

Parents' Perceptions of Health Care Professionals' Support in the Transition of their
Adolescent with Rheumatic Disease from Pediatric to Adult Care

by

Jacqueline vanNieuwenhuizen

Submitted in partial fulfillment of the requirements
for the degree of Master of Nursing

at

Dalhousie University

Halifax, Nova Scotia

December 2014

© Copyright by Jacqueline vanNieuwenhuizen, 2014

Table of Contents

List of Tables	viii
Abstract	ix
List of Abbreviations Used	x
Acknowledgements	xi
Chapter One: Introduction	1
Location as Researcher	5
Purpose of the Research	8
Summary	9
Chapter Two: Literature Review	11
Background	12
Transition Care Gap	12
Position Papers	13
Current Transition Care	13
The Complexity of Rheumatic Disease and Transitioning	16
Relationship Between Youths and Parents	19
Theoretical Model for Behaviour Change	21
Youth Role	23
Role of Youth Development in the Transition Process	23
Learning Self-Management: Communication the Cornerstone	25
Parental Role	28
Parents as Primary Socializing Agents	28
Parents' Emotional Suffering, Uncertainty and Loss	30
Transition Strategies Directed Toward Parents	32

Adult and Pediatric Service Models	35
Providing Best Practice for Transition Care	37
Principles of Effective Transitions	37
Transition Tools	39
Canadian Transition Programs	40
Barriers to Transitioning	43
Gaps in the Knowledge Base	45
Chapter Three: Methodology	47
Introduction	47
Appreciative Inquiry	49
Principles	50
Rationale for Choosing AI	51
Assumptions	52
Table I – Assumptions that Underpin AI	53
4-D Cycle	54
Discovery	55
Dream.....	56
Design	57
Destiny	57
Procedure	58
Design	59
Method	59
Sampling Strategies and Sample Size	59

Inclusion/ Exclusion Criteria	62
Participant Recruitment Strategies	63
Data Collection Methods	63
Interviews	64
Focus Groups	66
Data Analysis	68
Thematic Analysis	69
Ensuring Rigor: Qualitative Research and Trustworthiness	70
Credibility	70
Transferability	72
Confirmability	73
Ethical Considerations	74
Beneficence	74
Respect for Human Dignity	75
Justice	77
Summary	78
Chapter Four: Findings	79
Introduction	79
Findings	79
Participant Demographic Data	79
Table II- Participant Demographic Data	81
Table III- Youth Demographic Data	81
AI 4-D Model	82

Table IV- Themes and Sub-Themes from Interviews and Focus Group Data	82
Discovery Theme- Loss of Control	83
1.1 Perceptions of Transition Care	83
1.2 Families Live with a Degree of Uncertainty	86
1.3 Parents are Key Supports for their Child	89
1.4 Close Relationships with HCPs are Unique to Pediatrics	94
Dream Theme – Parents Desire Knowledge and Tools to Do More	100
2.1 Parents Encourage Youth to be Independent to the Best of their Ability	100
2.2 It is Important to Feel Connected with your Healthcare Professionals	106
2.3 There are Gaps in the System that Need to be Filled	110
Design Theme – Need for an Inclusive, Formal, Defined Transition Process	115
3.1 Partnering with Youth and Parents in the Planning and Execution of the Process and Timelines	115
3.2 Families Need to be Heard	118
3.3 Resources and Information Must be Available	120
Destiny Theme – Sustainability through Advanced Knowledge, Skills and Practices	123
4.1 Healthcare Professionals Require Education on Topics Related to Transitioning	123
4.2 There Needs to be a Restructuring of Services	125
4.3 Allocation of Resources is Key to Success	127
Summary	128
Chapter 5: Discussion	130
Introduction.....	130

Benefits of Using AI as a Data Collection Method	131
Affect on Parents' Psychosocial Health	132
Living with a Child with Chronic Illness	132
Parents' Role	133
Parents' Perceptions of the Transition Process	135
Transfer versus Transition	135
Transition Strategies Currently Employed	138
Youth Attending Appointments on their Own	138
Appointment with Pediatric and Adult Care Providers at Time of Transfer	139
Assessment of Substance Use and Sexual Activity	140
Emotional Support and Provision of Information	142
Posters Encouraging Transition Discussions	143
Transition Strategies Suggested by Parents	144
Acknowledgement that Parents are Partners	144
Formal, Defined Transition Process	145
Parent and Adolescent Support Groups	149
Systems Navigator	152
Provision of Information	154
Routine Check-Ins and Emotional Support	157
Adolescent Care Environment	158
Skills Parents Require	160
Summary	161
Chapter 6: Conclusion	164

Introduction	164
Strengths and Limitations of the Study	164
Clinical and Research Implications	166
Future Research	168
Dissemination of Study Findings	169
Summary	171
Appendix A 4-D Cycle	173
Appendix B Consent Form for Participants	174
Appendix C Demographic Data	178
Appendix D AI Interview Protocol (AIIP)	180
Appendix E Focus Group Guide	186
Appendix F Transcriptionist Confidentiality Agreement	188
Appendix G Transition Posters	189
Bibliography	190

List of Tables

Table I- Assumptions that Underpin AI	53
Table II- Parent Participant Demographic Data	81
Table III-Youth Demographic Data	81
Table IV-Themes and Sub-themes from Interview and Focus Group Data	82

Abstract

Youth with a chronic disease must prepare for the transition from pediatric to adult healthcare. Parents play a vital role in supporting their youth through the transition process. Using Appreciative Inquiry, interviews were conducted with 9 parents of 6 youth with chronic rheumatic disease at varying stages of transition. Their experiences of caring for their youth, their role in promoting independence and self-management, and the support they have received from Health Care Professionals (HCPs) in the transition process were examined. Strategies to enhance parental support through the transition process were explored. From the data, four predominant themes emerged: 1) loss of control, 2) parents desire for knowledge and tools to enhance their involvement in transition, 3) the need for an inclusive, formal, defined transition process and 4) sustainability of transition practice changes through a restructuring of services and provision of education and skills for HCPs.

List of Abbreviations Used

YSHCN	Youth with Special Health Care Needs
HCP	Health Care Professional
AI	Appreciative Inquiry
JIA	Juvenile Idiopathic Arthritis
SLE	Systemic Lupus Erythematosus
NSAID	Non-Steroidal Anti-Inflammatory Drug
DMARD	Disease Modifying Anti-Rheumatic Drug
TPB	Theory of Planned Behaviour
PTSRC	Parent-Teen Sexual-Risk Communication
HRM	Halifax Regional Municipality
CDHA	Capital District Health Authority
CRA	Canadian Rheumatology Association
ABKT	Arts Based Knowledge Translation

Acknowledgements

There are many people who supported me in the endeavor of conducting this research study and I will acknowledge them in the order in which they came on the journey with me. I have learned so much in this process and, while at times it felt like one big endurance test, I feel I am a better educator and care provider because of it. I am also very happy to be contributing to the knowledge base of youth transition care. May we continue to see improvements in the care we provide as youths and their families transition from pediatric to adult health care.

First, I would like to thank the IWK Health Centre Rheumatology Clinic nurses: Andrea Weagle and Lynne Broderick. These nurses brought to light the many challenges that youth with rheumatic disease and their families endure and encouraged me to do research with this population. I also appreciate the time you took out of your extremely busy days to recruit parent participants. Your dedication and skill in serving this population is very evident.

To Dr. Brenda Sabo, my ever patient and wise thesis supervisor, thank you for your support, words of encouragement and expertise. You have turned me into a better writer and researcher and I feel privileged to have the opportunity to work with you. I also appreciate that near the end of this project I gave you very little turnaround time and yet you returned my work to me with great speed.

To Dr. Margot Latimer, thank you for the work you did with me in the early days and for sparking my interest in Appreciative Inquiry. You were a pleasure to work with.

To Dr. Marilyn MacDonald, thank you for your support and guidance. You were very encouraging during a time when I was struggling and I appreciate you keeping faith in me.

To my readers, Dr. Elizabeth Stringer and Dr. Janet Curran Smith, thank you for taking time out of your busy schedules to offer your expertise and advice to me on this project. I admire both of you for your work and expertise in your fields. Elizabeth, I look forward to continue working with you as the findings of this study are disseminated.

I am very grateful to the parents who participated in this study. Thank you for sharing your stories with me. Your children are so lucky to have you as parents. Please know that I will continue to be committed to ensuring that your voices are heard.

To Nancy Cashen and Ashley Ryer, Co Leads of the IWK/ Capital District Health Authority Transition Project, thank you for sharing your knowledge with me and for tapping into my new found expertise. I look forward to continuing this work with you.

Thanks, also goes to Jackie Gilby, Secretary of Graduate Studies at the Dalhousie School of Nursing and Bev White, Manager of the Research Ethics Board at the IWK Health Centre. Thank you for answering my many, many questions and for doing it so pleasantly!

To all of my friends: Nadine, Leanne, Natalie, Gerald, Linda, Angela, Rebecca, Janice, Karen my fellow CLDs and my fellow PMU RNs: I'M DONE!!!! You were all so encouraging, thank you! A special thanks goes to my friend and colleague, Shelley Lowther, who paved the way for me. Thank you, Shelley for guiding me in the right direction.

Most importantly to my wonderful family: my mother Coba, my sister Arlene and my daughters Kiersten and Meaghan. I made it Mom! Arlene: I am taking you out to dinner and a movie. Kiersten and Meaghan: sorry I can't commiserate with you about school work anymore but you still have a qualified person to review your papers for you. I now have extra time to have fun with all of you and I am looking forward to it because you are the best family a person can have. I love you all and thanks for pushing me, understanding when I wasn't available to do things with you and for telling me how proud you are of me.

Chapter 1 Introduction

It has been recognized that providing good transition care to youths entering the world of adult health care is of the utmost importance as the majority of youth with special health care needs (YSHCN) are surviving into adulthood (Betz & Smith, 2011; Pai & Schwartz, 2011). Distinguishing between the terms “transfer” and “transition” is a necessary first step to having a discussion about this shift from pediatric to adult health care. Transfer is defined as “A one-time event that occurs at the time the child is transferred out of the child health system” (Provincial Council for Maternal and Child Health, 2009, p.3). A more inclusive term which was used for the purpose of this study is transition, defined as “a purposeful, planned process that addresses the medical, psychosocial and educational needs of adolescents and young adults with chronic physical and medical conditions as they move from child –centred to adult orientated health care systems.” (American Society for Adolescent Medicine, 1993, p.570). Unfortunately, for the majority of patients moving from pediatric to adult care, it is a transfer rather than a transition that occurs. The health care system has failed to provide continuity of quality care that addresses the medical, psychosocial and educational needs of the YSHCNs. For youth with chronic conditions transition is often described as unplanned, overwhelming, unstructured and unsuccessful (Adam, Fautrel, Clark, Duffy & Penrod, 2005). Given the many differences between pediatric and adult health services it is important that parents and youths are properly prepared to cope with these changes and to continue to function well in the adult system (Canadian Paediatric Society (CPS): Adolescent Health Committee, 2007). Successful transitioning is important and if a good relationship is not formed with the new healthcare providers young adults may avoid

seeking care until they have a medical crisis (Pywell, 2010; Tuchman, Slap, & Britto, 2008).

The phase of adolescence is not always easily demarcated due to many factors such as the effect of chronic illness, brain development, and social circumstances which may impact on development thus basing a definition of adolescence solely on chronological age is unjustified and impractical. The Canadian Paediatric Society (2011) states “adolescence begins with the onset of physiologically normal puberty, and ends when an adult identity and behavior are accepted” (Canadian Paediatric Society, 2011, p.1). This period of time is often equated with the years 10 to 19. It is important that healthcare providers take into consideration special circumstances such as a young person with a chronic condition who may experience delayed development or prolonged dependency or, at the other end of the spectrum, the emancipated minor, and allow flexibility with this age span (Canadian Pediatric Society, 2011). Various studies, papers and transition programs cited in this proposal state varying age ranges for adolescents and young adults but it is always important to bear in mind the biopsychosocial readiness of the young person to enter adulthood, not just calendar age.

It has been widely recognized and acknowledged that appropriate attention and supports should be provided for family members in the process of their YSHCNs transitioning to adult care (American Academy of Pediatrics, 2011; Canadian Paediatric Society :Adolescent Health Committee, 2007; Iles & Lowton, 2010; Kieckhefer & Trahms, 2000; Kingsnorth, Gall, Beayni, & Rigby, 2011; Provincial Council for Maternal and Child Health, 2009; Reiss, Gibson, & Walker, 2005; Rosen, Blum, Britto, Sawyer, & Siegel, 2003; van Staa, Jedeloo, van Meeteren, & Latour, 2011; Viner, 2008). Parents are

the primary socializing agents for their children and, as such, might be the single most important influence in their child's developmental process (Pequegnat & Szapocznik, 2000). As the primary socializing agents parents play a pivotal role in guiding and supporting their child as they raise them. For this reason, parental involvement in the transition process may play an important role in the successful transition from pediatric to adult healthcare systems (Casillas et al., 2010; Tuchman et al., 2008). When a child has a chronic illness the parent's role takes on greater significance as they assume responsibilities as experts and co-ordinators of health care, as well as advocacy and navigation roles (Kieckhefer & Trahms, 2000; Newacheck & Kim, 2005). Transition care and assisting the YSHCNs to achieve independence can be affected by the YSHCNs' developmental state and brain development that has not reached maturity (Kaufman, 2006). Health care needs and ongoing developmental processes support the continued involvement of the parents in this process (Kaufman, 2006). At the same time it is critical that parents recognize the importance of fostering independence in their youth. Relinquishing control can be very difficult when parents have been used to doing everything for their YSHCN. If parents are unable to hand over control to the YSHCNs, achievement of independence can be delayed (McDonagh, 2007; Westwood, Henley & Wilcox, 1999).

The literature shows that while the parental role is very important in providing ongoing support to the adolescent in transition (American Academy of Pediatrics, 2011; Canadian Paediatric Society: Adolescent Health Committee, 2007; Iles & Lowton, 2010; Kieckhefer & Trahms, 2000; Kingsnorth et al., 2011; Provincial Council for Maternal and Child Health, 2009; Reiss, et al., 2005; Rosen et al., 2003; van Staa et al., 2011;

Viner, 2008) it can also at times be detrimental to their success in acting as an independent adult (Iles & Lowton, 2010; Shaw, Southwood & McDonagh, 2004). These detriments include parental reluctance to withdraw from their youth's care which can be compounded by parental anxiety (Iles & Lowton, 2010; Shaw et al., 2004).

Parents need to acquire skills that facilitate communication with and support monitoring of the YSHCNs care while fostering independence (Reiss & Gibson, 2002; Reiss et al., 2005). It is incumbent upon health care professionals (HCPs) to provide the necessary resources and supports for parents to acquire these skills while balancing the need to closely monitor the YHCNs to ensure they can safely manage their care needs with the YSHCNs' need to act as an adult (Reiss & Gibson, 2002; Reiss et al., 2005). Parents have the ability to redirect a youth's focus from their current limitations to the possibilities of the future (Giarelli, Bernhardt, Mack & Pyeritz, 2008). Key principles, interventions, tools and programs are available and can all be employed by HCPs to provide the education and support needed to support the youth and their parents to successfully transition to adult health care.

A number of transition programs exist across the country but unfortunately few of these include specific strategies to assist and support the parent in encouraging self-management in their YSHCNs. The *Shared Management Model* is an approach that ensures both YSHCNs and family are involved in transition planning through the use of anticipatory guidance strategies by HCPs to encourage a shift in knowledge and responsibility from the healthcare professional to the parent and finally to the young adult (Provincial Council for Maternal and Child Health, 2009). It is recommended that

transition programs employ this *Shared Management Model* but it is unknown to what degree the model is used.

Only two studies were found in the literature that evaluated interventions directed towards the parent. The first study by Kingsworth and colleagues (2011) evaluated the outcomes of a pilot transition support group for parents of YSHCNs. Parent participants found the support group to be of value in that they gained new knowledge and became more active and future oriented in their planning. A second study by Stinson and colleagues (2010) evaluated an internet based self management program for parents which was found helpful.

In light of the limited research focused on the transition experience of and intervention supports for parents , further studies are necessary to more clearly uncover not only what and how parents experience the transition of their YSHCNs from the pediatric to adult health care setting but what they believe are necessary resources to better support the transition.

Location as Researcher

I have been working as a staff nurse and clinical educator at a tertiary care health centre for over 20 years. This health centre provides quality care to women, children, youth and families in the Maritime Provinces and beyond. My interest in this problem came about two years ago when as part of my graduate studies I conducted a single case study to examine the experience of an adolescent with juvenile idiopathic arthritis, and her family, as she underwent transitioning to the adult healthcare setting. It would seem intuitive that parents who have been a primary caregiver for a child with a chronic

condition for many years would face challenges in relinquishing this responsibility. How successfully a child transitions is affected by the parent's ability to relinquish care.

In this case study both the parents and the youth had difficulty communicating their needs to their HCPs. They expressed to me that there were times when they were dissatisfied with the youth's treatment regime but had difficulty in challenging the doctor. The parents expressed concern about what would happen once their youth graduated from high school; Would she get accepted to university or be able to get a job ?, How would the cost of her drugs be covered? The family was from a poor socioeconomic class and expressed frustration with trying to get answers to these questions. The parents felt that they were not properly prepared for transfer to adult care and the mother expressed shock when she was told at a doctor's appointment that that would be their last appointment at the pediatric facility. The youth seemed somewhat ambivalent about the transfer until her mother started crying and then the youth also became upset.

In the case study I discovered a number of fundamental learning objectives that parents and a child with a chronic illness must have to enhance the child's ability to cope and interact with HCPs throughout their illness. It is important that parents be active participants in planning their child's transition. They may need to receive education on how to empower their child to be self-advocates by relinquishing care while at the same time supporting and guiding the child as they increase the child's level of independence. It is also important for parents to feel supported and receive guidance from HCPs during this critical time as well. Learning so much from a single case study created a desire to conduct a study with even more participants to gain an even broader understanding of the

parental experience. It is important to know what and how parents experienced the transition process in order to identify areas for improvement.

Since conducting the case study in the rheumatology clinic as a graduate student, I have been working with other HCPs in the clinic to create and employ transition strategies. I am on the steering committee of a self management program designed to prepare youth (13-15) to initiate self-management of their chronic condition, and to enable their parents/guardians to initiate discussion and negotiation of behaviours leading to more independent self-management of the chronic condition. This self-management program compliments and helps build a foundation for existing work being done by health centre care teams around transition.

As a Master of Nursing degree student this was the first research study that I have conducted. While undertaking my thesis I was also working full time as well as being a parent to two young adults. As a mother of two young adults I understood firsthand how difficult it can be transitioning healthy adolescents to adult care and thus I suspected it would be even more challenging with a child with a chronic illness. With my combined experience as a pediatric nurse, student and mother, transitioning adolescents successfully to adult care and examining how we can achieve this has become a passion. I carefully considered my academic and experiential clinical knowledge when determining my research questions. I see providing interventions to parents of YSHCNs to learn the skills whereby they in turn can support and educate their youth in a positive relationship as key to a successful transition outcome.

Purpose of the Research

The purpose of this study was twofold:

1. To examine parents' perceptions of the process of transitioning from pediatric to adult health care for their youth with a rheumatic disease.
2. To examine parents' perceptions of the strategies that health care professionals employ or could employ that assist parents in gaining the skills enabling them to promote self-care and independence in their adolescent and facilitate the transition process.

This study took an Appreciative Inquiry (AI) approach in answering the questions. As a philosophy of inquiry and research methodology, AI takes a strengths based, capacity building approach to more clearly articulate and promote an understanding of the problem and how to resolve it (Kavanagh, Stevens, Seers, Sidani, & Watt-Watson, 2008). AI is effective in drawing out stories of research participants in a positive manner by asking questions and engaging in dialogue about the best of what already exists in a system and leading to a reflection of values and practices (Kavanagh et al., 2008). It is effective in addressing challenging issues by generating positive dynamics and effecting transformation by creating innovative ways to improve practices.

With this in mind the research questions for this study were:

1. How is the psychosocial health of parents affected as their youth transitions from pediatric to adult health care?
2. What are parents' perceptions of the process of transitioning from pediatric to adult health care for their youth with a rheumatic disease?

3. What strategies do health care professionals currently employ to assist and support parents in gaining the skills to promote self-care and independence in their youth and facilitate the transition process?
4. What strategies do parents believe healthcare professionals should employ to more effectively assist and support them in gaining the skills to promote self-care and independence in their youth and facilitate the transition process?

