (Tuchman, Slap, & Britto, 2008). For the parents of adolescents and young adults with chronic pain, they too may experience these similar anxieties. However, their transition related anxieties may be further heightened in comparison to parents of young people with other chronic conditions with these parents reporting social restrictions and high levels of parenting stress, anger, depressive symptoms, and anxiety (Eccleston, Crombez, Schotford, Clinch, & Connell, 2004; Palermo et al., 2014). One study showed that parental feelings of distress correlate with more pain and distress in their child (Caes, Vervoot, Eccleston, Vandenhende, & Goubert, 2010). Since transition can exacerbate stress, young people are at risk for negative transition related outcomes. Furthermore, the balance between parental involvement in care and increasing young persons autonomy appears to be more complex for those with chronic pain compared to parents of children with other chronic conditions (Evans, Meldrum, Fraynt, & Zeltzer, 2010; Palermo, Valrie, & Karlson, 2014). Since parents of adolescents and young adults with chronic pain tend to be greatly involved with managing their child's healthcare needs, they may inadvertently put their child at risk for a more difficult transition by not allowing their child opportunities to develop the knowledge and skills required to successfully navigate the adult health care setting.

Assessment of young people with chronic conditions are ready to transition (healthcare transition readiness) is linked to successful transition, and the chronic pain population is no exception. It is not only the healthcare transition readiness that requires assessment but also the young person's affective, behavioural, and cognitive capacity to manage in a new healthcare

environment. Pediatric patients and their care-provider should be comprehensively assessed in terms of readiness and available supports to ensure that the transition is seamless, appropriate, and successful. Healthcare transition readiness is associated with age, disease or condition, participation in transition clinics, anxiety, and confidence in the adult provider (Schwartz et al., 2014). For the adolescent patient with chronic pain, these factors as well as disease specific factors may impact their transition preparedness and readiness and warrants further study. The purpose of this thesis was to understand the transition climate for young people with chronic pain, in Canada. This was achieved through two studies. The first study described the transition nursing supports available to young people with chronic pain. The second study explored the experiences of young people with chronic pain recently transitioned in the adult healthcare system.

Theoretical Model

As defined by Meleis and colleagues (2000), transition is a process of passage from one life phase, condition, or status to another during which changes in health status, role relationship, expectations, or abilities create a period of vulnerability. Adolescence is a time of developmental transition, which is marked by the increased self-identity and growing independence (Meleis, 2010). Developmental transition denotes changes in the lives of adolescents that can range in number and context and may include transitions in their social, academic, and employment lives. However, adolescents who live with a chronic condition, such as chronic pain, face a second transition—that of transitioning from the pediatric to adult healthcare system. This form of transition has been defined as a situational transition (Meleis, 2010), which includes transition in the roles and relationships. For example the change in roles of the child in the home to an independent adult and the impact this has on the family relationships or changes in health team

members (Meleis, 2000). Situational transition also includes geographical changes, such as where one may access their healthcare (Meleis, 2000). The nursing model on transition developed by Schumacher and Meleis (1994) (Figure 1), is a mid-range nursing theoretical model that was used to guide this study on the transition experience of a young person with chronic pain. This model identifies the main concepts of transition. Transition is viewed as a process of change with specific elements and therefore provided guidance for the development of the data collection tool for these studies as this theory may aid in future development of nursing interventions to best support this unique population.

The adolescent and young adult with chronic pain experiences two different types of transition: developmental and situational. Despite the diversity in these transitions, they share common properties that include the identification of role change, changes in relationships, abilities, and patterns of behaviour (Schumacher & Meleis, 1994). Inherent in both transitions is role acquisition, role loss, or the simultaneous loss of one role and gain of another (Meleis, 2010). The developmental transition is marked by a role change of the dependant adolescent to an autonomous young adult, while also considering the changes in the role of the parent during this time. For the parent, it is the transition of caring for adolescents and allowing them to gain independence. Within the situational transition process there is the introduction of the new adult healthcare team, and the loss of the pediatric healthcare team. Both healthcare teams must consider the developmental changes experience by the patient and the caregiver as well as the situational changes and how these may effect an adolescent or young adult's successful healthcare transition (Meleis, 2010). Through this thesis, both of these transition processes were explored and their impact on adolescents and young adults with chronic pain.

According to transition nursing model, several factors affect both types of transition: meaning, expectations, levels of knowledge/skill, the environment/level of planning, and the emotional/physical well-being (Meleis, 2010). Although how one experiences these factors is idiographic, together these factors provide a framework to understand the transition of an individual (Schumacher & Meleis, 1994) and thus provide a supportive structure for this study.

Within the transition model each factor is defined. Meaning is the subjective appraisal of the transition and the effect the particular type of transition (i.e. development, situational) has on an individual's life (Schumacher & Meleis, 1994). For the young person with chronic pain, the meaning of the transition and how they felt leaving pediatric care was examined. The acquisition of their new role within the adult healthcare setting and how they felt about their new responsibilities was sought, as well as how they felt this impacted their pain management.

Expectation outlines what the individual expects from the transition (Meleis, 2010). Anxieties and uncertainties toward the transition into the adult healthcare setting have been identified. This population experienced some of these same concerns. Understanding how the expectation of the transition and if or how their pain management throughout the process was affected was explored.

Level of knowledge/skill that is required for transition determines the potential success (Meleis, 2010). Preparation for transition has been identified as essential for positive transition outcomes (Meleis, 2010). One of the studies in this thesis sought to improve understanding of the preparation participants experienced and whether or not they understand their chronic pain condition prior to transition and the effect this had on their transition. The other study sought to improve understanding the current practices and programs available to young people with chronic

pain in Canada to determine the existing healthcare practices to support transition for this population.

The environment in which the transition takes place has been described as an external facilitative resource (Meleis, 2010). The setting in which the young person transitioned from and transitioned to was identified. Data on the current services they receive and how these meet their current pain management needs (e.g. physiotherapy, pharmaceutical, psychology, vocational counselling) were captured. Identifying and understanding successful practices and programs in both the pediatric healthcare system and adult healthcare system provided needed information to inform the development of health systems programming to support successful transition for adolescents and young adults with chronic pain.

Lastly, emotional and physical well-being is the emotional and physical experience of the transition (Schumacher & Meleis, 1994). Transitions can conjure positive or negative emotions, which can impact the outcome of the transition. Exploring the experience of transition from those who have lived through the process allowed for a deeper understanding of the positive and negative emotional and physical effects of healthcare transition for adolescents and young adults with chronic pain. This transition framework informed and guided the data collection in this thesis research to describe the elements of a healthy transition for a young person with chronic pain (Schaumacher & Meleis, 1994).

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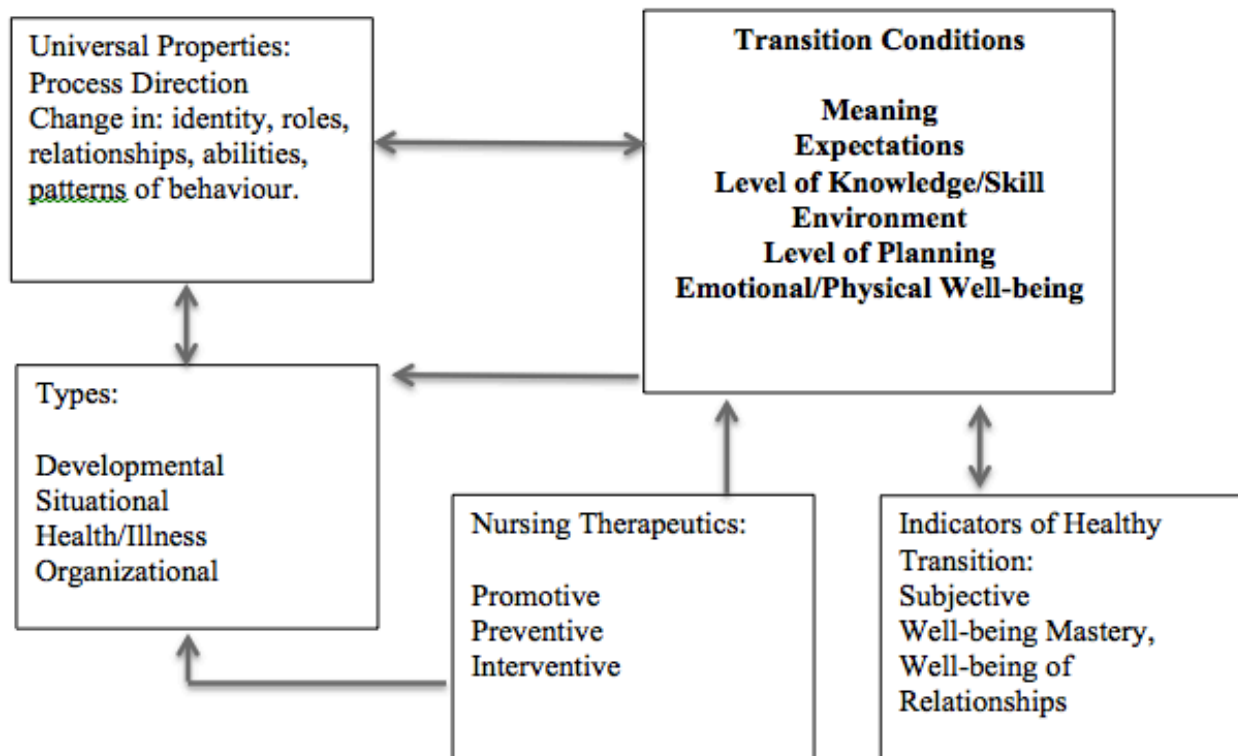
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Figure 1.1 The nursing model of transition (Meleis, 2010, p. 47).



Chapter 2
Literature Review

Literature Review

The following literature review was conducted to delineate what is known about successful transition from pediatric to adult healthcare services for young people with chronic pain and to identify the gaps in this knowledge. The specific transition of the pediatric patient with chronic pain to the adult healthcare system has not been systematically explored. However, research involved in transition of young people with different chronic illnesses has been identified. This literature was pertinent because it identified the struggle of the pediatric transition in general, and therefore provided an understanding of some of the struggles that young people with chronic pain may face. There were 3 main themes identified in the literature to describe transition. They include: the importance of independence, the shift in parental role, and the difference between healthcare systems (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014; Tuchman, Slap, & Britto, 2008; van Staa, Jedeloo, Meeteren, & Latour, 2011; van Staa, & Sattoe, 2014).

Independence

Pediatric transition into the adult healthcare system should be seamless, developmentally appropriate, psychologically sound and comprehensive (Rapley & Davidson, 2010). The youth related factors that need to be considered in pediatric transitioning are: age and development, executive functioning, knowledge of disease, and self-efficacy (Reed-Knight, Blount, & Gilleland, 2014). Little is known about how the experience of chronic pain affects these factors. However it is known that many young adults with chronic pain rate themselves as behind their peers in several areas related to these factors (i.e. identity formation, and independence) (Eccleston, Wastell, Crombez, & Jordan, 2008).

Age and development. The age of transition and when to begin preparing an adolescent and their families for transition to the adult healthcare system has been examined in the literature. In a position statement published by the Canadian Paediatric Society: “medical practitioners involved in the care of adolescents must often deal with an arbitrarily set, chronological threshold between adolescence and adulthood, which varies from province to province and even between jurisdictions within the province” (Sacks, 2003). Nationally, one prescribed age has not been agreed upon for a designated time for transition. Adolescence is the final development stage before an individual is considered an adult. Once adolescent development is complete, the individual is supposedly prepared for the adult healthcare setting. The developmental period of adolescence has been identified by the Canadian Paediatric Society as between 10-19 years of age (Sacks, 2003). Although the appropriate age of when to transition adolescents has been examined in the literature no one has identified a certain age to be as appropriate. Lawson and colleagues (2011) conducted a cross-sectional survey that examined self-reported adherence and healthcare related behaviours among young people with rheumatic disease prior to transition to the adult healthcare system to determine transition readiness. These researchers determined that older patients did not necessarily demonstrate an increase in proficiency in self-management independence (Lawson et al., 2011) suggesting that age alone should not be the sole determining factor of when transition should occur. In fact adolescents with chronic pain report that age is independent of their transition readiness (Forgeron & McGrath, 2008). Successful transition is linked to a young person’s ability to independently navigation the healthcare system and management their health condition, accompanied with the ability to advocate for themselves within the adult health care setting (Tuchman, Slap, & Britto, 2008). The development of these

determinants (self-management, self-advocacy) is essential for navigating the adult healthcare system and for proper chronic pain management.

Although age itself is not enough to ensure readiness for transition, older age at the time of transition has been associated with better health outcomes and less anxiety (Rutishauser, Sawyer, & Ambresin, 2014). It is possible that older adolescents engage in more of their healthcare management and have had more time with their pediatric healthcare providers to gain mastery over the knowledge and skills needed to manage one's health condition, advocate for themselves, and make decisions regarding their care. Thus a more carefully planned developmentally appropriate approach must be taken as opposed to automatically transitioning a young person at an arbitrary pre-set age.

The prevalence of chronic pain and pain-related disability peaks during adolescence (Palermo, Valrie, & Karlson, 2014; Roth-Isigkeit et al., 2005). Reasons for this peak may be related to pubertal development and associated physical cognitive, emotional and social changes that accompany adolescences (Palermo, Valrie, & Karlson, 2014). Therefore young people with chronic pain may be further disadvantaged by a pre-set arbitrary age of transition, as they may not have mastered the knowledge and skills necessary for self-management and self-advocacy prior to transition. Additionally, transition to the adult healthcare system is more likely successful when the young person is in optimal health (Peter, Forke, Ginsburg, & Schwartz, 2009). Chronic pain is complex as it can negatively impact all domains of a young person's life. Thus, if chronic pain develops later in adolescence the young person may not be truly stabilized prior to transitioning to adult healthcare services if a pre-set age is used as the determination of when transition must occur.

The transition from child-centered to adult-oriented healthcare systems is part of a longer life-course transition for adolescents with chronic conditions, as opposed to simply maturing into adulthood (van Staa & Sattoe, 2014). Maturity is necessary for executing the skills required for self-management of chronic illnesses. Increased age for transition is further supported by neuroscience research which indicates that the adolescent brain continues to develop into one's early twenties (Rutishauser, Akre, & Suris, 2011). Chronic pain may disrupt cognitive functioning activities such as perception, information processing, learning, attention, memory, decision-making, planning inference and abstraction (Dick & Riddell, 2010). Therefore an early age of transition of young people with chronic pain could predispose a young person to negative outcomes as pain interferes with one or more of these cognitive processes that are essential for transition readiness.

Whitfield and colleagues (2015) explored the relation between self-assessed ability to perform tasks and duration of disease, and age of the young person with Irritable Bowel Disease (IBD) at the time of the transition assessment. These researchers found a significant improvement in self-reported skills such as assuming healthcare responsibilities with increased age. When further analyzed, all knowledge and skills essential for successful transition continued to improve with age including: basic disease knowledge, understanding medication and treatments, and disease management. Adequately assessing young people for transition readiness and allowing for maturity and development of the independent skills is important to a successful transition. Interestingly, in a qualitative study conducted by Forgeron & McGrath (2008) on the self-identified needs of youth with chronic pain, when asked about transition to the adult healthcare system, participants did not believe that self-advocacy and self-management skills were necessary to successfully interact in the adult healthcare system. However, they agreed that they

were too old to remain in the pediatric setting but too young to transition to adult-centred care. This suggests that adolescents with chronic pain may not understand the demands of the adult healthcare setting as they still believed their caregiver should be in charge in the disease management needs. Therefore research is warranted to determine how best to prepare young people with chronic pain for transition from the pediatric to the adult health care setting.

Social readiness. School is the primary arena for social development, particularly in adolescence, when peer relations take on increasing significance (Logan, Simons, Stein, & Chastain, 2008). However, many adolescents with chronic pain miss a significant amount of school. In a study by Logan and colleagues (2008), close to half of the adolescents with chronic pain in the study missed at least a quarter of school days with some missing more. The quantity of missed school days may contribute to patterns of long-term disability (Logan et al., 2008). Without normal social interactions, young people with chronic pain may have poorer social functioning. A systematic review on the social functioning and peer relationships of children and adolescents with chronic pain concluded that in comparison to peers without chronic pain this population has fewer friends, experience more peer victimization, experience increase rates of social isolation, and are perceived by peers as less likeable (Forgeron et al., 2010). Positive peer support is associated with better transition outcomes for adolescents and young adults with chronic health conditions. If young people with chronic pain have fewer peer supports they may experience difficulty with transition. However, there little known about the relationship between social readiness and transition for this population.

Adolescents who engage with peers with similar chronic diseases have opportunities to discuss their feelings and concerns. This type of peer support has been associated with a positive transition experience (Fegran et al., 2014). However, within the population of young people with

chronic pain many are challenged in maintaining and initiating friendships and positive peer relationships (Forgeron, Evans, McGrath, Stevens, Finley, 2013), so it is unclear if or how these social challenges affect transition. It has been determined that adolescents with chronic pain have voiced losing friends or a negative change to friendships as a result of chronic pain (Forgeron & McGrath, 2008; Forgeron et al., 2013) suggesting perhaps fewer peers available to provide social support. In another study, Eccleston and colleagues (2008) examined the perception of 110 adolescents with chronic pain in relation to peers in terms of various areas of development (i.e. independence, and school development). Fifty-one percent of adolescents with chronic pain rated themselves as behind their peers on four or more domains of the social development; school progress, confidence around others, independence, and the ability to form romantic relationship. However, stronger peer relationships predict positive judgements for independence, emotional adjustment, and identify formation (Eccleston et al., 2008). Given that perceptions of the adolescent's ability to influence health outcomes, the environment, and health behaviours have an impact on transition (Reed-Knight, Blount, & Gilleland, 2014) it is critical to understand how adolescents and young adults with chronic pain perceive the need of peer support in helping them successfully transition to adult healthcare settings.

Executive functioning. Executive functioning is a part of cognitive functioning and is the development of many different skills including planning, problem-solving, self-monitoring, organization, and working memory (Reed-Knight, Blount, & Gilleland, 2014). Development of these executive functioning skills is important for a young person to assume full responsibility of their chronic illness. However, this may be more difficult for young people with chronic pain as pain may interfere with one or more of these processes (attention and memory) (Dick & Riddell, 2010), which are needed for successful transition. Normative development in nonmedical aspects

of an adolescent's life has been linked to the success of transition of healthcare responsibilities (Reed-Knight, Blount, & Gilleland, 2014). As for adolescents with chronic pain, their condition affects this normative development (e.g. school performance, social functioning, cognitive functioning) and puts them at an increase risk for an unsuccessful transition. There is limited research on the decision-making of adolescents with chronic pain in relation to increased responsibility for their care. However, in one study participants identified that their parents attended all appointments, renewed prescriptions, and were responsible for contacting the healthcare professionals when questions arose (Forgeron & McGrath, 2008). These findings suggest that young people with chronic pain may not have developed the necessary skills required to successfully navigate the adult healthcare system. It is unclear as to why the participants in the study by Forgeron and McGrath (2008) did not perceive this lack of involvement and responsibility as a warning sign that transition may be challenging. It may be a lack of understanding of what the adult healthcare system would demand or it may be a sign that their executive functioning is still developing in some aspects of their lives. In order for transition interventions to be effective we need to understand if young people with chronic pain feel ready to make health related decisions and take responsibility for their healthcare.

Reliable performance of adolescents to carry out prescribed healthcare behaviours (e.g. administration of medication, disease knowledge, scheduling and attending appointments, communication with healthcare providers) is associated with transition readiness (Reed-Knight, Blount, & Gilleland, 2014). Therefore, when age alone is the determining factor for transition many adolescents and young adults may experience a negative transition, due to lack of preparation. Young people with various chronic conditions have reported that a sudden transition and lack of preparedness has left them feeling unimportant and unwanted (Fegran et al., 2014).

Lack of preparation and assessment is linked to poor outcomes and difficulty with transition. Advocates suggest that the transition process needs as much time and support as necessary to prepare the young person to take responsibility for their own health and for them to demonstrate their self-care abilities (Fegran et al., 2014). Therefore, transition is best described as a process that prepares the young person to transition and should be initiated early on to facilitate success.

Disease and treatment knowledge and skills. Adult healthcare clinicians have identified that disease and treatment knowledge is necessary but not sufficient for young people to assume healthcare responsibilities (Reed-Knight, Blount, & Gilleland, 2014). The development of self care skills is necessary for transition, and this entails a clear understanding of what is required and why this skill development has oftentimes been lacking for young people transitioning into the adult healthcare system (Reed-Knight, Blount, & Gilleland, 2014). Chronic pain has a complex disease pathology and entails an interprofessional treatment approach. It may be that young people with chronic pain transitioning into the adult healthcare system require more coordination and understanding than other adolescents with chronic illnesses due to the complexity of their condition. Providing a young person with disease and treatment knowledge and skills to support their ability to manage their chronic pain may improve outcomes and encourage adherence to treatment.

In a systematic review conducted by Pai and Ostendorf (2011), they identified that multiple studies have found that pediatric patients experience a significant decline in treatment adherence during transition and that this finding holds across a number of chronic illnesses (Pai, & Ostendorf, 2011). For example, attendance at medical follow-ups has been reported to decrease after transition to adult healthcare (Lugasi, Achille, & Stevenson, 2011; Rapley & Davidson, 2009; van Staa & Sattoe, 2014). Psychological factors impact adherence to treatment after

transition. A longitudinal study young adults with diabetes, the study followed participants over eight years found an association between antisocial behaviours and conduct disorders during adolescence and higher mean Hb_{A1C} (a marker of poor diabetic control) throughout the transition period (Bryden et al., 2001). Therefore, if young people experience behavioural problems and mental health challenges they may be at greater risk for poor health outcomes after transition. Moreover, for those who find it difficult to follow through on medical treatment, transitioning without sufficient disease and treatment knowledge and skills puts them at greater risk of negative sequelae post transition. The degree to which treatment adherence declines for a young person with chronic pain, and associated negative health outcomes occur post transition is not known. However, research does suggest that unsuccessful transition preparation results in treatment non-adherence and lost to follow-up, both of which increases the likelihood that adolescents and young adults will present to hospital emergency rooms in unnecessary crisis (Rapley & Davidson, 2010).

Self-efficacy. The patient's level of independence and their ability to achieve self-efficacy should be a priority when assessing transition preparedness (Reed-Knight, Blount, & Gilleland, 2014). Self-efficacy refers to a young person's perception of his or her ability to influence health outcomes, the environment, and health behaviours (Scharwarzer & Luszczynska, 2008). Once a young person has transitioned into the adult healthcare system, not only are they faced with performing different health managing skills, but they also must function and perform these tasks in an unfamiliar environment and take on an unfamiliar role in their care (such as communicating with healthcare providers, and negotiating time off from work or school) (Reed-Knight, Blount, & Gilleland, 2014). After transition, the young person is generally expected to have acquired full responsibility for his or her own healthcare needs. However, some adolescents are reluctant to

assume responsibility as they have been dependent on their parents to collaborate with healthcare professionals and take care of their healthcare needs (Fegran et al., 2014). Obtaining care in the adult system requires independent navigation, which can be difficult for the young person who has been reliant on their caregivers (Tuchman, Slap, & Britto, 2008). Viewing transition as a process as opposed to a one-time event would allow young people to gain the knowledge and skills needed for self-management of their chronic condition and learn skills necessary to become literate health care consumer (Betz, Nehrig, & Lobo, 2015), furthermore gain the navigations skills needed for independence (Tuckman, Slap, & Britto, 2008). Ironically, many adolescent patients report that they desire independence when it comes time for transition but they do not necessarily understand what this independence means (Lugasi, Achille, & Stevenson, 2010). To support the development of self-efficacy to manage their health care needs after transition young people with chronic pain not only require knowledge and skills to manage disease and other health related activities but they need opportunities to practice these skills gradually over time. It is unknown if the present health care environment allows for the gradual development of health related self-efficacy for young people with chronic pain.

Shift in Parental Role

Within the pediatric setting parents have a key role in accessing healthcare for their child and managing their child's chronic condition. However, there is a significant shift in the parental role during the transition to the adult healthcare system that can impact the young person as well as the parents. Three factors related to parent's role in transition have been identified: protection of the child, the shift of responsibilities, and anxiety of transition. Understanding how these three parental factors impact transition may suggest ways to promote parents involvement that is supportive of successful transition of young people with chronic pain.

Protection of their child. Research to examine the influence of the parental role on an adolescent's chronic pain experience has been conducted, however there is limited empirical evidence examining the effect this relationship may have on the transition outcomes to the adult healthcare system (Palermo, Valrie, & Karlson, 2014). Some parents of young people with chronic pain have been found to be overly protective and these protective responses are linked to poorer functional outcomes. Logan and colleagues (2012) identified that parental catastrophization about their child's pain and their protective responses to their child's pain independently predict their child's school attendance and school impairment. This study outlined the importance of intervening with parents as they may have an impact on their child's success in school. Both school performance and transition require a certain level of independence on behalf of the young person with chronic pain, therefore parental behaviours of over protectiveness and castastrophization about pain, may negatively impact successful transition into the adult healthcare system. Furthermore, higher levels of parent catastrophization, make parents more likely to engage in behaviours that restrict the child's activity engagement (Caes et al., 2011). Limiting or allowing an adolescent to disengage from social activities, such as school, could impede the growth of their independence, identify development, and social relationships with other children and adults that are necessary for social development (Sato et al., 2007). All three of these areas of growth represent areas of knowledge and skill development that are essential for successful transition.

Shift of responsibility. In general, parents are primarily responsible for medical management including medication taking, disease knowledge, maintaining appointments and communicating with healthcare providers (Reed-Knight, Blount, & Gilleland, 2014). A significant change brought about by transition is the shift in who is primarily responsible for the

young person's healthcare. Parental involvement during the process of transition has contributed to positive health outcomes for young people (Fernandes et al., 2014; Rapley & Davidson, 2010; Tuckman, Slap, & Britto, 2008). For example, increased parental monitoring during transition has been found to improve outcomes such as better medication adherence (Pai & Ostendorf, 2011). When parents are able to shift their role from being the responsible and accountable decision-maker for their child's healthcare needs to a more supportive and consultative role for their child, transition outcomes improve (Betz, Nehring, & Lobo, 2015; Pai & Ostendorf, 2011; Reed-Knight, Blount, & Gilleland, 2014). Gradually shifting the focus of treatment responsibility from parents to the young person throughout the span of adolescence should be part of the transition (Reed-Knight, Blount, & Gilleland, 2014). This can help guide their child as parents have an important role in the development of an adolescent's decision-making skills (Rapley & Davidson, 2010). Parental encouragement provides a nurturing progression to independence (Peeters, Hilberink, & van Staa, 2014). Yet, it is unclear how young people with chronic pain perceive the role of their parents during their transition in care.

Although some studies suggest that sustained parental involvement during transition to the adult healthcare setting is related to better outcomes such as increased adherence to medical treatment regimens (Pai & Ostendorf, 2011), parental over involvement may influence negative outcomes. Parental over involvement may impede a young person's transition by not providing opportunities for their developing child to assume their role as an emerging adult. Therefore parents also must navigate this difficult transition period. However, it is not known how young people with chronic pain negotiate their parents' involvement during the transition process, and their perspectives on what makes a helpful balance between involvement and disengagement during the transition process.