Summary

To achieve success in seeking and receiving proper healthcare as an independent young adult, youth need to be gradually transitioned from pediatric to adult healthcare. Parents can play a pivotal role in this successful transition but require supports and guidance from HCPs. To date, limited research has focused on the transition experience of and intervention supports for parents. In conducting an appreciative inquiry it was anticipated that effective interventions would be revealed that may be provided by both health care and parents to achieve a more reflective, effective, efficient and supportive transition process. We might learn what works best in practice and build on this. The findings might assist in designing transition strategies that enable the parent to promote self-care and independence in their child.

Chapter 2 will examine the literature on transitioning from pediatric to adult care with specific attention given to a comprehensive understanding of the parents' role in affecting a successful transition. Chapter 3 will explain the methodology of AI and lay out the method I used in conducting this study. Chapter 4 will reveal the study findings and organize and present them within an AI model. In Chapter 5 a discussion of the study findings takes place. Findings are compared and contrasted with the literature to make

note of similarities and differences between what is known and the findings of the study. Finally, in Chapter 6, the strengths and limitations of the study, clinical and research implications and suggestions for further research will be discussed. As well, I will describe how I intend to disseminate my study findings.

Chapter 2 Literature Review

The literature review found evidence on the importance of: 1) good transition care for Youth with Special Health Care Needs (YSHCNs) and their families when transitioning from pediatric to adult care: and, 2) what this care should entail. Further, it described transition principles, tools and available transition programs. Emphasis was placed on provider, family and youth roles during the transition process. Specific attention was given to the parents' role and the effects of the parent-youth relationship in the youths' transition outcome.

Key words entered in the search strategy included: transition, adolescents, young adults, parent-adolescent relationships, parents, mothers, healthcare professionals, family-provider relationship, special health care needs, parenting and family support. Relevant studies between 1998 and 2012 were included in this literature review. Databases selected included MEDLINE, CINAHL, PUBMED, EMBASE, PSYCHINFO and the Cochrane Library. Bibliographies and recent relevant pediatric journals were reviewed for relevancy. A number of relevant research articles were found that: 1) described the current state of youth health care transition, 2) supported parent participation in the transition process of youths from pediatric to adult health care settings, and, 3) described the impact of the youth –parent relationship on the transition outcome. Few studies focussed on interventions that impacted the parents' ability to support and encourage independence and self-management for YSHCNs as they transitioned to adult care settings.

Background

Transition Care Gap

Transitioning from adolescence to adulthood is a natural developmental progression. For YSHCNs transition includes not only accomplishing developmental milestones but also learning to cope and adjust to their new disease self management responsibilities as they transition from pediatric to adult healthcare. With over 90% of YSHCNs surviving into adulthood it is imperative to engage youth, families and healthcare professionals (HCPs) in preparing the youth for the adult world of healthcare (Betz & Smith, 2011; Pai & Schwartz, 2011). This transition should be a well organized, smooth process yet for most youth little is done to assist and/or prepare them for entry into the adult world of medical care (Adam et al., 2005; Canadian Paediatric Society (CPS): Adolescent Health Committee, 2007). Evidence suggests that only 50% of parents of YSHCNs have discussed changes in their youth's health care needs with their physician; only 30 to 59% had a plan to address these changing needs; and 30 to 42% had discussed having the youths see a health care provider within the adult care setting (Lotstein, McPherson, Strickland & Newacheck, 2005; Scal & Ireland, 2005). This further reinforces the limited transition services YSHCNS and their families receive from their HCPs. Without planned transition care that takes into account factors of illness severity or emotional and cognitive maturity as well as parental resource needs to support youth they may be unlikely to become independent self-managers of their health. This is of particular importance if time- of -transfer decisions are based solely on “aging out of treatment” (Reiss et al., 2005).

Position Papers

In light of serious concerns raised by the pediatric profession in the first decade of the millennium a number of key position papers were published (American Academy of Pediatrics, 2011; Betz, 2010; Provincial Council for Maternal and Child Health, 2009; Reiss & Gibson, 2002; Rosen et al., 2003; Viner, 1999; Viner, 2008). These papers are replete with suggestions on how to better improve transition care from the pediatric to adult healthcare settings including: 1) the health care of the youth should be uninterrupted, coordinated, as well as developmentally appropriate and psychologically sound (Canadian Paediatric Society (CPS): Adolescent Health Committee, 2007) ; 2) enhanced patient and parent preparation for differences between pediatric and adult healthcare settings, such as adjusting to new roles that take into account self-management and ; 3) the need for greater collaboration and personal links between pediatric and adult healthcare providers (van Staa et al., 2011).

As the majority of YSHCNs are surviving into adulthood it has been recognized that providing good transition care to youths entering the adult world of health care is of the utmost importance (Betz & Smith, 2011; Pai & Schwartz, 2011). Sadly, transition care is commonly not provided and many families and youths have not even discussed transferring to adult care with their pediatric provider (Lotstein et al., 2005; Scal & Ireland, 2005).

Current Transition Care

The Pediatric Rheumatology clinic at the IWK Health Centre, a children's tertiary hospital in Halifax, Nova Scotia, Canada, has been employing transition strategies for a number of years. One such strategy, Transition Clinics, began in 1995. These are

dedicated clinics for youth, usually in their final year of pediatric care, and are held six times per year. They are attended by at least one pediatric rheumatologist, a local adult rheumatologist, a pediatric rheumatology nurse, a pediatric physiotherapist, a pediatric occupational therapist and a pediatric social worker. A patient may attend one to four clinics before transfer to the adult rheumatologist and those patients who attend are only the patients who will be transferred to the local rheumatologist. The standard practice is for patients to initially be seen alone, with the parent/s joining at the end of the appointment if in attendance. These clinics give the youth an opportunity to have an introduction to their adult rheumatologist, provide them with the opportunity to communicate their health history and concerns independent of their parent, and allow a transfer of information and consultation to occur on the youth's care between the pediatric nurse, rheumatologist and physiotherapist and the adult rheumatologist. Transition and impending transfer is the primary focus of the health care team during these clinics. Generally youth are transferred to adult care when they are finished high school and their disease is at a stable point.

A year in advance of transfer nurses educate the youth and their parents about access to medications and drug plan coverage once they graduate high school. If necessary, they are booked in with the social worker to have further conversations. The occupational therapist has conversations with those in high school, encouraging them to apply for scholarships and to volunteer to increase their chance of being awarded a scholarship. Those youth who plan to go on to post secondary education are encouraged to access disability services at the institution they will be attending. Those students who

wish to go out of province for their education are reminded to register with Nova Scotia Medical Services Insurance as an out of province student.

From as early as age 12 yrs, youth are encouraged to attend a portion of their medical appointment on their own. Again, this is in an attempt to gradually enable the youth to give a health history and to verbalize their concerns in privacy. These are skills that youth will require when they transfer to adult care. The purpose of the youth attending the appointment on their own is explained to the youth and parent ahead of time. The youth is initially asked how they feel about seeing the doctor on their own and are told their parent may come in at any point if they so desire.

Youth are encouraged to get a print out of their medications from their pharmacist and to learn the names, doses and purposes of their medications. The clinic nurses begin asking youth about their medications at 12-13 years of age.

Youth are screened about high risk activity (sexual activity, drug and alcohol use) during assessments. Preventative discussions around high risk activity also take place. This screening of, and discussion around, high risk activity can be dependent on the health care provider and at times may not occur.

While these strategies are all very worthwhile activities there are many areas where transition care can be improved upon. These strategies occur in the pediatric facility and there is not the same focus on transition strategies once the youths are transferred to adult care. The strategies are not always consistently employed and gaps in transition care continue to exist.

The Complexity of Rheumatic Disease and Transitioning

This study will focus on transitioning within the context of YSHCNs with rheumatic disease. YSHCNs with rheumatic diseases often require ongoing treatments and follow-up and thus have had a lot of exposure to the health care system. Rheumatic diseases are chronic multisystem disorders representing the clinical manifestations of acute and chronic inflammation. Multiple systems can be involved including the musculoskeletal system, skin, blood vessels, and organs as diverse as the eye, kidney, brain, lungs and bone marrow (Cassidy & Petty, 2011). The most common chronic rheumatic disease of childhood is juvenile idiopathic arthritis (JIA). Systemic diseases such as juvenile dermatomyositis, systemic lupus erythematosus (SLE), and vasculitis are rarer but can result in significant morbidity and even mortality (Cassidy & Petty, 2011). Many treatments for rheumatic diseases can also cause toxicity to the cardiovascular system, bones and reproductive organs (Hersh, von Sheven & Yelin, 2011). Furthermore, there is evidence that some illnesses such as SLE have a more complex and aggressive disease course than their adult counterparts and can accumulate damage and medication toxicity over a longer duration of disease (Hersh, von Sheven & Yelin, 2011).

As juvenile idiopathic arthritis (JIA) is the most common chronic childhood rheumatic disease the literature pertaining to JIA will be examined to gain a better understanding of what it is like for youth to live with this condition. JIA is an overarching term referring to a group of disorders characterized by chronic arthritis (Weiss & Ilowite, 2007). About one in 1000 Canadian children have JIA, making it one of the most commonly diagnosed chronic diseases (Manners & Bowers, 2002). The etiology of JIA

is unknown and the condition can be very debilitating, impacting the child's ability to participate in physical activity and may contribute to increased school absenteeism due to chronic fatigue and pain (Weiss & Ilowite, 2007). The disease is characterized by joint stiffness, swelling and pain and can occur in one or several joints. Youth with JIA may also experience generalized growth retardation and delayed puberty, osteopenia /osteoporosis, and disability (Weiss & 2007). Although JIA remits in some patients, studies have demonstrated that 30–60% percent of JIA patients continue to have active disease into adulthood.

There is no cure for JIA and treatments can be quite varied and extensive depending on the individual's response. Treatments include managing joint stiffness and pain through the use of physiotherapy, occupational therapy and pain management strategies as well as the use of medications to reduce the inflammation, pain and swelling (Weiss & Ilowite, 2007). Most medication treatment plans start with non-steroidal anti-inflammatory drugs (NSAIDs) and, depending on response, may evolve to include the use of oral steroids, steroid joint injections, disease modifying anti-rheumatic drugs (DMARDs) (i.e., methotrexate, leflunomide, hydroxychloroquine, sulfasalazine and azathioprine), and biologic agents (i.e.: etanercept, adalimumab, anakinra , rituxumab, toclizumab, etc.) (Weiss et al., 2007). Many of the drugs are accompanied by serious side effects that may at times be of more concern than the underlying disease itself (Rabinovich, 2010). Another consideration of these medications, when used in adolescents, is potential toxicities of medications in pregnancy (Krause, Amin & Makol, 2014) and when using alcohol (Britto, Rosenthal, Taylor & Passo, 2000). Youth who do not respond to the standard therapies of NSAIDs, corticosteroids and DMARDs risk joint

damage, functional limitations, and lower quality of life (Leblanc et al., 2012). Biologic agents, which are prohibitively expensive for most people, may provide an effective alternative for children with recalcitrant arthritis. All biologics are presently administered by subcutaneous injection or intravenous infusions. The frequency of treatments is quite varied, however, most are given at minimum every 2 weeks (Weiss & Ilowite, 2007). Pediatric coverage for biologic drugs through provincial formularies is limited and inconsistent across the country and access to these drugs can be difficult (Leblanc et al., 2012). Youth who do not continue on to post-secondary education (thus continuing to receive coverage under their parent's health plan) or secure a job with a good health plan may experience difficulty in accessing these biologic drugs.

In light of multi- system involvement and the associated treatments, significant early cumulative morbidity, disability and early mortality may be a significant issue within this population and affect their outcomes into adulthood. Over 50% of young adults with JIA continue to have active disease contributing to a higher risk of joint destruction and prosthetic joint replacement (Minden, 2009). Of young adults with JIA 40% are somewhat limited in their functional capacity and 10% are in need of assistance to manage daily routines (Minden, 2009). There is a consistent and significantly higher self-reported rate of unemployment in the JIA population as compared to an aged matched control population (Packham & Hall, 2002). With regards to educational outcomes previous studies have found that adults with JIA do not fare worse compared with healthy controls (Gerdhardt et al., 2008). Active disease and disease flares was found to be high at the time of transfer in a population of children with rheumatic disease with 30% of subjects being hospitalized for disease treatment or management of flares in

the year prior to transfer and 58% having active disease at the time of transfer (Hersh, Pang, Curran, Milojevic & von Scheven, 2009). Missed appointments can also be a problem in the post transfer period. In a study reviewing the charts of 100 young adults with JIA who had transferred to adult care, findings showed that 17 made no initial contact with their adult rheumatologist and 35 young adults were lost to follow-up 2 years after transfer (Hazel, Zhang, Duffy & Campillo, 2010).

There is evidence with other populations that suggests morbidity increases in young adults once they transfer to adult care. A study which examined young adults with diabetes mellitus found increasing rates of hospitalizations during transition to adult healthcare and that this may be attenuated in youths for whom there is no physician continuity (Nakhla, 2009). In examining 20 youths with renal transplants who had been transferred to adult care Watson (2000) found that 35% of grafts were lost post-transfer unexpectedly; medication adherence was felt to be a factor in graft loss (Watson, 2000).

Considering the ongoing disease process and the disability these young adults experience, learning the skills of self advocacy and how to independently manage their health care are important goals for the youth to achieve in order to experience a successful transition to adulthood (Pywell, 2010). In addition, having access to rheumatologic expertise is likely another crucial factor in optimizing outcomes for young adults with childhood onset rheumatic disease.

Relationships Between Youths and Parents

Evidence reveals both benefits and detriments that can arise in the youth/ parent relationship through the support that parents provide to their youth as they transition to adult care. There are reciprocal links between youths and their parents highlighting the

need for parents to help empower young people by facilitating interdependence (Shaw et al., 2004). Four domains of perceived parental support identified in the literature are: 1) Providing non-clinical practical and emotional support; 2) Acting as ‘trouble-shooters’ in times of health-related crisis; 3) Working in partnership with offspring in ongoing disease management in the home and clinic; 4) Acting as ‘protectors’ of their children (Iles & Lowton, 2010). Trouble shooting was further broken down into three elements: 1) liaising with primary and specialist services; 2) arranging admission for acute episodes of illness or medical emergencies; and, 3) dealing with perceived inappropriate inpatient care. These domains of support had varying degrees of continuity into adult care (Iles & Lowton, 2010).

While there are definite advantages to parental support, this support can also have detrimental effects on the youths as well. Parental reluctance to withdraw from young people’s care has been noted as a major issue reinforcing the need to support parental ability to ‘let go’ if the youth is to be successful in self-management (Shaw et al., 2004). Youths and HCPs have identified parental anxiety and over-involvement as unsupportive to the youth (Iles& Lowton, 2010). Difficulties may be encountered as a result of discordance between youths and their parents. There needs to be a balance between the parents/guardians wishes re: treatment, consent, medication, promoting physical/emotional maturity/independence, with the youths’ (Shaw et al., 2004). Perceived risk factors considered to place youths at risk for transitional difficulties include family/parent dynamics such as family composition; over protectiveness; changing status as caregiver with the maturation of the child; reliance on financial benefits; lack of confidence, motivation, education and poor social network (Shaw et al.,

2004). Additional risk factors include youth intrapersonal characteristics (e.g. dependence; psychosocial maladjustment; poor social skills; low control cognitions; lack of knowledge) and complexity/ severity of condition (e.g. co morbidity; delayed puberty; short stature; significant functional disablement) (Shaw et al., 2004).

Reiss et al. (2005) demonstrated that adult healthcare providers' focus on the individual patient has been shown to leave parents without a role in their young adult's treatment compromising their ability to share important knowledge with the new health care team. This left parents feeling excluded after the many years of active involvement in their youth's health care. Parents frequently continue to be the main source of support for the young adult thus necessitating the need to know the plan of care as determined by the young adult and their care provider; at the same time, healthcare providers within the adult healthcare setting must remain mindful to maintain the YSHCN's confidentiality (McDonagh, 2007). Although it is important that, as the adolescent transitions to adult care and s/he learns to be an effective advocate for herself/himself there is still an important role for the parent (Reiss et al., 2005).

Theoretical Model for Behavior Change

The theory of planned behavior (TPB) indicates that a behavior is a direct function of a person's intent to perform the behavior (Ajzen & Fishbein, 1980). In the past seven years researchers in the field of adolescent sexual risk behaviors have expanded the TPB to more explicitly incorporate the influences of parents on adolescent behavior (Eastman, Corona, & Schuster, 2006; Hutchinson & Wood, 2007). Researchers believed that the exclusion of parental influences when looking at behavior change in adolescents was a significant omission that limited the utility of the TPB. In the TPB

intentions are determined through the internal psychological process of integrating behavioral beliefs about the consequences of the behavior (attitudes), normative beliefs referring to the perceived social pressure to perform or not perform a behavior (subjective norms), and control beliefs about how difficult or easy performing the behavior would be (Ajzen & Fishbein, 1980). In the parent-based expansion of the TPB, the external influence of greatest interest is parent-teen sexual-risk communication (PTSRC). In this model parenting behaviors of interest are themselves primarily determined by the parent's intention to perform those behaviors. Parents are more likely to discuss sexual risk topics with their children if they intend to do so and if they view PTSRC positively (behavioral belief), believe that important others would approve of doing so (normative belief), and believe that they have the skills necessary to engage in PTSRC effectively (control belief) (Hutchinson & Wood, 2007).

Eastman et al. (2006) applied three beliefs that most strongly influence behavior change to a work based program to help parents learn parenting and communication skills to facilitate communication with their adolescent children, promote healthy adolescent sexual behaviors, and reduce sexual risk behaviors. This program was later evaluated through a randomised control trial which found that the three beliefs had substantial effects on communication between parents and adolescents about sexual health (Schuster et al., 2008). Other studies have also demonstrated the significant influence parents exert on the sexual risk –related beliefs, attitudes, and behaviors of adolescents (DiIorio, Pluhar, & Belcher, 2003; Hutchinson, 2002; Hutchinson et al., 2003; Pequegnat & Szapocznik, 2000).

Parents' role in the youths' lives and successful progression to independence has been undervalued by HCPs. As the evidence demonstrates that if parents are able to affect change in youth's sexual behavior then it follows that they may affect behavior change in other areas of their lives as well. This theoretical model may be helpful in understanding how parents promote independence by encouraging the youth to take responsibility for their health as they transition to adult care. To date, no studies have looked explicitly at interventions provided to parents to affect positive youth-parent relationship outcomes which in turn may have the ability to influence positive youth transition outcomes within the context of chronic illness. The youth is required to learn many new behaviors on their journey to self-management and will face many obstacles and challenges along the way. Parents will be critical to facilitating the YSHCNs ability to make this transition safely and with the least amount of distress.

Youth Role

Role of Youth Development in the Transition Process

The developmental stage of the youth plays a significant role in the transition process and their continued dependence on his/her parents. It is important for both HCPs and parents to have an understanding of the impact of youth development on the transition process. Changes in cognition, emotional attachments, autonomy, self-identity, sexuality, physical development, life philosophy, and education/vocation are all involved in this development (Kaufman, 2006). The frontal lobe, which controls executive functions including organization, planning, self-regulation, selective attention and inhibition, may not complete development until a person reaches the age of thirty (Kaufman, 2006). Not having the full ability to complete these functions can impede the

youth's ability to keep appointments, adhere to medication regimes, communicate independently with HCPs and inhibit inappropriate emotional impulses (Sowell, Thompson, Holmes, Jenigan & Toga, 1999; Casey, Giedd & Thomas, 2000; Steinberg, 2010). Due to the late maturation of the prefrontal regions of the brain (beyond 18 years), young adults may have difficulty functioning in the adult healthcare system. Adult services expect transitioning youths to behave as mature adults. Knowing their brain function capacity informs how one should be offering care. HCPs need to remember that youth development does not stop at the time of transfer of care but that maturation and learning continue after transfer to adult care. As a result, there is an ongoing need for continued support and assistance from the youths' parents after the transfer to the adult healthcare setting has occurred.

Adolescents without developmental impairments are in the psychosocial stage of development identified by Erikson as "identity versus role confusion" (Wong, 1999). Typically adolescents move to independence and spend more time with their peers than their parents. They are attempting to learn new roles and integrate their values and beliefs with those of society. Furthermore, this is a time to consider which occupation they will pursue. Adolescents who are unable to achieve this stage of development may experience role confusion while those mastering this stage will have devotion and fidelity to others as well as to values and ideologies (Wong, 1999). Youths with chronic illness may be more dependent on their parents because of the illness or because the parents have been more protective of them resulting in delayed independence (Kaufman, 2006). Future concerns are significant for youth with a wide range of chronic illnesses (Davies et al., 2011; Moola & Norman, 2011; van Staa et al., 2011); examples include concerns

about deteriorating health, occupational restrictions, reproductive ability, and a loss of time (Moola & Norman, 2011) which may lead to dependency on their parents.

Positive outcomes have been reported with the process of transferring to adult care settings. Research has shown that some youths with chronic illness have expressed strong desires to be actively involved in their future health care (Moola & Norman, 2011). Youths who have completed this process noted that they felt greater control and more involvement when it came to decision making about their own care (Tuchman et al., 2008). Youths often view leaving pediatric care as a logical step and frequently display a “wait and see” attitude, meaning they had a positive attitude and would wait and see what the adult system had to offer, while parents have a harder time leaving familiar surroundings (van Staa et al., 2011). Parents expressed fear leaving care providers who knew their children and situations well, where everything was familiar to them and where they felt in charge (van Staa et al., 2011).

Learning Self Management: Communication- the Cornerstone

It has been recommended that YSHCNs who are transitioning to adult health care spend time alone with their care provider prior to the formal transfer (Callahan, Winitzer & Keenan, 2001; Canadian Paediatric Society: Adolescent Health Committee, 2007; Stinson et al., 2010; Tuchman et al., 2008). In a position statement from the Adolescent Health Committee, Canadian Pediatric Society (2007) it is stated “as youth move closer to the age of transfer, professionals have the opportunity to provide developmentally appropriate information and to teach the skills of negotiation and communication in the adult system” (p.786).

It is important that the youth learn to convey the important information to their health care provider in a short period of time due to the shorter appointment times in the adult healthcare setting. In a review of the literature on doctor-patient communication, researchers established the importance of doctor-patient communication and the influence it has on satisfaction with care, adherence to treatment, recall and understanding of medical information, coping with disease, quality of life and state of health (Ong, de Haes, Hoos & Lammes, 1995). In order for doctors to establish the correct diagnosis and treatment plan they need complete information from the patient (Ong et al., 1995). Patient's communication styles and personality characteristics may influence the amount of information doctors give to their patients (Street, 1991). The communication styles that elicit more information from the physician were: asking more questions, expressing more concerns and acting more anxious. In her systematic review of 43 transition studies published between 1982-2003, Betz (2004) found that service features that were important to study respondents were the ability to communicate their needs to service providers and take an active role in decision making.

Not only should youths learn effective communication and advocacy skills they should also be knowledgeable about how to seek help from HCPs as well as how to navigate and function within the adult healthcare system. To achieve this they should be provided with information on their healthcare rights and effective ways of dealing with medical staff (Viner, 1999). If a good relationship is not formed with the new healthcare providers young adults may avoid seeking care until they experience a medical crisis (Pywell, 2010; Tuchman et al., 2008). Tuchman et al. (2008) identified four major themes of the subjects before, during and after transitioning. These themes included: beliefs

about the desirability of transfer, feelings about medical care, relationships and decision making/ parents role in the process. Being unable to identify benefits of transferring, fear of the unknown, difficulty in ending close relationships and parent's difficulty turning over control to the youth were all cited as themes during the transfer process itself. Several successful strategies have been implemented to assist the youth in the transition to adult services which include: having a specific transition coordinator; developing young adult clinics in adult centred care; having youth friendly services such as afterhours telephone services (Crowley, Wolfe, Lock, & McKee, 2011).

Stinson et al. (2008) conducted a descriptive qualitative study of 36 adolescents aged 12-20 years to explore the self-management needs of adolescents with juvenile idiopathic arthritis and the acceptability of a web-based program of self management aimed at improving quality of life. They found that adolescents were able to articulate strategies on how they managed or attempted to manage the goals of "letting go" from parents and HCPs who had managed their illness and "gaining control" over managing their arthritis independently. The two strategies used to assist in achieving these goals were 1) acquiring knowledge and skill to manage the disease and 2) experiencing understanding through social support. Acquiring knowledge and skill was further subdivided into five subthemes which included; 1) listening to and challenging care providers, 2) acquiring skills to communicate with the doctor, 3) managing pain and discomfort, 4) managing emotions and 4) acquiring knowledge and awareness about arthritis.

A study by Lawson et al. (2011) examined self- reported medication adherence and self care skills among adolescents with chronic rheumatic disease between the ages

of 13-20 years. The study revealed that 54% of participants reported perfect adherence to medications, mean concordance for knowing medication names was 89%, for knowing the correct dosing regimen was 78% and for knowing the purpose of their medications was 54%. Among health care tasks, as participants aged, they were more able to fill prescriptions, schedule appointments, arrange transportation, ask questions of doctors, manage insurance, and recognize symptoms of illness. The following skills did not improve with age: ability to take medications as directed, keep a calendar of appointments, and maintain a personal medical file. This study highlighted that lack of improvement in self-management independence with increasing age suggests that youth are not mastering certain critical self-management skills.

Youths need to learn self-management skills, how to self-advocate and communicate effectively and concisely to be able to function independently in the adult world of health care (Canadian Paediatric Society: Adolescent Health Committee, 2007). Incomplete brain development can impede their ability to function in the adult world without support (Kaufman, 2006). Youths with chronic illness have concerns about their future (Moola & Norman, 2011) but still have the desire to achieve developmental milestones (Tuchman et al., 2008). It is important that they are given support and guidance by those closest to them to help achieve these communication and self-management skills.

Parental Role

Parents as Primary Socializing Agents

Parents are at the core of this study as their role is that of the primary socializing agents of their children. As such, they may be the single most important influence in the

lives of their children and/or adolescents (Pequegnat & Szapocznik, 2000; van Wel, ter Bogt, & Raaijmakers, 2002). Parents play a central role in children's lives as they raise them; children depend on them for support and guidance as they navigate their way to adulthood. When a strong connection exists between parent and child as a result of chronic illness, parents may be unwilling or unsure of how to support their child's independence and transition to an unfamiliar adult healthcare setting. Appropriate attention and supports should be provided for family members to better facilitate a successful transition from the pediatric to adult healthcare setting (American Academy of Pediatrics, 2011; Canadian Paediatric Society: Adolescent Health Committee, 2007; Iles & Lowton, 2010; Kieckhefer & Trahms, 2000; Kingsnorth et al., 2011; Provincial Council for Maternal and Child Health, 2009; Reiss et al., 2005; Rosen et al., 2003; van Staa et al., 2011; Viner, 2008).

In a survey conducted by Shaw et al. (2004) professionals employed within health, social support, education and vocation systems identified the planning of transitional care to be a multidisciplinary activity with the youths and parents rated as the top two persons necessary in planning transitional care. Of the 478 respondents 97% rated the youth's involvement as being very important and 80% identified the parents' involvement as being very important. Rank ordering of other individuals from highest to lowest was the pediatric rheumatologist, the adult rheumatologist and the hospital nurse. Seventy-five percent of study respondents also felt that it was important to address the transitional needs of the parent.

It has been demonstrated that parents play a significant role in the transition process and that youths report that their parents' support and involvement were important

components of a successful transition (Casillas et al., 2010; Tuchman et al., 2008) .When a child has a chronic illness the parent's role becomes even more involved and complex as they have the additional responsibilities of being experts in their child's medical care, co-ordinators of health care, advocates for their child and navigator of health care systems (Kieckhefer & Trahms ,2000; Newacheck & Kim ,2005). It is challenging for parents who have been the primary caregiver of a child with a chronic condition for many years to relinquish this responsibility. This period of transition coincides with other transitional life stages for both the young adult and their parents. Families with adolescents are in the "Families Launching Young Adults" phase. In this phase parents learn to let go of their children after working hard to prepare them for an independent life (Friedman, Connelly& Williams, 1998). Anxiety over transitioning to adult care and giving up control of the youth's health care are common experiences for parents (McDonagh, 2007; Westwood et al., 1999). It is important that parents learn to adjust to this change and encourage their youth's independence in order for them to successfully transition to adulthood (McDonagh, 2007; Westwood et al., 1999).

Parents' Emotional Suffering, Uncertainty and Loss

Potential consequences in the lack of transition care were unveiled in a study by Davies, Rennick and Majnemer (2011). In their qualitative interpretive study to gain an in-depth understanding of parents' perceptions of their young adults' transitioning from pediatric to adult healthcare findings revealed how a poor transition process can result in negative experiences for the parents (Davies et al., 2011). Parents believed that barriers within the transition process included a lack of sufficient co-ordination, vulnerability of the YSHCNs, and the lack of appropriate resources in the adult health care system to

appropriately care for the multifaceted needs of their YSHCNs (Davies et al., 2011). These barriers led to parents perceiving a sense of abandonment by their health care team further increasing a sense of loss, fear and uncertainty as they navigated the transition of their young adult (Davies et al., 2011). The transition process was felt to be facilitated by the parent's resourcefulness, support from extended family and the ability to establish new relationships within the healthcare setting (Davies et al., 2011). These feelings may also be the result of the unfortunate reality that YSHCNs do not actually transition to adult care, rather they transfer to their new care providers. Although much is known about the importance of implementing a true transition process the reality is that little is done to assist and/or prepare families and youth for entering the adult world of medical care (Adam et al., 2005; Canadian Paediatric Society (CPS): Adolescent Health Committee, 2007). Until the time of transfer parents and their YSHCNs have known only their pediatric care provider and have in all probability established a trusting relationship with them. Given the differences between the adult and pediatric provider models the parent and youth are moving from a model that has been very nurturing to one where appointments are more difficult to obtain, offer less time to answer questions and provide individualized care (Amaria, Stinson, Kullen-Dean, Sappleton & Kaufman, 2011). This lack of adequate preparation for entering the world of adult care is bound to result in these feelings of abandonment, loss, fear and uncertainty.

Research has also revealed how the transfer from a specialized pediatric clinic to an adult healthcare setting can be marked by parents' emotional suffering and uncertainty that remained unexpressed to health care professionals (Dupuis, Duhamel, & Gendron, 2011). Professionals are adept at keeping parents informed about disease progression in

their child but often ignore the family's emotional experience which in turn promotes parent's suppression of their fears regarding the disease (Dupuis et al., 2011). This suppression is often misinterpreted by HCPs as the parents having come to terms with the disease and perpetuates a cycle of parents not expressing emotion and HCPs being oblivious to the parents' emotional experience (Dupuis et al., 2011).

Parents reported that the process of transition from pediatric to adult care was an extremely stressful time in their lives. Although they had learned to cope with their child's condition over the years, they perceived a loss in stability, diminished levels of energy to deal with the associated stress of transition which combined to adversely affect their emotional and physical well being (Davies et al., 2011). For those parents who have children with fatal illnesses, approaching adolescence increased the distress parents experienced; they saw their child moving closer to death which negatively colored the parents' experience with transition (Dupuis et al., 2011).

Evidence suggests that if patients do not ask more questions, express concern or act anxious that physicians are unlikely to explore their needs further (Ong et al., 1995). In order to establish a good relationship with care providers, parents and YSHNs need to be able to effectively communicate their feelings and needs. This evidence highlights the importance of assisting not only youths to be good communicators and self-advocates but in assisting their parents as well.

Transition Strategies Directed Toward Parents

To enable more effective transitioning, HCPs need to offer guidance to parents related to ways to relinquish control through the provision of support, actively listening to their concerns, and providing realistic feedback (Betz, 1998; Giarelli et al., 2008). A

review of the literature revealed only three studies were found that evaluated transition strategies specific to parents. These three strategies were: 1) encouraging parents to speak with other parents of youths who have successfully transitioned to adult care (Betz, 1998; Kingsnorth et al., 2011), 2) 12-week internet –based self-management program (Stinson et al., 2010) and 3) envisioning where their young child with special health care needs will be in the future (Reiss et al., 2005).

Encouraging parents to speak with other parents of youths who have successfully transitioned to adult care was found to be an effective approach (Betz, 1998; Kingsnorth et al., 2011). In a qualitative descriptive study conducted by Kingsnorth et al. (2011) a family facilitator who had a YSHCNs with similar needs to study participants and was a strong advocate for these children facilitated a parent support group. The family facilitator was supported by a team of inter-disciplinary health professionals. The authors concluded that the parent participants in the support group valued the facilitator role, benefitted from the social support they received from the group, and parents gained new knowledge which enabled them to become more active and future oriented in their transition planning.

In looking at other transition strategies directed toward parents Stinson et al. (2010) conducted a feasibility randomized controlled study involving 46 adolescents with juvenile idiopathic arthritis and 46 parents to determine the feasibility of a 12-week internet –based self-management program. Two modules were specifically for parents/caregivers to help them encourage healthy behavior: the effect of arthritis and helping parents learn to let go. While there were no statistically significant results found for any of the outcome measures (reduction of physical and emotional symptoms and

improving health related quality of care in the youth), completed by parents, the internet treatment was rated as acceptable and satisfying to use by both groups (Stinson et al., 2010). The lack of statistically significant results could be attributed to the small sample size, resulting in a loss of power and inability to measure small effects.

In a qualitative descriptive study conducted by Reiss et al. (2005) to determine which transition strategies study participants have found useful in their past experience 34 focus groups and interviews with a total of 143 youths with disabilities and special health care needs, 44 family members and 50 HCPs were conducted. The researchers examined the participants' transition experiences, the promising factors that facilitate successful health care transition and the obstacles that inhibit health care transitions. Study results showed that participants viewed transition as a developmental process composed of three stages: envisioning a future, age of responsibility and age of transition. Envisioning a future included envisioning the child growing up to be an adult which helped to promote future planning. Asking parents to envision their child's future; including future education, employment options, independent community living and needed healthcare while the child was at a very young age prompted families and providers to initiate activities that promoted the child's future independence. During the age of responsibility family members laid the foundation of future independence by teaching and giving responsibility to the child to carry out tasks of daily living and medical self care. The age of transition included 2 time frames: adolescence (ages 12-17) and young adulthood (ages 18-23). Maturity and experience were seen as necessary during this phase to successfully carry out medical responsibilities associated with transition. Viewing transition as a process composed of these three stages enabled

participants to cope with the transitioning from pediatric to adult care and to relinquish care to the youth.

Parents perceive the process of their child transitioning to adult care to be a very difficult period of time in their lives (Davies et al., 2011). Some parents have the ability to locate and establish new resources to assist them in navigating and succeeding in the world of adult health care while others do not (Davies et al., 2011). The emotional experience of parents as their adolescent children undergo transfer from a specialized pediatric clinic to an adult health care facility can be marked by suffering and uncertainty that remains unexpressed to health care professionals (Dupuis et al., 2011). Research has indicated that HCPs need to offer guidance to parents regarding strategies to gradually give up control by providing support, listening to their concerns and giving realistic feedback (Betz, 1998; Giarelli et al., 2008). Parent support groups with an expert parent facilitator benefitted parents in the social support they received from the group and assisted parents in gaining new knowledge and becoming more active and future oriented in their planning (Kingsnorth et al., 2011). Internet based modules directed at teaching parents the effect of arthritis and helping parents to let go can be a satisfying and acceptable intervention strategy (Stinson et al., 2010). Parents who envision where their young child with special health care needs will be in the future can better cope and prepare for the transition to the adult world (Reiss et al., 2004).

Adult and Pediatric Service Models

Centres that focus on children's health generally focus on the child and family and offer more time and assistance during an appointment (Callahan et al., 2001; Tuchman et al., 2008). Adult services offer less appointment time due to the large

population they serve and are accustomed to communicating more exclusively with the adult patient (Callahan et al., 2001; Tuchman et al., 2008). Pediatric care is also developmentally appropriate, delivered within a multidisciplinary team and has significant parent involvement in decision making (Canadian Paediatric Society (CPS): Adolescent Health Committee, 2007). Although adult healthcare has shifted to interprofessional teams as the basis for care delivery, the resources are fewer to support this approach. Furthermore, the adult healthcare system expects the patient to be autonomous, knowledgeable and able to navigate the system, skills which youths do not possess without adequate preparation (Canadian Paediatric Society (CPS): Adolescent Health Committee, 2007; Davies et al., 2011). Coming from a model where the parent is the primary communicator with the health care team to a model where the physician communicates almost exclusively with the young adult can leave the parent feeling disrespected and devalued as knowledgeable members of the health care team (Reiss & Gibson, 2002). The adult system is seen as unsupportive, less nurturing with little time to answer questions or provide individualized care (Amara et al., 2011).

The YSHCN requires services that are developmentally appropriate to address the changing and maturing needs of the young adult, including personal sexual and social development. In the pediatric setting there can be a lack of attention to these aspects of development within primary and preventative services, which include counselling on birth control, substance abuse, etc (Reiss & Gibson, 2002). Unfortunately there can be a lack of availability of physicians in the adult model who are willing to take on youth whose care may be complex due to their own lack of knowledge or experience (Reiss & Gibson, 2002). There are services that may be available in the pediatric system but once

the YSHCNs moves to adult care these services are no longer available or may require very long wait times due the sheer volume of patients in the adult system(Reiss & Gibson, 2002). Additionally, the adult system is designed for older adults and not young adults; many of the comforts of children's hospitals are not readily available (i.e., private rooms, free TV, internet access, teen lounge, child life specialists). Additionally, they are required to build new relationships with new HCPs (Amaria et al., 2011). Given the many differences between pediatric and adult health services it is important that parents and youths are properly prepared to cope with these changes and to continue to function well in the adult system (Canadian Paediatric Society :Adolescent Health Committee, 2007).

Providing Best Practice for Transition Care

It has been established earlier in the literature review that there is a definite need for a co-ordinated, planned, transition process from pediatric to adult care. In this section what constitutes an effective transition, which transition tools and programs are currently available for use and /or are being used will be highlighted. Lastly, a discussion about why transition planning and care are not taking place despite existing knowledge, tools and programs developed to deliver such care will be provided.

Principals of Effective Transitions

Several transition programs exist in Canada. It is helpful when evaluating a transition program that one is mindful of the core principles impacting the design and implementation of the program as well as the strategies that are employed. The Provincial Council for Maternal and Child Health (2009) lists seven key principles of effective transitions that should underpin any transition program:

- Start early; foster healthy development in all domains

- Involve child/ youth and family in transition planning
- Use of a planned and coordinated approach
- Ensure progressive movement towards active participation in health management
- Ensure excellent information transfer
- Reframe “leaving pediatrics” as an achievement
- Continually evaluate programs/ services (p.3)
- There are additional interventions cited in the literature to improve the transition process.

However, given the differences in the ways adolescents and adults think as a result of the developing brain it is important to educate adult providers regarding the unique attributes of youth (Amaria et al., 2011). Adult providers need to understand how adolescents think and cope in order to deal with them effectively.

Several unique collaborative approaches between pediatric and adult care providers have been recommended and include creating “young adult” clinics jointly staffed by pediatric and adult health providers (Nakhla, Daneman, To, Paradis & Guttman, 2009). Another approach would be to create teams that focus on particular diagnoses rather than age groups, with pediatric and adult providers collaborating on treatment plans and protocols (Sable et al., 2011). These approaches would detain the need to change care providers suddenly, facilitating a smooth transition from one care provider to the next.

Transitioning should be a process that begins in childhood and ends with adulthood (Amaria et al., 2011). The Royal College of Nursing (2004) recommend even more comprehensive guidelines including transitioning be divided into three stages; early (12-

14 years), middle (14-15 years) and late (15-16 years). They also suggest that flexibility is the key for transitioning as not all youths will be ready to make the transfer to adult services at the same time. The youth's cognitive and physical development, their emotional maturity and their state of health should all be considered when deciding on an appropriate timeline for transitioning. While pediatric care facilities may not have the resources to implement an entire transition program at the very least they can utilize existing transition tools as a first step to creating a culture of transition.