Anxiety of the transition. The shift in roles has been reported to create uncertainty and anxiety in parents whose child is transitioning from pediatric to adult healthcare settings, as many parents do not believe that their child is prepared to assume their own healthcare responsibilities (Fegran et al., 2014; Kingsnorth, Gall, Beayani, & Rigby, 2011; Lugasi, Acile, & Stevenson, 2011; Peeters, Hilberink, & van Staa, 2014). Parents of adolescents with chronic illness are reported to be more concerned than their child about their child's ability to be autonomous (Fegran et al., 2014). Other areas of parental concerns include parent's reservation about their child's treatment decision-making ability and their child's ability to develop appropriate healthcare relationships (Kingsnorth, Gall, Beayani, & Rigby, 2011). A recent qualitative study using semi-structured interviews with adolescents with chronic illnesses and their parents report that adolescents voiced that they wanted to become autonomous, however the parents voiced being doubtful of their child's ability to care for their own healthcare needs (Peeters, Hilberink, & van Staa, 2014). Furthermore, the researchers found that adolescents tended to focus on the present whereas their parents' were concerned about future management of the chronic illness. This difference in perspectives may create tension between parents and their child.

In a quantitative study researchers prospectively assessed the transition awareness and readiness of pediatric patients with spina bifida and their parents and investigated their reported barriers to transition (Stephany et al, 2015). Most parent participants, 88.9%, thought about transition in comparison to only 40% of the adolescent participants. Additionally, the anticipation of the transition contributed to the parent participant's feelings of anxiety, as they felt uncertain about the future. Perhaps due to the levels of anxiety, most parents attempt to retain responsibility for the management of their child's chronic condition during and after transitions (Peeters, Hilberink, & van Staa, 2014). This mounting anxiety could increase the risk for negative

outcomes for both parents and adolescent with chronic pain as many of these parents already experience heightened anxiety and other internalizing behaviours even before transition (i.e. emotional distress, clinically significant depression, parental role stress) (Eccleston et al., 2004; Palermo, Valrie, & Karlson, 2014). Parental support and involvement during the transition process is associated with positive transition outcomes (Tuckman, Slap, & Britto, 2008) presumably by decreasing parent anxiety allowing for increases in adolescent self-management. Therefore it is important that parents and caregivers actively participate in the transition process. However, it is unknown if there are chronic pain specific tensions (i.e. uncertain disease trajectory, risks of treatments) between young people and their parents during the transition process and how parental anxiety and stress before transition impacts a young person's transition experience.

Healthcare Delivery Systems

There are differences in the healthcare delivery approaches between the pediatric and adult healthcare settings, which influence the transition experience of the young people with chronic pain. The identified healthcare delivery factors that affect the transition experience are: the cultural differences in the two settings; access to services in the adult healthcare setting in comparison with the pediatric setting; collaboration between the two settings; and the transition preparation initiatives taken in the pediatric setting. These factors will be further explored in the following section.

Difference in cultures. The pediatric and adult healthcare cultures are described as vastly different and therefore potentially problematic for newly transitioned young people. The two systems are different in terms of care delivery philosophy and thus may pose barriers that heighten the anxiety of the transitioning patient and their parents (Tuchman, Slap, & Britto,

2008). The differing philosophies between pediatric and adult care stem from pediatric centres being guided by a family focused care approach whereas the adult centres are guided by a patient-care focused approach (Betz, 2013). This difference in approach can be problematic for young people when they are not ready to assume responsibility for their healthcare as expected in the adult centre, and for parents as they may feel they no longer have a formal role in their child's healthcare.

Others differences may contribute to young people and their parents viewing the adult healthcare system less favourably. Some describe the pediatric healthcare setting as family-centred where surroundings and relationships with staff are warm, familiar, cosy and trusting (van Staa et al., 2011). Prior to transition, the young person may have long standing relationships with the pediatric healthcare teams. Young people and their families experience feelings of loss and abandonment partly due to the loss of a trusting relationship with their pediatric providers (Fegran et al., 2014). These long-term relationships in pediatrics and their perceived importance to the quality of care can act as a barrier to young people engaging in the adult healthcare where they do not have long-term relationships (Rutishauser, Sawyer, & Ambresin, 2014). Moreover, the perceptions held by young people and their parents may also act as a barrier to transition as they perceive the adult providers as providing inferior care due to the patient-oriented philosophy (Tuchman, Slap, & Britto, 2008). Philosophical difference in the approach to care account for much resistance in the transition process (Tuchman, Slap, & Britto, 2008) and it is possible that the experience of transitioning to another healthcare clinician may have an even greater impact on the sense of loss for the young person with chronic pain because of the diagnosis process. While children and adolescents are being diagnosed with chronic pain they are subjected to numerous investigations and referrals to multiple health care professionals (Dell'Api, Rennick, &

Rosmus, 2007). Many times they face disbelief from healthcare professionals on their journey to a chronic pain diagnosis. Therefore leaving behind healthcare professionals who believe in their diagnosis may be difficult, as they may fear encountering disbelief in future encounters with adult healthcare professionals.

Access to services. Rapley and Davidson (2010) identified that patients from well-established, multi-service teams, such as cystic fibrosis, achieve better transition outcomes. They report that team transition is more formalized and established, whereas the transition for a patient without team support is more fragmented and may result in patients being lost in follow-up and unmet healthcare needs. Although young people with chronic pain who access care in an established pediatric chronic pain clinic in Canada receive care using an interprofessional approach there is limited research on the components of a transition process for this patient population. So, it is unclear if being followed by a team results in a positive transition process for young people with chronic pain in Canada. Often times, the young person with chronic pain is referred back to their general practitioner for their pain management. This is challenging for both the young person and their general practitioners as the young person who accesses care in an established pediatric chronic pain clinic in Canada generally receives care from physicians, psychologists, physiotherapists, and nurses with chronic pain expertise. The types of care include beginning and changing medications, increasing activity tolerance through physical therapy or routine exercise, and learning new cognitive-behavioural approaches to pain coping (Simons et al., 2010) and help with: parenting a child with chronic pain, coping with social challenges, and school support. General practitioners have identified barriers in meeting the psychosocial needs of their young adult patients as they may have insufficient knowledge in social resources, limited training in adolescent medicine, time limitations, and financial considerations (Peter et al., 2009).

Thus, despite having a pediatric interprofessional team involved in a young person's chronic pain care, they may experience gaps in health care needs being met when they transition to adult healthcare services.

In a study conducted by Simons et al. (2010), examining interprofessional interventions for chronic pain in children, complete adherence was observed when patients were asked to continue the psychological treatment with their current therapist. However in contrast, if they were referred to a new psychologist and/or new treatments were prescribed, adherence rates decreased with less than half the patients following through with the new recommended care plan. This finding would suggest that a change in psychologist could have an impact on chronic pain management especially if the young person is transitioned to a general practitioner for their psychological treatment. The potential negative impact of changing care providers was further identified in a quantitative study conducted by Helgson et al. (2013) in which they examined how self-care and glycemic control of type 1 diabetics changed over time as a function of physician group. They found that youth with prolonged treatment by the same pediatric providers had better self-care glycemic control compared to those whose healthcare providers changed. However accessing care from the same physician overtime may not be realistic for young people with chronic pain, as they transition into the adult healthcare system. Therefore the need for transition preparation is paramount and warrants further research.

Collaboration between healthcare providers. Principles suggested for successful transition have not been applied consistently among specialists, both adult and pediatric, and the level of communication required for transition between the two healthcare systems has been deemed inadequate (Suris, Akre, & Rutishauer, 2009). Patients and their families who face transition describe the adult healthcare setting as confusing, disease focused, disorganized, and

cold (Fegran et al., 2012; van Staa et al., 2011). Despite young people reporting efficiency as a benefit of adult system, they also indicate that they missed the nurturing setting of the pediatric system (Tuchman, Slap, & Britto, 2008). A warm welcome in the adult healthcare system along with open collaboration between the two systems has been identified as crucial to a smooth transition (van Staa & Sattoe, 2014). This is necessary for the young person to build a trusting relationship with the adult healthcare provider. Providing opportunities for young people to meet staff from the adult setting where they will access care (i.e. joint consultations with both the pediatric and adult clinicians) has potential to reduce anxiety, foster a relationship, and create positive transition experiences (Betz et al., 2015; Lugasi et al., 2010; Rutishauser et al., 2014). One factor associated with greater positive and seamless transition for young people is a closer relationship between the pediatric and the adult healthcare clinicians (Rapley & Davidson, 2010). Without a formal transition process between the pediatric and the adult healthcare teams, patients have been lost to follow-up, which results in them accessing healthcare when they are in crisis (Rapley & Davidson, 2009; Tuchman, Slap, & Britto, 2008). Additionally, without a formal transition process young people are reported to miss more appointments suggesting an increase in risk of disengagement in their healthcare (van Staa & Sattoe, 2014). Fragmented transition may contribute to poor health related outcomes, negatively impacting the lives of these young people and setting them back from achieving their optimal level of health. We do not know how young people with chronic pain in Canada experience transition and if they are at risk for disengagement when they are transitioned either to their family physician or to an adult chronic pain clinician.

Emotional attachment between pediatric patients and their healthcare providers is a significant barrier to transition (Fernandes et al., 2014). Pediatric patients are said to feel comfortable with the healthcare provider that in some cases have been following them for many

years. Ending this professional relationship has been described as difficult, not only for patients but for parents and pediatric healthcare clinicians (Fernandes et al., 2014; Rutishauer, Sawyer, & Ambresin, 2014). This is another reason that trusting relationships must be established with the accepting adult healthcare clinicians prior to full transition to increase the likelihood that the young person feels accepted and will continue to return for treatment (Rutishauser, Sawyer, & Ambresin, 2014). Meeting with the adult healthcare clinician may not always be a possibility but establishing a formal collaborative process, perhaps with the aid of technology, amongst the pediatric and adult pain clinicians as well as the young person and their family may be beneficial to improve transition outcomes. Research on innovative approaches for transition related collaboration are needed in the context of chronic pain.

Transition preparation. Transition preparation should start before the actual transition, which is why transition needs to be viewed as a process and not an event. By providing information and integrating transition strategies early on in a young person's pediatric care, pediatric healthcare providers can prepare the young person and their parents for transition. Approaching transition as a process allows clinicians to address transition concerns over time thereby reducing stress and increasing support for the acquisition of self-management skills (Rutishauser et al., 2014). A formalized, well-planned transition has been found to increase patient satisfaction, increase their feelings of empowerment, and increase their self-management abilities following transfer to adult care (Schwartz et al., 2014; Tuchman et al., 2008). In preparation and planning clinicians should include teaching patients about their condition, their treatment, and other issues pertaining to adolescence while encouraging them to be autonomous (Lugasi et al., 2010). However, formalized systems of transition care and programs are lacking to facilitate transition (Betz, 2013). Some pediatric facilities have created guidelines, however

transition has not been standardized across the country. Understanding more about clinicians' practices and health care programs in Canada that support young people as they transition from the pediatric to adult healthcare setting is warranted to help inform the design of formalized transition programs for this vulnerable population

Thesis Objective

The aim of this thesis is to understand the current transition environment for young people with chronic pain in Canada. This will be done in two separate studies. The first study will describe the transition programs and practices available to young people with chronic pain in Canada. The second will explore the transition experience of young people with chronic pain who have recently transitioned from the pediatric setting to the adult healthcare system from their own perspective. The findings from these descriptive quantitative and qualitative studies will provide insights into the transitional needs of this population and the available resources to meet these needs as well as inform interventions to improve transition outcomes. The research question of interest is as follows “ what is the transition experience of a young person with chronic pain into the adult healthcare system?”

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Chapter 3
Methodology

Method

Across methods triangulation was used to explore the pediatric to adult healthcare transition environment for young people with chronic pain in Canada. Across methods triangulation, also referred to as mixed methods, involves using different methods or methodologies to explore the same phenomenon (Polit & Beck, 2012). In this thesis a simultaneous across methods approach was used which consisted of conducting two studies at the same time. The results were analyzed separately and then integrated to provide a more comprehensive understanding of the phenomena, as the findings from each method are complementary (Casey & Murphy, 2009).

In this thesis one of the studies was a cross sectional descriptive online survey of nurses working in the chronic pain sector to understand the Canadian context in terms of nursing care practices, programs, and collaborations that support successful transition for these adolescents and young adults. The other study was a qualitative descriptive study using semi-structured interviews to explore the experiences of recently transitioned adolescents and young adults with chronic pain. By conducting two separate studies, a comprehensive analysis of the phenomenon of transition for young people with chronic pain was accomplished, as data were collected from both healthcare providers and young people informing recommendations for practice, education, policy and research. In the following sections, each study will be described separately.

Study 1: Nurses Practices and Setting Supports for Successful transition of Adolescents and Young Adults with Chronic Pain: A Descriptive Survey.

This study was a cross sectional descriptive online survey designed to capture Canadian nurses care practices and the system supports where they work to enhance successful transition of adolescents and young adults with chronic pain from pediatric to adult healthcare settings. A

survey of a broad population is a cost-effective approach to reach geographically dispersed respondents (Polit & Beck, 2012). Quantitative description is used to observe, describe, and document measurable attributes of a phenomenon (Polit & Beck, 2012) and survey approaches help to understand respondent's attitude, knowledge, and practice at a point in time (McPeake, Bateson, & O'Neil, 2014). In this study nurses care practices and system supports are captured to describe the current transition environment that adolescents and young adults with chronic pain experience in Canada. These findings will inform clinician care practices and health system supports to improve successful transition and outcomes for adolescents and young people with chronic pain. Approval for the study was granted through the Research Ethics Board at the University of Ottawa (Appendix A).

Sample and Setting

Nursing is the most diverse healthcare profession, and as a result, surveys of nurses are important tools in obtaining data on health policy and health services (VanGeest & Johnson, 2011) as well as their practices. A convenience sampling technique was used to recruit nurses who work in the chronic pain clinics across Canada to participate in the survey. Although this approach is limited by sampling bias, the phenomenon itself is experienced within the research population and therefore this approach was appropriate (Polit & Hulger, 1997). The sampling was specific to registered nurses (RN) and nurse practitioners (NP) who work in either the pediatric or adult chronic pain setting in Canada. Additionally this population of nurses is positioned such that they can answer questions on the healthcare system supports in their setting that aid or hinder successful transition. Participants were invited from both the private and public chronic pain clinics, as young people may transition to either of these settings to access chronic pain care.

The following were the inclusion/exclusion criteria for this study:

Inclusion Criteria:

1. Registered nurses who work directly with the chronic pain population (either pediatric or adult).
2. Registered nurses who work in Canada
3. Registered nurses who read and write English.

Exclusion Criteria:

1. Registered nurses who work with acute pain populations.

Recruitment

Potential participants for this study were recruited from the Yahoo Canadian Nurses Pain listserv. A listserv is an email list manager, which is an opt-in email list, and includes email newsletters, announcements, and discussion groups within an email community (Listserv, 2015). The Yahoo Canadian Nurses Pain Listserv is a closed email list, not open to the public, and is comprised of nurses who work in pain management across Canada. This email listserv is used to communicate and share information on clinical practice and evidenced based care. The administrator of this listserv (Dr. Mona Sawhney) approved the use of the listserv to recruit nurses to participate. Being a member of this list is free of charge and voluntary. An introductory email was sent to nurses who are part of the Yahoo Canadian Pain Nurse Listserv. This email briefly explained the purpose of the research study, contained the contact information for the principal investigator (PI) and her thesis supervisor (PF), and had the URL link to the study survey embedded within (Appendix B) (McPeake, Bateson & O'Neil, 2014). Two reminders were emailed three weeks apart (Appendix C) as reminders have a positive impact on the response rates (VanGeest & Johnson, 2011).

In conjunction with the email sent on the listserv, a poster (Appendix D) was posted on the PainHub, which is a website linked through the University of Ottawa. This website provides an opportunity for the public to view pediatric pain research initiatives taking place at the School of Nursing, University of Ottawa. The poster was also posted on social media, such as Kijiji to recruit as many nurses who work in the chronic pain field as possible. A link was embedded directly in the poster, identical to the link provided through the email (Appendix B).

Once the participant read the email and selected the link, they were directed to a three question screening process (Appendix E). If they were unsuccessful in passing the screening, a message thanking them for their time was automatically generated (Appendix F). Those nurses who successfully passed the screening and were interested in participating were then presented with an information and consent form at the beginning of the survey. This information and consent form (Appendix G) described the study, provided assurances of confidentiality, and outlined the benefits and risks of participating. The letter and consent, approved by the Research Ethics Board of the University of Ottawa, are found in Appendix A. Interested participants clicked the 'I agree to participate' icon to gain entrance to the survey. If they clicked the 'I do not agree to participate' icon they were presented with the same thank you message as mentioned from the nurses that did not pass the screening and they did not gain access to the study (Appendix F). The information and consent form was printable so they could have a copy for their records. The researcher posted the invitation to participate on the Yahoo Listserv, and then posted it a second time 3 weeks later and then a third time following 3 weeks. The data collection for the survey was completed in 3 months (Appendix D).

Data Capture

An online survey was used as this survey format has several benefits over paper surveys including; shorter response times, cost effectiveness, and adaptability in question design (Dykema, Jones, Piche, & Stevenson, 2013). Shorter response times are due to the fast accessibility to the survey and the submission time. As well shorter completion time, due to the use of branching logic and adaptable questions, is a particular advantage, as shorter surveys are more likely to be completed. This is particularly important factor in recruiting busy clinicians. Also, given that nurses are comfortable with both online and pen and paper surveys (McFall & Milke, 2007) an online survey method was chosen due to the geographical distances between the researcher and potential participant.

The survey was hosted on the Research Electronic Data Capture (REDCap) platform. REDCap is a web application for building and managing online surveys and databases (CHEO Research Institute, 2015). Access to this application was provided by the Children's Hospital of Eastern Ontario's (CHEO) Research Institute free of charge to researchers affiliated with CHEO (the primary investigator is a CHEO employee, the supervisor is an affiliated researcher in the CHEO Research Institute, and one of the thesis committee members has a joint appointment at CHEO).

The questions in the survey were pilot tested by the thesis committee members and two practicing nurses in the field of chronic pain. The two nurses that pilot tested the survey had experience working in the chronic pain setting; however, both currently work in acute pain. A combination of closed and open ended questions were based on suggested interventions identified in the literature that support a successful transition as well as demographic questions of the nurses and characteristics of the chronic pain clinic (Appendix H). For example, participants first

identified which province their clinic is located because transition protocols may differ between institutions and across provincial border (e.g. in Nova Scotia adolescents as young as 16 years of age are transitioned, in Ontario usually at 18 years of age). Then they indicated if they work in the private or public sector, followed by pediatric or adult healthcare setting. Branching logic was used so that participants' further questions were based on previous higher-level questions to decrease response burden. Web based surveys allow for greater ease in adaptability in their design (Couper & Miller, 2008). This survey examined the transition practice in both pediatric and adult healthcare settings. As the nursing practices in these settings with respect to transition are different, the survey itself was adaptable by asking different specific questions addressing transition processes. Web based surveys can be programmed to ensure that respondents are administered only the questions that are pertinent to them (Dykema et al., 2013). Branching logic allowed the participant to answer the questions that were specific to their care setting.

Finally, the data collected in REDCap was secured by CHEO Research Institute and hosted on CHEO Research Institute's server. After the completion of the study the results were downloaded in a printed report and will be kept in a secure locked cabinet for 5 years in the researcher's supervisor's office. The online version was permanently deleted from the CHEO Research Institutes server after data collection.

Upon completion of the survey a 'thank you for participating' email was sent to the participants to thank them for participating in the study (Appendix I).

Data Analysis

A descriptive synthesis of the data was conducted using both narrative descriptive categories for open-ended questions and descriptive statistics (e.g. means, frequencies) for closed ended questions. Descriptive statistics are useful for addressing research questions in studies that

are primarily descriptive (Polit & Beck, 2012). Presentation of the data describes the current transition environment in both the pediatric and adult healthcare setting and helps identify the gaps in transition care that would be amendable by intervention.

Data Management

Data collected from the survey was exported from REDCap into Excel or SPSS. From this point the data was managed offline. The data was saved on a password-protected computer and the encrypted password protected electronic file is being stored on Dr. Forgeron's University of Ottawa private server space for five years after the completion of the study. After the five years, Dr. Forgeron (the thesis supervisor) will permanently delete the file from her computer.

Anonymity of the participant was protected, as individual identifying features (e.g. their names or initials, name of their institution) were not asked, and emails of the nurses were not captured by the REDCap survey. However, this means that although participants had the right to stop participating at anytime we could not remove any of their previous data from the study (this was included on the consent form). As we were not able to connect their data to the participants names, all data was collated and reported as aggregated data in publications and presentations.

Risks and Benefits

This was a minimal risk study. However, some nurses may have felt distressed over their answers if they felt they were unable to meet the needs of their patient population due to resource and program limitations. Nurses had the opportunity to stop answering questions at anytime if they were distressed and were made aware that they could call Dr. Forgeron if they wanted to discuss their feelings. Dr. Forgeron is a registered nurse with over 30 years of experience and is recognized as an expert in the nursing care of adolescents with chronic pain (no nurses contacted

Dr. Forgeron). Additionally, if the nurses were distressed, as they may have been unsure of how best to support adolescents and young people with chronic pain in their transition from pediatric to adult health care systems the researcher would direct the nurse to the Canadian Pediatric Society where research and a transition position statement are available to provide information to best support this population.

Study 2: Exploring the Transition Experience of Adolescents and Young Adults with Chronic Pain from Pediatric to Adult Chronic Pain Services: A Qualitative Descriptive Study

Due to the paucity of literature on the transition experience of adolescents and young adults with chronic pain a qualitative approach using semi-structured interviews was employed in this study. Qualitative research is well suited for “how” questions about human behaviour, motives, views, and barriers (Neergaard, Olesen, Andersen, & Sondergaard, 2009). A qualitative descriptive design as described by Sandelowski (2000), was implemented to capture the experience of the participants in detail. Qualitative description is a useful method, particularly in healthcare, because it can focus on the experiences of patients, professionals, and/or their perceptions of patient-professional interactions and the organization of the health care system (Neergaard et al. 2009). Qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events (Sandelowski, 2000) and can provide insights into understudied phenomena (Pilot & Hungler, 1997).

Qualitative descriptive research generally uses a constructivist approach, which has the goal of understanding the world through human experience (MacKenzie & Knipe, 2006). From a constructive paradigm, realities are attained by multiple, intangible mental constructions, socially and experientially based, local and specific in nature and dependent on the individuals holding

the constructions (Lincoln & Guba, 1994). Qualitative descriptive studies present comprehensive summaries of an event and tend to be dynamic and multi-faceted when they are grounded in a constructivist inquiry approach (Polit & Beck, 2012). Thus, through the exploration of the experience of young adults with chronic pain who have transitioned from the pediatric to the adult health care setting their individual realities provide powerful insights into the needs of adolescents and young adults to support successful transition.

Sample and Setting

Adolescents and young people who have been transitioned from pediatric to adult chronic pain settings within the past three years were invited to participate. In the literature there have been studies examining patients with chronic illnesses and their families anticipating the future transition to adult healthcare, however, this study examined the transition experience of the young adults specifically with chronic pain. Participants who have already transitioned into the adult healthcare system are in a position to identify the outcomes of the transition as opposed to the anticipated experience. Recruitment was done through the following pediatric chronic pain clinics: Stollery Children's Hospital, Alberta, and IWK Health Centre in Halifax, Nova Scotia. These outpatient clinics use a similar approach to the care of children and adolescents with chronic pain: family centre care approach, each patient and family is seen simultaneously by the chronic pain inter-disciplinary team (e.g. nurse, physician, psychologist, physiotherapist), and ongoing support is offered to facilitate parent support, school re-integration, medication management, cognitive behavioural strategies, and physical therapy strategies to improve pain.

Purposeful sampling techniques were used which is advocated for in qualitative descriptive studies (Sandelowski, 2000; Polit & Beck, 2012), as the participants need to have experience with the phenomena under study. The sample size in qualitative studies is not

predetermined but is based on the depth and richness of the data, which is influenced by the scope of the study, nature of the topic, quality of the data obtained, and the study design (Morse, 2015). Sample sizes in qualitative studies collecting data through individual interviews can range from sizes of one to fifteen, and as a rough guide, six is suggested (Smith & Osborn, 2003). Nine participants were recruited and interviewed for the study.

The following were the inclusion and exclusion criteria for this study.

Inclusion

1. Adolescent or young adult who has transitioned within the last 3 years
2. Twenty-three years of age or less (to ensure that variations in age of transition from the pediatric healthcare to the adult healthcare system would allow for those who had transitioned as old as 20 but ensured it had not be longer than 3 years since the transition).
3. Currently accessing chronic pain care in an adult setting
4. Be able to converse in English or French

Exclusion Criteria

1. Pain from a potentially life limiting illness (e.g. ongoing cancer pain)
2. Cognitive impairment (e.g. developmental delay)
3. No longer experiencing pain

Recruitment and Consent Procedure

Ethics approval for the study was granted from the following ethics boards: the Stollery Children's Hospital, University of Ottawa, and IWK (Appendix J, Appendix K, Appendix L). The participants for the study were recruited through the chronic pain clinic at the IWK, and the Stollery Children's Hospital by having the study introduced by clinicians who have had previous

relationships with the potential participants (clinicians who were part of their circle of care). This was accomplished by sending the invitation letter to former eligible Stollery Children's hospital patients (Appendix M) and former eligible IWK patients (Appendix N). The letter contained a brief description of the study and the contact information (e.g. phone number, email, mail address) for the principal investigator (PI), and her thesis supervisor (PF). Participants were asked to contact one of these two individuals (PI or PF) if they were interested in more information about the study.

Additionally, to reach a broad group of adolescents and young adults who have transitioned from pediatric chronic pain health services to adult health services community advertising was also conducted as there was the potential that previous patients may have moved and therefore the letter would not have reached them; Stollery Children's Hospital (Appendix O), University of Ottawa (Appendix P), and IWK (Appendix Q). Community advertisement strategies included such methods as local post boards through the Internet such as Kijiji and postings on websites such as the UOttawa Pain Hub and the Centre for Pediatric Pain. These advertisements briefly described the study, the target population, and the voluntary nature of the study as well as the contact information for the PI and her supervisor. The posters asked interested individuals to contact the investigators for more study and consent information.

Along with the invitation letters, consent forms adhering to the specifications of each institution; Stollery Children's Hospital (Appendix R), University of Ottawa (Appendix S), and IWK (Appendix T) were sent to those who contacted the researchers. Documents were sent either by email or post based on participant preference. The researcher followed up by either email or phone (based on participant preference) 5 days after sending the information and consent form to answer any questions and seek confirmation of their interest in participating in the interview and

if so arrange a time to conduct the Skype interview or in person. Given the age range of potential participants (17-23 years of age) they are able to consent for themselves. The interviewer used the verbal consent script to obtain consent during the meeting but prior to beginning and recorded with permission, and later transcribed (Appendix U). Participants were reminded that they were under no obligation to participate in the study, and that they could have withdrawn from the study at any point.

Data Collection

Semi-structured individual interviews provided a method to collect data that facilitated an in depth understanding of the participant's experience. Through semi-structured individual interviews participants with chronic pain were able to acknowledge experiences or issues with their transition that were significant to them. The interviews used a combination of close-ended and open-ended questions (Sandelowski, 2000). The closed-ended questions were used to capture demographic type questions (i.e. age of the onset of pain, age they were transitions, age now, where they receive their pain care). The open-ended questions were used to provide participants with the ability to emphasize the important issues from their transition experience. The researcher prepared an interview guide (Appendix V), which was a list of topics or questions that needed to be covered during the interview (Polit & Beck, 2012). The interview guide was informed by Meleis' transition theory and focused on the transition experience from the pediatric healthcare setting to the adult healthcare setting. However due to the open-ended nature of the questions the interview was flexible to allow participants to discuss the transition experiences of importance to them. The interviews were audio recorded and transcribed. Additionally, field notes of the interviews were written. Field notes are the researchers impressions about the participants and the interview that were helpful during analysis (Polit & Hugler, 1997).

Method of Interview

Videoconferencing was used to conduct some of the interviews due to the geographical distances between the researcher and potential participants. Videoconferencing is an acceptable alternative to face-to-face interviews and may be superior to telephone interviews as it allows the researcher to be observant of nonverbal cues and alter questions or attempt to clarify what they are observing (Hamilton, 2014). Videoconferencing is convenient for participants (they do not have to travel) and enables a more personal relationship between researcher and participant, as it closely resembles a face-to-face interview (Hamilton, 2014). In 2012, 83% of Canadian households had access to the Internet, which is an increase from 79% in 2010 (Stats Canada, 2013). In 2009, 75.1% of Canadians under the age of 34 used the Internet daily. In 2014, more than 80% of people in Canada 18-34 years of age have reported using a smartphone device (eMarketer, 2015). The age range of the participants for this study facilitated the use of videoconferencing for this study as there was a high likelihood that this population had experience using Internet based communication technology.

Skype software was used to interview participants from a distance. Skype is available to download from the Internet and is free of charge to the participant and the researcher (Deakin & Wakefield, 2014). Skype software has greater national and international recognition than other online software applications (Deakin & Wakefield, 2014). It provides a variety of communication options, including audio and video calling. Possible barriers to this method of interviewing include participant's having a degree of discomfort of being on camera, which could distract from the interview (Deakin & Wakefield, 2014; Hamilton, 2014), and technology literacy. However issues of technology literacy are more dependent on age and young adults and adolescents may find using the Internet second nature (Hamilton, 2014). Nevertheless, if the participant identified

that they did not feel comfortable at anytime during the interview or if there was technical difficulties (e.g. insufficient bandwidth), the researcher was prepared to continue the interview via telephone if this was acceptable to the participant (at no cost to the participant). Although one can record video as well as audio during Skype calls the researcher only recorded the audio of the interviews and these were transcribed for analysis. To ensure ease with the use of Skype, when potential participants contacted the researcher (or supervisor) expressing interest in participating the researcher determined if the participant had used Skype in the past and/or their comfort with technology and being interviewed on camera.

Data Analysis

Qualitative inductive content analysis was used to analyze the data. Qualitative inductive content analysis allows for a condensed yet broad description of a particular phenomenon, through the use of concepts and categories (Elo & Kyngas, 2007). The knowledge generated from qualitative content analysis is based on the participants' unique perspectives and grounded in the actual data (Elo & Kyngas, 2007). The benefit of using this approach was that given the limited research on pediatric to adult health care transition for young people with chronic pain insights into the phenomenon of the transition from the experiences of those most affected (adolescents and young adults) were obtained without imposing preconceived categories or perspectives.

Reflexivity was used to identify awareness of the researcher's values, background, and previous experience that can affect the research (Cope, 2014). Reflexivity entails continuous evaluation of subjective responses, inter-subjective dynamic, and the research process itself (Finlay, 2002). By maintaining a reflexive journal, the researcher was able to bracket perceptions and subjectivity in the hope to remain neutral (Cope, 2014). During the study the PI maintained employment at the CHEO as a RN and member of the Community Discharge Planning Team.

Working for the Community Discharge Planning Team means that she coordinates and supports the transition of patients and families to home. Therefore the researcher has an understanding of the transition process, although not the same transition as the focus of the study. By keeping a reflective journal the researcher was able to question her interpretations of the data to ensure that they remained grounded in the data.

Qualitative descriptive research is characterized by the simultaneous collection and analysis of data whereby both mutually shape each other (Sandelowski, 2000). Therefore, after the first interview the researcher met with her thesis supervisor to discuss the findings (both the interview and the field notes) to determine if and what type of changes may be required in the semi-structured interview guide. This open dialogue between the researcher and thesis supervisor continued throughout the data collection phase and added another format through which to maintain reflexivity. Once each interview had been conducted a professional transcriptionist was employed to transcribe each interview verbatim. To begin the process of analysis the researcher immersed herself into the data by reading each interview as it was received while listening to the audio files to ensure accuracy of the transcription. By rereading and listening to each transcript gave her a clear understanding of its content (Elos & Kyngas, 2007). An inductive approach moves from the specific meaning to the general categories to help understanding of the phenomena. As it is an inductive approach the categories were determined upon examination of the data and were not determined *a priori*. Generating meaning was done by organizing the qualitative data using three methods; open coding, creating categories, and abstraction (Elos & Kyngas, 2007).

Open Coding

The PI began by open coding the transcripts. This technique is when the PI read through the transcript and identified headings (codes) and made notes directly on the document. In this study, the PI highlighted and identified exact words in the text that captured the key concepts and thoughts of the participants (Hsieh & Shannon, 2005). As many headings (codes) as possible were determined and written down in the margin (Elos & Kyngas, 2007). After the first two transcripts had been coded a code list was developed and reviewed with the PF. This list was used to help code the remaining interviews. A plan was made to add new codes to the list if they emerged in subsequent interviews and previously coded interviews would be reviewed to ensure that the code did not apply. However, this was not required.

Categories

Once the codes were identified, they were categorized. Determining categories is a main activity of qualitative content analysis (Graneheim & Lundman, 2004). Codes are collapsed into categories by determining how a broader descriptive level of content fit the data (Graneheim & Lundman, 2004). During the process of refinement no data was excluded because it falls between two categories or fits into one or more categories. These categories (and the direct quotes, exemplars, that support these categories) were further refined to reflect patterns of behaviour that are relevant to the study as described in the interviews (Polit & Beck, 2012).

Abstraction

The researcher then used abstraction to compile the data together. Abstraction is the general description of the research topic through generating main categories (Elo & Kyngas, 2007). Through an analysis of how the categories string together, an understanding of the experience of transition for young people with chronic pain was described using these main

categories. Each main category name was constructed from the content-characteristics of data (Elos & Kyngas, 2007). The thesis committee reviewed the identified main categories to ensure that they were grounded in the data.

Quality (Rigor)

Within the qualitative research approach rigor is assessed by the concept of trustworthiness, which includes credibility, transferability, dependability and conformability (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Credibility

Credibility is the element that allows the consumer of researcher to recognize the experiences of the participants contained within the study through the analysis and interpretation of the researcher (Thomas & Magilvy, 2011). Lincoln and Guba (1985) describe credibility, as the degree of confidence in the findings that the researcher inspires in the reader. Strategies to improve credibility include; prolonged engagement, persistent observation, and triangulation (Lincoln & Guba, 1989). In this study the strategy of immersing oneself in the data was used. The researcher conducted all the interviews, reviewed the transcripts while she listened to the recordings for accuracy, and then she re-read the transcripts several times to be immersed in the data.

Dependability

Dependability is achieved when the researcher accounts for the alterations in the researchers decision during the analysis process (Guba & Lincoln, 1989). Interviewing and observing are evolving processes where the researcher acquires new insights into the phenomena, which influenced the subsequent interviews or observations (Graneheim & Lundman, 2004). The researcher maintained an audit trail to remain transparent to the reader as to how decision were

made in the direction and focus of the subsequent interviews, and the changes in the analysis process. Strategies to maintain dependability that were used in this study include; describing the audit trail; describing the specific purpose of the study; discussing how and why the participants were selected for the study; explaining how the data was reduced for analysis; discussing the interpretation and presentation of the research findings; and communicating the specific techniques used to determine credibility of the data (Thomas & Magilvy, 2011).

Confirmability

Confirmability is when a study reflects responses of participants and no one voice is dominate (including the researchers voice) (Cope, 2014; Polit & Beck, 2012). Reflexivity was used to help the researcher identify where her own bias was overshadowing the voices of the participants. The thesis supervisor and committee members were included in the analysis by having them review the preliminary description of the main categories and sections of accompanying quotes. This ensured that the analysis is grounded in the data. The strategy to enhance confirmability was through the audit trail and triangulation (Guba and Lincoln, 1989).

Transferability

Transferability relates the extent to which findings may have application to different settings (Graneheim & Lundman, 2004; Twycross & Sheilds, 2005). Guba and Lincoln (1989) and Thomas & Magilvy, (2011) suggest that thick description is essential for a reader to transfer the original findings into another context. In this study the description entails a description of the chronic pain clinical setting (both the pediatric chronic pain setting that they once attended and the adult chronic pain setting that they now attend), the unique participants characteristics (e.g. age of pain onset, type of community where they live—rural or urban, gender, present age), context for the interview (e.g. Skype), data collection (e.g. semi-structured interviews), and data

analysis (e.g. inductive content analysis) (Graneheim & Lundman, 2004). Additionally, a rich description of the participants' experiences of transition with the use quotes to support the main categories will aid the transferability of the findings. As this was a multi-site study, the transferability is further enhanced as the participants may have differing treatment pathways but the same underlying common experience.

Confidentiality and Data Management

The privacy of the participants was maintained. Several steps to assure confidentiality were taken. The interviews that were conducted over Skype could have had an increased risk to confidentiality if the participant was to engage in the interview from a public location. Therefore, the PI allowed the participant to decide when and from what computer the interview was to be conducted. When the PI conducted, the interviews face-to-face were held in a private room. When they were over Skype, the PI was in a private room with a closed door and no one else was present. The identifying information in the data was removed (e.g. their names and those of others mentioned in the interview will be removed during transcription). Each participant was given a study number to link them to their data, and their personal identifying information was removed prior to transcribing. A transcriptionist was used to transcribe the data. The transcriptionist signed a confidentiality agreement (Appendix W) provided by the researcher. This document indicated that the transcriptionist would: removed the names of the participants from the transcripts; not disclose any information outside the study except for the PI or PF; not make copies of the transcribed information; and dispose any notes taken during the transcribing process. Lastly, the transcription confidentiality agreement indicated that the transcriptionist would delete any electronic data stored on her computer after transcription was completed and Ms. Higginson has received the transcript. All electronic data was encrypted and password

protected. Verbal consent forms and paper documents pertaining to this study are kept in locked cupboard in Dr. Forgeron's locked private office at the University of Ottawa for 5 years in compliance with the regulations for the ethics boards. Digital data (audio recordings, electronic files of the transcripts) are being kept on Dr. Forgeron's password protected University of Ottawa private server space. These files are also be encrypted and password protected and will be kept for 5 years. All paper and digital files will be destroyed (shredded or permanently deleted) at the end of the 5-year period.

Benefits and Risks

Benefits to the study are that the participants had the opportunity to contribute to research. This research has the potential to inform strategies to help future adolescent patients with chronic pain prepare for transition from pediatric to adult healthcare services for their chronic pain needs.

This was a minimal risk study. There was the potential for participants to become distressed speaking of their transition experience. If the participants expressed distress during the interview the plan was for them to be referred to Dr. Paula Forgeron (thesis supervisor) or Dr. Bruce Dick (committee member) for debriefing. Dr. Forgeron is a registered nurse with over 30 years of experience and has over a decade of direct clinical experience with this patient population. Dr. Dick is a registered pediatric psychologist, is an internationally recognized expert in pediatric and adult chronic pain with extensive experience working this patient population. None of the participants expressed distress in taking part in the study.

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Chapter 4

Moving On: Transition Support for Young Adults with Chronic Pain in Canada

A Quantitative Descriptive Study

Authors:

Andrea Higginson RN BScN, BA, MScN (student)
University of Ottawa

Paula Forgeron RN MN PhD
University of Ottawa

B. Dick, PhD, R Psych
Stollery Children's Hospital
University of Alberta

Denise Harrison RN PhD
University of Ottawa
Children's Hospital of Eastern Ontario Research Institute

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Abstract.

Purpose: To describe the current clinical practices used in the pediatric and the adult healthcare setting to support transition of young people with chronic pain in Canada.

Materials & Methods: An online survey was constructed based on best practices for transition. Using branching logic, the survey was divided into two separate sets of questionnaires: one for nurses working in pediatrics and one for nurses working in adult healthcare settings.

Results: Twenty-two nurses completed the survey; 10 (45.5%) from the pediatric chronic pain setting and 12 (54.4%) from the adult chronic pain setting. Of the pediatric nurses surveyed none used a psychometrically valid tool to assess young people for transition preparedness however one used a tool to assess their understanding of chronic pain. Most of the healthcare facilities in which these pediatric nurses worked offered a non-specific transition clinic but only one of these facilities also had a specific chronic pain transition clinic. The nurses who worked in the adult setting perceived transitioned young people as not prepared to navigate the adult healthcare system. Nurses in both settings reported that young people experience increased levels of stress and anxiety around the time of transition.

Conclusion: Current nursing practices for transitioning young people with chronic pain requires formal care practices such as the use of psychometrically validated tools to assess transition preparedness, strategies to help young people gain knowledge and skills in self-management, and increased collaboration between the two systems. Research is needed to determine transition needs of young people with chronic pain.

Key words: *transition, chronic pain, young adults, adolescents, young people, healthcare system*

Introduction

One in five children and adolescents in Canada experience chronic pain (1)(2)(3)(4) and a significant portion will continue to experience chronic pain into adulthood (5)(6). However, transition from pediatric to adult chronic pain services has unfortunately not been a primary focus of research. Yet, without a coordinated and informed transition, young people with chronic illness are at risk for negative psychological and physical consequences (7) as well as a loss to follow-up, which can result in unnecessary crisis presentations to hospital emergency departments (8)(9)(10). Although there is a growing body of literature on the components, processes, and outcomes of transition for young people (adolescents and young adults) with other chronic illnesses (7)(11)(12)(13) findings may not be transferable to the pediatric chronic pain population due to the unique challenges of chronic pain (i.e., stigma and disbelief of chronic pain, individuality of pain and pain treatment, lack of formal chronic pain education for non-pain clinicians). Additionally, individuals with chronic pain report a lower quality of life than those with most other chronic illnesses (14), which could be further reduced by uncoordinated transition practices. It is therefore imperative to determine effective transition strategies for young people with chronic pain to mitigate associated negative transition outcomes.

In 2016, the Canadian Association of Paediatric Health Centres (CAPHC) published guidelines to support the transition of pediatric patients to adult care (15). These guidelines included three main components; person or patient centered care, clinical approach, and system level recommendations. The aim of the guidelines was to influence transition at the person and clinical level, affecting change over time on a systems level. Most importantly, the guidelines identify the need for collaboration between all stakeholders and promote the use of tools and resources for transition as strategies to promote the successful transition of the pediatric patients

with special healthcare needs. Although these guidelines are not specific to those with chronic pain and thus may not meet all their transition needs, they do provide a foundation on which to build.

There are at least three main major factors that may act as barriers or facilitators to a successful transition for young people with chronic illness. They include: the importance of independence to the adolescent or young adult, the shift in parental role, and the difference between healthcare systems (16)(17)(18)(19). According to CAPHC (2016) a “one size fits all” transition is not possible (15). Transition supports need to be individualized, coordinated, and be a collaborative process between the young person, family, and the pediatric and adult care providers occurring over time and spanning both adolescence and early adulthood (20). The guidelines are to influence change and provide recommendations on transition from a person centred, clinical, and systems level approach. Therefore specific strategies and supports for healthcare transition of young people with chronic pain are not included.

Although healthcare transition requires support from all clinicians who work with young people and their families, nurses in particular can play a pivotal role in facilitating a positive transition experiences. Nurses are key clinicians on the interprofessional team who collaborate with others to assess and partner with patients and families to manage the effects of chronic pain and nurses coordinate much of a young person’s chronic pain care. Therefore, nurses are in a unique position to assess and prepare patients and families for transition as well as continue to support the young person and their family’s adjustment to the adult healthcare setting post-transition. Psychometrically validated clinical tools have been developed to help determine transition preparedness for young people with chronic illness. These tools advance the measurement of transition readiness and are essential to better understand the interventions that

are necessary to enhance the likelihood of engagement in the adult healthcare system (21).

However, tools specific for the chronic pain population have not been developed and therefore it is unclear if the tools that exist fully assess all the factors that may present challenges to a young person with chronic pain as they approach transition. Individual patient transition-related factors that require assessment are; the age of the young adult, disease knowledge, self-efficacy of the young person, executive functioning, and autonomy (7). Parents or family members also need to be prepared for transition by focusing on their ability to support their child's growing capacity to manage their chronic pain and navigate the adult healthcare setting. As parents and guardians have been the primary care providers, a shift in health management responsibilities must take place for a successful transition. Parents should also be supported to focus on strengths and abilities of the young adult to develop positive, realistic and developmentally appropriate expectations of the transition (22). Although there are similar transition readiness factors for all adolescents and young adults who face transition, those with chronic pain may require additional assessment as chronic pain can have a negative impact on developmental trajectories as children and adolescents with chronic pediatric pain experience significant disruption to their activities of daily living such as going to school or socializing with friends (23).

Despite the recognized need to have a planned process for transition (24), there is little guidance on best practices for nurses working with young people with chronic pain and their families to support a successful transition. Moreover, guidelines geared towards nurses who work with recently transitioned young people with any form of chronic illness in the adult settings are lacking. Therefore, the purpose of this study was to gain an understanding of the current nursing care practices and clinic supports available in the pediatric setting pre-transition and in the adult setting post-transition for young people with chronic pain and their families in Canada. This

understanding will help identify gaps in care that can be used to design and test strategies to improve the healthcare transition of this population.

Method

This study was a cross sectional descriptive online survey designed to capture Canadian nurses' transition care practices for adolescents and young adults with chronic pain and their parents along with their workplace system resources to support their practice. The survey was hosted on the Research Electronic Data Capture (REDCap) platform. Access to this survey platform was provided by the local university affiliated children's hospital. Given that nurses are comfortable with both online and pen and paper surveys (25) an online survey method was chosen due to the geographical distances between the researcher and potential participants. Additionally, in comparison to paper surveys, online surveys allow for shorter response times, cost effectiveness, and adaptability in question design (26). The shorter response times were due to the fast accessibility to the survey, the use of branching logic and adaptable questions, and immediate submission time. This is a particularly important factor in recruiting busy clinicians.

Participants

A convenience sample of nurses who work in chronic pain clinics across Canada was recruited to participate in the survey. Nurses were the focus of the study as they are in a position to answer questions regarding health system supports in their setting that aid or hinder successful transition. Participants were recruited using several advertising approaches. One approach was posting the study on the Yahoo Canadian Nurses Pain listserv. A listserv is an email list manager, which is an opt-in email list, and includes emails newsletters, announcements, and discussion groups within the email community (27). The Yahoo Canadian Nurses Pain Listserv is a closed email list and is comprised of nurses who work in the both pediatric and adult acute or chronic

pain management across Canada. In conjunction with posting the online survey on this listserv, public posters were posted on faculty websites, as well as disseminated through social media. The survey was posted in major cities across Canada via an online classified advertisements website. Participants were invited from both the private and public chronic pain clinics, as young adults may transition to either of these settings to access chronic pain care. The inclusion criteria for the study were: 1) participants must be a registered nurse (RN) or Nurse Practitioner (NP) providing care in a chronic pain setting in either an adult or a pediatric setting and 2) could read and write in English. Exclusion criteria were: 1) RNs or NPs who worked solely within the acute pain setting; 2) RNs or NPs who worked outside of Canada.

Measures

There are no standardized measures to capture nurses' transition care practices in the chronic pain setting. Therefore a study specific questionnaire was created based on the transition literature, published guidelines on best healthcare transition processes, and informed by the nursing model on transition developed by Schumacher and Meleis (1994). Based on this mid-range nursing theory, adolescents and young adults with chronic illnesses (such as chronic pain) experience two different types of transition when they are leaving the pediatric health care setting: developmental and situational (28).

Developmental transitions are described as moving from one stage of life to another, such as infancy to toddlerhood or adult to geriatric. Adolescence is one such developmental transition within this theory and is characterized by increased self-identity and independence. This developmental transition is also mirrored in the changes and responses in their parents' role (29).

Situational transitions are described as changes to roles and relationships that occur due to relocation (29), such as the changes to roles and relationships such as those experienced by an

adolescent or young adult with chronic pain and their healthcare provider as a result of the change in healthcare delivery services when they leave the pediatric health care setting and enter the adult healthcare setting healthcare. Despite the diversity in these transitions, inherent in both transitions is role acquisition, role loss, or the simultaneous loss of one role and gain of another (29). Thus, developmental and situational transitions informed the development of the questionnaire for this study.

The online survey allowed for the use of branching logic, which is when the response to a question will influence what questions will follow, thus nurses who worked in the pediatric setting were only presented with pediatric healthcare specific questions. The same process was used for adult nurses ensuring that adult nurses were only presented with adult healthcare specific questions. The questions in both the adult and pediatric versions of the survey were pilot tested by the thesis committee members and two experienced and practicing nurses in the field of chronic pain (one adult RN and one pediatric RN). Minor modifications to wording were made as a result of the pilot testing.

Demographics

Three questions were asked to all participants to confirm eligibility prior to gaining access to the survey (participant was a RN or NP practicing in the chronic pain setting, practicing in Canada). Participants had to click yes to these three questions to gain access to the information and consent form. Participants then had to click yes to agreeing to participate to gain entrance to the survey. If participants said no to either of the eligibility questions or no to agreeing to participate they were immediately redirected to a thank you page and were unable to gain access to the survey. All consenting participants were asked demographic questions including province of employment, practice setting (pediatric or adult healthcare). Once those questions were

answered, branching logic embedded in the survey directed them to either the pediatric or adult focused survey.

Pediatric Setting

All participants who identified that they worked with pediatric chronic pain patients were asked to answer 20-25 questions, based on the branching logic, using a combination of dropdown menus and open-ended text. These questions captured information about their transition practices such as the age at which they transition young people to adult programs, if they engaged in transitions discussions with patients and parents, if patients attended appointments (or portions of appointments) on their own in preparation for transition. Next, a series of seven questions designed to capture nurses' healthcare transition assessment practices were asked. This series of questions included such questions as how they assess young people and parents for transition preparedness (including the young person's understanding of chronic pain); how they assessed the young person's self-management abilities, and ability to manage in the healthcare context. The four questions that followed tapped into the nurse's use of formal and informal supports (such as use of transition clinics, and parental role during transition). The next two questions captured the participant's perception of the adolescent's psychological health (increased stress, anxious behaviours or depressed mood) at the time of transition. Finally, the participant was asked an open text question to provide their suggestions on how to improve transition.

Adult Healthcare Setting

The questions for nurses who work in the adult healthcare system followed a similar process as those for the pediatric nurses in that they used branching to capture their care practices and system processes and resources to support their transition practices. The first question asked the type of chronic pain clinic they worked in, publically or privately funded as not all

adolescents and young adults were necessarily transitioned to adult publically funded chronic pain clinic and therefore could access care privately. The second series of questions were designed to capture data on policies that governed access to the clinic's care to help determine if a formal collaborative approach to the transition of the pediatric patients was in place (e.g. minimum age of patients, existence of formal transition clinics, process for referrals from the pediatric setting). The next five questions focused on practices surrounding the consent for the inclusion of parents or guardians in the adult health care setting chronic pain clinic (e.g. acceptance of parents attending the appointments with the young person, acceptance of parents making appointments, or asking for refilling prescriptions). The next series of questions were designed to capture the nurses' perception of ability of young people with chronic pain to navigate the adult healthcare setting and participate in self-management. Similar to the question format for the nurses who worked in the pediatric setting, answers to higher-level questions would direct participants to further questions. For example, if they responded yes to having resources in place to support newly transitioned young adult patients, more specific questions on the types of support available were asked (e.g. existence of support groups, average age of people in the support groups, after hours availability). Similar to the pediatric nurse participant questions, two questions directly asked the adult healthcare nurses about their perceptions of the newly transitioned patient's mood (level of stress, anxious behaviours and or depressed mood). At the end of the survey, participants were asked an open-ended question to provide further information regarding their beliefs related to transition issues for adolescents and young adults with chronic pain seeking care in the adult healthcare system.

Ethics

Ethics approval was obtained from University of Ottawa Research Ethics Board. This was an anonymous survey; links to users identification (e.g. IP—internet protocol—addresses, names or initials of users) were not captured.

Data Analysis

A descriptive synthesis of the data was conducted using both narrative descriptive answers (for open ended questions) and descriptive statistics (e.g. means, frequencies) for closed ended questions. Descriptive statistics are useful for addressing research questions in studies that are primarily descriptive (30). This analysis approach provided an understanding of the current transition environment in both the pediatric and adult healthcare setting to enable identification of the gaps in transition care that are amendable to intervention. The results are presented below in two sections; one synthesizing the results from pediatric nurse participants and the other synthesizing the results from the adult nurse participants.

Results*Demographics*

Twenty-two registered nurses who work in the chronic pain setting provided consent for the study. Ten (45.5%) participants worked in the pediatric setting and twelve (54.4%) reported working in the adult healthcare setting. However, not all participants answered all questions. Nine out of the ten pediatric nurses completed the entire survey and the tenth nurse only consented to the study but did not complete the survey. Twelve nurses providing care in the public adult healthcare setting completed the screening questions and provided consent, but only nine completed any part of the survey. No participants reported working in the privately funded sector. There are approximately 180 RN's or NP's across Canada registered to the listserv,

however it is difficult to know whether they work in the acute or chronic pain field or the pediatric and adult healthcare setting. However, at the time of the study there were only 10 pediatric chronic pain clinics in Canada. The nurses that responded from each province are as follows; British Columbia (n=1), Alberta (n=3), Ontario (n=12), Quebec (n=1), and Nova Scotia (n=4). This question was asked pre-branching logic questions to ensure that they practiced in Canada and therefore the distribution of province and setting is not possible.

Pediatric Setting

All of participants (n=9) responded that they have a discussion with the adolescents in their clinic about transition. However, the participants varied in their responses to which areas were assessed for transition preparedness, such as the adolescent's ability to self-manage, ability to understand their disease, understand medication, and ability to advocate for themselves. Seven of the nine nurses who responded, assessed the adolescent for transition preparedness using informal assessment practices during a routine clinic visit. Nurses were least likely to assess an adolescent's ability to navigate the healthcare environment (e.g. make their own appointments, have their medications filled), with only 5 of the 9 respondents indicated they that they assessed this area of transition preparedness. None of these respondents used a formal set of questions to assess this area of assessment. The most frequently assessed area of transition preparedness was the adolescent's understanding of chronic pain with all respondents reporting that they conducted this area assessment and the majority (7 out of 8) of nurses using a formal set of questions to conduct this assessment. See Table 1 for assessment of transition preparedness details.