Transition Tools

A number of tools have been developed to address systems issues in transitions. Multiple tools are described by Amaria et al. (2011) which have been used by the *Good to Go Transition Program* established in 2006 at The Hospital for Sick Children in Toronto. One of these tools is a transition poster which serves as a visual reminder that healthcare providers are preparing patients to transition out of the pediatric setting. These posters serve not only as a reminder to the youths but also to the parents and assist in creating a culture of transition. They could spark dialog between the youth, parent and HCP on the subject of transition. *Readiness checklists* are another tool employed by the Hospital for Sick Children and are completed by youth with the assistance of parents if necessary. They measure a youth's medical knowledge, autonomy and skills needed to self-manage healthcare. HCPs can access and use this tool to create a plan for skill development and monitor progress. These checklists may also serve as a reminder to families that are striving towards independence for their YSHCNs. The *Three –Sentence Summary* is a tool that teaches the youth to succinctly state their health concerns, an important component when in the adult care setting. *My Health Passport* is an on-line

program that helps a young person to create a wallet-sized card with their important health information. This enables the youth to be able to communicate this important information during consultations. Transfer clinics are clinics that take place prior to transferring to adult care and allow the youth to meet their new adult provider. These clinics also allow the pediatric provider to convey important information to the adult provider. Use of these tools enhances the transition process and aid in teaching the important self-management skills needed in adult care. Again, while these tools are not directed specifically towards the parent they do serve as a reminder to the parent of what the ultimate goal is for the youth and can also serve as a means of providing an opening to dialog about transitioning with their YSHCNs and their care provider and learning the necessary skills required. The ultimate goal however is to employ a complete transition program to ensure that the key principals of effective transitions are being carried out.

Canadian Transition Programs

It is important to examine existing transition programs and to evaluate if the needs of the parent and youth are being met. Grant and Pan (2011) compared and contrasted five well known Canadian transition programs for chronically ill adolescents in light of the Society of Adolescent Health and Medicine and the Canadian Pediatric Society recommendations for best practise in terms of transition care for youth. The principles include the following: 1) provide developmentally appropriate care; 2) enhance patient autonomy; 3) ensure collaboration between healthcare providers; 4) teach skills of negotiation; 5) gradation of responsibility to the adolescent; 6) provide community resources; 7) designated professional who takes responsibility for transition; 8) provide

patient a portable summary of their healthcare needs; and 9) have current transition plan documented.

The parents' role in transition programs is crucial. If parents are unable to hand over control to the youth, achievement of independence may be delayed (McDonagh, 2007; Westwood et al., 1999). Parents have the ability to redirect a child's focus from their current limitations to the possibilities of the future (Giarelli et al., 2008). Transition programs employing the *Shared Management Model* ensure that the youth and family are involved in transition planning (Provincial Council for Maternal and Child Health, 2009). In this model, HCPs employ anticipatory guidance to encourage a shift in knowledge and responsibility from the HCP to the parent and then finally to the youth as the youth matures. This shift allows for the youth to ultimately assume responsibility for his/her care (Kieckhefer & Trahms, 2000). Health care providers develop a therapeutic alliance with the family at the time of the youth's diagnosis and progress through a continuum of social, developmental, and health outcome achievements that help shape an independent, healthy adult. This model is not rigid and allows for negotiation when circumstances dictate that a youth requires parental assistance or support despite previously mastering a physical or cognitive task (Kieckhefer & Trahms, 2000). Serious consequences may occur if transition services do not allow for this shift in knowledge and responsibility.

The programs that were compared and contrasted by Grant and Pan (2011) included: *ON TRAC* (Children's and Women's Health Centre of British Columbia); *Good2Go* (Hospital for Sick Children in Toronto); *The Maestro Project System Navigator Model* (Winnipeg Regional Health Authority); *The Be Your Own Boss Program (BYOB)* (Edmonton); and *Young Adults with Rheumatic Disease (YARD)* clinic

(Calgary Foothills Hospital, Alberta). *ON TRAC* is a flexible program based on meeting the unique physical and cognitive abilities of each individual and family as they move through the early, middle and late adolescence stages of transition care. The youth is required to master skills or tasks at each stage prior to moving on to the next stage. A clinical pathway is utilized to address six content areas: self-advocacy and self-esteem, independent healthcare behaviors, sexual identity and health, social supports, educational and vocational planning, and health and lifestyle behaviors. The *Good2Go* program employs the shared management model and its aim is to arm all YSHCNs with the necessary skills and knowledge to self-advocate, maintain health promoting behaviours and to be able to navigate their way through the world of adult healthcare. To achieve this end the program employs the tools described in the previous section. The *Maestro Project System Navigator Model* was designed to target and alleviate the barriers youths face in obtaining treatment, with attention paid to primary reasons for dropping out of adult health care. This model employs an administrative coordinator (Maestro) who maintains contact via telephone and e-mail with the adolescent to provide assistance and support in overcoming barriers in navigating adult care. The *Be Your Own Boss Program* is a community- based, peer led program designed to help youths develop self – management skills. This is done through facilitated workshops by trained leaders who are non-health professionals with chronic diseases themselves. Finally, the *Young Adults with Rheumatic Disease* clinic provides continuity in transition from pediatric to adult rheumatology care and encourages illness self – management. Support is also offered to youths in areas such as career counselling, education, and financial concerns. A designated care co-ordinator (RN) ensures that patients return for regular appointments

and helps them understand the restrictions of their medication and health insurance. Of these programs, *ON TRAC* and *Good2Go* incorporated all of the principles for best practice, including gradation of responsibility to the youth, or the shared management model.

No formal evaluation has been undertaken on the effectiveness of the *ON TRAC* model or the *Good2Go* program (Grant & Pan, 2011). The *Maestro Project System Navigator Model* was evaluated with an initial study which demonstrated a lowering of adult care dropout from 40% to 11% in those who had received the benefits of the program compared to those who had not (van Wallegem, MacDonald & Dean, 2006). To date no studies have taken place to evaluate chronic disease self-management programs for youth (Grant & Pan, 2011). It is necessary to do formal evaluation in the form of qualitative and quantitative studies measuring young adult outcomes to ensure that these programs are effective in reaching their goals. The outcomes that are measured should include the outcomes of the programs, for example are the young adults attending clinic appointments, are they enrolled in education programs or are they employed, do they adhere to their medical treatments, are they engaged in health promoting behaviours. It is only through conducting measures of the effectiveness of these programs that we can appreciate the value in them or make necessary improvements.

Barriers to Transitioning

The following issues have been perceived as barriers to successful transitioning by health care professionals: a) families and youth are overly dependent on the pediatric providers; b) pediatric providers foster dependency; c) a lack of communication between pediatric and adult providers; and d) lack of insurance coverage (Hauser & Dorn, 1999).

Pediatric facilities have been known to foster dependency in youths and families by “doing for” families rather than empowering them to do for themselves. Examples of this are following up with families when they don’t show up for appointments and rebooking them right away and specialists filling prescriptions that should be filled by the family doctor. Pediatric teams are also more inclined to go out of their way to accommodate patient and parent requests. The pediatric team may not have confidence in the adult team in managing the specific needs of their long term patients (McDonagh & Kelly, 2003). Barriers to providing developmentally appropriate transitional care to youths include lack of training, lack of teaching materials geared towards youths and limited clinic time (McDonagh, Southwood & Shaw, 2004). In a survey of 103 primary care pediatricians in Rhode Island it was demonstrated that few responders had practice policies on transfer or employed transitioning strategies leaving researchers to conclude that there is need for additional training and education of primary care pediatricians in the field of youth transitioning (Burke, Spoerri, Price, Cardosi & Flanagan, 2008).

In examining the perceived and anticipated barriers in the provision of transitional care Shaw et al., (2004) found that 11% of 263 health professionals surveyed identified parental intrapersonal characteristics (e.g. over protectiveness; lack of interest) as a perceived or anticipated barrier. The barrier identified by the highest percentage (47%) of study participants was lack of resources.

Key principals that should underpin transition programs have been identified (The Provincial Council for Maternal and Child Health, 2009) as well as interventions that can improve the transition process (Amaria et al., 2011). Transition tools that enhance the transition process and aid in teaching the important self-management skills needed in

adult care are available for use (Amaria et al., 2011). There are a number transition programs in Canada that incorporate all or some of the Society of Adolescent Health and Medicine and the Canadian Pediatric Society recommendations for best practise in terms of transition care for youth (Grant & Pan, 2011). These principles, interventions, tools and programs can all be employed by HCPs to provide the education and support needed for the youth and their parents to successfully transition to adult health care. Unfortunately there are many barriers which prevent this transition care from occurring (Burke et al., 2008; Hauser & Dorn, 1999; McDonagh et al., 2004).

Gaps in the Knowledge Base

The majority of the literature in this field focuses on the youths' experiences with transition care and the transfer process. In the past two years there have been isolated studies focussed on parents' experiences of their youth with special health care needs transitioning to adult care. Until recently the literature in this area has been sparse. Published literature reviews have addressed different aspects of transition. Some articles describe how the main participants involved in the transition process (patient, family, pediatric, and adult providers) may facilitate or impede the process. Several describe different transition models and the importance of timing the transition. There is currently a gap in the tracking and measuring of healthcare transition planning outcomes, which by definition can't be measured while youths are still in pediatric care as these are outcomes which should be seen once the youth has transitioned to adult care, such as ability to adhere to health promoting behaviours and attending medical appointments (Amaria et al., 2011).

Research has indicated that HCPs need to offer guidance to parents on ways to gradually give up control by providing support, listening to their concerns and giving realistic feedback (Betz, 1998; Giarelli et al., 2008). One study demonstrated that parent support groups with an ‘expert parent’ facilitator benefitted parents in the social support they received from the group and assisted parents in gaining new knowledge and becoming more active and future oriented in their planning (Kingsnorth et al., 2011). Other studies noted that it was important for parents not to overpower their youth and suppress their independence (Shaw et al., 2004; Iles & Lowton, 2010).

Given that parents play a vital role in the transition process of their youth from pediatric to adult health care it is important to better understand the experiences that parents have endured in this process and how health care providers may best support and educate parents to facilitate parents’ ability to equip their youth with the skills necessary to successfully transition from pediatric to adult care. Few studies have been done that have piloted interventions with parents. Research described the many steps and actions parents should take to ensure a successful transition but a clearer understanding of what parents experience and how health care providers can best support them is lacking. While emphasis has been placed on understanding what the youth has experienced during the transition from pediatric to adult care it is equally important to have a comprehensive understanding of the parents’ role in affecting a successful transition. This study delved into the parents’ perceptions of what they perceived to be effective strategies HCPs can employ to support and enable parents to promote self care and independence in their YSHCNs.

Chapter 3 Methodology

Introduction

The research literature provides evidence to support the parental role as key in the successful transitioning of YSHCNs to adult care. Several noticeable gaps including specific strategies to: 1) support parents in this transition process, 2) assist their YSHCNs to acquire the self management skills required to gain independence and to be able to cope in the adult care world, and 3) and absence of research providing the parent's perspectives were noted.

In light of the gaps, a qualitative research approach using in-depth interviews with parents of youths with rheumatic disease was used to gain a more robust understanding of how and in what way health care professionals currently support parents' ability to facilitate the transition process of their adolescent to adult care as well as areas for change. As a naturalistic tradition, qualitative research maintains that humans have the ability to shape and create their own experiences and that "truth" can consist of many realities (Polit & Beck, 2008 b). Situating this methodology within a constructivist paradigm further enhanced understanding through the study of meaningful social interaction in the natural setting. In performing naturalistic inquiry the inquirer uses techniques that allow the phenomenon of interest to emerge (Sandelowski, 2000).

Creswell (2007) states,

In the choice of qualitative research, inquirers make certain assumptions. These philosophical assumptions consist of a stance toward the nature of reality (ontology), how the researcher knows what he or she knows (epistemology), the

role of values in research (axiology), the language of research (rhetoric), and the methods used in the process (methodology) (p.16).

My philosophical beliefs most closely align with a paradigm or world view of constructivism. Within the nature of reality or ontology, the constructivist paradigm asserts that multiple realities exist. Participants' understandings are informed in many ways. Reality is value laden and the world is socially constructed (Guba & Lincoln, 2005). Constructivism affirms the validity of individuals' experiences and takes into account the multiple subjective constructions of reality (Schindler, 1999). In examining the epistemology of this paradigm the researcher and the researched co-create knowledge (Guba & Lincoln, 2005). Our understanding of reality emerges out of the relationship with the participants, that is, the researcher interacts with study participants throughout the research process to access the multiple views of reality that may exist. Constructivist axiology acknowledges the value laden and potential biases inherent within the researcher (Guba & Lincoln, 2005). Constructivist language or rhetoric of inquiry employs a literary, informal style using first person pronoun (Creswell, 2007). Within this paradigm the researcher tells the participants' story in their own words. The language of qualitative research draws heavily on the narratives of participants through direct quotes.

The constructivist paradigm provides the researcher with the ability to understand the participant's view of situations, issues or problems through their experiences. Participants have created meaning out of their experiences through relational, historical, and sociopolitical norms as well as how they are situated within their world (Appleton & King, 2002).

Choosing a methodology that fit within my worldview of constructivism was important in order to achieve an understanding of the participant's experiences. Healthcare professionals have the ability to support parents in the transition process and positive stories about parents' experiences can reveal important information about strategies that have been employed that have been of assistance to the parents. I will proceed to describe in detail the methodology that I have chosen that fits within this paradigm: Appreciative Inquiry (AI). Using AI, this methodology best allowed me to discover positive stories and narratives that may facilitate transformation.

Appreciative Inquiry

Appreciative Inquiry (AI) effectively elicits narratives from research participants which focus on positive strategies for change by engaging research participants in dialogue about the best of what already exists within a system (Cooperrider & Whitney, 2005). AI addresses challenging issues and effects transformation by generating ideas for change. An Appreciative Inquiry process "restores trust, generates hope, invites vision, and opens up infinite vistas of possibility" (Peterson, 2003, p1). AI initially began as action research and became a methodology for human system change. AI is defined as: the cooperative, co-evolutionary search for the best in people, their organizations, and the world around them. It involves systematic discovery of what gives life to an organization or a community when it is the most effective and most capable in economic, ecological, and human terms (Cooperrider & Whitney, 2005, p. 8).

Principles

AI methodology effectively initiates a dialogue that eventually leads to a reflection of values and practices (Kavanaugh et al., 2008). There are five basic principles of appreciative inquiry that inform the methodology: 1) the constructionist principal, 2) simultaneity 3) the poetic principal, 4) the anticipatory principle, and, 5) the positivist principle (Cooperrider & Whitney, 2005). The constructionist principle means that words create worlds and that these worlds are living, dynamic, human constructions that need to be understood and analysed if change agents are to be effective. Understanding the world of my study participants through exploring their values and experiences as parents of YSHCNs transitioning to adult healthcare was a first step. Understanding and analysing these experiences lead to strategies that could be effective in supporting them through the transition process. Simultaneity denotes the changes that occur naturally through the process of inquiry. The stories people relate are implicit in the questions that are asked and these in turn generate our findings. Through the questions I asked my participants I discovered what has worked well for them and what they envision could work well. The poetic principle means we can choose what we study. Organisations are open to interpretation and reinterpretation and there is always potential for inspired new stories to be related. In choosing to examine the inspired stories of my study participants as their adolescent transitions to adult care I chose to examine revelations that may inspire change in the transition process. The anticipatory principle means that image inspires action. The positive images created in the inquiry can reframe the future. Participants in my inquiry recalled positive stories about what worked well in the past. These stories may inspire images of what could work well and offer suggestions for changing how we

facilitate the transition process with regards to supporting the parents. Finally, the positive principle suggests that positive questions lead to positive change. AI challenges the negative focussed problem-solving based approach. Rather than focussing on what is wrong in a system it focuses on what is right. Within my inquiry having the participant recall positive experiences instilled positive energy evoking optimistic images of change.

The purpose of this research project was to gain the parents' perceptions of effective support strategies that pediatric health care professionals employ or could employ that may assist parents in gaining the skills enabling them to promote self-care and independence in their YSHCNs and facilitate the transition process. Questions that effectively challenged parents to tell stories about things that worked well for them in turn inspired them to think of other strategies that could be helpful for healthcare professionals to support them through this transition process.

Rationale for Choosing AI

AI was chosen as a research methodology over other approaches for several reasons. I have been a part of an appreciative inquiry within my organization and have been inspired by the generation of ideas that came out of the positive stories that were shared during the inquiry. I witnessed firsthand how easily creativity flowed when participants were free of the weight of negative discussion. I also feel that participating in an appreciative inquiry can be empowering and parents participating in my study were given the opportunity to be active partners in identifying strategies to assist them facilitating their YSHCNs in transitioning from pediatric to adult health care. As a first time researcher, I felt there is value in undertaking a study whereby findings are

described and hopefully ideas for change are generated. This study allowed me to gain basic data collection and data analysis skills that I can build on with future research.

Other research methodologies which could have been utilised to conduct my study include grounded theory and phenomenology. A researcher may choose to use grounded theory when a theory is not available to explain a process (Creswell, 2007; Polit & Beck, 2008 b). In this stage of my research I was interested in unveiling strategies which could assist parents in assisting their youth through the transition process thus this methodology was not best suited to my study. Phenomenology is appropriately used when it is important to understand several individuals' common or shared experiences of a phenomenon (Creswell, 2007; Polit & Beck, 2008 b). While both approaches may be used, my research was focussed on the identification of positive strategies for healthcare professionals to utilize to support parents in the transitioning of their YSHCNs from pediatric to adult healthcare rather than creation of social theory or understanding the meaning given to an experience. The use of AI as a methodology allowed me to gain understanding of a phenomenon while at the same time providing a framework specifically designed to elicit positive, innovative ideas from the research participants.

Assumptions

Hammond (1998) identifies eight assumptions that underpin AI. It is important to reflect on these assumptions when using AI as a nursing research methodology and when engaging in the act of inquiry with the participants. These assumptions are listed in table 1 along with an explanation of how they apply to my study.

Table I- Assumptions that Underpin AI

Assumption	Application to this Study
Something works well in every society, group or organization.	There are interventions that healthcare professionals have provided to assist parents in supporting their adolescent through the transition process that parents feel were beneficial.
What we focus on becomes our reality.	If we focus on these interventions they can be routinely utilised by healthcare professionals.
Reality is created in the moment, and there are multiple realities.	What one parent experienced when receiving transition support may be different from what another parent experienced.
Asking questions begins the change.	Asking parents questions about the positive interventions they received, and about improving the transition process, instinctively initiates a positive change in the support parents could receive.
People have more confidence and comfort to journey to the future (the unknown) when they carry forward parts of the past (the known)	Identifying strategies that parents felt were helpful in the past will enable them to envision strategies that may help them in the future.
If we carry parts of the past forward, they should be what is best about the past.	All health care professionals should be aware of, and be able to implement, the strategies that worked well.
Differences are valued.	Parents may have had different experiences, and different strategies may have had different effects, but it is important to value the positive potential in each of them.
The language we use creates our reality.	Using positive language creates a positive environment and can evoke from parents strategies which worked well in the past and inspire them to envision strategies which could work well in the future.

The AI interview design lends itself to revealing the organization’s positive capacity in regard to the chosen affirmative topic, in order to discover and make explicit

what works (Havens, Wood & Leeman, 2006). In conducting the AI interview the flow of the questions moves from reflecting on past experience, to exploring what about the experience worked, and finally, identifying ways to build on past positive experiences (Havens et al., 2006). AI focuses on successes such as achievements, strengths, positive choices, and resources and can assist participants in the recall and building upon of these successes.

In this study AI was used as an overall theoretical basis for questioning to elicit positive innovative ideas from the parents' perspective as has been done in other research. The AI approach has been used for organizational improvement in healthcare settings (Baker & Wright, 2006; Carter et al., 2007; Lavender & Chapple, 2004), family centered programs (Madsen, 2009; Taylor, Mills, Schmied, Dahlen, Shuiringa et al., 2012), and discharge planning processes (Reed, Pearson, Douglas, Swinburne, & Wilding, 2002). AI methods were successfully utilized to employ service providers and young parents in identifying strategies to engage young parents in support services and programs (Taylor et al., 2012).

4-D Cycle

There are two contrasting models for organizational change. The first is a deficit based model in which a problem is identified, the cause of the problem is analyzed, possible solutions are analyzed and then there is action planning to solve the problem. This approach may work in the short term but unfortunately the problems often resurface with the lack of positive momentum to keep moving forward. This negative approach can be demoralizing and the dynamics and energy do not change (Cooperrider & Whitney, 2005). If one was to utilize this model in change theory one might get bogged down in the

negatives and overlook the positives. The focus in this model is on fixing what is wrong rather than building on what is right.

In the constructionist based model there is a focus on collective strengths in order to construct something better. In AI the change efforts flow through a 4-D cycle:

Discovery leads to **Dream**, is followed by **Design**, and eventually creates **Destiny** which can in turn lead to further Discovery and thus the cycle repeats creating a cycle of positive change (Cooperrider & Whitney, 2005). The interview process addressed all phases of the 4-D cycle through mutual learning about what worked best when families were preparing for and transitioning from pediatric to adult care, how it could inspire future innovations, and how structures and processes can be built on to advance health professionals support of parents through the transition process with their youth. The content of the questions was developed from several areas; my experience as a clinician and a parent, the literature on youths transitioning from pediatric to adult health care, and articles on how to frame questions when using AI.