Insert Table 1 here

Most of the participants (n=6) identified that their healthcare facility has a transition clinic that they could refer the adolescent to for transition assessment, however only one participant

indicated that they had a formal chronic pain transition clinic with adult healthcare providers. In terms of resources to help with transition (i.e., support groups, after hours telephone support) for the adolescent and their parent(s) or guardians, the majority of the participants (n=8) indicated that those additional supports were not available. Moreover, the majority of participants (n=6) identified that they did not provide literature to the patient and family on transition. In terms of collaboration between the two healthcare systems, the majority of the pediatric nurses (n=6) indicated that their transition process consisted of sending a letter to the adult chronic pain physician from the pediatric physician and interdisciplinary team, as well as a follow-up phone call to the adult chronic pain team. In addition to the collaboration between pediatric and adult healthcare providers, few participants (n=3) identified that they had a final face-to-face meeting to complete transition. Please see table 2 for pediatric system supports.

Insert Table 2 here

Adult Healthcare Setting

Most of the nurses (7 out of 9) who identified as working in the adult healthcare setting indicated that the chronic pain clinic where they worked accepted patients referred from pediatric chronic pain clinics. The other two adult nurse participants were unsure if their patients were transitioned from a pediatric chronic pain clinic. Of the participants who reported caring for transitioned patients, a few (n=3) identified a formal collaboration between pediatric and adult healthcare providers of members of the multidisciplinary teams (physician, registered nurse, psychologist, and physiotherapist). One participant identified that they did not contact the pediatric clinicians, as the patient would arrive for their first appointment with a written copy of their medical history from the pediatric chronic pain physician. See table 3 for the adult chronic pain nurses' transition processes and procedures.

The majority of participants (n=8) in the adult healthcare setting reported that they did not obtain formal consent from patients to allow parents or guardians to attend the appointments with adolescent or young adult patients, however 4 out of the 9 participants reported that the facility would obtain a formal consent when it came to sharing information with the parent or guardian. Despite acquiring a formal consent, the majority of respondents (n=7) identified that they would include parent(s) or guardian(s) in the first and concurrent appointments, 6 out of the 7 identified that the parent or guardian was only included for part of the appointment. In terms of healthcare navigation, such as calling for appointments, and refilling prescriptions, the majority (n=6) reported that they would allow parent(s) or guardian(s) to perform these tasks (n=8), however most (n=6) noted that this would require consent. Please see table 4 for parental involvement after transitioning to the adult healthcare system.

Insert Table 4 Here

In terms of transition preparation, most of the participants perceived that the patients were not prepared for the adult healthcare setting, and none of the adult chronic pain nurse participants reported the ability to offer supports to the transitioning patients after clinical hours. The majority (n=7) of the adult chronic pain nurse participants indicated that support groups for patients with chronic pain were available at the clinic where they worked however; the average age of the support group attendees was between 40-50 years of age, and only 2 out of 9 participants identified the availability of a support group for young adults. Only 4 of 9 participants identified that they had the ability to provide further supports in terms of assistance in securing school or work accommodations. For these four participants, they supported the newly transitioned patient in securing accommodations by providing a letter or telephone call to the appropriate institution

(i.e., employer or university). Table 5 summarizes adult healthcare nurses' perceptions of patients' transition preparations and provided supports.

Insert Table 5 here

Perceived stress and anxiety

The majority of participants from both the pediatric and adult healthcare setting identified that patients experience an increase in stress levels (including perceived anxiety) around the time of transition. All of the pediatric nurse participants believed that adolescents and young adults experienced an increase in anxiety prior to transition, whereas 4 out of the 9 adult nurse participants believed that newly transitioned young people experienced an increase in stress and or anxiety. The other 5 adult nurses reported that they were unsure if their newly transitioned patients experienced an increase in stress or anxiety as a result of transition. A summary of reasons given for why young people may experience an increased level in stress and or anxiety as a result of transition are found in Table 6.

Insert Table 6 here

Discussion

This study explored the transition practices of pediatric and adult nurses who are involved in the care of adolescents and young adults with chronic pain. Despite research indicating that successful transition is a process and that poorly planned and executed transition can lead to negative health outcomes (e.g., loss to follow up, increase use of emergency departments for health management) formal transition processes for young people with chronic pain across Canada are early in their implementation, as the guidelines from CAPHC were only released in 2016. Nevertheless, adolescents and young adults with chronic pain need to be prepared and supported during the transition process. The majority of the pediatric chronic pain nurses who

participated in this study reported that they informally address transition with their patients. Informal transition, although well intended, may result in varying practice between and within clinics meaning that not all young people with chronic pain benefit from best practices. For example, although the majority of pediatric nurses in this study informally assessed patients with chronic pain for transition preparedness, they do not use a psychometrically validated tool to accurately determine if the young person is prepared. However, two psychometrically validated self-report tools (TRANSITION-Q and Am I ON TRAC) have been identified by CAPHC (2016) as appropriate for assessing health related knowledge, self-efficacy, and skills for transition (15). These tools could improve transitional care as gaps in transition knowledge and skills in young people would be readily identified so that clinicians' interventions could be targeted to specific transition needs. Furthermore since transition is a process and not a one-time event, these tools could be used to measure change in the young person's readiness over time (31). Despite these tools not being specific to the chronic pain context, they do focus on knowledge and skills needed by all transitioning young people, and could provide a foundation on which to build. Using a standardized assessment tool is critical to ensure that all non-disease areas of transition preparedness are evaluated and this is of particular concern for those with chronic pain, as pain can disrupt cognitive function, information processing, learning, attention, memory, decision-making, planning inference and abstraction (32). The evidence strongly suggests that transition planning must start early to help build knowledge, skills, advocacy, and self-efficacy in young people over time (7)(15)(24). Given the effects of chronic pain on cognitive function, using these tools early in the process may help nurses and other clinicians strategize how best to prepare young people for transition. Nevertheless, research is needed to determine if young people with

chronic pain have additional transition needs that may need to be addressed such as how to manage stigmatization during transition.

Interestingly, the majority of the participants who work in the adult healthcare system believed that their young patients who transitioned from a pediatric healthcare setting were not adequately prepared. Furthermore, these nurses indicated that there were minimal resources to support young people after transitioning to the adult healthcare setting. It is unclear if the nurses and other clinicians in the adult healthcare setting perceive a role for themselves in the transition process. Only one pediatric nurse participant reported that an adult chronic pain clinician attended the last pediatric clinic appointment prior to transferring the young adult to the adult chronic pain clinic. Research suggests that effective supports offered to young people post-transition could include separate young adult care clinics and out of hours phone support, however the nurses in this study did not identify these interventions as a possibility (33). Healthcare transition is a responsibility for both pediatric and adult clinicians, it can only be achieved through the collaboration of providers representing both sides of the healthcare system (34) but this does not appear to be routine practice within the Canadian chronic pain context.

Young people with chronic illnesses have reported experiencing fear and anxiety from the unknown when changing healthcare providers, however, transition preparation has been found to alleviate these feelings (17). Rutishauer and colleagues (2014) identified that the greatest barrier for young people during transition is the impact of the attachment and the importance of the relationship with the pediatric provider (35). This highlights the importance of the pediatric provider helping the young person establish a trusting relationship with the adult healthcare providers. Entering in a new healthcare system and meeting a new provider can invoke feelings of anxiety. Given that anxiety about the transition is the second greatest barrier to a successful

transition, it is critical that strategies to manage transition anxiety (e.g. inviting young people to attend all or part of their clinic appointment without their parents in the pediatric and adult setting; meeting the adult healthcare providers prior to transition; visiting the new healthcare facility) be instituted in both pediatric and adult healthcare settings (35).

Increases in transition-related fear and anxiety is significant as these types of psychosocial factors are associated with the prevalence of a variety of different chronic pain types (3) and anxiety in particular is associated with exacerbations of pain and pain-related disabilities (36). Since a significant portion of adolescents with chronic pain have increased levels of anxiety even without fears of transition (23)(36), when confronted with transition, our findings suggest they may be at risk for added levels of anxiety and related pain exacerbations. Although both pediatric and adult nurses perceived young people as experiencing increases in stress and anxiety during transition, there were minimal formalized transition strategies reported to be in place to help manage the sources of these concerns. Although the pediatric nurses reported the existence of a non-specific transition clinic in their hospital, they did not report that all their patients used this service or if they were referred early enough to gain the needed knowledge and skills for transition. Research is needed to determine if early assessment, preparation, and support decreases transition-related stress and anxiety for young people with chronic pain. Research is also needed to determine if non-specific transition services meet the needs of young people with chronic pain.

Additionally, research suggests that parents also require transition preparation to enable them to identify their child's strengths and weaknesses to encourage them to develop positive and realistic expectations to improve their transition (22). However, our findings suggest that at present, nurses may not be maximizing support for parents as they do not offer formal assessment

of the parent's ability to support their child's transition. Parental involvement with transition is an important component of a successful transition, and therefore, the parents require assistance to support, encourage, and problem solve transition related challenges with their child (37). This finding may not be limited to nurses who work with patients with chronic pain and may extend to other clinicians of the team. As parents experience increased levels of stress during the transition period (16), they may benefit from targeted interventions by nurses and other interprofessional clinicians. Parental preparation may be especially important for parents of young people with chronic pain due to the stigma and lack of understanding about chronic pain in society as well as the fact that many of these parents experience levels of clinically significant distress, including anxiety and depressive symptoms, and parental role stress (38). One strategy that may be helpful to parents is to welcome them into appointments in the adult healthcare setting, at least in the short term, as adolescents and young adults are not always able to voice important issues (39). Witnessing that their child is comfortable in discussing their needs with their new healthcare team may help alleviate some parental stress and if their child is not comfortable parents' will be in a better position to support their child by knowing the proposed treatment. Clearly, research is needed to determine the best ways to support parents of young people with chronic pain through this process, in both the pediatric and adult healthcare setting.

The resources presently available for this population before and after they transition may be limited. For example, the reported age of the support group members in the adult chronic pain healthcare context in this study were substantially older than that of the newly transitioned young person. While this is largely a result of the epidemiology and age distribution of chronic pain in the general population, more attention to programming for young adults with chronic pain is important. Peer support from a person with a similar chronic illness has been described as helpful

in managing life as an adult, and peers are helpful during the transition process as they provide opportunities to share similar experiences and coping strategies (16). Peers may also provide a feeling of belonging and understanding by providing a milieu to talk openly about one's pain problem without the impression that these peers are disinterested (40). However, being confronted by older patients who have experienced a chronic illness for a longer period of time can result in young people feeling more fearful about their own future (11). As well, it may be that the prognosis for young adults with chronic pain may be quite different from middle aged or older adults with chronic pain and may give young adults an incorrect impression regarding their future potential. Therefore, adult chronic pain clinics need to consider offering support groups that are mindful of the age differences and varying needs between their younger patients and those of their older patients.

In this study, the majority of nurses working in the adult chronic pain clinics reported believing that young adults were not prepared to receive care in the adult healthcare system. Yet, most of these nurses identified only receiving written discharge letters or a phone call as the typical transition practice and thus it may not be surprising that young people are not prepared to navigate an unfamiliar healthcare setting. This suggests that at present formal processes are not in place to assist in coordinating the transition process for this complex and at risk population. This is not surprising as Suris and colleagues (2009), purport that the principles of a successful transition are not well applied within adult healthcare (41) for any health condition. Furthermore, the adult healthcare system continues to be described by young adults as impersonal, disease focused, and difficult to establish relationships with healthcare providers (16). Therefore, research is needed to determine if furthering the involvement of adult chronic pain providers in the transition process improves the experience and outcomes for young people with chronic pain.

That research then needs to be carefully and effectively translated into education initiatives and hospital policies in order to ensure that health care providers use best practice methods with young adults during the care transition process.

Research suggests that an interprofessional approach is the most effective way to treat chronic pain (14). This approach is generally in place in the pediatric chronic pain clinics in Canada. Unfortunately, this is not necessarily the case in adult chronic pain clinics where caseloads are significantly greater. To date, transition processes have been led by a medically orientated focus with an emphasis on the role of the physician (42). However, given the significant role of other modalities in the management of chronic pain, research into the transition care practices of other professionals (such as physiotherapy, occupational therapy, pharmacology) is warranted as young people with chronic pain rely on these other professionals to provide therapeutic interventions.

Despite the contribution this study makes in improving understanding of the transition practices for young people with chronic pain, this study has several limitations. First, the sample size was small, particularly in terms of participants who worked in adult chronic pain clinics. There are multiple chronic pain clinics across Canada, both private and public. Adolescent and young adult patients may transition to either sector and supports available in the private sector may differ from the public healthcare system. However, no participants in this study identified, as working in the private sector therefore information about the private sector was not captured. However, presently there are only 10 tertiary pediatric chronic pain clinics across Canada, suggesting that our study is representative of the pediatric transition care practices for young people with chronic pain. Second, the survey was limited as it addressed the perceptions and self-reported practices of nurses working in these systems; however since many of the pediatric

tertiary chronic pain clinics in Canada are interprofessional, other healthcare providers may carry out some of the transition care. Nevertheless, nurses generally coordinate care and thus it is unlikely that overall transition practices differ amongst members of the interdisciplinary team.

Conclusion

Transition for young people with chronic pain is inevitable. Despite published guidelines for best practice in general transition care there are no uniform transition processes and practices for young people with chronic pain in Canada. Most nurses who work in pediatric chronic pain clinics assess transition readiness informally. The use of validated transition assessment tools could identify gaps in transition readiness and identify areas requiring intervention. Transition supports and programming in the adult healthcare chronic pain setting are limited and this may have a negative impact on healthcare engagement post transition. Through collaboration, pediatric and adult healthcare providers could help create a more seamless transition, which may have a positive impact on the transition experience and overall health outcomes of young people with chronic pain in Canada.

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Table 1: Assessment of transition preparedness in the pediatric setting.

	(n)	Yes (n)	No (n)	Formally assess (n)	Informally assess (n)	Transition tool (n)	Other (n)
Assessment of ability to self manage their chronic pain	9	7	2	1	7	0	0
Assessment of the ability to manage in the healthcare context	9	5	4	0	3	0	0
Assessment of understanding of chronic pain	8	8	0	7	7	1	1
Assessment of understanding of medication	8	6	2	1	6	0	0
Assessment of understanding of psychological strategies to management pain	8	8	0	2	7	0	1
Assessment of understanding of the physical approaches to pain management	8	8	0	3	7	1	2
Assessment of ability to advocate for themselves in different settings	8	7	1	1	6	0	1

Notes: n= total number of participants who answered this question; Informally assessed= informal discussion on the topic during patient encounters. Formally assessed= planned sets of questions asked during planned patient encounters. Transition tools= use of standardized transition assessment tools.

Table 2: Pediatric transition system supports.

	Yes (n)	No (n)
Does your healthcare facility have a transition clinic to refer the patient to?	6	2
Do you have a formal chronic pain transition clinic with adult healthcare providers?	1	7
Is there a formal support group available for adolescent seeking support with transition	3	5
Is there a support group available for the parents or guardians of the transitioning adolescent seeking support with transition?	0	8
Do you offer any patient literature on the transition experience?	2	6

Notes: n= total number of participants who answered this question out of a maximum of 9

Table 3: Adult chronic pain nurses and transition process and procedures

	(n)	Yes (n)	No (n)	Unsure (n)
1) Are you referred patients that were treated in the pediatric setting?	9	7	0	2
1-a) If yes, would your pain treatment facility contact the pain treatment facility of the transitioned young patient?	6	5	1	0
1-b) If yes, do you have a formal discussions with the referring:	3	Physician: 2 Psychologist: 2	Registered Nurse: 3 Physiotherapist: 1	
1-c) If no, does the patient come to the first appoint with a written copy of their medical history?	1	1	1	N/A
2) Do you receive a referral letter from the services?	9	8	1	N/A

Notes: n= total number of participants who answered this question out of a maximum of 9

Table 4: Adult chronic pain nurses process for parent involvement

	(n)	Yes (n)	No (n)
1) Do you obtain a formal consent from the patient to allow the parent/guardian to attend the appointments?	9	1	8
2) Does your facility obtain a formal consent from the patient to share health information with the parent or guardian?	9	4	5
3) Do you include parents or guardians in the first appointment?	9	7	2
3-a) If yes, do parents attend the entire or part of the appointment?	7	Part of the appointment: 6	Entire appointment: 1
4) Do you permit parents to attend further appointments?	9	7	2
5) Do you permit parents to call for appointments, refills, update information, pain management advice?	9	2 Only if consent was given: 6	1

Notes: n= total number of participants who answered this question out of a maximum of 9

Table 5: Adult chronic pain nurses: Patients' transition preparations and provided supports.

	(n)	Yes (n)	No (n)
1) Do you find that newly referred transitioned patients are prepared for treatment in the adult healthcare system?	9	2	7
2) Does your clinic provide support to newly transitioned young adult patients after hours	9	0	9
3) Does your clinic offer group sessions to people living with chronic pain	9	7	2
3-a) If yes, does your clinic offer sessions to young adults only?	7	2	5
4) Do you provide support in advocating for school or university accommodations for younger patients?	8	4	4

Notes: n= total number of participants who answered this question out of a maximum of 9

Table 6: Participants perception of reasons for patients' stress and anxiety due to transition

Pediatric System	Adult Healthcare System
n=(8)	n= (4)
Multiple transitions! Not just from us, usually from their primary care providers, other sub specialties PLUS life transitions - school, work, moving away	It is all new to them. They have been with professionals for usually many years and now we are completely changing that along with maybe how we deliver care in adult world
Fear of unknown. New team to get to know.	Expectations, immaturity and communications skills require development/coaching.
Uncertainty about their future pain management.	Unrealistic expectations of care in tertiary care setting
They are anxious about the unknown within the adult healthcare world. Adolescents are also anxious about advocating for themselves once they are transitioned.	Some, particularly those who have worked with pediatrics for years, have difficulty with working with a new team.
Perceived minimal access.	
Most adolescents are aware that (generally speaking) adult services involve a more self- management approach.	
Due to the unknown and uncertainty. Unfamiliar with new medical teams and clinics. Leaving a hospital or clinic they have built relationships with	

Chapter 5

Moving On: Transition Experience of Young Adults with Chronic Pain

A Qualitative Descriptive Study

Authors:

Andrea Higginson RN BScN, BA, MScN (student)
University of Ottawa

Paula Forgeron RN MN PhD
University of Ottawa

Denise Harrison RN PhD
University of Ottawa
Children's Hospital of Eastern Ontario Research Institute

G. Allen Finley, MD FRCPC FAAP
Dalhousie University
Centre for Pediatric Pain Research, IWK Health Centre

B. Dick, PhD, R Psych
Stollery Children's Hospital
University of Alberta

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Abstract

Purpose: To explore the transition experience of young adults with chronic pain in Canada from the pediatric healthcare setting to the adult healthcare setting.

Materials & Methods: A qualitative descriptive approach using semi-structured interviews to capture the transition experiences of young people with chronic pain who have recently transitioned from the pediatric setting to the adult healthcare setting. Participants were recruited from west, central, and east coast of Canada to situate the findings within the context of Canada. Interviews were transcribed and analyzed using qualitative inductive content analysis.

Results: Nine participants were interviewed; 3 from each part of Canada (west, central, and east) Five common categories, unique to the transition experience of young adults with chronic pain were determined: i) *I can do it, maybe?: Independence*; ii) *Stress and pain along for the ride: Pain trajectory*; iii) *Need a shoulder to lean on: social support networks*; iv) *Obviously they are there: Parental support*; and v) *The Bridge: Collaborative systems*.

Conclusion: Young adults with chronic pain experience unique challenges when faced with transitioning to adult healthcare setting. Supporting the young adult and their family in preparation and readiness, and collaboration between the pediatric and adult healthcare settings are essential to ensure a smooth transition and avoid negative transition outcomes. Further research is needed to determine the best ways to prepare young people for transition and the care activities required in both pediatric and adult healthcare settings to improve pain related outcomes post transition.

Key words: *transition, chronic pain, young adults, adolescents, young people*

Introduction

Over 1.5 million Canadians between the ages of 12 to 44 live with chronic pain.(Ramage-Morin & Gilmour, 2010) One in five Canadian children report experiencing some form of chronic pain during childhood and adolescence with an estimated 5-8% of children and adolescents suffering from chronic pain severe enough to interfere with their quality of life.(Huguet & Miró, 2008; King et al., 2011; Ramage-Morin & Gilmour, 2010; von Baeyer, 2011) Furthermore, longitudinal studies suggest that childhood chronic pain predisposes children for the continuation of pain into adulthood as well as the development of new onset chronic pain.(Walker, Dengler-Crish, Rippel, & Bruehl, 2010) Undertreated chronic pain has a negative impact on all aspects of health-related quality of life including: physical (poor sleep, and activity limitation), emotional (anxiety, and depression), social (peer and family relationships), cognitive function and learning, and role function (absence from school and work).(Stinson et al., 2013) A significant proportion of adolescents with chronic pain will continue to require health services for pain management into adulthood.(Dengler-Crish Christine, Horst Sara, & Walker Lynn, 2011; Mulvaney, Lambert, Garber, & Walker, 2006) Considering the impact that chronic pain has on these aspects of life, they may pose unique challenges for young people with chronic pain and their ability to transition into adulthood and into the adult healthcare system to access treatment. However, little is known about the best practices for this specific population, and little is understood about the transition experience of this population moving into the adult healthcare system.

In recent years, transition from pediatric healthcare to the adult healthcare system has gained attention, as transition has proven to be a challenge for adolescents and young adults with diverse pediatric chronic illnesses including congenital heart disease and type I diabetes. (Heery,

Sheehan, While, & Coyne, 2015; J. Okumura, Saunders, & Rehm, 2015; Sheehan, While, & Coyne, 2015) The healthcare transition process requires the affective, behavioural, and cognitive capacity of an adolescent and members of their primary support system, including family and medical team, to prepare for, begin, continue, and finish the healthcare transition process.(Pierce & Wysocki, 2015; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004) However, for many children with chronic illness, transition to adult healthcare settings has not always been successful.(Crowley, Wolfe, Lock, & Mckee, 2011; Rapley & Davidson, 2010; Reed-Knight, Blount, & Gilleland, 2014; Sonneveld, Strating, van Staa, & Nieboer, 2013) The Canadian Association of Pediatric Healthcare Centres (CAPHC) recently published a guideline to support successful transition for youth with special health care needs(CAPHC National Transitions Community of Practice, 2016). The aim of the guidelines was to influence transition at the person and clinical care level, provide a framework for a supportive process for the transition, and to identify collaborative processes, tools and resources for all stakeholders in transition (CAPHC National Transitions Community of Practice, 2016). Considering that the guideline has only recently been developed, it is difficult to determine if it has had an impact on the transition of adolescents with chronic pain.

Transition to adult healthcare services for young people with chronic pain is generally unavoidable. In other populations with chronic conditions, ensuring that young people are ready to transition (healthcare transition readiness) is linked to successful transition (CAPHC National Transitions Community of Practice, 2016; Moynihan, Saewyc, Whitehouse, Paone, & McPherson, 2015). It is not only the healthcare transition readiness of a young adult that requires assessment but also the young person's emotional, behavioural, and cognitive capacity to manage in a new healthcare environment. Thus, comprehensive ongoing assessment of young people and

their supports, and their transition readiness is needed to ensure that their transition is seamless, appropriate, and successful (Moynihan et al., 2015). Elements that impact healthcare transition readiness include the age of the young person, their disease or condition, the young person's participation in transition clinics, their anxiety, and the young adults and their parents' confidence in the adult provider (Schwartz et al., 2014).

Several studies examining patients with chronic illnesses and their transition experience to adult healthcare have been conducted (Heery et al., 2015; Hislop, Mason, Parr, Vale, & Colver, 2016; Rutishauser, Sawyer, & Ambresin, 2014; Sonneveld et al., 2013). Although these studies provide some insights into concerns and preparations for transition for young adults with chronic illnesses, the chronic pain population may have different experiences. This population may have unique challenges that have significant potential to impact health related outcomes. Improving understanding of the transition experience for young people with chronic pain will provide insights into strategies to ensure a smooth transition and decrease potential negative outcomes in this population. Thus, the purpose of this study is to understand the transition experience of young people with chronic pain who have recently moved into the adult healthcare system. Participants who have recently transitioned into the adult healthcare system are in a position to identify the outcomes compared with their anticipated experience. A three-year timeframe after transition was used in this study to help ensure that potential participants' experiences were recent and that each participant had a clear recollection of their experience.

Material and Methods

Due to the paucity of literature on the transition experience of young people with chronic pain, a qualitative approach using semi-structured interviews was employed in this study. A qualitative descriptive design, as described by Sandelowski (2000), was implemented to capture

the experience of the participants in detail. This method focuses on the experiences of patients, professionals, and/or their perceptions of patient-professional interactions and the organization of the healthcare system (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Qualitative descriptive studies offer a comprehensive summary of an event in everyday terms (Sandelowski, 2000) and can provide insights into understudied phenomena (Polit, 1997). The exploration of the experience of young people with chronic pain who have transitioned from the pediatric to the adult health care setting will illuminate their individual realities which will provide helpful insights into the needs of adolescents and young adults to support successful transition.

Sample and Setting

Young people who transitioned from pediatric to adult chronic pain settings within the past three years were invited to participate. Recruitment was done through community outreach in an urban Ontario city (e.g. community posters), and online recruitment approaches (email listserves, The University of Ottawa Pain Hub website posting) across Canada. Community notifications included a brief description of the study, eligibility criteria and contact information for the primary investigator (AH). In conjunction, targeted recruitment was also conducted through two pediatric chronic pain clinics; one in Western Canada and one in Eastern Canada. These outpatient clinics use a similar approach to the care of children and adolescents with chronic pain: family-centre care approach, each patient and family is seen simultaneously by the chronic pain multidisciplinary team (e.g. nurse, physician, physiotherapist, psychologist), and ongoing support is offered to facilitate parent support, school re-integration, medication management, physical therapy, and cognitive-behavioural strategies, and physical therapy strategies to improve management of pain. Clinicians in these two clinics sent invitation letters to eligible participants who had transitioned from their clinics to an adult healthcare services for

their chronic pain condition. The invitation letters included a brief description of the study and the primary investigator's contact information.

The inclusion criteria for the study were that participants must: have received care in the pediatric healthcare system for their chronic pain; continue to need treatment for their chronic pain; aged between 16 and 23 years (pediatric centres in Canada transitions patients at different ages—typically 16 years of age and older in Nova Scotia to 18 years of age and older in Alberta and Ontario); have transitioned within the past 3 years; and be able to speak and read English or French. Exclusion criteria were: those with developmental delay; and those experiencing pain from a life-limiting illness.

Purposeful sampling techniques were used in the recruitment process, and are advocated for qualitative descriptive studies (Polit, 2012; Sandelowski, 2000) as the participants need to have experience with the phenomena under study. The sample size in qualitative studies is not predetermined but is based on the depth and richness of the data, which is influenced by the scope of the study, nature of the topic, quality of the data obtained, and the study design. (Morse, 2015) Sample sizes in qualitative studies collecting data through individual interviews can range from sizes of one to eighteen, to capture a rich understanding of the phenomena (Smith, 2003).