Discovery.

In the discovery phase positive questions are created to generate insight into the affirmative topic and to find out what works well. It is important during this phase to gather a story of the person's "peak experience" about the affirmative topic in the form of a concrete story and not a generalization (Cooperrider & Whitney, 2005). The interviewer should probe with open ended questions, listen deeply, search for the positive energy and be intuitive and empathic. The purpose of this phase will be to discover the positive capacity of: the parents of YSHCNs, the YSHCNs and the healthcare team as the YSHCNs transitions to adult care. Research questions asked in this phase provided parent

participants with an opportunity to identify positive experiences when they were engaged in the transition process of their YSHCNs. Parents were asked what is like to be the parent of a child with “x”, what their strengths are in supporting their youth as they transition to adult healthcare as well as what their youths’ strengths are in the transition process. Parents were also asked how HCPs can best support them through the transition process. For example, one question was “Tell me about a shining moment when you felt that you were really supported by the healthcare team in moving through the transition process.” Information gained in this phase will often inspire creativity, motivation and enthusiasm (Cooperrider & Whitney, 1999).

Dream.

During the dream phase the interviewer looks at the stories that were generated in the discovery phase and identifies the key positive attributes and skills that the stories reflect (Havens et al., 2006). The positive attributes are then reflected back to the participant who is then asked to envision a future and articulate what might be (Cooperrider & Whitney, 2005).

During this phase questions were asked of participants to stimulate them to envision what ideal transition services and support would look like. The first question asked “What strategies work best for you in assisting your child to become more independent?” Another question asked “What would the health care system look like if adolescents and their parents were always supported throughout the transition from pediatric to adult care?” Through exploration of the best of what can be, participants were able to articulate strengths and best practices for HCPs supporting them through the transition process.

Design.

During the design phase the participants must look at the structures and processes that need to be in place in order to construct a reality of the preferred future (Cooperrider & Whitney, 2005). The focus of this phase was to create an ideal service based on the known past successes and achievements of the parents, healthcare professionals and the organization, thus offering realistic and achievable ideals. One question asked “If a healthcare professional asked how they could best support you in supporting your adolescent as he/she transitions to adult healthcare what would you describe as the most effective strategies?”

Destiny.

During this phase participants focus on sustaining the AI approach by seeking the positive and in turn building relationships, continuing to redesign structures and sustain processes based on the hospitals best attributes (Havens et al., 2006). Participants need to look at what can we begin to put in place to achieve these dreams.

In this phase participants are asked to declare intended actions and identify support systems that will enhance the practice environment (Cooperrider & Whitney, 1999). Participants should think into the future and think strategically how they would make and measure improvements in the health care environment in order to sustain the positive changes they have previously envisioned. The opening question of this phase asked “What are the innovative, long lasting changes that you believe are necessary to better support parents in the transitioning of their adolescent from pediatric to adult care?” The closing questions of this phase asked “If you were to wake up tomorrow, what

would be the one change you would like to see have happened within the current healthcare system? What would it take for this to happen?”

Through a qualitative approach using in-depth interviews, parents can articulate valuable information about their interactions with HCPs in transitioning from pediatric to adult care. In using AI and the 4-D cycle we are able to examine the best of what can be and envision and evoke positive transformation.

Utilising AI as a methodology for human system change pairs well with Hutchinson and Wood's (2007) *Expanded Theory of Planned Behaviour* as described in chapter 2. This theory was cited only as an example to demonstrate that if parents have an ability to affect change in adolescent's sexual behaviour they may have the possibility to affect change in other areas of their lives as well. This theory helped to inform an analysis of the narrative by examining the ways study participants affected behaviour change in their YSHCNS in encouraging their independence and self management skills: did these parents have the intention and necessary skills to encourage self management in their youth and did they view this positively? The hope is that the research study will unveil positive strategies that healthcare professionals can utilise to support parents in guiding their YSHCNs through the transition process. Ultimately this would require the parents to effect the necessary behavior changes in their YSHCNs to become independent and be able to care for themselves.

Procedure

The following sections will review the study design and then describe in detail the method and analysis procedures which were utilized in this study. Prior to data collection, ethics approval was obtained from the Research Ethics Board at the IWK Health Centre.

In conducting this research study the ethical standards established by the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans (December 2010) were adhered to. Ethical considerations will be discussed at length at the end of this chapter.

Design

The design of this study was qualitative, explorative, appreciative and contextual in nature. As a qualitative design, the naturalistic approach offered the opportunity to uncover the nature of parents' experiences with support they received from HCPs as their YSHCNs transitioned from pediatric to adult care. The purpose of its exploration was to gain a richer understanding of the experiences they encountered. Using the methodology of AI allowed the researcher to discover, and the participants to unveil and build on, the best strategies the HCPs utilized in providing transition support. The study is contextual in that the data is only valid in the context in which the research was studied: parents of youth with a rheumatic disease transitioning from pediatric to adult care.

Method

Sampling strategies and sample size.

In qualitative research it is important to ensure that a rich holistic understanding of the phenomenon of interest is developed (Patton, 2002; Polit & Beck, 2008 c). Purposeful sampling, focusing in depth on relatively small samples, is the sampling strategy of choice in conducting qualitative research (Patton, 2002). Purposeful sampling targets individuals with experience in the phenomenon of interest that is, selecting cases

that will most benefit the study (Morse, 1991; Polit & Beck, 2008 c). In this instance for purposeful sampling I used maximum variation sampling. Maximum variation sampling allows researchers to explore the common and unique expressions of the target population across a broad range of phenomenally varied cases to achieve broad insight into the phenomenon (Morse, 1991; Neergaard et al., 2009; Patton, 2002; Sandelowski, 1995). The lack of heterogeneity in a small sample becomes a strength; patterns that emerge from great variation become of value in capturing the core experience of the phenomenon (Patton, 2002). In order to maximize variation in a small sample it is important to identify diverse criteria for constructing the sample (Patton, 2002). To achieve maximum variation I asked the rheumatology clinic nurses at the IWK Health Centre to identify parents of youths who were at different stages of the transition process, for example parents of youths who were in their early teens, mid teens and those in their late teens who had already transferred to adult care. I also asked the nurses to identify parents who have had a range of experiences- for example those who have struggled with the transition process and those who seem to be doing well. Other variations in sample that I strived to attain were parents of different socioeconomic status, single parents and married parents, those who live rurally and those who live within Halifax Regional Municipality, same sex couples versus opposite sex couples. I was able to achieve variation in stage of transition, location, and how well the transition process was going. I was not able to achieve variation in marital status, socioeconomic status or same sex versus opposite sex couples. To the clinic nurses knowledge there were no same sex couples whose youth were going through the transition process. Single parents and

parents of lower socioeconomic status were approached to participate in 3 cases and in all cases refused.

My sample size was 9 parents of 6 youths with a rheumatic disease who transferred or were in the process of preparing to transfer to adult care. Demographic details of the participants are revealed in Chapter 4. In quantitative research the focus is on the quantity of data in a category so that statistical significance can be demonstrated for the purpose of making generalizations about some 'thing' (Morse, 1995; Morse, 2000). In contrast, in qualitative research sample size is determined by what you want to know, the purpose and scope of the study, the quality and amount of useful information obtained from the participants, what will have credibility, and allowing adequate time for each participant to tell their story (Morse, 1995; Morse, 2000; Patton, 2002). In employing maximum variation sampling I believe that a sample size of 9 parents gave me high quality detailed descriptions of each case emphasizing their uniqueness and that I was still able to identify shared patterns that cut across cases. It is the observational/analytical capabilities of the researcher and the information richness of the cases that helps establish trustworthiness rather than the sample size (Patton, 2002). Ultimately in conducting my interviews, I determined that I was able to saturate my categories to a point where no new evidence emerged by using my judgement and evaluating the quality of the information collected (Sandelowski, 1995). Morse (1995) suggests another way of knowing that saturation has been reached is to return to the participants and this was achieved through conducting a focus group with my participants after the initial interviews were completed.

I accessed my sample through the clinic nurses in the rheumatology clinic at the IWK Health Centre. I obtained permission from the manager of the IWK Rheumatology clinic prior conducting the study to ensure the nurses were willing and had the time to participate in recruitment and they both agreed to participate. Ten to fifteen adolescents transfer to adult rheumatology care within the Halifax-metro area alone and another ten to fifteen adolescents transfer to adult care within Nova Scotia each year (A. Huber, personal communication, Dec.1, 2011). That gave me a potential population of 60-90 parents to draw from.

Inclusion/ exclusion criteria.

Study participants were parents of a youth with a rheumatic disease who was either preparing for transfer to adult care or had recently transferred to adult care (between the ages of 15-20 years). The youth of the parent needed to have a minimum recommended follow up with the rheumatologist of 3 times per year- this ensured that the parent and youth had been involved with the health care system and had enough exposure to the processes within the health care system to have experiences to draw on. The youth of the parent could not have any mental developmental delays as successfully transitioning these children has additional challenges (McDonagh, 2007). Eligibility criteria may reflect considerations other than substantive or theoretical concerns such as costs, practical constraints, people's ability to participate in a study and design considerations (Polit & Beck, 2008 c). Taking these other factors into consideration participants were considered eligible if they lived on mainland Nova Scotia within a 2 hour drive of Halifax, and were able to read and speak English.

Participant recruitment strategies.

In recruiting a sample Polit and Beck (2008 c) state; “Researchers should ask themselves, ‘What will make this research experience enjoyable, worthwhile, convenient, pleasant and nonthreatening for subject?’” (p.352). While Polit and Beck (2008 c) endorse face to face recruitment as being more effective than solicitation by a phone call or letter this is not practical in my case due to time constraints. Once participants identified as interested to clinic nurses I had either a telephone or face to face (if they were in the clinic at the time) conversation with them and explained the purpose of the study, screened them for eligibility criteria that may have been unknown to the clinic nurse, and explained the benefits of participating in the study. I was then able to immediately answer any questions the potential participant had as well as addressing any of their concerns. This was all done in a very courteous manner. If a potential participant was hesitant about participating I asked them to think it over and asked if I could call them back. I ensured potential participants that the interviews would take place at a time and a place that was convenient for them. Potential participants were also assured by being told who will see the data, what use will be made of the data and how confidentiality will be maintained.

Data collection methods.

Parent participants were clearly informed of their role in the study through a verbal discussion and written consent form. At the time of the interviews, informed consent and permission to audiotape the interview was obtained. An identification (ID) number was assigned to each participant and this ID number was attached to the transcribed narrative data to ensure anonymity. Participants were informed that a separate

linking document with participant's names and ID numbers pertaining to the study would be kept in a locked cabinet in my office at the IWK Health Centre. Participants were informed that information for this study would be kept for five years after publication, as per IWK Health Centre guidelines, and after that time all data will be destroyed. I informed participants that their participation in this study was voluntary, that their confidentiality would be maintained, and that they could withdraw from the study at anytime.

Interviews.

The purpose of an appreciative interview is to help the participant to delve into their experience and then to look at them from new frames and perspectives to generate new insights (Cooperrider & Whitney, 2005). I developed an AI Interview Protocol (Appendix D) based on Cooperrider and Whitney's (2005) format. This protocol includes semi-structured and open ended questions. Interviews were audio taped after obtaining consent from the participants. The literature review that I conducted points to the parents' role as key to the YSHCNs successful transition to adult care. Specific strategies to support parents in this transition process, including strategies to assist them in relinquishing care of their youth, are lacking in the literature. Parents' perspectives are also lacking in the literature. The questions in the interview guide for my proposed study (Appendix D) were developed with the aim of guiding participants in the process of self-discovery about strengths and capabilities, in turn opening the door to forward thinking about strengths and possibilities. The questions were positively framed with the goal of supporting an encouraging/ helpful/ optimistic atmosphere to inspire imagination and creativity. This process enabled participants to describe support strategies that were

helpful in transitioning, and to dream about and envision strategies that could potentially be helpful in supporting the parent to assist them to support their child in the transition process. The questions were arranged in the 4-D cycle to guide the AI process and to draw out responses in a story-like format; each phase building on the preceding one.

Despite the attempt to evoke stories about what worked well, participants did start talking about things that do not work well. Participants should not feel that they do not have permission to talk about things that need fixing. When this situation arose it could have been handled in a number of ways. The first was to postpone the negative dialog; this is an approach I did not need to use in my interviews. In this case I could have told the participant that I would make a note of what they have said and come back to it later and ensure that I do allow them time to address it. Parent participants did start to talk about things that did not work well. The participant found it necessary to discuss this aspect before continuing, therefore I continued to listen to what they had to say while maintaining a caring and affirmative spirit (honors the experience/ subjective reality of the participant). Some of the participants were unable to disclose appreciative stories until they expressed challenging and/ or negative areas of concern. Once I had listened enough to understand the negative issues I redirected participants by stating “If you had this to do over again, how might you do it differently to more effectively....(insert topic we were discussing at the time).

I also included questions around context so that I could better understand the context in which the process took place. Probes are also used in qualitative description in order to achieve clarification and depth of the data collected (Milne& Oberle, 2005). I used probes to assist in fully capturing the elements of the experience while at the same

time being mindful not to lead the interview. It is important to make the participant feel comfortable in speaking with me during the interview and thus spending a few minutes conversing casually with the participant prior to embarking on the interview was a strategy I used to do this. Having an emic or insider perspective affords flexibility to allow the participants to tell their own stories while establishing a sense of partnership and trust between the researcher and the participant because of shared understanding of the phenomenon of interest (Milne & Oberle, 2005). To ensure that my interviewing skills were sufficient and to have some practice in conducting an interview I conducted a mock interview with a peer who has experience conducting research and who also has a YSHCNs who transferred to adult care 2 years ago. This allowed me to get feedback on my interviewing techniques as well as the questions in my interview guide prior to conducting my study interviews.

Focus groups.

After completing the interviews and identifying key themes that came out of the interview data analysis I held a focus group to ensure that the themes resonated with what participants said and also elicit new information arising from the core themes. The goals of the focus group sessions are presented in the focus group guide (Appendix E). The groups were asked to generate their own themes for the response information that is provided to them.

Focus group sessions can access rich information by taking advantage of the group dynamics and are beneficial to obtain broad insight into a subject or phenomenon of interest (Milne & Oberle, 2005; Neergaard et al., 2009; Polit & Beck, 2008 d). Focus groups are appropriate to use when one wants to look for a range of feelings or ideas

people have about a topic (Kruger & Casey, 2000). Through focus group discussion and interaction further new ideas for the dream, design and destiny phases of AI may be generated as study participants are provided with the opportunity to build upon each other's thoughts or reflect on the situation in a way they may not have considered before. When conducting a focus group it is important to bear in mind that they are public. Participants will only disclose what they are prepared to say in public. Also, sharing themes that emerged from the interviews could make others feel vulnerable. This was mitigated by making the data I discussed anonymous by removing any reference to gender or any identifying data. As the facilitator of the focus group I was cognisant of group dynamics, ensured that participants had equal opportunity to speak and that participants were respectful of each other. The focus group took place in the community room (booked only for this group) of a grocery store that was central to all participants.

Other data collection techniques can include observation of targeted events and the examination of documents or artifacts (Sandelowski, 2000). If parents had received any written information such as pamphlets, letters and instructions that are sometimes given to the parents or youths prior to or after transferring to adult care that concern transferring to adult care and any of the skills required to achieve a successful outcome I would have examined these. In conducting my study none of the parent participants had received any pamphlets or written information with regards to transition care. The only documents mentioned were transition posters and these will be described and discussed in Chapters 4 and 5.

Data Analysis

Cooperrider and Whitney (2005) describe data analysis as mapping the positive core of strengths through repetition of themes related to the best features of the practice environment, envisioning what might be, and dialoging what should be. This process was conducted with both the interview data and the focus group data. These two data sets were initially analyzed separately and then were later combined. The two data sets were grouped together by AI cycle; discovery, dream, design and destiny. The data was analyzed for common threads and differences using thematic analysis. The process of analyzing the data thematically included the steps of data transcription, identification of themes, organization of results into tables, and verification of the findings with participants.

Once the interview was completed the audio recording was accurately transcribed word for word by an independent transcriptionist. Conducting accurate word for word transcription in a timely manner ensures authenticity of the data as well as scientific and ethical integrity (Milne & Oberle, 2005). The transcript was assigned a number but no identifiers. The transcriptionist was required to sign a confidentiality agreement (Appendix G) before the interviews were transcribed. It was important for me to immerse myself in the data as soon as possible by listening to the audio recordings and reading each transcript several times to become very familiar with the content of the data. Field notes taken during the interviews were also transcribed and added to the interview transcript. I wrote notes on the interview transcript to document any impressions, ideas or possible themes that came out while reading the transcript.

Thematic analysis.

Thematic analysis is a method to organize a data set in rich detail by identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). In reviewing the content of the participants stories the recurring themes are identified in an individual interview or set of interviews (Morse & Field, 1995). A theme is described as capturing “something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p.82). After immersing myself in the data I organized, labelled, and grouped data into emergent themes. I supported the themes with quotes from participants and excerpts from stories told (Creswell 2007; Gerrish & Lacey, 2010). van Manen (1990) describes three approaches toward uncovering or isolating thematic aspects of a phenomenon in some text. In the wholistic or sententious approach the researcher looks at the text as a whole and tries to come up with a sententious phrase that captures the meaning or primary significance of the text. The detailed or line- by- line approach involves examining every single sentence or sentence cluster to question what it reveals about the phenomenon or experience being described. The approach that most appeals to me is the selective or highlighting approach. Taking such an approach was used to uncover thematic aspects of experience from participants’ descriptions. Through the process of conducting the interviews, listening to the audio recordings, and reading the transcripts and field notes, I utilized the selective or highlight approach by highlighting or pulling out statements or phrases that appeared essential to the experience I was studying. I identified key themes with different colored highlighters and created a key to reference those themes by color.

Once themes were established I summarized the main themes and the patterns characterizing them. I interpreted these patterns by returning to the original research question and the theoretical interests underpinning them (Attride- Stirling, 2001). I identified patterns, themed the data, and placed the results in the context of established knowledge based on my experience as a health care provider and parent, and on relevant literature. Analysis was completed when there was enough data to write a complete, detailed description of the interventions health care providers can employ to best support parents of adolescents with rheumatic disease in transitioning from pediatric to adult health care.

Ensuring Rigor: Qualitative Research and Trustworthiness

There are four criteria one must examine and plan for when establishing trustworthiness in qualitative research. These criteria are; credibility, transferability, dependability and confirmability (Lincoln& Guba, 1985). There are different techniques that one can employ to achieve these criteria when designing a qualitative research study. I will outline the techniques I used in this study.

Credibility.

When a qualitative study is credible there is confidence in the data and interpretations of them. A qualitative study is deemed credible when participants reading the study descriptions and interpretations recognize the experience as their own (Sandelowski, 1986). Lincoln and Guba (1985) point out that credibility involves two aspects; first, carrying out the study in a way that enhances the believability of the findings, and second, taking steps to demonstrate credibility to external readers. The

techniques that I used in my study to enhance credibility were; triangulation, peer debriefing and member checks.

Triangulation involves the use of multiple sources to improve the probability that findings and interpretations will be found credible (Lincoln & Guba, 1985; Williamson, 2005). Multiple sources can imply multiple copies of one type of source or different sources of the same information (Lincoln & Guba, 1985). In using a multi- methods approach to data collection potential errors and biases inherent in any single methodology can be avoided (Williamson, 2005).In my study I employed triangulation by interviewing 9 participants, conducting a focus group with study participants and also by looking at written documents such as letters, and pamphlets. Again, the only written materials that entered into the study were the posters.

Peer debriefing is the next technique I employed to enhance the credibility of my findings. Peer debriefing involves having a peer who is neither your superior nor inferior, play the devil's advocate to probe the investigator's biases, explore meanings, and clarify the basis for interpretations (Lincoln & Guba, 1985). I drew on my thesis supervisor's experience and had her review codes and themes with me throughout the analysis to ensure that they were data driven and that they reflected what was truly in the data. The themes were discussed at length with my supervisor to ensure they flowed logically from the interpretations and to invite alternate interpretations (Milne & Oberle, 2005). I also enlisted a peer who is mastered prepared and has experience with qualitative research to assist me with my analysis. Involving a group of researchers in the analytic process reduces the subjective element (Neergaard et al., 2009).