Data Collection

Semi-structured interviews, done in person, over the phone, or over Skype, facilitated an in depth understanding a participant's experience. The first author, a clinically practicing registered nurse with pediatric discharge planning expertise conducted all of the interviews. Through semi-structured interviews participants with chronic pain were able to acknowledge their own important experiences or issues with their transition. An interview guide was prepared, which included a list of topics to be covered during the interview (Polit, 2012) and moved from

closed-ended questions to open-ended individual questions (Sandelowski, 2000). The closed-ended questions were used to capture demographic type questions (i.e. age of the onset of pain, age they were transitions, current age, where they receive their pain care). The open-ended questions provided participants the opportunity to emphasize the important issues from their transition experience. The interview guide was informed by Meleis' transition theory and focused on the transition experience from the pediatric healthcare setting to the adult healthcare setting. Transition, as defined by Meleis and colleagues (2000), consists of a passage from one life phase, condition, or status to another during which changes in health status, role relationship, expectations, or abilities create a period of vulnerability. The adolescent with chronic pain experiences two different types of transition simultaneously: developmental and situational. The developmental transition occurs as they move from adolescence to adulthood and according to Meleis, this is marked by the increased self-identity and growing independence (Meleis, 2010). The situational transition is a result of the transition that takes place in individual roles and relationships, for example the change in roles of the child in the home to an independent adult and the impact this has on the family relationships (Meleis et al., 2000). Also, situational transition includes geographical changes, such as changes in where a young person lives when they move away from home or the change in team membership from whom the young person receives healthcare (Meleis et al., 2000). The interview guide was created recognizing the possibility that these transitions could create unique challenges for the young adult with chronic pain. The open-ended nature of the questions allowed the interview format to be flexible and facilitate an open discussion about the transition experiences of importance to the participant. The following are examples of questions used: "Can you tell me about how you felt about leaving the pediatric setting?" "Can you tell me how you take care of yourself between visits with the

chronic pain team now?” “Can you tell me about how the pediatric team prepared you for the adult healthcare system?” “Can you tell me what has been good about your transition?” “Can you tell me about the most difficult things about your transition?” and “Can you tell me about how your parents helped or continue to help your management your chronic pain?”. The interviewer also wrote field notes after the interview to capture impressions and observations of the interview. The interviews were audio recorded and transcribed for analysis.

Data Analysis

Qualitative inductive content analysis was used to analyze the data. This method allowed for a condensed yet broad description of a particular phenomenon, through the use of concepts and categories (Elo & Kyngäs, 2008). The knowledge generated from qualitative content analysis is based on the participants’ unique perspectives and grounded in the actual data (Elo & Kyngäs, 2008). The benefit of using this approach was that given the limited research on pediatric to adult health care transition for young people with chronic pain, their insights into transition was obtained without imposing preconceived categories or perspectives. Although Meleis’s theory of transition (along with the literature on healthcare transition) informed the development of the interview guide it was not used as a framework in the inductive content analysis.

A professional transcriptionist was employed to transcribe each interview verbatim. To begin the process of analysis the researcher immersed herself in the data by reading each interview while listening to the audio files to ensure accuracy of transcription and then rereading each transcript to have a clear understanding of its content (Elo & Kyngäs, 2008). An inductive approach moves from the specific meaning to the general categories to help understanding of the phenomena. Categories were determined upon examination of the data, not *a priori*. Generating

meaning was done by organizing the data using three methods; open coding, creating categories, and abstraction (Elo & Kyngäs, 2008).

Open coding is when the researcher reads through the transcript and identifies headings (codes) and makes notes directly on the document. In this study the principal investigator (A.H.) highlighted and identified exact words in the text that captured the key concepts and thoughts of the participants (Hsieh & Shannon, 2005) using as many headings (codes) as necessary (Elo & Kyngäs, 2008). After the first two transcripts had been coded a code list was developed and reviewed with the second author (PF). This list was used to help code the remaining interviews. When a new code emerged in subsequent interviews the plan was to add these to the code list and review previously coded interviews to ensure that the code did not apply. However, no new codes emerged after the coding of the first two transcripts. Once the codes were applied, they data were categorized. Determining categories is a main activity of qualitative content analysis (Graneheim & Lundman, 2004). In this study, codes were collapsed into categories by determining how a broader descriptive level of content fit the data (Graneheim & Lundman, 2004). During this process of refinement no data was excluded because it fell between two categories or fit into one or more categories. The categories (and the direct quotes that act as exemplars that support these categories) were further refined to reflect patterns of behaviour that were relevant to the study as described in the interviews (Polit, 2012).

The researcher then used abstraction to compile the data together. Abstraction is defined as general descriptions of the research topic through generating main categories (Elo & Kyngäs, 2008). Through an analysis on how the categories string together, an understanding of the experience of transition for young people with chronic pain was described using main categories. Each main category name was constructed from the content-characteristics of data (Elo &

Kyngäs, 2008). All authors then reviewed the identified main categories to ensure that they were grounded in the data.

Rigor

The most commonly used criteria to assess rigor in qualitative research are credibility, dependability, conformability, and transferability, as proposed by Lincoln and Guba (1985) (Houghton, Casey, Shaw, & Murphy, 2013). Credibility is described as the degree of confidence in the findings that the researcher inspires in the reader. Strategies to improve credibility include; prolonged engagement, persistent observation, and triangulation (Lincoln & Lincoln author, 1985). In this study the principal investigator immersed herself in the data by reviewing each transcripts while listening to the recording for accuracy, and then re-read the transcripts several times. Dependability is achieved when the researcher accounts for the alterations in the researchers' decision during the analysis process (Lincoln & Lincoln author, 1985). Dependability in this study was achieved through peer debriefing with the second author. Transferability refers to the extent to which findings may have application to different settings (Graneheim & Lundman, 2004; Twycross & Shields, 2005). Guba and Lincoln (1989) and Thomas & Magilvy, (2011) suggest that "thick description" is essential for a reader to transfer the original findings into another context (Guba, 1989; Thomas & Magilvy, 2011). In this study this description entailed a description of the chronic pain clinical setting (both the pediatric chronic pain setting that they once attended and the adult chronic pain setting that they now attend), the unique participants characteristics (e.g. age of pain onset, type of community where they live—rural or urban, gender, present age), context for the interview (e.g. Skype, telephone), data collection approach (e.g. semi-structured interviews), and data analysis (e.g. inductive content analysis)(Graneheim & Lundman, 2004). Additionally, a rich description of the participants'

experiences of transition with the use exemplar quotes to support the main categories offer further detail to enable the transferability of the findings. As this was a multi-site study, the transferability was further enhanced as the participants' experiences were from across Canada.

Ethical Considerations

Ethics approval was obtained through the Research Ethics Board at the following institutions: IWK Children's Hospital, in Halifax, Nova Scotia; University of Alberta, in Edmonton, Alberta; and the University of Ottawa, in Ottawa, Ontario. Participation in the study was voluntary and verbal consent was obtained and transcribed on the date of the interview. Participants were assured of confidentiality. Aliases were given to each participant as part of the confidentiality technique. The professional transcriptionist signed a confidentiality form, which included the permanent deletion of the audio and typed files.

Results

Demographics

Nine participants were interviewed for the study; eight women and one man. All had been treated in the pediatric chronic pain setting, eight were actively receiving care for their chronic pain in the adult healthcare setting, and one was no longer receiving care despite still experiencing chronic pain (see Table 1). They were spread evenly across Canada, three from each area; west, central, and east. They reported a wide range of transition experiences including positive experiences (successfully receiving care for their chronic pain in the adult healthcare setting) to negative experiences (long delays to be seen by an adult care provider to manage their pain). Although the participants discussed their experiences of transitioning between the healthcare environments, each story encompassed developmental transition experiences, which were interwoven with their healthcare transition.

Insert Table 1: Demographics of Participants here

Just over half (n=6) of participants had moved to a different city in order to further post-secondary education. All of the participants received care from a tertiary pediatric chronic pain clinic in their region and continued to receive care by an adult care provider in that same region (west, central, and east). This situation created another level of complexity for their transition as they had to access chronic pain care in a city that differed from where their pediatric providers were located and not all pediatric pain clinicians knew a chronic pain adult healthcare provider to refer them to in their new locations. For some of the young people, this meant that they were transitioned to either their previous or a new general practitioner and for others they were not transitioned to a specific adult chronic pain specialist at all. For those participants who remained in the same city where they accessed their pediatric pain care, their transition experience was voiced as being more successful and straightforward, citing that their pediatric clinicians knew the adult clinicians to whom they were being transitioned.

From the analysis of participants' collective experiences, five distinct major categories emerged. Although these categories are distinct, there is also overlap between the categories as it is not possible to delineate one's life experience into isolated events. Nevertheless, what follows is a discussion of the five major categories, which include; *I can do it, maybe?: Independence; Stress and pain along for the ride: Pain trajectory; Need a shoulder to lean on: Informal supports; Obviously they are there: Parental support; and The Bridge: Collaborative systems.*

I Can Do It, Maybe? Independence

Many of the participants expressed that when they were getting ready to transition into the adult healthcare system they were not concerned about that change. They felt confident and ready to go to university and to move to the next chapter of their lives. From a developmental perspective, feeling confident and excited about the next stage of life (e.g. attending post-secondary education, moving away from home, starting a career) should be viewed positively. However, in terms of their healthcare transition, this confidence was perhaps overly optimistic as they were not fully cognizant of potential limitations or needs due to their chronic pain. For some participants, the management of their chronic pain was not a concern and they began university trying to live a life like their peers. For Betty, age 21 years, she expressed excitement about moving and began the year with high hopes. However she predicted being able to achieve more than what she was actually able to, and as the semester progressed she realized that her chronic pain created limitations.

(University) was a good experience and it started giving me life again cause I think I was in a pretty depressive state, so as soon as I got there, I signed up for everything and over did it and burnt out pretty quickly.

The majority of the participants voiced that when they were leaving the pediatric pain clinic they recall being instilled with the notion that accessing healthcare for their chronic pain management would be straightforward even when moving away to university. Although they had discussions about transition with their pediatric chronic pain team they reported that they were not really clear about what transition truly meant. When Jen, age 18 years, was asked about what her transition assessment process consisted of before leaving the pediatric chronic pain clinic, she could not specifically identify what was done to prepare her for transition. *“They didn’t ever have*

me take a survey or anything like that, they just kind of said, do you feel ready? And I said well, I'm as ready as I can feel". This notion of access to healthcare being straightforward once they transitioned to adult care created a sense of confidence suggesting that everything would work itself out. Participants shared that they did not realize the amount of effort they would require to locate and access chronic pain management services within the adult healthcare system. All still believed all their care needs would be coordinated for them—the way it was in their pediatric chronic pain clinics. The foundation of their confidence in the coordination of their future care is uncertain. However, given the positive experiences in coordinated care in their pediatric chronic pain clinics, these young adults may have simply presumed that this would continue.

Nevertheless, their belief, and perhaps naiveté, in transition challenges led to healthcare access issues that left them feeling less than confident in their abilities to be independent in managing their chronic pain and accessing care to support their care needs. Here Brenda, age 20 years, shares how when she went away to university she believed the transition to the adult chronic pain team in her new city would have been established and that she would seamlessly access care in the adult chronic pain clinic. Unfortunately, at the time of the interview, she had been at university for three years, and was still waiting to have an appointment with the chronic pain team.

I thought when I got to school there'd be something set-up already, again... I was pretty naïve in grade twelve and I didn't know that I had to actually push them for extra.

Furthermore, Brenda believed that her pediatric chronic pain team contributed to her confidence by not preparing her for how challenging it could be once she arrived at university.

Honestly no [preparation for transition]. Like not now, I may have felt [then I was ready for transition] I was leaving because it had been two years [attending pediatric chronic

pain services] and it's just like 'oh this is great it [city she was moving to] has many services there', but it appears that there is no services and no support, I'm still in this 'like but wait...[where do I get help]'

The other participants shared this belief. From their shared stories, these participants described that they did not feel overly concerned or stressed about preparing to leave the pediatric chronic pain clinics they had attended because they perceived or believed that arrangements would be made or that it would be straightforward to access the care they required. However when they went to seek care in the adult healthcare system, the barriers they faced created concerns and stress, as they were not fully prepared for the challenges of accessing healthcare services in the adult system. Being solely responsible to manage their chronic pain appears to have been difficult for some participants.

Stress and Pain Along for the Ride: Pain Trajectory

Along with the transition in healthcare, the participants were transitioning to their next stage of life. Like other people of similar ages, they were moving on after high school to post-secondary education or employment. The majority of the participants embarked on a transition to university and some moved away from their home city. Like their healthy counterparts, these young people experienced stress and anxiety about leaving home and beginning their university education. However, unlike their healthy counterparts, increased stress was associated with exacerbations of their chronic pain. Furthermore, unlike their peers, their stress was not isolated to issues surrounding the typical university experience but also included concerns about seeking care if their pain became unmanageable in their new environments. Lisa, age 21 years, expressed experiencing concerns about being in a new city and not being able to access the same pediatric providers. However, Lisa's experience was unique as she was treated for chronic pain in her

hometown by videoconferencing the pediatric chronic pain team, and continued to videoconference with the adult healthcare providers. Fortunately for Lisa, this experience of changing cities did not impact her access to regular appointments with the pediatric or adult chronic pain team. Nevertheless, Lisa continued to have access to her pediatric team through her first year of university, which she expressed gratitude for, as she believed this led to a successful transition.

Oh yeah absolutely and I mean she was fabulous in that way (the support of the pediatric chronic pain nurse), she was always just an e-mail away but I think where my anxiety came from was that I no longer had like the physio clinic that I had gone for years behind me and I didn't know necessarily how to get those resources at first and on top you're moving away for school you know, university and it's all a new experience and all of those wonderful things. So, hum, there was actually my pediatric team, it's like very like, confusing at the time because they overlap so much, so my pediatric chronic pain team, at the time ended up continuing to work with me, because I was nervous for school hum, they help me connect with my advisor [student access service advisor].

Lisa experienced a well-supported transition, as she identified that she was able to contact the pediatric and adult chronic pain team as she needed. At the time of the interview, Lisa stated that she could contact the pediatric providers but that she no longer required the connection because she had established a relationship with the adult healthcare providers. Furthermore, she identified that she was able to manage her own chronic pain and that this was something that the pediatric team had worked with her to accomplish. Despite her supportive transition, she still experienced increased stress during her transition but that her supportive transition helped her manage, as she had access to expert pain care. Similarly, Stephanie, age 23 years, noted that although her stress

about starting university caused an increase in her chronic pain, she was able to manage. She transitioned to the adult pain clinic in her hometown, and although she had to commute home for appointments she had access to expert pain care. She also was starting to develop strategies to manage between appointments. *“Stress of going away definitely made my headaches worse, but I sort of learned to deal with them on my own”*.

Unfortunately, for those who voiced not having an identified chronic pain clinician in the adult healthcare system, they experienced worse outcomes. For Julie, age 20 years, she did not have services in place when she left the pediatric chronic pain team and she had not been transitioned to an adult chronic pain clinic. This less than ideal situation resulted in stress, which she felt contributed to making her pain worse. *“It has gotten worse like I said now I see more inflammation where my knee gets red hot to touch like through my clothing.”* It may be that Julie was not prepared to manage her pain independently before leaving the pediatric chronic pain clinic. She was trying to finish her high school credits and was having difficulty going to work, which further exacerbated her stress and pain levels creating a vicious circle with no adult chronic pain clinicians available to help her.

Although the majority of the participants spoke of experiencing increases in stress when starting university and how this stress contributed to an exacerbation of their pain, for a few participants, the opposite was experienced—increases in their pain intensity exacerbated their stress and anxiety. Melissa, age 23 years, explained how during class when her pain would increase her anxiety would also increase and that this experience almost became unmanageable.

I just work through it, I sat there in a whole lot of pain trying to do the work and trying to get stuff done and I was miserable like, the anxiety shot right up. I almost had to go onto pills for that (anxiety).

The interplay between pain and stress or anxiety is known but the experiences of these participants illustrates that transition is coupled not only with stressful events associated with healthcare transitioning but also with developmental stage transition. For Sally, age 21 years, she was prepared to manage her chronic pain. She understood her limitations and had expectations that there would be times of stress during the transition. Due to her preparations while in the pediatric setting, Sally reported to have experienced a positive transition. Although she managed her chronic pain with her general practitioner, she had developed the skills necessary to be autonomous, and was able to identify her chronic pain needs. The pediatric setting had been successful in preparing her for the adult healthcare setting.

I got to a point where I can manage it [the pain] pretty well and I'm pretty good at knowing myself. Like when I need to rest or just when I just need some time by myself.

A Shoulder to Lean On: Social Support Networks

The need for peer support and being able to form peer networks are part of adolescent and young adult life. This was true for the participants in this study as well; however the majority of the participants voiced that creating friendships and lasting relationships was difficult as a result of their chronic pain. For Jen, age 18 years, she acknowledged the importance of having a network of friends but identified that this is challenging for people with chronic pain. *“I think that’s really important, to have a social network, I know it’s really difficult for people with chronic pain to get out and have a social network”*. When these participants were challenged to garner support from peers and build a reliable peer network it had negative consequences on their healthcare and developmental transition outcomes. Fear of judgement and a perceived lack of understanding of chronic pain were cited as reasons why many of these participants did not share their chronic pain condition with peers. Brenda, age 20 years, identified that she does not share

that she has chronic pain with her new friends at university because she has faced negative reactions from others in the past which left her fearful of disclosure.

I do not personally tell people until I feel I have a trusting relationship with them, cause again, I don't want to tell them and then have them hurt me 'cause it can flip and then they could just react negatively so I want to be able to build a relationship and trust them before I came out and say it.

For many of the participants they were either starting post-secondary education (e.g. university) or careers and therefore not feeling comfortable to disclose their condition to others, which created barriers to obtaining the social support they needed from these new friends. This is concerning as many of the participants moved away from home at the same time as they moved to adult healthcare services for their pain management needs, so just as they may need more support from friends, they were potentially receiving less. Furthermore, due to functional limitations associated with their chronic pain, if new friends do not understand the reason for limitations, the lack of disclosure may become a barrier to establishing new relationships.

Charles, age 19 years, stated that he was able to make new friends, however, his new friends did not know that he has chronic pain so it is difficult to understand the sorts of pain-related social support he is able to garner from them. *"Yeah, I made a, like four more friends from different classes that I rely on. Oh no, they don't [that I have chronic pain]"*.

Some participants felt that even when they disclosed that they had chronic pain, their peers did not fully understand, which made making new friends challenging. Stephanie, age 23, recalled how it was difficult going to university and meet new people as they did not understand chronic pain.

It's hard meeting new people and getting close with my friends, like my roommate and stuff never understood, I didn't want her to be partying in the room till four am when I had class the next day and if I didn't get eight hours of sleep I was going to have a bad headache.

One of the exciting experiences in transitioning to secondary education is the social connections one makes with others. However, what should be an exciting experience was a challenging experience for many of the participants in this study. Even when these young adults were able to establish new friendships some still needed other forms of social support. Melissa, age 23 years, found that although she had made new friends she had a difficult time relating to them about her chronic pain, as they did not share a chronic pain or chronic illness experience. It appears that negative social experiences in high school made participants perceive their new friends as unable to provide pain related social support. Therefore, for participants like Melissa, tried to find a peer support from others with chronic pain in the form of a group.

This past appointment which was probably the day before I first emailed you, I asked again (about a pain support group) because I have friends now, I have four really good friends which more than enough for me but none of them have the same problems that I do, they don't even have allergies.

Several of the participants identified that they sought formal peer support groups to cope with their chronic pain but that they encountered challenges in finding the right group for them as they were much younger than most members of the available peer support groups. Most of the participants interested in a peer support group wanted to attend a group of their similar aged peers—not adults who were considerably older—as hearing about the continued struggles of older adults with chronic pain was discouraging and key personal issues are often considerably

different between these age groups. Yet, these age specific chronic pain support groups did not seem to exist. Betty, aged 21 years, found the benefits of attending a support group consisting of older adults outweighed the risks.

The reason why I continued to go was because of that support, meeting other people who had gone through similar things. [But] I found it difficult because I found they pitied me more because I was younger.

The long-term impact of feeling pitied by others and for how long this sort of interaction would be perceived as helpful is unclear. It may be that being able to share challenges from time to time with others who did not question the validity of your challenges helps to decrease feelings of difference and as a result one may feel able to engage with others in their broader social networks.

Obviously They Are There: Parental Support

Not surprising, the participants in this study consistently talked about the role of their parents in their transition process. All of the participants talked of how their parents played a role in seeking treatment for their chronic pain condition while in the pediatric healthcare system. However, for many of the participants, this role continued when they transitioned into the adult healthcare system, meaning that many of these young adults continued to be dependent on their parents' active involvement in order to access care. Stephanie, age 23 years, recollected that had she not relied on her mother to push within the adult healthcare system she would have not have accessed the resources she needed. *"I feel like if I didn't have my mom as a connection then I would be lost"*. The need to rely on their parents to advocate on their behalf was also highlighted below by Jen, 18 years of age, and echoed by others. This perhaps reflects that most of these

young people may not feel completely confident in their abilities to advocate for themselves at the time that they transitioned.

They [parents] just really helped with not necessarily pushing but kept on asking the doctors at the pain center to make sure that the referral went through so I could see the specialists here as soon as I got here.

Continued reliance on their parents (mostly their mothers) may contribute to young adults not developing the skills and knowledge needed to negotiate the adult healthcare system. Many participants had the expectation that the parent would always be there to provide support to ensure that their chronic pain was well managed. Many of the participants in this study spoke of how, despite becoming an adult, it did not mean that they were independent of the child-parent relationship. Jen, age 18 years, shared that although she was an independent young adult, her mother was still responsible for caring for her. “*At home like mom is, I mean obviously she’s not technically responsible for me, I’m eighteen [being an adult], but she’s my mom*”. Similarly, Betty, age 21 years, spoke of being independent at university but when she would come home she would relinquish some of her independence back to her parents.

Well it was just a subconscious thing, food and making sure things are going well, like I had no motivation really to fight the pain or try and move forward when I was at home.

It is unclear if relying on their parents is any different for young people with chronic pain compared to their healthy peers when they return home from being away but the reasons and outcomes may be different. Melissa, age 23 years, expressed that while living at home, she relied on her mother to provide her with the healthcare support she needed, as she did not feel capable of doing it herself. Melissa lived at home with her mother while attending university and, at the time of the interview, continued to live there since she graduated and was working part-time.

“Sometimes she had to pull me off the couch to get me to the bedroom or off to get me my pills when they’re three feet away”. For some of the participants (but not all) their continued reliance on their mothers to take the lead in their chronic pain needs may impede their transition into adulthood. Charles, age 19 years, stated that his mother managed his chronic pain needs and that he viewed this as her role, not a shared responsibility. *“She’d deal with them [medication]. I have some right now, she puts these pills in containers and she gets them for me everyday.”* Clearly there was a range in reliance on their parents for help with their chronic pain management ranging from minimal reliance to total reliance.

The Bridge: Collaborative Systems

The healthcare transition journeys of these participants highlighted the critical role of collaboration amongst the pediatric and adult healthcare providers in bringing about a successful healthcare transition for adolescents and young adults with chronic pain. The range of experiences demonstrates the relatively smooth path that some of the participants experienced when collaboration was high and the rocky path when collaboration was low. For Lisa, age 21 years, the experience of transition from the pediatric to the adult healthcare team was characterized by teamwork in coordinating her transition activities.

We went over together (with the pediatric nurse) so she actually helped facilitate it, so it was gradual. It was in terms, this is your last day in the pediatric clinic. It wasn’t that I was at any point lacking care because the adult clinic had come in, they started working with my pediatric team to kind of bridge the gap.

It is possible that Lisa’s successful transition could be attributed to the physical proximity of the two teams, as they were both in the same city where she was already receiving care. For the majority of the participants such a coordinated team approach was not the case. For Betty, age 21

years, she explained that a meeting between the pediatric and the adult healthcare team had been discussed, however, it never took place.

No, they talked about having that, like having both come together (pediatric and adult healthcare teams) but from what I recall it didn't happen, I just kind of went straight into the adult system.

Although Betty's experience lacked the collaborative meeting between the two systems, she was accessing care for her chronic pain from an adult chronic pain multidisciplinary team.

Nevertheless, without the benefit of the collaborative meeting, the adult chronic pain team may not fully understand where newly transitioned young adult are in their pain trajectory requiring them to retell their whole history. For some of the participants who did not have a collaborative meeting the retelling of their stories to the adult providers left them frustrated and perhaps make them question the competency of their new healthcare team. Stephanie, age 23 years, expressed this frustration as the adult chronic pain team seemed not to have received her full medical history and this left her feeling that the adult chronic pain team had nothing new to offer in her pain management. *"I still felt like I had to go over all the same things and they were suggesting things that I have already done, and I was kind of like ahhhhh read the chart."* Despite the variation in processes for these three participants, they were all transitioned in a timely fashion to an adult chronic pain service.

Unfortunately, this was not the case for others. Some of the participants were referred back to their general practitioner in their hometown, which caused additional challenges in accessing pain care when they moved to a new city for university or careers. Sally, age 21 years, expressed her distress in saying *"I was kind of worried because I didn't have a doctor up here"*

and admitting that she really did not know who to turn to help her manage her chronic pain in the city where she was attending university.

Transitioning participants back to their general practitioner rather than to the adult clinic was not uncommon. The integration of one's primary practitioner along with specialist care is arguably an appropriate approach to provide more comprehensive care. However, these participants were surprised by the way in which their pain management care was referred back to their primary care provider, as this was perceived as different than when they accessed care in the pediatric healthcare system. Here, Jen, age 18 years, expressed her surprise at the difference between pediatric and adult healthcare systems in terms of referring ongoing management back to their primary care provider and this was echoed by others. *"I see like they are a lot more family doctor focussed, the pain specialist doesn't necessarily prescribe me anything, he makes notes for the family doctor I have here"*.

Complicating the situation for young adults who are transitioned to their primary care provider is that the range of knowledge and skills needed to effectively manage chronic pain vary greatly amongst primary care providers. This range of pain expertise can pose complications for the newly transitioned young adult. Betty, aged 21, experienced unexpected complications potentially as a result of her well-meaning primary care provider not having pain expertise.

At the clinic at the university, a doctor there had agreed to be my temporary physician, while I was at school and so he had contacted my chronic pain doctor and said that this was alright to put me on Fentanyl, I don't know why I didn't think of it cause I was already on pain killers, and because it's long lasting he thought it would be helpful, but they just put me on too high of a dose to early and that's why I left university, I couldn't stay awake,

so I would sleep through, I wouldn't wake up from alarms, my RA would have to, like people would be banging on my door to wake me up.

Betty's experience speaks to the need to not only ensure that young people are transitioned to care providers who have foundational chronic pain management knowledge but that they themselves are knowledgeable about their treatments. Despite collaborating with a chronic pain physician, it appears as though Betty was not instructed to stop her other opioid analgesia, which may have contributed to the degree of her side effects. It is possible that the adult healthcare providers assume that these young people have an understanding of their pain management treatments. The significance of poor management cannot be understated as not only was Betty at risk for safety issues due to over-sedation but she had missed classes and withdrew from her university education.

Some participants were transitioned solely to a primary care provider. This situation was voiced as either being related to no adult chronic pain providers where they lived or the pediatric chronic pain team did not have an established relationship with the adult chronic pain team in the city where the participant was moving. For example, Brenda, aged 20 years, was never transitioned to an adult chronic pain healthcare team once she left for university. Although she was placed on the waiting list as a new patient to be seen in the adult chronic pain clinic in her new city, three years later, at the time of interview, she was still waiting to be seen.