Member checks involve revisiting the study participants to review the findings and is usually done when data collection and analysis have been completed (Milne & Oberle, 2005). I conducted member checks through a focus group with all participants once the individual interviews were completed and analyzed. Each participant was given a transcript of their interview to review for authenticity prior to the focus group. I reviewed themes that focus group participants identified and compared them to the themes that I identified that emerged from the interviews to ensure that these resonated with what they said. This was also an opportunity for me to get further clarification on the data or ask further questions.

Transferability.

Transferability is an important aspect establishing trustworthiness of a qualitative study (Lincoln and Guba ,1985). Lincoln and Guba (1985) state” the naturalist can only set out working hypotheses together with a description of the time and context in which they were found to hold.”(p.316). Lincoln and Guba (1985) further state that the naturalist cannot specify the external validity of an inquiry; he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility (p.316).

The low-inference approach of qualitative description reduces the ability to transfer the study findings to another setting or population (Neergaard et al, 2009). With rich thick description and in employing maxim variation sampling someone reviewing this study and its findings should be able to determine whether transfer can be contemplated as a possibility. I plan on using my study findings to help improve the transfer process and start to create a true transition process and improve support for the

same population I am drawing my sample from thus I can apply the results of my study to this work.

Lincoln and Guba (1985) list dependability as the third criteria to establish trustworthiness in naturalistic inquiry. Dependability refers to the stability of data over time and conditions (Lincoln and Guba, 1985). To evaluate the rigor of a study one must look at how well the study meets the methodological standards for qualitative inquiry (Morse, 2003). The detailed account of my research design as presented in this chapter and the detailed account of my analysis and findings support the dependability of the study. Having a detailed account of the research process enables the study to be replicated. Polit and Beck (2008 e) state, “The dependability question is: Would the findings of an inquiry be repeated if it were replicated with the same (or similar) participants in the same (or similar) context?”(p.539)

Confirmability.

The last criterion for establishing trustworthiness of a qualitative inquiry, as posited by Lincoln and Guba (1985), is that of confirmability. Confirmability is concerned with how well the findings are grounded in the data; that is, the findings must reflect the participants’ voice and the conditions of the inquiry, and not the biases, motivations or perspectives of the researcher (Lincoln & Guba, 1985). One method to ensure confirmability is triangulation while the other involves reflection or reflexive journaling (Lincoln & Guba, 1985). I kept a reflective journal (sometimes considered memos, field notes, etc.) while I was conducting this study.

Field notes are notes kept before, during and after an interview to document observations, impressions, and assumptions and contribute to participant meaning (Milne

& Oberle, 2005). I kept field notes during my study so that I was always examining the context of the interviews and focus group. Immediately after the interview and focus group I wrote a page of notes detailing the atmosphere, mood and my thoughts about the interview or focus group.

In the reflective journal I identified my values and assumptions as I went through the research process. If I had any issues that arose during the research process I identified them in the reflective journal and stated what I did about them. The reflections in this journal actually became data and were integrated in my report. The aforementioned process will allow the reader to know that I have distanced myself enough that it is the participants' voices they are hearing in the presentation of the findings and not mine.

Ethical Considerations

Ethical considerations for this inquiry were examined in light of three primary ethical principles on which standards of ethical conduct are based: beneficence, respect for human dignity, and justice (Polit & Beck, 2008 a). Each of these principles will be defined and I will lay out my procedures to comply with these principles.

Beneficence.

Beneficence is described as the duty of the researcher to minimize harm and to maximize benefits (Polit & Beck, 2008 a). As my research did not involve the use of an intervention, ie; a procedure or a medication, there was little risk of imposing harm to my participants. The possible harms stemming from the participants involvement in this study are no greater than those encountered by the participant in those aspects of their everyday life thus this study is of minimal risk (Canadian Institutes of Health Research et al., 2010). I was however cognisant of the psychological consequences of participating in

a study. My participants were asked about personal information and experiences and this required sensitivity on my part. Participants could potentially become distressed as they discussed their experiences. Participants did not get overly distressed but some did exhibit some mild distress during the interview process and at times expressed frustration. I acknowledged their distress/ frustration and assured them that one of the goals of the research study is to improve the level of support provided to parents during the transition process. Their distress was readily resolved, but had it not been they would have been encouraged to seek additional support through accessing the social worker or psychologist associated with their YSHCNs care team. While parent participants may not benefit directly from the study, their stories may benefit other parents. Participants were assured that information they provided, or their participation in the study will not be used against them in any way. Informed consent must be obtained from participants and this consent must be voluntary, that is, without exerting coercion (Miller & Bell, 2002). It was also important that the gate-keepers, in my case the clinic nurses in the pediatric rheumatology clinic, did not exert coercion. In gaining access to my study participants I needed to ensure that the gate-keeper did not exert power in deciding who I was allowed to access but instead followed my inclusion criteria when presenting me with potential participants (Miller & Bell, 2002).

Respect for human dignity.

Respect for human dignity includes the right to self-determination and full disclosure (Polit & Beck, 2008 a). These are the principles on which informed consent is based. The general principles of consent are that it must be free, informed and ongoing (Canadian Institutes of Health Research et al., 2010). Consent is a process that begins

with the recruitment and screening of participants and continues throughout their involvement in the research (Canadian Institutes of Health Research et al., 2010). Polit and Beck (2008 a) list 15 items that need to be communicated to participants when obtaining informed consent, these are: participant status, study goals, type of data that will be collected, data collection procedures, nature of the commitment, sponsorship, participant selection, potential risks, potential benefits, alternatives, compensation, confidentiality pledge, voluntary consent, right to withdraw and withhold information and contact information. In addition, the TCPS (Canadian Institutes of Health Research et al., 2010) recommends including the contact information of the relevant research ethics board. My informed consent form included information clearly defining this as a research study and that the data they provided will be used for research purposes (see appendix B). The consent included information on the purpose of the study. The expectation of the participants was laid out as follows: to participate in a 1 hour interview, a 90 minute focus group with the other research participants within 4-6 weeks to review themes emerging from the interview data and possibly generate new ideas. Prior to the focus group participants were reminded about the consent form they signed and the importance of maintaining the privacy and confidentiality of the other participants. I did not have any sponsorship to disclose. I explained to the participants how they were selected for recruitment and that 9 people would be participating in the study. There were no risks to disclose in participating in the study and the benefits included the potential to use the research findings to identify areas for further research, identify what is working well in the transfer of youths with a rheumatic disease from pediatric to adult care and ways to build on the support provided to parents or build on what is working well with the

transfer process itself. Compensation for the participants cost of gas and parking to attend the interview was offered in the amount of \$40.00 Participants were informed that their privacy at all times would be protected and anonymity would be guaranteed. I also let the participants know that they could withdraw from the study at any time without penalty. Lastly, I provided my contact information as well as the contact information of the relevant research ethics board to the participants should they have any questions or concerns.

Justice.

Justice is the final ethical principal and includes the participants' right to fair treatment and their right to privacy (Polit & Beck, 2008 a). Justice concerns as one aspect the fair and equitable distribution of the benefits and burden of research (Polit& Beck, 2008 a). Researchers abiding by the TCPS (Canadian Institutes of Health Research et al., 2010) have an ethical obligation to keep anything participants reveal to them in confidence – that is, not sharing this information in such a way that would identify participants, and protecting it from unauthorized access, use, disclosure, modification, loss or theft. Fulfilling the ethical duty of confidentiality is essential to the trust relationship between researcher and participant, and to the integrity of the research project. Right to fair treatment and privacy will be practiced by the following steps as laid out by Polit and Beck (2008 c) and are in accordance with the standards of the TCPS (Canadian Institutes of Health Research et al., 2010):

- Obtain identifying information from participants only when essential
- Assign an identification number (ID) to each participant and attach the ID number rather than other identifiers to the actual data

- Maintain identifying information in a locked file.
- Enter no identifying information onto computer files.
- Destroy identifying information as quickly as practical.
- Make research personnel sign confidentiality pledges if they have access to data or identifying information.
- Report research information in the aggregate; if information for a specific participant is reported, take steps to disguise the person's identity, such as through the use of a fictitious name. (p.180)

I took all of these steps with my study. I received ethics approval from the IWK Health Centre Research Ethics Board prior to conducting this study.

Summary

This study was designed utilizing a qualitative research approach comprising in-depth interviews and focus groups to obtain rich data. This data will facilitate the ability to gain greater insight into the supports that healthcare professionals currently employ with parents to facilitate the transition process as well as areas for change to better support parents. In an attempt to effect transformation and generate ideas for change the methodology of appreciative inquiry was chosen as it focuses on positive strategies for change. The design, method, analysis and ethical considerations were all carefully planned and considered with the intention of carrying out a study that is rigorous and ethically sound.

Chapter 4 Findings

Introduction

In this chapter, participant demographics, general themes and sub-themes from the interview and focus group data will be presented and discussed. The interview process addressed all phases of the Appreciative Inquiry (AI) 4D cycle: Discovery, Dream, Design and Destiny. In conducting the interviews I was able to learn how the psychosocial health of parents is affected as their child transitions from pediatric to adult care, what works best when families are preparing for and transitioning from pediatric to adult care, how it could inspire future innovations, and how structures and processes can be built on to advance health professionals support of parents through the transition process with their youth. Themes and sub-themes uncovered in the analysis of the interviews were organized and presented using the AI 4D model.

Findings

Participant Demographic Data

Nine parents of six youth with rheumatic disease were recruited. Three interviews involved the youth's mother and three interviews included the mother and the father. When mother –father couples were interviewed the mother and the father each gave their own responses for the majority of the interview questions. One of the mother- father couples and two of the mothers participated in a focus group session. All of the parent participants were married and all of them ranged in age between 46-53 years. Seven of the parents had university degrees: three at the graduate level, two at the master's level and two at the doctorate level. The highest level of education for the other two participants was a high school diploma. All of the parents were employed. Attempts were

made to recruit parents with lower levels of education without success. The three couples and one of the mother participants lived outside of Halifax Regional Municipality (HRM) and two of the parent participants lived within HRM. All participants had drug coverage for their youths. The youth ranged in age from 15-20 years. Five of the adolescent children of the parents with rheumatic disease had Juvenile Idiopathic Arthritis (JIA) and one had Lyme Arthritis. Age of onset for the disease ranged from 15 months to 11 years. The number of years the youths had been living with arthritis ranged from 5 years to 19 years. All of the youths had scheduled medical appointments with their rheumatologist at least three times a year. Four of the youths were male and two were female. Four of the youths were in high school and two were in university. All of the youths lived at home with their families with the exception of one who lived in residence during the university school year. Four of the youths had part time summer jobs. Two of the youths transferred to adult services at the ages of 17 and 18 years and had been under the care of adult services for one and three years respectively. One youth was in the process of transferring to adult care. Three of the youths had not yet been involved in formal discussions with the rheumatology health care professionals about either transitioning or transferring to adult care.

Table II- Parent Participant Demographic Data

Type of Parent Participant	Marital Status	Ages	Highest Level of Education Obtained	Employment Status	Living Location
3 mothers of 3 youths	All married	All between 46-53 years	highschool diploma x 2	All employed	3 couples and 1 mother lived outside of HRM
3 mother – father couples of 3 youths			graduate degree x 3		2 mothers lived within HRM
			masters degree x 2		
			doctorate degree x 2		

Table III – Youth Demographic Data

Age	Sex	Age at Diagnosis	Education Level (Enrollment at time of Data Collection)	Employment Status	Living Arrangements	Drug Coverage?
15 yrs x 2	Male x 4	15 mos x 2	Grade 9 x 1	Part time summer employment x 3	Live with parents year round x 5	Yes x 6
17 yrs x 1	Female x 2	4 yrs x 1	Grade 10 x 1	No employment x 3	Lives at school and lives at home during summer x 1	
18 yrs x 1		8 yrs x 1	Grade 10-11 x 1			
19 yrs x 1		10-11 yrs x 2	Grade 12 x 1			
20 yrs x 1			University x 2			

AI 4D Model

Themes and sub-themes that evolved from the interviews and focus groups were organized using the AI 4-D model. Findings from the interviews and focus group were fairly consistent which enabled the content to be woven together into themes and sub-themes. The data brought to light four major themes imbedded in the discovery, dream, design and destiny phases of the 4D cycle. Focus group discussion verified the validity of these themes and sub- themes. A summary of the themes and sub-themes derived from the content of the interviews and focus group are presented below and will be discussed in detail in the following sections.

Table IV-Themes and Sub-themes from Interview and Focus Group Data

Themes	Sub-themes			
<i>Discovery Theme- Loss of Control</i>	1.1 Perceptions of transition care	1.2 Living with uncertainty	1.3 Parents as key supports	1.4 Close relationships with HCPs are unique to pediatrics.
<i>Dream Theme- Parents desire the knowledge and tools do more.</i>	2.1 Parents encourage their youth to be independent to the best of their ability.	2.2 It is important to feel connected with your HCPs.	2.3 There are gaps in the system that need to be filled.	
<i>Design Theme- There needs to be an inclusive, formal, defined transition process</i>	3.1 Partnering with youth and parents in the planning and execution of this process.	3.2 Families need to be heard.	3.3 Resources and information must be available.	
<i>Destiny Theme- Sustainability through advanced knowledge, skills and practices</i>	4.1 HCPs require education on topics related to transitioning.	4.2 There needs to be a restructuring of services.	4.3 Allocation of resources is key to success.	

Discovery Theme – Loss of Control

The questions asked of the participants in this phase of the interview revealed that parents experienced a loss of control in caring for a child with a rheumatic disease.

Asking parents about their understanding of the terms “transfer” and “transition” revealed not only their experiences to date but the emotions surrounding these events. Listening to parents’ descriptions of interventions that health care professionals employed with their youths highlighted how current processes utilized in the rheumatology clinic had some elements of a transition but in most instances it was a transfer that occurred. This lack of a defined transition process left parents and their children with a lack of understanding about what to expect in the adult care system and how to successfully navigate it.

Parents expressed that since their child was diagnosed with rheumatic disease they lived with a level of uncertainty as JIA is an unpredictable disease. One parent expressed that your life could be different every day depending on how your child felt. Parents recognized that they played a key role in supporting their children and that they needed to step up to the plate to assist their child in coping with the disease and teaching them the self-management skills that were required to be independent. Parents of five of the six adolescents expressed worry over their child leaving pediatric care given the close established relationships with their pediatric healthcare providers and their availability to parents and youths. The participants felt that this would not or did not exist to the same degree in the adult care world and expressed concern over this reduction in services.

1.1 Perceptions of transition care.

As a starting point to the interview, participants were asked to describe what the words “transfer” and “transition” mean to them. For the purpose of this study, transfer was

defined as “A one- time event that occurs at the time the child is transferred out of the health system” (Provincial Council for Maternal and Child Health, 2009, p.3). In contrast, transition, a more inclusive term, was defined as “ a purposeful, planned process that addresses the medical, psychosocial and educational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult oriented health care systems”(American Society for Adolescent Medicine, 1993, p.570). The terms “transfer” and “transition” had been described to participants when they were given an explanation of the study during the recruitment process and in obtaining consent. It was important to get an understanding of what it meant to the study participants based on their experience. These terms were defined in advance for the parents as the questions in the interview guide referred to either the transfer event or transition process. If the parents did not understand the meaning of these phrases they would not have been able to answer the questions accurately.

For those parents whose youth had undergone the transfer to adult care or were in the process of undergoing transfer to adult care transfer was described in terms of abandonment by the health care system. Transfer was described as “*an image of the anchor being gone. ...so he’s just kind of set out on a raft*”, or “*the ropes were going to be cut and she was going to be on her own*” and “*we’re out*”. Parents felt this way because transfer to adult care came suddenly, with little or no warning or preparation, and they knew once their youth was being cared for in the adult world there would be no going back to their pediatric HCPs. For parents of youths with whom transfer had not yet been discussed they described transfer as “*a change in care*” and parents of two of the

youths expressed that they did not know exactly what that would entail and that transferring to adult services had not been discussed with them yet.

The term transition was described in terms of a process. The parents of two of the three youths who had not had any discussions to date about transitioning voiced that they believed transition would be something that would happen in stages; an incremental process that would take place at the very least over the year leading up to transferring to adult care. The parent of the other youth with whom no discussions to date about transitioning had been held had a hard time articulating what transitioning meant or would involve. This parent stated “*transition gives me more of a sense of.....the same thing only in a different area. It gives me more of a sense that things will remain as we know them. Whereas transfer to me sounds all new.*” As one parent whose child was in the midst of preparing to transfer to adult care said: “*I would imagine a step by step process, but that’s not what’s happening.*” Both for those parents whose youth had not yet transferred to adult care and for those who did, the term transition had not been used with them in terms of describing a process that occurs over several years. The clinic staff themselves seemed to have used the terms “transfer” and “transition” interchangeably. As one parent said “*transition- transfer, it’s just a change....it wasn’t really a word we ever used before*”. This parent offered a description of what took place when transitioning their youth was first discussed and the course of action that ensued:

They said, well we’re going to start transitioning you, we’ll get you a couple of things – I can’t even remember. They just said, we’re going to transition out of the Kids (IWK), so X and I thought we still had three or four months left, and then we came back in the next month and they said, okay, this is your last IWK, you’re

going to go see Dr. X now. And X and I were kind of like, what do you mean? We're not ready. And they said, because she's/he's doing so good because X was adjusted, you know, I have been working with him/her since he/she was little, ordering his/her own pills and all that stuff, X's been handling that for so long. So we weren't ready to go. We really weren't ready to leave.

This lack of a defined transition process is one of many factors that contributes to the uncertainty families must deal with on a daily basis.

1.2 Families live with a degree of uncertainty.

All participants expressed that the unpredictability of rheumatic disease led to uncertainty about the future. Parents unanimously expressed that they grieved the loss of their healthy child when their child was diagnosed with having a rheumatic disease. Some of their youths also grieved the loss of their health. As one parent stated:

Disappointing.....this child's life has changed. And I mean, he's/ she's in chronic pain all the time. He/ she can't play sports. He /she was an avid soccer player; can't play sports. He/she can ride a bike and he/she does swim in the summer, but as far as sports – and he/she was an active, active kid, right, so it's disappointing. It is you know, and I believe, in a perfect plan, I believe that God has planned for X's life as well as anyone's, but it's still disappointing. And to watch him/her and to see the frustration, the great disappointment with him/her, the feeling of just being wronged. You know, he/she feels gypped, big time. So that's hard.

One youth who was 15 years old was doing physically better than the youths of the other parents. These parents expressed that it was an emotionally upsetting time when their youth was younger and first diagnosed but their youth's health had improved

considerably over the years. They saw that their adolescent was managing well and so likewise they were also doing well. These parents stated “*Now we can put things in perspective and manage most aspects of his/her life, as long as things stay in a constant of almost what is now.*” The problem of course is that their youth’s condition is always at risk of becoming worse.

Having a child with a rheumatic disease is frustrating because it is an invisible, chronic disease. The public doesn’t realise that what he/she may be experiencing such as suffering with pain or decreased range of motion. Parents of five of the youths expressed sentiments similar to the one this parent described:

It’s frustrating because it’s not an obvious disease that people understand, and you can’t see it from the naked eye. So if he’s/ she’s in pain or he/she has lack of range of motion or you know, having really bad inflammation in 90 percent of his/her joints, people don’t see that. And they don’t understand because it’s chronic. People tire of hearing about it or they forget, or they think you can be better and it’ll go away, but it never does.

All of the parents described times in the family’s life when they had difficulty coping with the amount of pain and physical limitation their child experienced. The parents of one youth who was quite ill from an early age made the decision that one of them would stay home to care for their child. As this parent explained,

There were lots of tears, there was lots of frustration, your life changed every day. Every day your life changed, whether he/she was going to school or not going to school.... And when he/she was tired, you just stop. You work your life around his/hers.