I see a general physician that I've seen since I was a kid I mean in my hometown. I've been trying to get into the adult chronic pain centre here. I have two letters sent to me saying that the nurse will be phoning to set up time for a referral.

Furthermore, Brenda had to take the initiative to send in the referral letter from the pediatric team to the chronic pain team in the adult system, in the city where she went to university. Even

though she had the same primary care physician since childhood she voiced that this person did not fully understand her history or her pain management strategies. This suggests that her primary care physician was not an integral member of her pediatric chronic pain team, which now meant that she was accessing her chronic pain care from a physician who did not have the adequate knowledge of chronic pain or a full understanding of her medical history. Moreover, this practitioner was not in the same city where Brenda was attending school, which made receiving any medical treatment or follow-up a challenge.

No, I had to do it all myself, I mean like I have a general physician but again their knowledge of chronic pain is a very limited and they don't even know my history.

The lack of medical management, for Brenda, when she arrived to her new city, resulted in a hospital admission for an exacerbation of her chronic pain halfway through the semester. Despite this admission to the hospital in the adult healthcare setting, the adult chronic pain team had still not seen Brenda at the time of the interview.

Discussion

Through the sharing of transition experiences of by the participants in this study, it became clear that these young people with chronic pain share some challenges with other populations of young people with chronic conditions but also experience some unique challenges. As adolescents preparing for transition, the participants expressed having anticipatory excitement about moving on to the next chapter in their lives such as leaving home to attend post-secondary education. Many of the participants felt a sense of confidence initially leaving the pediatric setting. They believed that the transition to receiving care in the adult healthcare setting was going to be simple, only to realize that it presented its own challenges. This sense of confidence coupled with their inability to attain needed services suggests that at the time of transition, they

may not have developed the necessary knowledge and skills to manage the adult healthcare system and thus may not have been ready for transition.

At the time of transition, the participants of this study were all in the developmental phase of emerging adulthood. According to Arnett (1998), emerging adulthood is defined as a time when adolescents are between adolescence and adulthood. It is described as a process during which young people are learning to develop their individuality and is represented by becoming independent from others (especially from parents) and learning to be a self-sufficient individual (Arnett, 1998). In addition, transition to adulthood entails becoming responsible for one's self and for making independent decisions (Arnett, 1998). Thus, healthcare transition comes at a time when most young people are still developing the abilities to be self-sufficient individuals, despite many of them needing these abilities to access care. The participants in this study are no exception as they identified the necessity of relying on their parents to help them secure the care they needed. As adult healthcare systems claim to be patient-centred, adult patients need to manage their conditions and navigate the healthcare system themselves; it may be unreasonable to expect emerging adults to do this independently without at least initial support from their parents.

Contrary to the literature on transition, the majority of these participants did not voice experiencing heightened levels of anxiety leading up to the transition to adult healthcare services (Lugasi, Achille, & Stevenson, 2011; Rutishauser et al., 2014; Schwartz et al., 2014). The reasons for this are not clear but it may be that the participants in this study believed that accessing pain care in the adult healthcare setting would be similar to their pediatric experience. Due to the limited number of chronic pain clinics in Canada, geographic barriers may pose a challenge for pediatric practitioners to transition them to an adult chronic pain clinic (Lavis, 2009). As seen in

this study, this resulted in some young people with chronic pain to be transitioned to a general practitioner who may not have the expertise to provide them with the care that they require. General practitioners have identified experiencing challenges in treating their patients with chronic pain including understandable reservations about prescribing opioids for chronic pain management (Lavis, 2009). Although this was not necessarily the case for all participants in this study, at least one participant had negative outcomes from the opioid that was prescribed by the general practitioner. More research is needed to determine the best ways to help general practitioners improve their knowledge and skills in caring for young people with chronic pain and be integrated into the transition process.

Although the participants in this study did not experience a high degree of anxiety before they were transitioned, participants talked of experiencing increases in stress after their departure from pediatric chronic pain care. They experienced stress as a result of moving away from home, starting university, and for many of the participants, these challenges resulted in pain exacerbations. This is not surprising as there is a correlation between increased levels of stress and increasing levels of pain (King et al., 2011). However, for those without organized pain related adult healthcare services they were challenged as to where to turn for help with pain exacerbation, which led to negative outcomes including hospitalization in one case. For one participant, poor pain management after departing from pediatric care contributed to her leaving university. Not completing post-secondary education may have a negative lifelong impact on a young person's life. Given that successful transition cannot take place during a time of crisis (Peter, Forke, Ginsburg, & Schwarz, 2009) it may be reasonable to consider not transitioning young people with chronic pain until after they have had an opportunity to adjust to university—especially if they are not transitioned to adult chronic pain experts. Although university should

not be viewed as a crisis, major life events are certainly times for increases in stress related challenges, which may trigger pain exacerbations as experienced by many of the participants in this study. Research is needed to examine if continued care from a pediatric pain team for a period of time after a young person's move to post-secondary education or starting a career results in improved outcomes.

By mid-adolescence, most young people identify their best friend as their main source of social support (Bokhorst, Sumter, & Westenberg, 2010; Furman & Buhrmester, 1992). However, adolescents with chronic pain experience multiple challenges in peer relationships and friendships (Forgeron et al., 2010) and many voice experiencing friendship loss since the onset of pain (Forgeron, Evans, Mcgrath, Stevens, & Finley, 2013). Peer support has been identified as having a positive impact on transition for young adults with chronic illnesses (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014). However, for these young people with chronic pain, establishing a reliable peer support network proved to be a challenge. Some participants in this study identified that they found it difficult to create lasting friendships during high school and this challenge carried over as they entered the phase of emerging adulthood when attempting to create social networks at university or work. Without being able to establish and maintain friendships young people with chronic pain who are transitioning to another developmental stage in their lives may not be able to secure needed social support to help them cope with their chronic pain. The role of strong friendships, perhaps as a predictor of transition readiness warrants further investigation.

Research suggests that peer support from a person with a similar chronic illness can be helpful with the transition process (Fegran et al., 2014) and some of the participants in this study sought peer support groups as a strategy to cope with the lack of social support they perceived

from their friends. However, not all adult healthcare services offer age-specific peer support groups and, as highlighted by participants in this study, one has to question if ‘peer’ support by people considerably older offers the same benefits as peer support by those closer to one’s own age. Research is needed to understand what kind of peer supports may be helpful in the context of transition for young people with chronic pain.

Parents play a positive supportive role in the transition process (Heery et al., 2015; Reed-Knight et al., 2014; Sonneveld et al., 2013; Tuchman, Slap, & Britto, 2008) and are key in helping their children develop decision-making skills (Rapley & Davidson, 2010). Learning decision-making skills in a supportive setting with the encouragement of parents, is linked to positive transition outcomes (Reed-Knight et al., 2014). The majority of the participants in this study voiced that their parents played a supportive role in their transition to the adult healthcare setting. However some participants still relied on their parents to organize their care (e.g. organize their medications) and others spoke of regressing to the point where they would get their parents to help them mobilize. The transition process encompasses not only the transition between clinicians but also the transition between the role of the young adult and the parent in managing healthcare (Pai & Ostendorf, 2011; Reed-Knight et al., 2014). This may be more difficult for parents of young adults with chronic pain. Research suggests that the relationship between adolescents with chronic pain and their parents can create challenges for adolescents to achieve autonomy from their parents both emotionally and in terms of their decision-making abilities (Palermo, Valrie, & Karlson, 2014). This further highlights barriers to transition into adulthood as well as being able to function autonomously in the adult healthcare setting. Furthermore, higher levels of parent involvement in chronic pain related disease management activities are associated with increased levels of adolescent disability (Oliver-Carpenter, Barach,

Crosby, Valenzuela, & Mitchell, 2011; Palermo et al., 2014). Both of these findings suggest that clinicians in the pediatric and adult chronic pain settings may need to help parents and adolescents to gradually shift care. This gradual shift in care responsibility needs to begin early and not only include the tasks related to acquiring healthcare services (e.g. making and attending appointments on their own) but also includes the management of chronic pain on a daily basis (e.g. taking their medications, doing their exercises, understanding their treatments), in order for young people to be equipped to seek care as an adult healthcare consumer (Reed-Knight et al., 2014). However, little is known about the transition process from the perspective of parents whose child has chronic pain and thus transition strategies to support parents are not specific to the chronic pain context and warrant study.

Open collaboration between the pediatric healthcare clinicians and the adult healthcare clinicians prior to transition is linked to improved outcomes (Lugasi et al., 2011). Strategies, such as a joint meeting between the patient, family, and a member from both teams provides an opportunity for collaboration between all stakeholders. Collaboration between stakeholders can reduce anxiety, foster a more effective working relationship, and create a more positive transition experiences (Betz, Nehring, & Lobo, 2015; Lugasi et al., 2011). Research suggests that the closer the relationship between the pediatric and the adult healthcare clinicians, the more positive and seamless the transition will be for the young person transitioning (Crowley et al., 2011; Rapley & Davidson, 2010; Sonneveld et al., 2013). Of note, only one participant in this study reported having the opportunity to meet adult healthcare providers before transitioning, and another was able to receive care from both pediatric and adult chronic pain care providers for a period of time. For this participant being able to access care from both teams meant that her transition process was positive and although she experienced an increase in her pain intensity when she started

university, her ability to seamlessly access care resulted in her pain not interfering with other aspects of her life.

However, most participants did not have such a collaborative process during the transfer of their care and these participants experienced significant negative outcomes; dropping out of university, admission to hospital for pain care, being over-sedated on opioids, not receiving care despite continued chronic pain. Promoting continuity of contact with pediatric healthcare providers has been found to reduce the risk of long-term disengagement with care for young adults with chronic illnesses requiring transition, reduce missed appointments in the adult system (van Staa & Sattoe, 2014). Research into the barriers in providing more collaborative care transition processes for young people with chronic pain is needed to inform the development of strategies to improve transition outcomes for young people with chronic pain.

Transitioning to an adult healthcare provider with chronic pain expertise was a challenge for many of the participants in this study and as a result, many were transitioned to a general practitioner. In Canada there is inadequate access to regional multidisciplinary chronic pain management centres. Collaboration and shared care in transition needs to extend and include the young person's primary care providers earlier in their care. Most of the participants in this study expressed surprise in the differences of how the pediatric and adult chronic pain teams functioned. The adult chronic pain teams referred ongoing care back to the general practitioner but this was not the case in the pediatric chronic pain setting. Collaborating more formally with general practitioners when adolescents with chronic pain are accessing care from a pediatric chronic pain team may result in family general practitioners having a better understanding of chronic pain treatment for young people, which may improve their transition and decrease negative outcomes. This strategy warrants further research.

Strengths and Limitations

The strength of the study was that it captured the experiences of participants across Canada. The nine participants were from western, central, and eastern Canada and although each participant had a different experience, the challenges they faced with were similar. There were, however several limitations to this study. First, was the possibility that participants did not recollect their experience with clarity; as for some it had been 3 years since they had transitioned. Second, it may be that those who decided to take part are those who faced challenges in their transition process and wanted to tell their stories. However, several of the participants had successful transitions from pediatric to adult chronic pain providers suggesting that the participants' experiences are not solely negative. Finally, the goal of qualitative description is not to generalize, therefore it is not known if the experiences of the participants represent the majority of young people with chronic pain who are transitioned from pediatric to adult chronic pain care.

Conclusion

Young adults with chronic pain face many challenges when seeking care and moving forward into adulthood. Formalized transition processes are not well established in many centres that serve young people with chronic pain, which can lead to negative outcomes. It is the responsibility of stakeholders (i.e. young people, parents, healthcare providers) to understand their roles and responsibilities in supporting a successful transition. Starting the transition processes early, in partnership with the pediatric and adult healthcare teams, the general practitioner, parents, and the young person is paramount to successful transition for young people with chronic pain.

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Table 1: Demographics of participants

Alias	Current age	Age of diagnosis	University/working	Method of interview
Stephanie	23	16	Completed/working	Face-to-face
Lisa	21	12	University	Skype
Brenda	20	16	University	Face-to-face
Jen	18	17	University	Skype
Melissa	23	15	Completed/working	Skype
Betty	21	15	Not in school not working	Skype
Julie	20	16	Not in school/not working	Skype
Sally	21	16	University	Skype
Charles	19	12	University	Phone

Chapter 6

Integrated Discussion

Introduction

The overall purpose of this thesis was to understand the transition process for young people with chronic pain in Canada. This was achieved through two studies. One study was a quantitative descriptive study (Chapter 4), examining the nursing care practices in the pediatric and adult healthcare setting about transition preparations and supports for this population. The other study was a qualitative descriptive study (Chapter 5), examining the transition experience of young adults with chronic pain who had recently transitioned to adult healthcare services. This chapter will summarize the findings and discuss how the two studies highlight the unique challenges for young adults with chronic pain by integrating the findings. Furthermore, the implications for nursing practice, nursing research, policy, and further research will be discussed.

Study 1: Moving on: Transition Support for Young Adults with Chronic Pain in Canada

Twenty-two nurses started, however, eighteen completed the online survey consisting of two questionnaires designed to capture data based on the best practices for transition found in the literature and published guidelines. One questionnaire focused on the transition preparation and assessment practices that should be conducted within the pediatric setting and was completed by nurses who work in pediatric chronic pain clinics. The other questionnaire focused on the transition supports post transition to the adult healthcare setting and was completed by nurses who work in an adult chronic pain clinic. Of the pediatric nurses surveyed, none reported using a psychometrically validated tool to assess for transition readiness and preparation. However, one pediatric nurse participant identified that a validated tool was used to assess a youth's understanding of chronic pain during clinic visits. Of the pediatric nurses surveyed, six participants noted that the healthcare centre in which they practiced had a generic transition clinic and that they had the ability to refer the young person and their caregiver for formal assessment

of transition readiness. Only one participant identified that the pediatric pain clinic held a formal transition clinic with their adult counterpart for young people with chronic pain and their parents. Interestingly, the nurses working in the adult healthcare setting perceived recently transitioned young people as not being prepared to navigate the healthcare setting on their own suggesting that perhaps there is a mismatch between generic approaches to transition readiness in the pediatric setting and the skills, knowledge, and competencies needed for young people with chronic pain to navigate care in the adult chronic pain setting. However, the nurses in the adult setting did not identify differing practices to support the needs of newly transitioned young people with chronic pain compared to older adults with chronic pain. Of note, nurses in both settings identified that transition was a stressful time for young people suggesting that strategies are needed to help young people manage this stress.

Study 2: Growing Pains: Transition Experience of Young Adults with Chronic Pain

Nine young people between 18 and 23 years of age with chronic pain who had transitioned within the last three years were interviewed to capture their transition experience to the adult healthcare setting (Sandelowski, 2000). Transcribed interviews were analyzed using inductive content analysis (Elo & Kyngäs, 2008). The participants were recruited from western, central, and eastern Canada. The semi-structured interviews were conducted using an interview guide informed by the transition theory developed by Meleis and colleagues (2000) (Meleis, Sawyer, Im, Hilfinger, & Schumacher, 2000). Five main categories arose from the analysis: *I can do it, maybe?: Independence*; *Stress and pain along for the ride: Pain trajectory*; *Need a shoulder to lean on: Informal support networks*; *Obviously you are there: Parental supports*; and *The bridge: Collaborative systems*. These categories suggest that the experience of transition for young people with chronic pain needs to consider both their developmental transition challenges

as well as their healthcare transition challenges. Unlike other young people with chronic conditions many of the participants were either (a) not transitioned to a clinician with pain expertise or (b) not transitioned in a timely manner even if they were referred to an adult pain clinic. Moreover, in moving along their developmental transition trajectories some of these participants faced disbelief of their condition as they started university or careers. This presented a situation that is not faced by most others with a chronic condition (e.g. diabetes). The result of these challenges led to negative outcomes for some of these participants which included having to leave university due to poorly managed pain and having to access emergency departments for their ongoing chronic pain care needs.

Integrated Discussion

In keeping with the key themes described in the literature review chapter (Chapter 2) the significant integrated findings from the two thesis studies will be discussed under three separate headings: the individual, the parental role, and the collaborative system.

The Individual

The time of transition to adult healthcare comes when adolescents themselves are entering emerging adulthood, which is defined as the time between adolescence and adulthood (Arnett, 1998). During emerging adulthood young people are developing the knowledge, skills, and capacities necessary to become independent self-sufficient individuals such as those needed for seeking and securing needed support. Both of the studies, (Chapters 4 & 5), suggest that these criteria (knowledge, skills, and competency) amongst young people with chronic pain have not been fully developed at the time of transition into the adult healthcare setting. This finding is not overly surprising as chronic pain has been found to disrupt cognitive function including information processing, learning, attention, memory, decision-making, planning, and abstract

thought (Dick & Pillai Riddell, 2010). Furthermore, chronic pain peaks during pubertal development and thus may impede the physical, cognitive, emotional and social changes that accompany adolescence (Palermo et al., 2014) suggesting that young people with chronic pain may not be developmentally ready to take on the responsibilities expected in the adult healthcare system.

Some of the recently transitioned adolescent and young adult participants in this study believed that they were ready to transition when they were still being cared for by their pediatric chronic pain team; however after transition, realized that they had not developed the knowledge or competencies expected within the adult healthcare setting. The need for more systematic transition assessment is supported by the findings of the quantitative study (Chapter 4), as most pediatric nurses reported that they did not use a validated transition assessment tool to assess for transition preparedness and the adult healthcare nurses perceived young people with chronic pain as unprepared for transition. Research is needed to determine if young people with chronic pain who are assessed for transition preparedness and receive targeted strategies specific to their needs while in the pediatric setting experience have more successful transition outcomes.

The use of transition preparedness assessment tools could diminish the levels of anxiety around transition by suggesting the areas nurses and other interprofessional clinicians should target in their care both pre and post transition (Moynihan et al., 2015). By beginning the discussion about transition early, young people would have the adequate time prepare which in turn, may alleviate some of their transition-related anxiety. Rutishauser and colleagues (2011) reported that 20% of participants with a variety of chronic conditions identified that transition related anxiety (e.g. meeting a new transition provider) was the second greatest barrier to transition; the first barrier being the ease that the participant felt with their pediatric provider in

comparison with the anxiety they felt speaking with new adult healthcare providers (Rutishauser, Akre, & Suris, 2011). Strategies to decrease transition related anxiety are critical to young people with chronic pain as anxiety is associated with pain related disability (Benore, D'auria Banez, Worley, & Tang, 2015). Thus additional anxiety caused by transition may exacerbate pain-related disability at a time when young people need to be more independent.

Both young people with chronic pain who participated in the qualitative study and the nurses who participated in the quantitative study indicated that increased stress and pain exacerbations occurred during the transition process. By providing the emerging adult with the knowledge and skills necessary to transition and time to practice their skills, their transition related anxiety could be further diminished. However, young people with other chronic conditions often tend to emerge earlier in life, facing transition have, on average, been accessing care within the pediatric setting for nine years (Rutishauser et al., 2014) whereas chronic pain peaks during adolescents, limiting the time for these transition preparations and discussions. Thus transition preparation for young people with chronic pain needs to be prioritized by the pediatric healthcare provider to allow sufficient time to prepare young people with pain for transition.

Parental Role

A primary factor related to a successful transition is the gradual shift of responsibilities of healthcare management from parent or caregiver to the young adult (Pai & Ostendorf, 2011; Reed-Knight et al., 2014). Parents have an important role in the development of young adults' decision-making skills, especially in a time of increased stress (e.g. during the transition process) (Rapley & Davidson, 2010). Parents are essential in encouraging and providing opportunities for the development of the knowledge, skills, and decision-making needed to be independent and autonomous. Ideally parents are relinquishing the care management role and supporting young

people in their ability to make care management decisions. However, for parents of young people with chronic pain this may be more challenging, as the balance between parental involvement and autonomy has been reported to be complex (Evans, Meldrum, Tsao, Fraynt, & Zeltzer, 2010; Palermo et al., 2014). Logan and colleagues (2012) found that the protective responses of parents of adolescents with chronic pain were linked to poorer functional outcomes for adolescents (Logan, Simons, & Carpino, 2012). Similarly, for some young people in the qualitative study (Chapter 5), they stated that they still required significant support from their parents, which extended well beyond assistance with accessing healthcare. Most of the participants did not voice an understanding that transition to the adult healthcare setting would or should entail a shift in responsibility from their parents to their own independence. None of the nurses reported a formalized assessment or support of parents to help them ‘let go’ pre, during, or post-transition. Taken together the findings from these two studies reinforce the notion that parents need support to encourage their children in their own acquisition of their healthcare.

Most of the literature on parental preparedness is grounded in the pediatric context (e.g. (Peeters, Hilberink, & van Staa, 2014). Yet, the pediatric nurses in the quantitative study (Chapter 4), identified that their clinic does offer formalized assessment of the parents’ ability to help transition their child to the adult healthcare, setting suggesting a gap in the uptake of transition care knowledge in practice. Furthermore, the nurses in the adult healthcare teams from the quantitative study did not offer targeted support of parents (apart from parents being permitted to attend clinic visits) as they expected young people to manage independently. The studies from this thesis suggest that an understanding of parents’ needs throughout the transition of parent-child care is warranted. Moreover research exploring parental experiences could inform the development of a transition assessment tool that focus on parents of the young people with

chronic pain, as currently, the parental perspective are absent from most transition measures (Schwartz et al., 2014).

Collaborative Systems

Closer relationships between the pediatric and adult care providers have been found to result in more seamless transitions for young people with chronic health conditions (Rapley & Davidson, 2010). Collaboration between pediatric and adult care providers is a contributing factor to a successful transition. Furthermore a joint meeting between the pediatric and the adult healthcare providers prior to transition provides an opportunity for the young person and their parents to meet the healthcare providing team, which has been shown to reduce anxiety, foster a collaborative relationship amongst all stakeholders (young adult, parent, pediatric and adult care providers), and creates a positive transition experience (Betz et al., 2015; Lugasi et al., 2011; Rutishauser et al., 2014). Unfortunately, the narratives of most of the young people with chronic pain who took part in this research did not describe an open collaboration between the pediatric and adult healthcare systems (Chapter 5). A contributing factor to open collaboration (e.g. joint meetings) could be that the majority of the young people who participated in this research were enrolled in university and moved to a different city from where they received pediatric care. Moving away from where one has accessed pediatric pain care poses a challenge for the pediatric and adult health care providers as they may not know one another and as a result they would not have an established relationship, which may be an additional challenge to open collaboration. Nevertheless, the importance of a joint transition meeting does not appear to be part of the routine practice in clinics across Canada as only one pediatric nurse reported providing routine collaborative joint meetings prior to transition.

Further these studies suggest that, pediatric providers may not know who best to transition the young person's care when they move to a different city or province. One of the additional challenges to collaboration between the two healthcare sectors could be that there is an inadequate geographical access in Canada to regional multidisciplinary chronic pain management centres to transition this population (Lavis, 2009). This means that for those young people who are leaving home for the first time and moving to a city where there is limited adult chronic pain services, the bridge to the adult healthcare setting is disrupted as the pediatric team does not have connections established in the city where the young adult is moving. The establishment of a national network for pediatric and adult chronic pain interprofessional providers to have access and connections with one another in order to establish the bridge between the two systems is needed.

Electronic consultation technologies, or telehealth, could offer promising improvement in accessing chronic pain specialist in the adult healthcare system (Liddy et al., 2016) for this transitioning young adult population. This technology would allow for a collaborative transition meeting amongst the young person, parents, and pediatric and adult chronic pain specialists regardless of where the adult chronic pain specialist is located. Furthermore, with the advancements in this form of technology, patients do not need to be seen in a traditional clinical setting. For the young people who participated in the qualitative study (Chapter 5), they identified that one of the barriers to accessing chronic pain treatment was the inability to find an adult chronic pain team in the city where they had recently moved. It is possible that in the future chronic pain patients and their specialist pain provider (e.g. physicians, psychologists, nurses) would not have to be in the same location to provide and receive pain care. Indeed, electronic consultation has the potential to bridge the care gap between patients and specialist eliminating

the need for the face-to-face consultation (Liddy et al., 2016). With the advancement of technology, nurses need to be supported in acquiring new knowledge and skills in providing patient care using telecommunications technology (Fronczek, Rouhana, & Kitchin, 2017). However, the use of technology to support the transition of young people with chronic pain warrants further research.

Implications for Nursing

Nurses are particularly well positioned to support successful transition of young people with chronic conditions, such as chronic pain, by virtue of nursing's ontological underpinnings as a discipline whose mission is to support health, well-being, quality of life and the human experience as a whole (Joly, 2016). However, in many cases, there is a lack of role delineation within the interprofessional team in identifying which provider will take the lead. Given the interprofessional nature of chronic pain treatment, nurses are in an ideal position to have a defining scope within transitional healthcare practices (Betz, 2013). The results from this thesis have several implications for nursing practice, education, policy development, and research as well as implication for other interprofessional team members.

Nursing Clinical Practice

Nurses have a key clinical role in educating and facilitating the transition process for young people and their families (Betz et al., 2015). Within the direct clinical setting nurses are positioned to assess young people's transition preparedness and provide interventions targeted at identified gaps. For example, in a study conducted by Heery and colleagues (2015), the importance of education for the patient and their families about the implications of their condition as well as the differences between the pediatric and the adult healthcare setting was highlighted (Heery et al., 2015). Through the use of psychometrically validated transition tools they can work

with the young people and their families in determining if the young person has the knowledge and skills required to navigate the adult healthcare system and manage their chronic pain (Moynihan et al., 2015). Although there are validated transition tools available they are not specific to the chronic pain population and therefore may need to be supplemented with clinical expertise. Nevertheless, the use of validated transition tools can help nurses (and others) track progress of transition readiness over time (Schwartz et al., 2014). These validated tools can direct clinical practice through supporting patients and their caregivers to acquire and master the skills necessary for a successful transition.

Through the role of care coordinators nurses could lead the organization of supports and care for a smooth transition to an adult healthcare provider. In addition through the process of leading the coordination of transition, nurses would be able to create networks with other providers (Joly, 2017). This is needed within the context of chronic pain as the participants with chronic pain in this research voiced that it was difficult to find adult chronic pain interprofessional teams outside of urban centres (Chapter 5). Nurses could ensure that a link was made to the adult healthcare system by networking with adult healthcare providers (including post-secondary student services) in the communities in which the young person is transitioning and provide a comprehensive handover to the new care provider.

Nursing Research

Through these studies, it is clear that this clinical population of young adults with chronic pain face some similar and significant challenges as well as some unique challenges compared to other populations of young people with chronic health conditions. Although validated assessment tools support the robust assessment of transition readiness, the tools available do not address the specific needs of young people with chronic pain. Research is needed to develop assessment tools

to address the specific areas of care for this population. For example, many young people were transitioned to a family physician but findings suggest that some of these young people did not understand their treatment adequately to engage effectively in their care with a family physician. Thus, assessment tools and interventions designed to help young people with chronic pain understand their condition and treatment are needed.

The age when a young person transitions from pediatric healthcare to adult healthcare is variable and there is no national level agreement (CAPHC, 2016). Most of the young participants talked of transitioning to adult healthcare services at the same time that they moved away from their hometown to attend university and pediatric nurse participants' responses corroborated this finding. Given the amount of change that occurs during this typical developmental trajectory it may be that these young people are too vulnerable to negative sequelae that may accompany poor transition (e.g. pain exacerbations, loss to follow up) to transition at this time. Research is needed to determine if transitioning young people after they have adapted to their new stage of life improves transition outcomes.