The parents of this youth also described that they experienced financial struggles due to the loss of one income as one parent chose to stay home during their child's school years and also due to the cost of attending medical appointments. Another parent described in detail what his/her youth experienced on a daily basis:

It's our life. So I don't really know what it's like to not have it our life. But you know, the mornings are a struggle. Days can be really bad. It's much easier now because he's/she's 18, he's/ she's more mature and he's/ she's worked through a lot of issues. But in junior high it was very difficult. Because school didn't understand; he/she was in a lot of pain. He/she wasn't very happy. Because you're dealing with all the issues of being a teenager; becoming a teenager in middle school is not a pleasant experience for most kids anyhow. So to have that on top of it, and you know, he/she at that time wasn't a self-advocate, and he/she didn't want to talk about it, so it was really difficult for him/her. But the mornings are you know, he/she has to have a bath, he/she has to have time to have a rest, he/she has to have time, you know, he's/she's very slow, he/she has to have time to stretch. H/ she has to make sure he/she feels well enough because he/she has a pile of medication that he/she has to take. And then he/she rides the bus to school so sometimes he/she gets motion sickness; because in junior high the school is really far away. So a lot of times, by the time he/she got to school he/she was really ill. But you know, we've worked through all those things. The high school is quite close, and he/she can drive now. So if he/she doesn't feel well, he'll/she'll sleep in and take my car, and take himself/herself to school. So it's much easier.

Not only does the disease have an impact on the youth and their parents but it can also have an impact on the siblings. To deal with the pain one adolescent was experiencing h/she started self medicating with illegal marijuana. This behaviour adversely affected his/her relationship with his/her siblings and parents.

Furthermore, the lives of the entire family can be disrupted by frequent medical appointments and hospitalizations. As these parents describe,

Our problem is we live one hundred kilometers away from IWK, so it's pretty much a day when we have these appointments. So last week we had something on Tuesday, something on Thursday, that was just two days out of my schedule and X's schedule right in the middle of (a busy) period. It's better now than it was when the children were younger. We weren't comfortable leaving the (children) home all day alone obviously, so we had to take them with us. So the appointment would be an all day family affair in the IWK, and that was very hard often.

Despite the unpredictability of the rheumatic disease and living with uncertainty parents had their own strengths and skills in helping their child cope.

1.3 Parents are key supports for their child.

All of the parent participants in this study recognized the importance of teaching their child self management skills and promoting independence in their child. In this study it was evident that the parents played a key role in supporting their children, teaching them to be self-advocates and in helping them to make decisions. When asked “What are your strengths in supporting your child as they transition to adult healthcare?” parents unanimously voiced teaching their children to be self advocates and encouraging their children to be independent as their strengths. Parents of four of the youths also

verbalized the importance of advocating for their child when they felt that things weren't being done properly. One parent described that for a parent finding your place in the transition process can be a balancing act. In the rheumatology clinic youths are encouraged to go into their doctor's appointment on their own from the time they are in their early teens. Parents of five of the youths did not have an issue with their child attending doctor's appointments on their own. This parent described some of the difficulty he/she had with this as follows:

...your child is going in, seeing the doctor, having the examination, having a chat, and then sometimes the doctors come to get you and bring you in, and give you an overview. Or if he's/she's running late, that doesn't happen. So if you don't have a child that's going to come out and tell you verbatim what went on, you might be a little in the dark. ...I think I need to develop ways to talk with him/her when he/she comes out and find out what's going on....So it's a bit of a balancing act to find my own place in this transition as well. ...I don't feel like this has been a gradual process at all. I'm not sure how he/she would feel about whether or not he/she was getting any preparation and guidance behind the door, on the inside of the examining room.

While this parent did encourage the youth to be a self-advocate he/she felt it important to be knowledgeable about his/her child's condition so that he/she could step in and advocate for him/her when necessary.

Parents of another youth encouraged self advocacy when their child was at an early age. The parents rationalized this as being important so that their child would not have issues of pain and discomfort and that hopefully people would be more

understanding if , for example, he/she needed special accommodations such as being able to sit for a bit. The parents hoped that if they taught and encouraged their child to be forthcoming with his/her illness then he/she wouldn't internalise a lot of the issues. As the parents explained:

So when he/she started grade primary he/she had splints. I said the first day to take his/her splints in and to stand up at the front of the class and explain why he/she had to wear them, and he/she had to wear them every day. And he/she made it very matter-of-fact and the teachershe was very good to, you know, she knew everything about not having to sit on the floor, so she was there to support and saying in the class, well X gets to sit on the chair because – and it just became very matter-of-fact all through school that X had arthritis and it didn't seem to be an issue, right? At times – there was maybe a couple of instances.

A parent of another youth described his/her strength as being able to assist his/her child to be a self-advocate with HCPs. This parent encouraged his/her child to be independent and to stand up for his/her body and the kind of treatment he/she wanted. This parent said he/she always encouraged him/her to research all of his/her options and to make informed decisions about his/her health.

Parents of two youth described scenarios where they were able to come up with activities their children could participate in despite their physical limitations in order to encourage their independence and increase their confidence. One youth wanted to take part in a sport but because of his/her physical limitations had difficulty in succeeding in them. The parents brainstormed and suggested he/she try sailing. The youth ended up

excelling at it and became a certified sailing coach and taught sailing full time during the summer. Parents of another youth sent their child to Europe on their own to stay with a relative for 5 weeks during the summer. These parents recognized the need for their child to have something of his/her own; a special activity to take part in and to talk about with their peers. As one parent explained,

And so he/she had to be responsible enough to do that, and he/she is. We gave him/her independence, and that's what you have to do with these kids. You have to give them the independence to handle the challenge that they have. And I mean, any kid, whether it's diabetes, Cohn's, all these kids grow up fast. But you as the parents have to give them the capabilities to do that. You've got to let them go sooner.

These parents went on to describe that it was to their youth's advantage and to their advantage to have her be independent at an earlier age. As this youth had a lot of responsibilities in caring for his/her chronic illness they wanted his/her independence to be a strength so that he/she would have a head start in being able to manage his/her chronic illness.

Parents of another youth described how they valued promoting independence in their children. This included preparing their own breakfasts and lunches, helping with cleaning and in participating with other self-management and household chores. This parent described how encouraging independence is a mindful process:

.....as our children grow, we tend not to be casual about the process whereby they gain skills. We actually pay attention to it and we literally focus our minds on how

*we can design strategies for advancing that. And we try to educate our children
.....to acquire different skills at different times.*

Another parent was also able to put his/her education to use in assisting his/her child by knowing his/her educational rights and being able to fight for accommodations for him/her. As previously mentioned, one parent stated their youth was medicating their pain with marijuana and the parent did not approve of this behaviour. The parent expressed his/her concerns to his/her youth's rheumatologist whom he/she said just brushed it off and replied with "what are you going to do?" This parent had to find a program that would deal with his/her child's addiction and mental health on his/her own and eventually had him/her enrolled in a program to deal with these issues. He/she stated that the rheumatologist's blasé response lead him/her and his/her youth to lose respect for the physician.

Parents are also key in providing emotional support to their children. Parents of three youths described how their children had feelings of anger and frustration and that helping them cope with this can be emotionally draining and that they are not always sure about what approach to take. A parent described how his/her youth had difficulty sitting in a waiting room, sometimes for hours, with young children who could at times be crying and whiny. As the parent described,

He/she just finds the waiting room frustrating, with a bunch of tiny, crying children. And when you're coming in for an appointment like that, there's a bit of sense of anxiousness anyway, just for the appointment, just sitting there and wait. I mean, appointments aren't usually on time with specialists, so there's that anxiousness and frustration. And if a child kind of bends towards that way

anyway, it amplifies it sometimes..... and the trying to talk him/her through the frustration – keep his/her mind occupied, talk to him/her, keep the conversation going, you know? There was one day that he/she had seen his/her doctor and waiting to see the physiotherapist, and we went back out and sat in the waiting room, and he/she was in such a state at that point, and then mad and just angry, didn't want to be there. I got up and walked out of the room. I said, if you don't stop, I'm leaving. And he/she didn't. He/she just kept expressing his/her frustration. And I mean, you know, this isn't a quiet conversation that he/she and I are having ear to ear, right? He's/she's expressing it so everyone in the waiting room can hear him/her.

The parents' ability to promote self care and independence in their child was evidenced by the youths' strengths in transitioning to adult care. All of the parents revealed that their child administered their own medications and performed their exercises independently and are knowledgeable about their disease and medications. Two of the youths who had already transferred to adult care were managing refilling their own prescriptions and scheduling doctor appointments. Parents of three of the six youth stated that their children were good self advocates and were articulate at describing their needs and in giving a health history.

1.4 Close relationships with HCPs are unique to pediatrics.

In the last part of the “dream” phase of the interview parents were asked to describe some of the shining moments when they felt they were really supported by the healthcare team while moving through the transition process. As well they were asked to identify some of the challenges as their youth transitions to adult care and to describe

how they managed them. The common theme that came out of this discussion is that families have established close relationships with their pediatric HCPs and feel they are readily available to them. The parents however believe that these close relationships and availability do not exist to the same degree in the adult care world.

Parents of four of the six youths described that they felt that health care providers in the pediatric rheumatology clinic have been there for them and that they felt supported. All of the parents described the close attention they particularly received from the clinic nurses. Parents of four of the youths described scenarios whereby their child was informed by the clinic nurses about arthritis camp. They felt the nurse really took the time to encourage their child to attend. All of the youths ended up attending and the parents found that their children had very rewarding experiences and gained a lot from attending. They were able to connect and share with peers who were experiencing many of the same things they were, they had a chance to be away from home for a week and experience some independence from their parents, and they got to do things within their physical capacity that they really enjoyed.

Another parent described a time when the nurse was emotionally connected to her child. The nurse was giving her child painful intramuscular injections into the thigh and as the parent said, *“X said she (the nurse)felt bad, right? Anyhow. But it’s also an emotional thing, so I would say, yeah, it’s nice to know they care, I guess is the point.”*

Parents also described feeling supported by the pediatric rheumatologists and other physician specialists. Parents of one youth described a time when a specialist phoned their house and asked to speak directly to their child. This made the parents feel proud that their child was capable of communicating with the specialist and of making

his/her own decisions as the parents want their child to be independent. Another parent described his/her child's rheumatologist as being open to suggestions that he's/she's made and willing to discuss things.

Four of the youths had not transferred to adult care yet. Parents of three of the four youths expressed concern that once their child transferred to adult care that they would not be seen in a timely manner if they had an issue. A parent of one of the youths who had already transferred to adult care confirmed this by stating,

Oh yeah, it's a totally different world for him/her. He's/she's used to calling the IWK or I used to call the IWK and say, he's/she's flaring up, he's/she's in pain. They've got him/her in there the next day. I have say, they don't fool around there at the IWK. They'll have him/her in the next day or they're on the phone with me the next day or whatever, trying to figure out a solution. I have to say, they're top-notch in that way. Now the adult care world, completely different. He's/she's had quite a few flare ups and he'll/she'll contact the nurse line, because you have to leave the information with the nurse line and then they get back to you. And a lot of the times they'll say, well his/her clinic's busy and he's/she's got a lot of patients, you'll have to go to Emerg or you go to your family doctor.

This quote highlights the differences between pediatric and adult care. There are a lot more patients in adult care and the HCPs can't respond to their patient's needs with the same timeliness. The parent went on to describe,

And he/she looks at it, and I look at it the same way, well they're not rheumatoid doctors. What can they do for him/her? Like he'll/she'll go to Emerg and they'll

say, well you have arthritis, you know that. You have a flare up, you know that. Here's some morphine. Like it's just another push of drugs. Well here, take this.

Primary care physicians should remain involved in their patients' care across the lifespan. Had this youth maintained steady contact with their primary care physician, the physician would have an understanding of their current condition and treatment and this gap in care could have been dealt with. The parent went on to describe the pit falls that happened when the youth is cared for by someone unfamiliar with their condition and how to treat it,

And then he's/she's got to function in school. He's/she's on hydromorphone, how is he/she supposed to function and go to university and live? So that's where he's/she's at today, and it just seems like one big push of medication on top of medication. Oh, take this medication to offset this medication. So that's his/her frustrations. And Dr. X doesn't get back to you, like the IWK would call. I mean, he's/she's a busy doctor, we get that, and as you are an adult, they don't call you as much. They're not going to coddle you because you're an adult. I should say that he/she does get a call eventually from Dr. X, it could be a day or two later, but it's not as fast as it would be in the IWK.

However, another parent whose child had also transferred to adult care did not have the same experience in adult care. His/her child had a hip replacement two years ago and in speaking of the surgeon who performed the replacement the parent stated, *"He/she gave him/her his/her personal phone number and said, if it gets worse, phone me. That is the kind of treatment we've always got – always, right from day one of the IWK, even to now."*

One parent whose child transferred to adult care describes a scenario that at first was not supportive but in the end became supportive:

Well first we didn't know we were going into transition. They weren't very knowledgeable about that part of it. They didn't call it transition at first, and then all of a sudden we found out we were in transition, and we're like, oh, okay. It just seemed like they were talking about transition and that it was coming up for him/her, and then all of a sudden, bang, it was like three appointments later, oh, well you're in transition....Like once they realized that we didn't know what was going on, they stepped up and they started giving us information, and giving us more information on what was going on and what was going to happen in the transition clinics....So that was quite helpful after that.

Another parent also expressed that transfer to adult care came up suddenly and without warning. For this family there was no prior discussion of what the plan would be. The parent expressed that fortunately, transfer ended up getting delayed as their child needed to be on a new medication and the team wanted him/her to be stabilized prior to transfer. The parent feels that in pediatric care there is more consideration over the plan of care for the child and that in adult care there is less time to do this.

Lack of knowledge about the availability of treatments and cost coverage in other provinces resulted in one youth not attending the university of his/her choice. The person who had been assisting the family with their funding had never had a youth who wanted to leave the province to go to university and thus was inexperienced with this situation. The youth and his/her parents decided to have him/her attend university in his/her home

province instead. They later found out they could have received the infusions out of province.

In the “discovery” phase of the interviews it was uncovered that discussions around transitioning are lacking and thus parents are unclear about what this process entails and when it should start. One parent stated that they noticed a poster in the waiting room that encouraged people to talk to your doctor about the transition. The parent stated,

Well I think – he/she was 16 and just, I noticed a poster in the waiting room in the medical day unit that encouraged people to talk to their doctor about the transition. And I’m thinking, okay, he’s/she’s 16. I’m not sure how much longer he’s/she’s treated here. We should be having the discussion. And so we did with Dr. X and he/she indicated that how it went was there’s like a transition clinic, when we would meet the adult care doctor, and that type of thing, and then usually they go to one or two of those before. So that’s kind of how it started, but it wasn’t mentioned – it wasn’t brought up to us or anything.

Parents and youths face many challenges in dealing with the uncertainty of the youths’ rheumatic disease but have many strengths and skills to help them in assisting their youth to become independent self managers of their care as well as self advocates. These parental abilities are evident in the skills their youths have already acquired. Parents have received support and encouragement from healthcare professionals but there is still much that HCPs can do in order to have a smooth, planned, transition process to further support parents and to adequately prepare them to assist their child in navigating the world of adult healthcare. In the next phase of the interview process, the dream phase, an exploration of “what might be” will be uncovered.

Dream Theme – Parents Desire Knowledge and Tools to do More

The questions asked of the participants in this phase of the interview revealed that parents do the best with the knowledge and skills they have but ultimately desire to have the knowledge and tools to do more. This phase will delve more into looking at strategies that worked best for parents in assisting their child to become more independent and ways in which HCPs made them feel supported throughout the transition process. Exploring those topics leads parents to a vision of what the healthcare system would look like if youths and their parents were always supported throughout the transition from pediatric to adult healthcare. We will look at the subthemes of parents encouraging their youth to the best of their ability and the importance of feeling connected with your healthcare providers. Parents continue to recognize that there are gaps in the system that need to be filled and start to envision how to fill these gaps. In the subthemes that follow key positive aspects that were identified in the discovery phase are drawn out and expanded upon.

2.1 Parents encourage youth to be independent to the best of their ability.

In the discovery theme of “Loss of Control” it was established that parents play a key role in supporting their children, teaching them to be self-advocates and helping them make decisions. In this subtheme how they achieve this will be expanded upon.

While parents encouraged independence in their youth they still see a role in assisting their youth with tasks by completing some of the ground work. Parents in the next two scenarios believed their youths already have a lot on their plates in dealing with

the limitations inherent in having a chronic illness on top of dealing with normal life issues including school work. One parent shared that their youth had gone through a lot of anger issues in dealing with his/her arthritis. This youth was also experiencing issues in managing his/her chronic pain, and also in having difficulties weight bearing due to loss of mobility in his/her ankle. The parent described that his/her and his/her spouse's goal for their youth was *"to try to teach him/her independence on how to be a happier, healthy adult and handle situations going into life."* This parent explained that he/she has done this over the years by having discussions with his/her youth and helping him/her to identify areas of his/her health she needed help with, discussing the importance in managing his/her health, and making appointments with the appropriate HCPs to help manage or treat these areas. The parent helped relieve some of the burden on the youth of managing his/her health issues by researching clinics or practitioners that his/her youth could see. The parent had recommended his/her youth attend a pain clinic and then his/her youth took the initiative to contact them on his/her own. The parent justified taking on this task stating, *"I mean, I'm not going to stop doing that because I think that's important for a parent to help him/her sort through all that. Because it's a lot to take on, especially with school and everything."*

Another parent described in detail how he/she enabled his/her youth to accomplish the tasks and helped him/her overcome his/her limitations:

Well I kind of, well we encourage him/her to do whatever he/she wants, you know, nothing should be an obstacle. And I will set things up for him/her. Like for instance, with applying for scholarships, you know, he/she tires easily, he/she has a full workload in high school, he's/she's doing really well, but I mean, he/she

does have his/her limits. So in terms of scholarships, I found the ones he/she should apply for, and I printed them off. Anything that's handwritten, like forms that need to be filled out, I'll scribe for him/her, but he/she has to do everything else. But I'll encourage him/her. I'll say, like I'll help him/her because it's something different, I'll say, okay, this weekend coming you're going to have to be prepared to give a couple of hours or whatever you need, because he/she needs time management – that kind of stuff, you know, to pace himself/herself, in case he/she has too much homework or he/she knows that heshe has – but you know, this year has been much easier.....So it's the whole idea of teaching him/her time management and speaking out when his/her cup is full, rather than trying to back away from it or avoidance....

Overseeing their youth's health by assisting them in identifying health issues, recognizing the need to manage them, researching resources and time management are necessities which were identified by all parent participants. Another important skill parents need to assist their youth with is making an informed decision. A parent described a time when his/her youth had been suffering with pain in his/her knee. The doctor offered to give him/her a joint injection and the youth refused because he/she had plans for the day and didn't want to have a sore knee all day. This example illustrates that youths are not always rationale in their decision making and that they don't always see the long term consequences of their decisions. This same parent however was able to teach his/ her youth how to think things through and make an informed decision.

I noticed the last appointment we had with the orthopedic surgeon, he/she was giving him/her a couple of options of things he/she could do. And I just sat there

and never said a word. And he/she was laying there on the examining table, and you could tell he/she was thinking, and then he/she said, well mom, what do you think? So I thought, okay, he's/she's asking my opinion, I'm going to tell him/her what I think. So I chatted about our experience that morning, you know, he's/she's frustrated with his/her pain level. He/she figured we were going to go in there and he/she wasn't going to do anything for him/her. I said, okay, he's/she's offering you two choices. It would probably be silly for us to sit out there in the waiting room, you complaining about pain and us not to take any of the choices, wouldn't it? Well he/she agreed with that and he/she decided he'd/she'd take the injection that day, and go on a list for a scope.

While parents were sometimes discouraged to sit in on their child's pediatric rheumatology appointments they were welcome to accompany their child when being seen by the adult care orthopedic surgeon.

So I guess that's a process, you know? I'm teaching him/her how to think things through and make a decision. And sure, it's fine for him/her to want someone else's input, and to want my input, and I wouldn't want to be anywhere else but there giving him/her my input. But you know, I can see he's/she's a little like- and it's funny, adult care, they have no problem with me going in the room with him/her, and that type of thing.

This parent's story illustrated that a parent's perspective can still be important because they sometimes think of things that the youth doesn't think of. Parents of five of the six youths viewed their youth going into their doctor appointments on their own positively and saw it as the youth forming their independence and learning how to speak up for

themselves. The parent who felt that attending appointments on their own wasn't right for their youth described,

I had to convince him/her (to attend appointments on his/her own). That was where the convincing had to be. Although a parent knows, I think, and I know some kids you know, if you never challenge them they'll never rise to the occasion. But a parent knows when their kid is ready or not to deal with that on their own. A parent knows what mind frame their child is in, what they're going through inside and outside of appointments, and whether or not that's just one more thing they can tackle and handle. So I guess I don't necessarily agree with the carte blanche age, all of a sudden the parents don't go in. I mean, to think about starting at 14, I think that's ridiculous. I really do.