This thesis found that an understanding of the parent role in transition for young people with chronic pain was lacking. Research has identified the impact of the parental relationship on chronic pain suggesting that the parental role is central in a child's adaptation to pain and therefore suggests that working closely with parents offers important targets for treatment and intervention (Finley, Chorney, & Campbell, 2014). Transition is a time of major change in relationship with clinicians in the healthcare system for parents as well as young people. Since higher parental involvement in pain management activities has been found to be associated with higher levels of youth disability (Oliver-Carpenter et al., 2011; Palermo et al., 2014) transition-related assessment and interventions for parents of this population warrants further attention.

The findings of this thesis suggest that collaboration between the two healthcare settings is mostly influenced by proximity of adult healthcare providers to the pediatric chronic pain providers. Moreover, those young people who were transitioned to adult chronic pain clinicians with whom their pediatric chronic pain clinicians had an established relationship had smoother transitions with better outcomes. Presently in Canada it may be that transition related leadership within the pediatric interprofessional team is not formalized. A nursing philosophy of care (holistic in nature) suggests that pediatric and adult nurses are in a position to provide needed leadership in the area of transition especially given their scope of practice, knowledge, and skills (Betz, 2013). Research is needed to determine if having a designated transition leader on the young person's chronic pain team improves transition outcomes and whether and how this process helps to establish connections amongst care providers.

Policy Development

Policies and protocols regarding the transition of young people with chronic pain from pediatric to adult healthcare settings appear to be lacking. Nurses are in a position to have a positive impact on transition through the development of policies. With the publication of the national transition guideline by CAPHC in 2016, nurses need to advocate for their adoption as a minimum standard to guide transition for young people with chronic pain (CAPHC, 2016). Nurses working in both the pediatric and the adult healthcare setting can advocate through the development of policy for further involvement with the young person and their family past the age of transition. Nationally there is no one specific age of transition as healthcare policies are determined by the province and health services in which the young person is being treated and typically range between 17 and 19 years of age (CAPHC, 2016). Developing a health centre policy that would allow the age of transition to be more flexible and based on assessment of

transition readiness would be more appropriate for those with chronic pain. This may be of particular importance to young people with pain for several reasons. First, many young people with chronic pain are transitioned to adult healthcare providers who do not have chronic pain expertise and thus demonstration of reliable performance of prescribed healthcare behaviours needs to take precedents over chronological age of patients for transition (Reed-Knight et al., 2014; Rutishauser et al., 2014). Second, chronic pain tends to peak in adolescence (Palermo et al., 2014; Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, & Schmucker, 2005) which was also found in this research with an average diagnosis age of 15 years. Thus young people's time in the pediatric healthcare setting is limited, meaning that they may benefit from an older transition age as the immediate need when they meet their pediatric chronic pain team is focused on chronic pain management not transition preparation. Finally, chronic pain may be difficult to diagnose and many adolescents have had multiple unsuccessful health care interactions, which has led to scepticism of professional abilities to help them (Dell'Api, Rennick, & Rosmus, 2007). Therefore being transitioned soon after they have developed a therapeutic relationship may negatively impact the young person's engagement in the prescribed multimodal chronic pain treatments if they have to transition relatively soon to a new healthcare provider. These factors suggest that having a policy that allows for more flexible age of transition for young people with chronic pain may be especially helpful at improving transition outcomes.

Finally, policy-makers in the adult healthcare setting have minimal understanding of the services required to support newly transitioned young people and their parents once they need to access care in the adult healthcare setting (Joly, 2017). Nurses and other interprofessional clinicians who work with young people with chronic pain are positioned to advocate for the development of policy in the adult healthcare setting to improve transition related outcomes.

Increasing awareness of the needs of this population to adult healthcare administrators is a first step

Nursing Education

Transition-related education is needed for nurses and other clinicians who work with young people with chronic pain. Education is needed both pre and post licensure as healthcare transitions occur throughout the lifespan and best practices change as knowledge is generated over time. Transition related education should include information on healthcare transition but also information about the developmental transition from adolescence to stage of the emerging adult. Nurses and other clinicians who work in the chronic pain field must have an understanding of the specific needs of this population and the challenges they face with regards to transition. Given the differences in care philosophy between settings—family-centered care compared to patient-centered care—knowledge about both systems may help pediatric nurses and interprofessional clinicians better prepare young people and their parents to navigate the adult healthcare system and the adult nurses and interprofessional clinicians understand how best to support young people and their parents.

Conclusion

This thesis sought to understand the experience of transition from the pediatric setting to the adult healthcare setting for young people with chronic pain in Canada. This research suggests that young people with chronic pain have similar transition related needs to other young people with chronic conditions as well as additional unique challenges. Needing to access care from non-pain experts, limited time to prepare for transition, challenges with self-management, as well as a lack of understanding of chronic pain encountered in society may hamper successful transition. Access to chronic pain services is limited and remains so for young people despite accessing

chronic pain care in the pediatric setting. Even when young people with chronic pain are transitioned to adult chronic pain clinics most nurses report pre transition assessment and interventions are provided informally. Nurses report few services targeted specifically for young people with chronic pain and their parents who have recently transitioned to the adult setting. Nurses and other interprofessional team members could have a positive impact on transition outcomes for young people with chronic pain by developing formalized processes and forming a network of practitioners interested in working with young people with chronic pain in order to improve outcomes. Further research is warranted to determine effective interventions to meet the unique transition needs of this population.

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Appendices

Appendix A: the University of Ottawa Research Ethics Board Approval

File Number: H03-16-04

Date (mm/dd/yyyy): 04/07/2016



Université d’Ottawa **University of Ottawa**
 Bureau d’éthique et d’intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice
Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Paula	Forgeron	Health Sciences / Nursing	Supervisor
Bruce	Dick		Co-investigator
Denise	Harrison	Health Sciences / Nursing	Co-investigator
Andrea	Higginson	Health Sciences / Nursing	Student Researcher

File Number: H03-16-04

Type of Project: Master's Thesis

Title: Nurses care practices in supporting transition of young people with chronic pain: A Canadian descriptive study

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
04/07/2016	04/06/2017	Approval

Special Conditions / Comments:
 N/A

Appendix B: Introductory Email

Hello,

My name is Andrea Higginson, and I am conducting a study as part of my Master's in Nursing thesis. This study is exploring the practices and resources presently available to support adolescents and young adults with chronic pain as they transition from the pediatric health care setting to the adult health care setting. This study has been granted ethics approval by the University of Ottawa ethics review board.

If you are a registered nurse who works with either children/adolescents or adults with chronic pain we invite you to complete a short (15-20 minute survey) to help us describe the present transition context. This is an anonymous survey and is hosted on the secure server of the Children's Hospital of Eastern Ontario (CHEO's) Research Institute. There is an information and consent form at the beginning of the survey. By clicking on the link below, it will take you to the beginning of the study. However, we invite you to contact either myself, or my supervisor Dr. Paula Forgeron (contact information below), if you would like further information.

The link to the survey is here: <https://redcap.cheori.org/surveys/?s=8DR79C94N7>

I do hope you will consider participating and helping us understand more about the transition context for adolescents and young adults with chronic pain here in Canada.

Thank you

Andrea Higginson BScN RN

Masters of Nursing student

University of Ottawa

E:

T:

Paula Forgeron RN MN PhD

Assistant Professor, School of Nursing

University of Ottawa

E:

T:

Appendix C: Follow-up Email

Dear Participant,

This is reminder that there is still time for you to participate in a study examining the transition of the adolescent patient with chronic pain into to the adult healthcare system. The aim of the study is to identify current transition interventions that are in place across Canada for this population. The intention of the study is to examine if adolescents with chronic pain experience these same challenges or if we can identify ways to better support them.

You are being asked to be part of this study because, as a chronic pain nurse, you are in a position to understand all aspects of patient care delivery. Nurses are in a position to understand the process that adolescent patients may face or have faced to achieve chronic pain management. By participating in the study, you will be asked to complete an online survey, which will take approximately 15-20 minutes. Depending on which setting you deliver care (pediatric or adult) you will be asked questions about transition and care delivery prior, during and post this transition. The Ottawa University Research Ethics Board (REB) has reviewed and approved this study. Your participation in this study is voluntary.

Confidentiality and privacy

All information gathered will be kept confidential. All information will remain anonymous and no identifying information about any of the respondents or specific clinics will be identifiable.

The link to the survey is here: <https://redcap.cheori.org/surveys/?s=8DR79C94N7>

I would ask that you would have the survey completed by (*beginning of September, 2016*). By completing and submitting this survey online, you have provided consent to participate in the study.

Please feel free to contact feel free to contact Andrea Higginson at _____, if you have any questions about the study.

Your assistance with this survey is greatly appreciated. Thank you for your time and consideration.

Andrea Higginson BScN, MScN (c)

University of Ottawa

Appendix D: Recruitment Poster



CHRONIC PAIN and TRANSITION

**Are you an RN that works with adolescents
or adults with chronic pain?**

**We are conducting a study to explore the
practices and resources to support
adolescents and young people with chronic
pain as they transition into the adult
healthcare setting.**

**The survey will only take approximately 10
minutes.**

PLEASE CLICK HERE

**<https://redcap.cheori.org/surveys/?s=8DR79C94N7>
TO COMPLETE THE SURVEY ANY TIME.**

FOR MORE INFORMATION PLEASE CONTACT US:

**Andrea Higginson
Primary Investigator
University of Ottawa**

**Paula Forgeron
Research Supervisor
University of Ottawa**

Appendix E: Screening Questions

Do you work in the chronic pain setting?

1. Yes
2. No (if participant answers no, a pop-up screen will appear stating: did you mean to answer no to the previous question, if the participants answers yes, then the survey will automatically send the thanks you for participating screen (Appendix))

Are you a Registered Nurse?

1. Yes
2. No (if participant answers no, a pop-up screen will appear stating: did you mean to answer no to the previous question, if the participants answers yes, then the survey will automatically send the thanks you for participating screen (Appendix))

Do you practice nursing in Canada?

1. Yes

3. No (if participant answers no, a pop-up screen will appear stating: did you mean to answer no to the previous question, if the participants answers yes, then the survey will automatically send the thanks you for participating screen (Appendix))

Appendix F: Thank you message sent if participant answers “no” to screening questions

Dear Participant,

Thank you for taking the time to read the correspondence and answer the screening questions.

Your participation to this point is greatly appreciated, however is no longer required for the study. If you have any questions, please do not hesitate to contact us.

Thank you,

Andrea Higginson BScN RN

Masters of Nursing student

University of Ottawa

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T:

Paula Forgeron RN MN PhD

Assistant Professor, School of Nursing

University of Ottawa

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T:

Appendix G: Consent for REDCap

uOttawa

Title of the study: Nurses practices and setting supports for successful transition of adolescents and young adults with chronic pain: A descriptive survey.

Name of Researcher: Andrea Higginson, RN BScN MScN student

University of Ottawa, Health Sciences Department, School of Nursing

T:

Name of Supervisor: Dr. Paula Forgeron, RN PhD

University of Ottawa, Health Sciences Department, School of Nursing

T:

Invitation to Participate: I am invited to participate in the research study mentioned above conducted by Andrea Higginson RN BScN MScN student, and Dr Paula Forgeron, RN PhD.

Purpose of the Study: The purpose of this study is to identify current practices and resources across Canada that support young people with chronic pain as they transition from the pediatric healthcare setting into the adult healthcare setting. Studies indicate that transition is a challenge for the adolescent population with chronic illness, yet little is known about the transition experience of young people with chronic pain. The findings of this study will help us understand

the current practices and resources to identify the gaps that exist and identify ways to better support the needs of this population.

Participation: By participating in this study, I will complete an online survey, which will take approximately 10 minutes. Depending on which setting you deliver care (pediatric or adult) you will be asked questions about transition and care delivery prior, during and post this transition. The Ottawa University Research Ethics Board (REB) has reviewed and approved this study. My participation in this study is voluntary.

Risks: There are no risks in participating in this study.

Benefits: There are no direct benefits to my participation in this study. The study results will contribute to the limited body of knowledge on the supports of transition of the adolescent with chronic pain.

Confidentiality and Anonymity: I have been assured that all information gathered will be kept confidential. All information will remain anonymous and no identifying information about any of the respondents or specific clinics will be identifiable. All information given will be used for this study only. In order to minimize the risk of security breaches and to help ensure your confidentiality we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you are no longer using them / when you have completed the study.

Anonymity will be protected in the following manner. I will be given a participant identification number. My name or institution of employment will be erased from the data before the time for data analysis. All documents in the study will be password protected and encrypted.

Conservation of data: The data collected from the survey will be password protected and encrypted. The only people that will have access to the data will be Andrea Higginson, and Dr. Paula Forgeron. Andre Higginson, Dr. Paula Forgeron, and the thesis committee will have access to the anonymous data.

Compensation: There will be no compensation for my participation in this study.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I may withdraw from the study at any time and/or refuse to answer any questions. If I choose to withdraw, all data gathered until the time of withdrawal will be removed from the study if I do not want it to be included. If I do not identify that I do not want it to be used, the researcher may include it in the study. Permission from my organization has not been sought.

If I have any questions about the study, I may contact the researcher and/or her supervisor at the above information.

If I have any ethical concerns regarding my participation in this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, 550 Cumberland Street, Room 154.

ethics@uottawa.ca

T: (613) 562-5387

Completing and submitting the survey means that you have given your consent to participate in the study.

I consent to this study

I decline my consent to this study

We encourage you to print a copy of this consent form for your records.

Appendix H: Redcap Cover Page and Survey

Study title: Nurses practices and setting supports for successful transition of adolescents and young adults with chronic pain: A descriptive survey.

You are being asked to participate in an online survey conducted by the University of Ottawa to examine the current transition setting for adolescents and young adults with chronic pain in Canada. Transition for young adults with chronic illness to the adult healthcare system has been identified in the literature as having barriers and facilitators. The aim of this study is to describe the present transition context, specifically for adolescents and young adults with chronic pain.

Andrea Higginson, Master's of Nursing student, of the University of Ottawa is leading this study and Dr. Paula Forgeron is her supervisor. Taking part in this study is voluntary.

If you choose to participate you will be asked questions about the patients that you care for who are going through, or have transitioned into the adult healthcare system. Your input is of great value as you have a unique perspective on the practices and resources available in your practice setting that support adolescents and young people with chronic pain prepare for and access services during the transition phase. Once the study is complete, I will share a summary report of the results with you by posting them on the Yahoo Pain Nurses Listserv as I will not have your identifying information or personal contact information.

All information gathered will be kept confidential. Any publications of the findings will be anonymous and no identifying information about the participants or the organizations in which

they work will be reported. All surveys will be kept on a secured network at the Children's Hospital of Eastern Ontario Research Institute (CHEO RI) and all study data will be stored on Dr. Paula Forgeron's private server space at the University of Ottawa (encrypted and password protected). We will keep the data collected from the survey for 5 years after the completion of the study. At this time the data will be permanently destroyed.

The University of Ottawa has reviewed and approved this study. The REB is a committee of the university that includes individuals from different professional backgrounds. The board reviews all research that takes place through the university. Its goal is the protection of the rights and welfare of people participating in research.

Please feel free to contact Andrea Higginson at _____ or Paula Forgeron at _____ if you have any questions about the study.

Completing and submitting the survey means that you have given your consent to participate in the study.

Thank you for your time, your assistance is important and appreciated.

Survey Questions

Survey:

1. What province is the pain clinic located in?
2. Do you provide care in the pediatric or adult care setting?

Depending on the answer to question 2 above the participant will be asked only the questions that pertain to their setting.

PEDIATRIC SETTING

1. At what age do you transition adolescents to adult health care services?
2. Does the healthcare team discuss transition with the adolescent patient with chronic pain and their parents?
 - a. No
 - b. Yes, if so when do you have this discussion?
 - i. Last visit
 - ii. 6 months before transition
 - iii. 1 year before transition
 - iv. Over one year
3. Do adolescent patients attend the whole or part of appointments without their parent or guardian?
 - a. Yes
 - b. No
4. Do you assess the adolescent for their ability to self-manage their chronic pain without their parents' assistance?

- a. No.
 - b. Yes. If so, how is this assessed in your setting? (Open box to type in additional response)
5. Do you assess the adolescent for their ability to manage the health care contexts (e.g. make appointments, call for prescription refill, advocate for themselves)?
- a. No.
 - b. Yes.
6. Do you assess the adolescent for their ability to understand chronic pain?
- a. No.
 - b. Yes.
7. Do you assess the adolescent's understanding of their medications?
- a. No.
 - b. Yes
8. Do you assess the adolescent's understanding of the psychological strategies to help manage pain?
- a. No.
 - b. Yes
9. Do you assess the adolescent's understanding of the physical approaches to help manage pain?
- a. No.
 - b. Yes

10. Do you assess the adolescent's or young person's ability to advocate for themselves in different settings (i.e. with employers, teachers, professors) about their chronic pain condition?
- No.
 - Yes
11. Is there a support group available for the adolescent or young adults and their guardian or parent to seek support with transition?
- No.
 - Yes.
12. Do you offer any patient literature on the transition experience?
- No.
 - Yes.
13. Does your healthcare facility have a transition clinic to refer the patient to?
- No.
 - Yes.
14. Do you have a formal chronic pain transition clinic with adult healthcare providers?
- No
 - If no, how do you collaborate with adult healthcare workers
 - Referral letter from MD
 - Referral letter from each healthcare provider (e.g. psychologist, physiotherapist, physician, nurse)
 - Discussion over the phone with the adult healthcare providers.

- d. Meeting face to face with adult healthcare providers
- b. Yes.
 - ii. If yes, can you briefly describe what the pediatric and adult pain services team do together? (open-ended question for free text)
 - 1. Do all adolescents have the same formal transition process?
 - i. No.
 - 1. If no, why not (open text)
 - ii. Yes.

15. Is there anything else we should know about your transition practice? (Open-ended question for free text)

ADULT HEALTHCARE SETTING

- 1. Is your clinic private or publically funded?
 - a. Private
 - b. Public
- 2. Does the provincial government fund your pain clinic?
 - a. No.
 - b. Yes.
- 3. Are you referred patients that were treated in the pediatric setting?
 - a. No. **If no, then survey is completed at this point.**
 - b. Yes.
- 4. Does your pain treatment facility ever contact the pain treatment facility of the transitioned young patient?

a. No.

1. If no, does the patient come to the first appoint with a written copy of their medical history?

a. No.

b. Yes.

b. Yes.

1. If yes, do you have a formal transition clinic with the pediatric centre?

a. No.

b. Yes.

2. Do you have formal discussions with the referring: (tick box for all that apply).

a. Physician

b. Registered Nurse

c. Psychologist

d. Physiotherapist

e. Other:

3. Do you receive a referral letter from the services **only**?

a. No.

b. Yes.

5. Do you include the parents in the appointment?

a. No.

b. Yes.

1. If yes, do parents attend the entire or part of the appointment?
 - i. Part
 - ii. Entire
6. Do you permit parents to attend further appointments?
 - a. No
 - b. Yes
 - a. If yes, for how long do you permit parents to attend appointments with their adolescent or young adult?
7. Do you permit parents to call for appointments, refills, update information, pain management advice?
 - a. No.
 - b. Yes.
8. Do you find that newly referred patients and their parents are prepared for treatment for the adult healthcare system?
 - a. No.
 1. If no, what do you believe is missing from their preparation? (open-ended question, free text).
 - b. Yes.
9. Does your clinic provide support to newly transitioned young adult patients after hours?
 - a. No.
 - b. Yes.
 1. If yes, who can the patient contact?

- a. Physician
- b. Registered Nurse
- c. Psychologist
- d. Physiotherapist
- e. Other: (free text):
 - i. What method is available for them to contact you after hours: (drop down and click whatever answer applies): phone, in person, email, pager, text.

10. Does your clinic offer group sessions to people living with chronic pain?

a. No.

b. Yes.

1. If yes, do you offer sessions for young adults only?

i. No.

1. If no, what is the average age of the group in these sessions?

ii. Yes

1. If yes, what is the age range of participants for these young adult group sessions?

11. Do you provide support in advocating for school or university accommodations for younger patients?

a. No.

b. Yes.

1. If yes, how do you formally requested accommodations

- a. Phone
- b. Letter
- c. Face to face meeting
- d. Electronically (email)

12. What is the youngest age of a patient you have cared for in your clinic? (number age of patient).

13. Is there anything we did not ask about the care you provide for recently transitioned young people with chronic pain at your clinic that you feel we should know? (open-ended question, free text)

Appendix I: Thank you message when survey is completed or stopped midway

Dear Participant,

Thank you for taking the time to read the consent and participating in the survey. If you did not have the time to complete the survey and wish to return later, please feel free to start the survey again. If you have any questions, please do not hesitate to contact us.

Thank you,

Andrea Higginson BScN RN

Masters of Nursing student

University of Ottawa

E:

T:

Paula Forgeron RN MN PhD

Assistant Professor, School of Nursing

University of Ottawa

E:

T:

Appendix J: Research Ethics Board Approval from the Stollery Children's Hospital**Approval Form**

Date: July 15, 2016
 Study ID: Pro00064138
 Principal Investigator: [Bruce Dick](#)
 Study Title: Exploring the transition experience of young people with chronic pain from pediatric to adult chronic pain services: A qualitative descriptive study.
 Approval Expiry Date: Tuesday, June 20, 2017

Approved Consent Form:	Approval Date	Approved Document
	7/15/2016	Information Letter and Written Consent Form REVISED
	7/15/2016	Verbal Consent Script v2

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel . Your application, including the following, has been reviewed and approved on behalf of the committee;

Recruitment Poster V4 (6/14/2016)

Letter of Initial Contact (3/24/2016)

Interview Script (3/24/2016)

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services approvals should be directed to (780) 407-6041. Enquiries regarding Covenant Health should be directed to (780) 735-2274.

Sincerely,

Anthony S. Joyce, PH.D.
 Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix K: Research Ethics Board Approval from the University of Ottawa

File Number: H05-16-10

Date (mm/dd/yyyy): 08/16/2016



Université d'Ottawa **University of Ottawa**
 Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice**Health Sciences and Science REB****Principal Investigator / Supervisor / Co-investigator(s) / Student(s)**

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Paula	Forgeron	Health Sciences / Nursing	Supervisor
Bruce	Dick		Co-investigator
Allen	Finley	Others / Others	Co-investigator
Denise	Harrison	Health Sciences / Nursing	Co-investigator
Andrea	Higginson	Health Sciences / Nursing	Student Researcher

File Number: H05-16-10**Type of Project:** Master's Thesis**Title:** Exploring the transition experience of an adolescent with chronic pain

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
06/09/2016	06/08/2017	Partial Approval

Special Conditions / Comments:Partial Approval

Approval to recruit through IWK Health Centre will be granted once the permission letter from this institution has been received.

Appendix L: Research Ethics Board Approval from the IWK Health Centre

5850/5980 University Avenue
 PO Box 9700, Halifax
 Nova Scotia B3K 6R8
 Canada
 tel: 902.470.8888
 www.iwk.nshealth.ca

**Approval – Delegated Review
 August 23, 2016**

Principal Investigator: Dr. G Allen Finley
Co-Principal Investigator: Paula Forgeron
Title: Exploring Transition of Young People with Chronic Pain
Project #: 1021479

On behalf of the IWK Research Ethics Board (IWK-REB) I have reviewed the documents included in this study. I am pleased to confirm the Board's full approval for this research study, effective today.

Best wishes for a successful study.

Yours truly,



Linda Hamilton
 Co-Chair, Research Ethics Board

This approval includes the following study documents:

Comments	Version Date
Protocol	2016/08/15
Confidentiality Agreement	2016/01/12
Recruitment Poster	2016/06/09
Interview Guide	2016/01/12
Information and Consent Form - Written	2016/08/15
Information and Consent - Verbal	2016/08/15
Recruitment Letter	2016/03/30

The Board's approval for this study will expire one year from the date of this letter (August 23, 2017). To ensure continuing approval, submit a Request for Continuing Review to the Board

2 - 4 weeks prior to the renewal date. If approval is not renewed prior to the anniversary date, the Board will close your file and you must cease all study activities immediately. To reactivate a study, you must submit a new Initial Submission (together with the usual fee, if applicable) to the IWK-REB and await notice of re-approval.

Please be sure to notify the Board of any of the following:

- Proposed changes to the initial submission (i.e. new or amended study documents)
- Additional information to be provided to study participants
- Material designed for advertisement or publication with a view to attracting participants
- Serious adverse events experienced by local participants
- Unanticipated problems involving risks to participants or others
- Sponsor-provided safety information
- Additional Compensation available to participants
- Upcoming audits/inspections by a sponsor or regulatory authority
- Closure of the study (within 90 days of the event)

Approved studies may be subject to internal audit. Should your research be selected for audit, the Board will advise you and indicate any other requests at that time.

Important Instructions and Reminders

Submit all correspondence to Ethics Manager Bev White or Ethics Coordinator, Joanne Street at the address listed at the top of this letter (do not send your response to the IWK-REB Chair or Co-Chair)

Be sure to reference the Board's assigned file number, 1021479 on all communications.

Highlight all changes on revised documents and remember to update version numbers and version dates, include a clean copy of all revised documents.

Research Ethics Board Committee Members

Sarah	Belong	Legal
Kelly	Cameron	Lay Representative
Jill	Chorney	Psychology (Clinical Researcher)
Eleanor	Fitzpatrick	Nursing (Clinical Researcher)
Isabelle	French	Legal
Ron	George	Anaesthesia (Clinical Researcher)
Kevin	Gordon	Neurology (Clinical Researcher)
Linda	Hamilton	Obstetrics and Gynecology, Co-Chair
Adam	Huber	Rheumatology (Clinical Researcher), Co-Chair
Victoria	Price	Hematology/Oncology (Clinical Researcher)
Erna	Snelgrove-Clarke	Nursing (Clinical Researcher)
Marilyn	Tiller	Pharmacy

Julie	Walsh	Privacy
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* REB members are not in attendance during review of their own proposed research involving human subjects or where there is conflict of interest with the proposed research

This statement is in lieu of Health Canada's Research Ethics Board Attestation: *The Research Ethics Board for the IWK Health Centre operates in accordance with:*

- *Food and Drug Regulations, Division 5 "Drugs for Clinical Trials Involving Human Subjects"*
- *The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS(2)*
- *International Conference on Harmonization - Good Clinical Practice Guidelines - ICH-GCP*
- *FWA #: FWA00005630 / IORG #: IORG0003102 / IRB00003719*

Appendix M: Invitation from the Stollery Children's Hospital**Pediatric Chronic Pain Services**

Date

To: Patients of the Chronic Pain Clinic,

Dear: Patient,

I am writing you to let you know of an opportunity for young adults with chronic pain who used to receive care for their chronic pain at the Stollery Children's Hospital to participate in a research study. The name of the study is: *Exploring the transition experience of young people with chronic pain from the pediatric to the adult healthcare system*. The aim of the study is to understand the experience of young adults with chronic pain as they transitioned from the chronic pain clinic at the Stollery Children's Hospital to where they receive care now. The research will help us understand what this move was like for you so that we can find better ways to support teens and young adults as they transition from a place like the Stollery Children's Hospital to adult healthcare.

If you are interested, you will be asked to take part in a one on one interview via Skype or telephone with Andrea Higginson RN, Masters of Nursing student at the University of Ottawa. The questions will be about your experience in moving from the pediatric chronic pain clinic to the adult health care system.

To receive more information about the study please contact Andrea Higginson RN or her research study supervisor Dr. Paula Forgeron. You can reach Ms. Higginson at [REDACTED] or via email at [REDACTED]. You can reach Dr. Forgeron at ([REDACTED] extension [REDACTED] or via email at [REDACTED].

Taking part in this study is your choice. You do not have to take part. I will not know if you take part or if you do not take part. If you decide not to take part it will not have any effect on the care you or your family receives at the Stollery Children's Health Centre. People who choose to participate in this study will take part in the order that they have contacted our research team ("first come, first served basis"). Many thanks for considering participating in this study.

Sincerely,

[REDACTED]

Bruce D. Dick, PhD, R Psych
Associate Professor
University of Alberta
Stollery Children's Hospital
January 12, 2016 (v1)

Appendix N: Letter of Invitation from the IWK Health Centre

**Centre
for Pediatric
Pain Research**
*SCIENCE HELPING
CHILDREN*



G. Allen Finley, MD FRCPC FAAP
Professor of Anesthesia & Psychology
Director, Centre for Pediatric Pain Research
Dr. Stewart Wenning Chair in Pediatric Pain Management

June 8, 2016

To: Former Patients of the Pediatric Complex Pain Clinic,

Dear Patient,

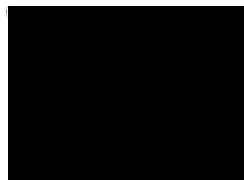
I am writing you to let you know of an opportunity for young adults with chronic pain who used to receive care for their chronic pain at the IWK to participate in a research study. The name of the study is: *Exploring the transition experience of young people with chronic pain from the pediatric to the adult healthcare system*. The aim of the study is to understand the experience of young adults with chronic pain as they transitioned from the Complex Pain Clinic at the IWK Health Centre to where they receive care now. The research will help us understand what this move was like for you so that we can find better ways to support teens and young adults as they transition from a place like the IWK Health Centre to adult healthcare.

If you are interested, you will be asked to take part in a one-on-one interview via Skype or telephone with Andrea Higginson RN, Masters of Nursing student at the University of Ottawa. The questions will be about your experience in moving from the pediatric chronic pain clinic to the adult health care system.

To receive more information about the study please contact Andrea Higginson RN or her research study supervisor Dr. Paula Forgeron. You can reach Ms. Higginson at [REDACTED] or via email at [REDACTED]. You can reach Dr. Forgeron at [REDACTED] or via email at [REDACTED]. Please note that participants will be selected on a first-come-first-service basis.

Taking part in this study is your choice. You do not have to take part. I will not know if you take part or if you do not take part. If you decide not to take part it will not have any effect on the care you or your family receives at the IWK Health Centre.

Best wishes,



IWK Health Centre, 5850 University Avenue
PO Box 9700, Halifax, Canada - B3K 6R8

T: +1.902.470.7708
F: +1.902.470.7709

allen.finley@dal.ca
www.pediatric-pain.ca

Appendix O: Poster for Recruitment for the Stollery Children's Hospital

CHRONIC PAIN and TRANSITION

What are we studying?

We are looking to understand the transition experience of adolescents with chronic pain from the pediatric to the adult healthcare system.

Do you have Chronic Pain and have recently transitioned into the adult healthcare system?

If you are between the ages of 17-23 and have recently transitioned into the adult healthcare system and continue to require support for chronic pain management, we would like to speak with you about your experience. The interview would take 45-60 minutes. Participants will be chosen on a first come first serve basis.

Your insight would help support research on supporting adolescents with chronic pain, and how to help them transition into the adult healthcare system.

FOR MORE INFORMATION PLEASE CONTACT US:

**Andrea Higginson
Principal Investigator
University of Ottawa**

**Paula Forgeron
Research Supervisor
University of Ottawa**

**Dr Bruce Dick
Co-Investigator
University of Alberta**

Appendix P: Recruitment Poster for the University of Ottawa



CHRONIC PAIN and TRANSITION

What are we studying?

We are looking to understand the transition experience of adolescents with chronic pain from the pediatric to the adult healthcare system.

Do you have Chronic Pain and have recently transitioned into the adult healthcare system?

If you are between the ages of 17-23 and have recently transitioned into the adult healthcare system and continue to require support for chronic pain management, we would like to speak with you about your experience. The interview would take 45-60 minutes. Your insight would help support research on supporting adolescents with chronic pain, and how to help them transition into the adult healthcare system.

FOR MORE INFORMATION PLEASE CONTACT US:

**Andrea Higginson
Primary Investigator
University of Ottawa**



**Paula Forgeron
Research Supervisor
University of Ottawa**



Appendix Q: Recruitment Poster for the IWK Health Centre

CHRONIC PAIN and TRANSITION

What are we studying?

We are looking to understand the transition experience of adolescents with chronic pain from the pediatric to the adult healthcare system.

Do you have Chronic Pain and have recently transitioned into the adult healthcare system?

If you are between the ages of 17-23 and have recently transitioned into the adult healthcare system and continue to require support for chronic pain management, we would like to speak with you about your experience. The interview would take 45-60 minutes.

Participants will be chosen on a first come first serve basis.

Your insight would help support research on supporting adolescents with chronic pain, and how to help them transition into the adult healthcare system.

FOR MORE INFORMATION PLEASE CONTACT US:

**Andrea Higginson
Primary Investigator
University of Ottawa**

**Paula Forgeron
Research Supervisor
University of Ottawa**

Appendix R: Written Consent Form for Stollery Children's Hospital

Title of the study: Exploring the transition experience of young people with chronic pain from pediatric to adult chronic pain services: A qualitative descriptive study.

Principal Investigator: Andrea Higginson RN
University of Ottawa: Masters of Nursing Student

Thesis Supervisor & Co-Principal Investigator: Paula Forgeron RN MN PhD
Associate Professor, School of Nursing
University of Ottawa

Co-investigator: Bruce Dick Ph.D., R. Psych. (AB)
University of Alberta/Stollery Children's Hospital

Denise Harrison RN PhD
University of Ottawa

G. A. Finley MD FRCPC FAAP
IWK Health Centre

Introduction

This Master of Nursing research thesis is exploring the experience of changing where adolescents and young adults go for treatment for their chronic pain after no longer being seen at a pediatric chronic pain clinic. This form provides you with information about the study. Before you decide if you want to take part, you will be provided with the reason for the study, its risks, and benefits. You do not have to take part in the study. You can take your time to decide if you want to take part in the study. If you do not understand what is being asked of you or if you have any questions, the researchers will be happy to answer any questions that you may have. You may ask questions if you need to. You can stop the study at anytime.

Reason for the study

The reason for the study is to learn about the transition experience of young people with chronic pain leaving the children's hospital and going to an adult chronic pain clinic or their family doctor. Previous studies have found that leaving a children's hospital and starting to go to an adult hospital or back to one's family doctor can be difficult adjustment. The two different health care settings (children's and adult settings) provide care differently, which can make it challenging for teens and young adults to adjust at times. However, studies also have found that some pediatric and adult health care settings provide supports that make this change easier. These previous studies have been done with teens and young adults with chronic conditions but not with teens and young adults who live with chronic pain. Therefore, we want to learn about how this experience was for you and other young people with chronic pain so that we can figure out how better to help make this change easier in the future.

Participation

To take part in this study you are asked to take part in an interview. The researcher will ask you questions about what leaving the pediatric chronic pain service was like for you. The interview will be between just you and the principal researcher (Andrea Higginson). There are no right or wrong answers to the questions in the interview, we are interested in what you think. The interview will be audio recorded and conducted at a time that is good for you and it will take approximately 30- 45 minutes. You have been invited to take part in the study because you were treated for chronic pain by the chronic pain team at a pediatric hospital and had to be referred to an adult health care provider (adult chronic pain clinic or your family doctor) because you became too old to continue to go to the pediatric chronic pain clinic for healthcare.

Risks

This study has minimal risks. However, you will be asked to tell us what it was like for you to move from the children's chronic pain clinic to another place for your pain management. If you found this difficult, you may find it upsetting telling the researcher your story. You can stop the interview at any time and you don't have to answer any questions that you don't want to. You do not have to share a reason why you are uncomfortable answering any questions.

Benefits

Your participation in the study will provide information about the experience of transition. This information can be used to help others with the process of moving from the pediatric chronic pain clinic to adult health care settings.

Confidentiality

Any information that is learned about you will be kept private. The interviews will be recorded and transcribed (typed) so that the information can be analyzed later. Each interview will be coded with a number and your name will not be on the transcribed interview itself. Your name and your code number will be kept separate from your transcribed interview. Only Andrea Higginson and Dr. Forgeron will have access to your code number, name, and contact information. They will keep this information locked in Dr. Forgeron's office at the University of Ottawa and only Andrea Higginson and Dr. Forgeron will have access.

The transcribed interviews, which only includes your study number, will be kept on a password protected computer, encrypted and password protected. The digital recording of the interview will be kept on Dr. Forgeron's private password protected server space at the University of Ottawa that only she can access. Andrea Higginson and Dr. Forgeron will share the de-identified transcript with the other co-investigators (Drs. Harrison, Dick, and Finley) and information from all participants. When presenting the data from the study, your name will not appear, nor personal information that can identify you. The secured digital files (recordings and de-identified transcripts) will be kept in a locked area for 5 years following publication of the results as required by the ethics boards. Only Dr. Forgeron will have access to the secured saved files.

Voluntary participation

You do not have to participate in the study. If you want, you can stop participating at any time. You do not have to answer any questions if you do not want to. There are no negative consequences to not answering any of the questions or stopping the interview at anytime. If you choose to stop the interview or decide to withdraw after the interview, the researcher will delete all the data from audio recording and the written version of the interview if you ask.

Acceptance

I, _____, agree to participate in the above study being carried out by Andrea Higginson, Masters of Nursing student, University of Ottawa. Her research is being conducted under the supervision of Dr. Paula Forgeron.

If I have any questions about the study, I can contact the researcher or her supervisor. I have been given the opportunity to ask questions about the study.

If I have any ethical questions about the ethical conduct of this study, I can contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa ON K1N 6N5
Email: ethics@uottawa.ca

There are two copies of the consent form, one for the researcher and one for mine to keep.

Participants signature: *(Signature)*

Date: *(Date)*

Researcher's signature: *(Signature)*

Date: *(Date)*

Appendix S: Written Consent Form for University of Ottawa

Title of the study: Exploring the transition experience of young people with chronic pain from pediatric to adult chronic pain services: A qualitative descriptive study.

Principal Investigator: Andrea Higginson RN
University of Ottawa: Masters of Nursing Student

Thesis Supervisor & Co-Principal Investigator: Paula Forgeron RN MN PhD
Assistant Professor, School of Nursing
University of Ottawa

Co-investigator: Bruce Dick Ph.D., R. Psych. (AB)
University of Alberta/Stollery Children's Hospital

Denise Harrison RN PhD
University of Ottawa

G. A. Finley MD FRCPC FAAP
IWK Health Centre

Introduction

This Master of Nursing research thesis is exploring the experience of changing where adolescents and young adults go for treatment for their chronic pain after no longer being seen at a pediatric chronic pain clinic. This form provides you with information about the study. Before you decide if you want to take part, you will be provided with the reason for the study, its risks, and benefits. You do not have to take part in the study. You can take your time to decide if you want to take part in the study. If you do not understand what is being asked of you or if you have any questions, the researchers will be happy to answer any questions that you may have. You may ask questions if you need to. You can stop the study at anytime.

Reason for the study

The reason for the study is to learn about the transition experience of young people with chronic pain leaving the children's hospital and going to an adult chronic pain clinic or their family doctor. Previous studies have found that leaving a children's hospital and starting to go to an adult hospital or back to one's family doctor can be difficult adjustment. The two different health care settings (children's and adult settings) provide care differently, which can make it challenging for teens and young adults to adjust at times. However, studies also have found that some pediatric and adult health care settings provide supports that make this change easier. These previous studies have been done with teens and young adults with chronic conditions but not with teens and young adults who live with chronic pain. Therefore, we want to learn about how this experience was for you and other young people with chronic pain so that we can figure out how better to help make this change easier in the future.

Participation

To take part in this study you are asked to take part in an interview. The researcher will ask you questions about what leaving the pediatric chronic pain service was like for you. The interview will be between just you and the principal researcher (Andrea Higginson). There are no right or wrong answers to the questions in the interview, we are interested in what you think. The interview will be audio recorded and conducted at a time that is good for you and it will take approximately 30- 45 minutes. You have been invited to take part in the study because you were treated for chronic pain by the chronic pain team at a pediatric hospital and had to be referred to an adult health care provider (adult chronic pain clinic or your family doctor) because you became too old to continue to go to the pediatric chronic pain clinic for healthcare.

Risks

This study has minimal risks. However, you will be asked to tell us what it was like for you to move from the children's chronic pain clinic to another place for your pain management. If you found this difficult, you may find it upsetting telling the researcher your story. You can stop the interview at any time and you don't have to answer any questions that you don't want to. You do not have to share a reason why you are uncomfortable answering any questions.

Benefits

Your participation in the study will provide information about the experience of transition. This information can be used to help others with the process of moving from the pediatric chronic pain clinic to adult health care settings.

Confidentiality

Any information that is learned about you will be kept private. The interviews will be recorded and transcribed (typed) so that the information can be analyzed later. Each interview will be coded with a number and your name will not be on the transcribed interview itself. Your name and your code number will be kept separate from your transcribed interview. Only Andrea Higginson and Dr. Forgeron will have access to your code number, name, and contact information. They will keep this information locked in Dr. Forgeron's office at the University of Ottawa and only Andrea Higginson and Dr. Forgeron will have access.

The transcribed interviews, which only includes your study number, will be kept on a password protected computer, encrypted and password protected. The digital recording of the interview will be kept on Dr. Forgeron's private password protected server space at the University of Ottawa that only she can access. Andrea Higginson and Dr. Forgeron will share the de-identified transcript with the other co-investigators (Drs. Harrison, Dick, and Finley) and information from all participants. When presenting the data from the study, your name will not appear, nor personal information that can identify you. The secured digital files (recordings and de-identified transcripts) will be kept in a locked area for 5 years following publication of the results as required by the ethics boards. Only Dr. Forgeron will have access to the secured saved files.

Voluntary participation

You do not have to participate in the study. If you want, you can stop participating at any time. You do not have to answer any questions if you do not want to. There are no negative consequences to not answering any of the questions or stopping the interview at anytime. If you choose to stop the interview or decide to withdraw after the interview, the researcher will delete all the data from audio recording and the written version of the interview if you ask.

Acceptance

I, _____, agree to participate in the above study being carried out by Andrea Higginson, Masters of Nursing student, University of Ottawa. Her research is being conducted under the supervision of Dr. Paula Forgeron.

If I have any questions about the study, I can contact the researcher or her supervisor. I have been given the opportunity to ask questions about the study.

If I have any ethical questions about the ethical conduct of this study, I can contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa ON K1N 6N5
Email: ethics@uottawa.ca

There are two copies of the consent form, one for the researcher and one for mine to keep.

Participants signature: *(Signature)*

Date: *(Date)*

Researcher's signature: *(Signature)*

Date: *(Date)*

Appendix T: Written Consent for IWK Health Centre

Title of the study: Exploring the transition experience of young people with chronic pain from pediatric to adult chronic pain services: A qualitative descriptive study.

Principal Investigator: Andrea Higginson RN
University of Ottawa: Masters of Nursing Student

Co-Principal investigator: Paula Forgeron RN MN PhD
Assistant Professor, School of Nursing
University of Ottawa

Co-investigator: Bruce Dick Ph.D., R. Psych. (AB)
University of Alberta/Stollery Children's Hospital

Denise Harrison RN PhD
University of Ottawa

G. A. Finley MD FRCPC FAAP
IWK Health Centre

Introduction

This research study is exploring the experience of changing where adolescents and young adults go for treatment for their chronic pain after no longer being seen at a pediatric chronic pain clinic. This form provides you with information about the study. Before you decide if you want to take part, you will be provided with the reason for the study, its risks, and benefits. You do not have to take part in the study. You can take your time to decide if you want to take part in the study. If you do not understand what is being asked of you or if you have any questions, the researchers will be happy to answer any questions that you may have. You may ask questions if you need to. You can stop the study at anytime.

Reason for the study

The reason for the study is to learn about the transition experience of young people with chronic pain leaving the children's hospital and going to an adult chronic pain clinic or their family doctor. Previous studies have found that leaving a children's hospital and starting to go to an adult hospital or back to one's family doctor can be difficult adjustment. The two different health care settings (children's and adult settings) provide care differently, which can make it challenging for teens and young adults to adjust at times. However, studies also have found that some pediatric and adult health care settings provide supports that make this change easier. These previous studies have been done with teens and young adults with chronic conditions but not with teens and young adults who live with chronic pain. Therefore, we want to learn about how this experience was for you and other young people with chronic pain so that we can figure out how better to help make this change easier in the future. Your participation in the study will be part of a Masters of Nursing thesis, but could be published through an academic journal, or presented at conferences. This could give you an opportunity to help other adolescents with their transition, as it has been shown to be a difficult time.

Participation

To take part in this study you are asked to take part in an interview. The researcher will ask you questions about what leaving the pediatric chronic pain service was like for you. The interview will be between just you and the principal researcher (Andrea Higginson). There are no right or wrong answers to the questions in the interview, we are interested in what you think. The interview will be conducted at a time that is good for you and it will take approximately 30- 45 minutes. The interview will be done over Skype, Facetime or over the phone. The way the interview is conducted is what would be easiest for you. It will be recorded so that the interviewer can listen to it later to best understand what you said. You have been invited to take part in the study because you were treated for chronic pain by the chronic pain team at a pediatric hospital and had to be referred to an adult health care provider (adult chronic pain clinic or your family doctor) because you became too old to continue to go to the pediatric chronic pain clinic for healthcare.

Risks

This study has minimal risks. However, you will be asked to tell us what it was like for you to move from the children's chronic pain clinic to another place for your pain management. If you found this difficult, you may find it upsetting telling the researcher your story. You can stop the interview at any time and you don't have to answer any questions that you don't want to. You do not have to share a reason why you are uncomfortable answering any questions.

Benefits

Your participation in the study will provide information about the experience of transition. This information can be used to help others with the process of moving from the pediatric chronic pain clinic to adult health care settings.

Confidentiality

Any information that is learned about you will be kept private. The interviews will be recorded and transcribed (typed) so that the information can be analyzed later. Each interview will be coded with a number and your name will not be on the transcribed interview itself. Your name

and your code number will be kept separate from your transcribed interview. Only Andrea Higginson and Dr. Forgeron will have access to your code number, name, and contact information. They will keep this information locked in Dr. Forgeron's office at the University of Ottawa and only Andrea Higginson and Dr. Forgeron will have access.

The transcribed interviews, which only includes your study number, will be kept on a password protected computer, encrypted and password protected. The digital recording of the interview will be kept on Dr. Forgeron's private password protected server space at the University of Ottawa that only she can access. Andrea Higginson and Dr. Forgeron will share the de-identified transcript with the other co-investigators (Drs. Harrison, Dick, and Finley) and information from all participants. When presenting the data from the study, your name will not appear, nor personal information that can identify you. The secured digital files (recordings and de-identified transcripts) will be kept in a locked area for 5 years following publication of the results as required by the ethics boards. Only Dr. Forgeron will have access to the secured saved files.

Voluntary participation

You do not have to participate in the study. If you want, you can stop participating at any time. You do not have to answer any questions if you do not want to. There are no negative consequences to not answering any of the questions or stopping the interview at anytime. If you choose to stop the interview or decide to withdraw after the interview, the researcher will delete all the data from audio recording and the written version of the interview if you ask.

Acceptance

I, _____, agree to participate in the above study being carried out by Andrea Higginson, Masters of Nursing student, University of Ottawa. Her research is being conducted under the supervision of Dr. Paula Forgeron.

If I have any questions about the study, I can contact the researcher or her supervisor. I have been given the opportunity to ask questions about the study.

If I have any ethical questions about the ethical conduct of this study, I can contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa ON K1N 6N5
Email: ethics@uottawa.ca

There are two copies of the consent form, one for the researcher and one for mine to keep. If you wish to have the studies results please provide your contact information in the area below.

Participants signature: (*Signature*)

Date: (*Date*)

Address:

Email:

Researcher's signature: (*Signature*)

Date: (*Date*)

Appendix U: Verbal Consent Script

This verbal consent is for a research study entitled, *Exploring the transition experience of adolescents and young adults with chronic pain from pediatric to adult chronic pain services: A qualitative descriptive study*.

The purpose of the study is to understand the transition experience of individuals with chronic pain, to understand how best to support them in the future. Your participation in the study will be limited to a one-time interview with me, Andrea Higginson, on the telephone or videoconferencing using Skype. The interview will be audio recorded and then transcribed, meaning our conversation will be typed out, and analyzed at a further date. The questions will be looking at your past transition experience. There are no risks to the study, however, if you become emotionally distressed from speaking about your experience, you can contact my research supervisor Dr. Paula Forgeron for support. If you want to stop or skip questions you may do so at any time. You do not have to share any information with me that you do not want to. If you wish to stop the interview and resume it at another time, we may arrange another time that works best for you. There are no direct benefits to participating in the interview, however the information that you provide me will contribute to supporting the transition experience of future adolescents and young adults with chronic pain. All the information you share with me will remain confidential. Your name and any identifying factors will be removed from the transcript to protect your identity. The transcript will be assigned a participant identification number that will be used to identify you and your demographics. All documents and transcripts related to this study will be stored on the University of Ottawa's secure server, or computer, and will be

password protected and encrypted. You are under no obligation to continue with the interview, and you may choose to stop the interview at any time. If you do decide to leave the interview or the study, the information that you will have provided could be used in the study unless you tell me that you want it to be removed. If you do not ask for the information to be removed, it can be used in the study. Do you have any questions?

Can you state and spell your name to record your consent.

This serves as documentation of verbal consent for: (participant's name).

On this date (DD/MM/YYYY) at (00:00). Do you (participant's name) understand the study, and give voluntary consent to participate in the above study?

I, Andrea Higginson, have made sure, to the best of my abilities, that the participant understands the above study. I confirm that the participant has had the opportunity to ask questions about the study, and that all questions have been answered to the satisfaction of the participant. You have voluntarily verbally consented to this study. A copy of this consent will be mailed to the participant. If you have any questions about the ethical conduct of this study, you may contact the ethics board. Their contact information will be on the consent form mailed to you.

Appendix V: Interview Topic Guide

Thanks for agreeing to participate in this study about the experience of adolescents and young adults with chronic pain transitioning into the adult healthcare system. This interview will take 30-60 minutes. If there are any questions that you do not want to answer, or if you want to stop at any time, please feel free. This interview is being audio recorded and will later be typed up but your name and anything that can identify will be removed before sharing with others. If you are not sure about what I am asking you, please do not hesitate to ask me any questions. Are you ready to start?

Three example questions

Demographic questions:

We will start this interview with a few short questions.

1. Can you tell me your age now?
2. Can you tell me your gender?
3. Do you go to school, university, or work?
 - a. If you do any of these is this full time or part time
 - b. If you do not do any of these, can you tell me why?
4. Do you live at home?
 - a. If not, when did you move?
 - b. Do you live in the same town or city you did when you were receiving care for your chronic pain at the pediatric chronic pain clinic?

Transition questions:

1. Can you tell me when you started going to the pediatric chronic pain clinic?

Probes:

- When did the pain start?
- Did you see the pediatric Chronic Pain Team for a long time?
- How is the treatment of your pain now, in comparison to how it was when you were being seeing in the pediatric setting?

2. Can you tell me about how you felt about leaving the pediatric setting?

Probes:

- How did you feel about transitioning into the adult healthcare system?
- Do you think that they treat you any differently in the adult setting?
- Were you nervous?
- Do you get any help to manage your pain at home?

3. Are you treated by a multidisciplinary chronic pain team now in the adult healthcare system?

Probes:

- If yes, did you have a wait time between your last appoint in pediatrics and your follow-up in the adult healthcare system.
- If no, depending on your treatment, do you see a psychologist, physiotherapist, and a physician?
- If no, who is treating your chronic pain, your family physician?

- Do you feel that your pain management has been affected by your transition to the adult system?

3. Can you tell me how you take care of your pain in between visits with the Chronic Pain Team?

Probes:

- Does your family help you manage your medications?
- Has your family come to your appointments with you?
- If yes, how do you feel about your family coming to the appointments with you
- Did you want them to come to the appointments when you change doctors? Do you still want them at the appointments with you?

4. Can you tell me about how the pediatric healthcare providers prepared you for the adult healthcare setting?

Probes:

- Did you meet with the adult healthcare team before transitioning?
- Do you think it was a smooth transition?
- Can you tell me about the support you had during the transition?
- Can you tell me about the most important part of the transition, and how it could have been better?
- Do you believe you were ready for the transition?
- When do you think is the right time for transition?

5. Can you tell me about how much your parents help you with the management of your pain?

Probes:

- Did your family help you manage your pain when you were younger?
(medication prompting, appointment making)
- Do they continue to help you take care of your pain management needs?

6. Can you tell me about your pain around the time of transition? Meaning, did the pain get any worse or any better once you started seeing the adult healthcare physician?

Probes:

- Were changes made to your treatment once you transitioned to adult centred care?
- If yes, did you believe the suggestions that were made? Did you trust the new physician right away?
- After transitioning to adult care, did you contact the pediatric healthcare providers?
- How did the pediatric healthcare providers prepare you for the adult healthcare setting, or did they?

Appendix W: Confidentiality Agreement for the Transcriptionist to Sign

Université d'Ottawa University of Ottawa

Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

CONFIDENTIALITY OF INFORMATION AND CONFLICT OF INTEREST AGREEMENT**THE UNIVERSITY OF OTTAWA RESEARCH ETHICS BOARD**

As a member of the research study: *exploring the transition experience of adolescents and young adults with chronic pain from pediatric to adult chronic pain services: a qualitative descriptive study*, I understand that all discussions, deliberations, records, and other information generated in connection with this study is privileged information. I agree to respect and maintain the confidentiality of and to make no disclosures of such information, except to persons authorized to receive it such as Andrea Higginson (Primary Investigator) or Paul Forgeron (thesis supervisor).

This includes, but is not limited to the following examples:

- I will not disclose information I have transcribed to any other individual otherwise indicated.
- I will not use any information gained during the transcription process to support purposes or initiatives outside of the above study.
- I will not alter or copy any information provided to me, unless during the transcription process.

- Following transcription sessions, I agree to dispose of any paper documents in a secure manner (e.g. 'confidential waste').

I will notify Andrea Higginson (PI) or Paula Forgeron (thesis supervisor) of any conflicts of interest or potential conflicts of interest that may exist with the study, and will excuse myself from the study if determined necessary.

By signing below, I agree to comply with the requirements as noted above.

_____	_____	_____
Name (please print)	Signature	Date

_____	_____	_____
Witness (please print)	Signature	Date