Parents of one youth described that they have had positive experiences with physicians whereby the physician has spoken directly to their youth about treatment options and looked to the youth to decide what they wanted to do. These parents felt that sometimes they need to sit back and observe and give their youth the opportunity to either fail or succeed. This next scenario illustrates how youths can learn from their mistakes and in the end make the right decision on their own. As this parent explained,

I guess the only thing maybe was when he/she went off medication for a summer, right, and X was included in that decision. And actually he/she became symptomatic again. We knew, but he/she didn't want us to know because he/she wanted to stay off the medication for [Oh, okay.] but then he/she walked into the appointment and fessed up right to the [Oh, he/she did.] oh, right to Dr. X. I was expecting we were going to have a little bit of, you know [The struggle?] yeah,

you're having symptoms, you know? And he/she did, he/she said right away off the bat, my symptoms are back and I don't want to go through this anymore, and I want to go back on medication. So there was another – and then Dr. X didn't tell him/her off, he/she didn't condone, you know, he/she said, that's okay X, and continued on and he/she reassured him/her that it was fine to make that decision and make those choices, and that they could get back on track. So once again, it was another time for the parent to realize that he/she was okay, and you didn't really need to take on that responsibility, that he/she could manage that. And he/she understood, it was actually A good learning thing for him/her, yes.

The parent of this youth who had already transferred to adult care and was for the most part supportive of his/her youth attending doctor's appointments alone at times still sees the need to accompany his/her youth. The parent stated,

No, he's/she's gone on his/her own. I requested once to go because sometimes they don't have that voice yet, like they're still a little nervous. So I asked him/her if it could sit in on one of his/her appointments, and he/she had agreed. So I had gone with him/her and listened to him/her, and it's there, but it's not strong enough yet. His/ her voice is there, like he/she tells him/her what he/she wants to do, but it's not strong enough yet for the doctor to – well, we're going to this instead or basically being told like, no, this is what we're going to do. The last one he/she went to, I wanted to go with him/her and he/she said, no. So I respected that. It's his/her body and it's his/her wishes, so – he/she said, you can drive me or you can sit in the waiting room, but he/she said, you can't come in.

Parents of another youth expressed that their youth knows his/her parent worries when he/she has pain. They feel it is best for their youth to see his/her doctor on his/her own as he/she may then be honest about expressing his/her pain. These same parents expressed that their biggest challenge with their youth was trying to assist their youth in transitioning from being a child who performs healthy behaviors to obey their parents to being an adult who performs healthy behaviors because h/shee recognizes it to be in his/her best interest. This parent clearly articulates this in stating,

That's a very, very deep cognitive adjustment, and it may be the single biggest part of the maturation process. I think it's a lot more challenging for a young person who has health issues and has to undergo painful and uncomfortable and ongoing procedures, to make that adjustment from thinking of it as doing something your parents want you to do, to doing something that you have to do just in order to have good health in the future.

The parents expressed that they would really appreciate receiving support from HCPs in emphasizing to youth what they can do to help themselves and the importance of being accountable in promoting their health. While parents are managing to the best of their abilities they look to the HCPs for emotional support, skills to communicate better with their youth, information and resources.

2.2 It is important to feel connected with your healthcare professionals.

In this stage of the interview parents were asked “How and in what way did healthcare professionals make you feel supported through the transition process, from the pediatric to the adult setting?” In the responses of the parents the common theme that

emerged was the importance of feeling connected with your HCPs. Parents benefitted from that emotional connection when it was present as it made them feel supported.

One parent described that at the last pediatric rheumatology appointment his/her youth had prior to transferring to adult care that their doctor had a heart to heart talk with them for the first time. As the parent stated,

Our last meeting with Dr. X I'd would be the most supportive because we actually had a one-on-one, like a really heart-to-heart one-on-one for the very first time, and he/she listened to my concerns and he/she listened to X's concerns and I found he/she really came down to our level and talked to us like, not doctor-patient, more one-on-one like human-to-human. And I found that was very helpful and very supportive to X and I, because he/she basically said – because X is a very stubborn (person), he/she gets that from her (parent). And he/she basically said that, if you're not willing to help yourself, then everything that your parents have been doing for you over the years, and going to therapy and doing this and doing that, is a waste of time because you need to want to do it yourself. So just hearing things like that and reassurances, I thought, oh god, somebody's been supporting what we've been trying to do all the years, like trying to get him/her to move forward and be more positive.

When asked if the parent thought that that conversation would have been more beneficial if it had happened earlier on he/she stated,

I think so, yeah, I think that would have been more beneficial because I think that was our very last appointment. And I think it's like all of a sudden it's like, okay, do you have any concerns? Do you want to discuss anything? And it's like, blah –

everything came out, right, and he/she spent extra time. I mean, he/she didn't seem like he/she was in a rush to move onto other patients, so he/she sat there and we had a talk, and it was really nice. But if they could have done that previous maybe and maybe a little bit more often, maybe that might have made a huge difference. Because it felt like they were actually listening and caring, and wanting to help. And not that they're not helping because they are, but just it seemed a little bit more personal.

Another parent explained that his/her youth did not have a good rapport with his/her pediatric rheumatologist and that was one of the reasons why he/she always wanted his/her parent to accompany him/her into the office for his/her appointments. He/she described that when he/she was dealing with a surgeon in adult care he/she had a much better rapport with him/her and thus was very willing to listen to what the surgeon had to say and discuss it with him/her. He/she did positively note that their pediatric rheumatologist made them feel supported in that he/she wanted to get the youth stabilized on his/her treatment prior to transferring him/her to adult care. The parent noted, *“You know, he/she doesn't want to send him/her when he's/she's kind of in limbo or not at a good point. And I appreciate that. And he/she did too. He/she explained that to me, and he/she was fine with that.”*

Parents of another youth felt that the pediatric rheumatology clinic staff inquired and probed to see if there were emotional issues without being obvious. In this passage the parent described encounters with the clinic staff:

I guess when he/she was younger they would communicate more with the parents, but ever since he/she was 12, they always ask how old you are. And he's/she's

grown a lot taller, so they recognize him/her now as someone more mature, and they pay a lot more attention to, they make more of an effort to communicate with him/her now, than just with me. They ask him/her and they talk to him/her about his/her condition, and they make eye contact with him/her. And so I get the sense that they're starting to treat him/her like an adult, and maybe that's not accidental. Maybe they're doing that deliberately as part of this, as you say, transition process that I never noticed.

This passage illustrates that transition interventions are being carried out in the clinic. Clinic staff do this without drawing attention to the fact that they are encouraging the youth to speak for themselves, answer questions about their health and start to make their own decisions. Along with encouraging youth to go into their appointments unaccompanied and having the youth answer questions, parents of two youth also cited that HCPs were having conversations around teen health issues including sex, and drugs and alcohol consumption. One parent did state though that his/her youth didn't care for the manner in which he/she was asked about these questions as HCPs asked the same questions of him/her each visit and each time he/she felt uncomfortable and as though he/she was being grilled.

This last parent fondly described the support that they received from clinic staff stating,

No. For us, we've never – X and X (nurses) and them, they all worked with us to the nth degree, so we never had any – other than it happened too fast, and we weren't ready. But the day that X (his/her child) left, I guess they had a – well they always had a birthday cake for X. I don't know if they do that – X (nurse)

started it, and X (another nurse) kept it going, so they always had a birthday cake. And the day we left, they still had a cake for X. And you know, there were no tears, thank god, but no, I've never felt where I didn't – that they weren't there. If we had needed them, I know I could have called. So it was there for us.

Parents in this study felt support from clinic staff but also felt that they could benefit from even more support or, at times, more defined support. While it came to light that transition interventions have been taking place to encourage the youths to be more independent in their interactions with HCPs there were still areas to improve upon. Most of the parents in the study were not able to identify that their youth was going through a transition process as this process was undefined and not talked about with any of the families until they neared the time of transfer to adult care. Only then were “transition clinics” discussed. These transition clinics took place with youths whose care was being transferred to one specific adult care rheumatologist. One to three appointments would be held with this adult care rheumatologist as well as their pediatric rheumatologist as a means of transferring care and enabling the youth and rheumatologist to get to know each other.

2.3 There are gaps in the system that need to be filled.

Parents in this phase of the interview were next asked, “What would the healthcare system look like if parents were always supported throughout the transition from pediatric to adult healthcare?” Parents identified gaps in the system when it comes to a transition process and in their interviews offered up many solutions to fill these gaps.

The overarching vision that was brought forth by all of the parents interviewed was that the transition process needs to be clearly defined, there needs to be a dedicated

conversation about the process with the families and youth, and HCPs need to receive the family's and youths' input into how the process will unfold. Families expressed that this process needs to start early but parent's ideas of the appropriate age to start varied from early teens to age 16 years.

One parent offered that he/she would like to see more support for parents in the transition process. He/she recommended having a support group for parents or self help information that addressed what other parents went through and how they handled situations. The parent explained,

....if you ask certain questions, and then the parents can have something to read. Oh, well my child went through it like this, or she was always angry or he was always angry, some kind of support material of just standard questions. Like what was your household like? Was it chaotic? Was it crazy? Was your child breaking down crying on the floor at night in pain? I know that's what we were like. Sometimes it was just crazy here, like you would not believe the stress you have in your home. Well you should come to my house. If they had more support that way, I think that would make the transition a little bit easier on both ends. And then even with the doctors on the other end from the adult world, to even be able to meet with them a little bit more and even say, well this is what we're going to do to help your child. Because you didn't really get that, you just met them for two seconds, like hi; I'm doctor such and such. I'm going to be taking care of your child into the adult world. That's it. And then your rope's cut, you're done....And even though they transition, you should still have a little bit of time to let the

parents get comfortable with the transition, because it's the parents transitioning too, not just the kids.

Parents of one youth whose child hadn't transferred to adult care yet offered a unique perspective. These parents suggested that after their youth transfers to adult care they would like to see a transition in the frequency of his/her medical appointments and also in the timeliness of accessing assistance. This parent stated,

I would like to see this graduated system where they're not totally cut off. You know, it's like you're cutting the umbilical cord all at once, where the visits are still regular, they're still there, you know, maybe once every six months, once every eight months, depending on the condition of the child. If they're still having severe inflammation and they're on the medical drugs, they can't just go from, oh well, just call us anytime. Continue with your medication and call us anytime you – it stops working, you know? I would like to see a still, regular appointments, number one, regular appointments and number two, if they're going to cut them off, do it very, very gradual.

This parent also held a world view that young people should have a priority to be seen before older people. As expressed by the parent,

And if they need to make an appointment, just make sure that they're towards the top part of the list, you know, the waiting list for appointments. Not just first come, first serve, you know? I would hope that a 19 year old or 21 year old would be way above a 48 year old on the pecking order and the waiting list for an appointment, especially with a chronic disorder.

This is a view that is personal and many people likely would not support.

Another parent echoed the sentiment of needing to provide support to parents around transferring to adult care. The parent described how at age 16 or 17 his/her youth started to have fears about transferring to adult care and saw a psychologist for this in the pediatric facility. The parent expressed that there is no support offered for parents. He/she felt having support for the parents would be helpful as he/she felt a lot of the youth's fears stem from the parent's fears. The parent expressed, "So it's this whole idea of being involved and then all of a sudden, can't be, or there's no place for you to be involved. And I think that that's difficult for parents."

Parents also expressed that currently in the pediatric centre all appointments are in the same facility and scheduled to take place in one day. Case management is employed in the pediatric facility. For instance, if an issue is recognized it is referred to the appropriate specialist and often dealt with right away. One parent described an occasion when their youth was being started on a new medication and there were concerns from an infectious disease standpoint. They said the doctor went off, located the infectious disease specialist, consulted with him/her and the concerns were dealt with right away. Parents did not expect this type of service in a large adult centre. However, they would like to receive education on how they and their youth can do their own case managing. The parents also felt that as part of the transition process they would like to gradually start seeing adult specialists in their offices. As the parent explained,

What I would say is, right now there are two things characteristic of his/her health care. Number one, it's fairly managed by sources within the IWK, which is to say, he/she does quite complicated things going to various specialists and then the various imaging departments and testing departments. And a lot of those

appointments are set up under the direction of a specialist, Dr. X or somebody else through the booking service. So that's number one, it's quite a unified set of elements. And number two, they're all in the same place. You go to the same building. We're sometimes there it feels like, from dawn to dusk, going from station to station....we go through a phase where some of the places we go are no longer in that hospital complex.....So gradually what they do is replace IWK people with out of institution people, i.e. the juvenile specialists with adult specialists. But still, there's a kind of overall case management that's happening through ..the rheumatology department. And that the whole case management isn't all of a sudden put in our hands.....And what we would hope to have is information and training for us and our son/daughter so that as case management goes from them to us to him/her, we can manage that part of it. It's not going to be out of building specialists that's going to be the problem. It's getting it all organized. That's what we're going to have to learn how to do.

Parents of four of the six youths concurred that it would be beneficial to have an appointment with the adult care rheumatologist in the adult facility prior to actually transferring to adult care so that they could have the opportunity to see what the space looks like, see how the adult clinics are organised and have an introduction to the HCPs in the adult facility. All parents expressed they would like to receive education on the differences between pediatric and adult healthcare and how the roles of the parent and youths may change.

Design Theme – Need for an Inclusive, Formal, Defined

Transition Process

In the design phase interview questions were related to “what should be”. In this phase parents were encouraged to go into detail about the practicalities, i.e., the processes and structures that need to be in place to make their dream a reality. The questions asked of the participants in this phase of the interview enabled parents to expand upon ideas that they were starting to formulate in the previous phase and go into more detail about what they would like to see as a reality in transition care.

3.1 Partnering with youth and parents in the planning and execution of the process and timelines.

The desire to have HCPs partner with youth and their parents in the planning and execution of the transition process was clearly voiced by all parent participants. Parents want the ability for them and their youth to be active in the development of processes and timelines. All of the parents expressed they should be given the opportunity to provide feedback about the transition process (i.e.: what will work for them and their child) as well as an opportunity to ask questions well in advance of the time to transfer. Parents expressed the desire for a formalized, clearly laid out transition process with a formal discussion that takes place prior to the process commencing and also after the transfer to adult care happens to answer any questions and to receive feedback on the process.

All of the parents expressed a need for themselves and their youths to be able to have a preview of what adult care will be like, to have the opportunity to process this mentally and to have any concerns dealt with prior to transfer. Parents of one youth explained how this could be achieved by stating,

P1 It's just that patient having that initial contact with the (adult care) rheumatologist, maybe what's going to come up. Let's say for X, he/she has three appointments, well maybe it would be the first one of that initial year, and then he/she goes back and has his/he two follow ups. You know, if h/she has any concerns, what he/she feels might be coming up, then he/she has more time to discuss and think about things. He's/she's had a little preview, he's/she's had an introduction of what it's like. More how the system runs, maybe how they just greet you, take you in, it's a bit more, I don't know, I can't say it's more clinical because I'm not sure what it would be like – and the parents maybe get to go. I'm not sure if that's necessary or not.

P2 I think it is also, you must be trying to appease parents too because you know, if the parents are anxious I guess that can also be something a child will ...

P2 So you have maybe a six month period to be able to, if you're a little fearful of things you've got a little bit of time to think something through and let people know, before you get dumped over there.

HCPs need to be forthcoming with information and solutions. HCPs may make assumptions that parents have knowledge of things. The parent who earlier described the situation with his/her youth's marijuana use and having to find his/ her own resources after not receiving help from his/her youth's physician expressed the importance of parents expecting to receive help when they discuss problems with HCPs.

Parents of three youths also recognized though that it is important to understand that while HCPs are available to provide support that parents and youths also have to help themselves. One parent voiced that parents can't assume that HCPs will inform them of

everything and that it is also incumbent upon the parents and youths to ask questions. Parents of another youth explained that everyone has their own values and their own methods to deal with things. The parents explained that it's also important for parents to analyze their own situations and to come up with their own strategies to deal with things. In speaking of their child's unique needs one spouse stated, "*Your strategies have to focus on their strengths and weaknesses.*" And the other spouse added,

...you've got to understand, you're charting a path that's as individual as your own child, and you have to be prepared for the complexity of that task. One of the things it involves is making mistakes galore, and learning from them. That's how you're going to learn, more than anything you read or are told, you're going to learn from your own mistakes. And be prepared both to make them and reflect on them, so that you can learn from them.

Parents of three adolescents also verbalized that just as the parent needs to know their child well, the HCPs need to have a good understanding of the youth's individual needs and as the parent stated "a cookie cutter approach" can't always be used. Parents saw it as their role to communicate to the HCPs how their youth copes and learns best.

One parent whose youth was undergoing the transfer process clearly expressed the need for a formal goodbye from their pediatric healthcare team. The parent and youth were told that the appointment they were having would be their last at the pediatric clinic. The parent stated,

It just seemed really abrupt. It was abrupt. It's just kind of like you have your whole life as a routine going there, and then all of a sudden it's just cut off... I said to them, well can't he/she come back sometime when everyone's here, and

he/she can see them and say good-bye? Because you know, it's been part of his/her life for like 10 years.

Parents recognized they have an accountability to perform certain tasks with their youth in the transition process and to communicate with their HCPs, offer suggestions on how their youth copes and deals with situations and to ask questions when necessary. Parents also would like the HCPs to have accountability for performing their roles to the fullest as well. Parents recognized that for the transition process to go smoothly that HCPs need to partner with the families in the planning and execution of the process.

3.2 Families need to be heard.

In this stage of the interview parents were asked “How might your story help other parents facing similar experiences to yours?” and “How might your story help healthcare professionals to better support parents during this time?” In this phase the responses to these questions revealed that not only do HCPs need to have a true understanding of the families’ strengths, weaknesses and needs but also that families and youth need to hear from their peers as well.

Parents of four adolescents indicated the importance of HCPs performing a formal check in with the parents to see how they are doing, if there is anything they need, or any guidance they can give. Two parents in the study made reference to a poster that hangs in the clinic waiting area. This poster reads as follows: “Talk with your Doc: Have you talked about transitioning into adult care? Talk early, talk often and prepare now.” One parent suggested that the posters could be effectively utilized by the HCPs as a conversation starter. As the parent explained, *“I’m wondering if it might multiply their effect a little bit just to have the physician make a point at some time in the interview with*

the parents of saying, by the way, have you noticed the posters?" The parent went on to further suggest,

So every single encounter between a physician and parents should probably close with a brief reference to that issue, and you know, a two minute conversation on that. Look, this is what's coming down the chute. You don't have to worry about it in a direct way yet, but we should start talking about it.

As the parents became more thoughtful about this suggestion they thought that this role could be delegated to another HCP, such as the nurse, who could have this conversation while performing their initial assessment.

Parents were also unanimous in voicing their desire for having support groups either for their youths or themselves. One couple expressed that there are benefits in both the youth and the parents discussing their youth's disease openly with others and letting them know what is going on rather than internalizing everything. This parent relayed an experience when she and her husband were involved in a focus group for a study and described,

.. but within the study when we had a discussion in a group of, I think there were about seven of us, two parents openly discussed the fact that the child had arthritis. The child discussed it openly. Both of those children were very outgoing, social interactions were very good, lots of friendships. And the other parents, you could see the pattern that, the parents were more – tried to hide it, you know, didn't want to discuss it so much. Didn't feel that everyone in the school needed to know or maybe just the teacher needed to and not the principals, that kind of thing. Those kids had a more difficult time with interactions socially and

friendships, and it's very obvious. So I would hope that the healthcare professionals would tell parents you know, this is a disease you need to let people – you don't need to put it out there, but don't let your child internalize all of this.

Another parent felt that a focus group could be beneficial to share stories of transitioning, to find out what others had experienced and how they coped or were coping with the process. The parent of a third youth stated that it would be helpful to hear other parents' stories of what they have experienced with their youth to know that they are not alone.

All of the parents expressed that it would provide them with a sense of relief and comfort to have their youth have their own support group to be able to discuss teen issues amongst their peers and know that they are not alone in what they are going through. One parent suggested that this group could be facilitated by an HCP and could also do double duty as an information session providing the youth with lifestyle information and encouraging the youth to take ownership of their healthcare and well-being.

3.3 Resources and information must be available.

Parents unanimously expressed that they want to know what the transition process will look like and what adult care will look like. Parents suggested that to learn about the transition process it would be helpful to have an information packet or even a one day seminar for families. Once their youth has transferred to adult care the parents felt it important to know who the people are whom the youth can contact if he/she had a major issue with their rheumatic disease.

Parents of two youths suggested that it would be helpful to have a “go to” person during the transition process, particularly after the youth has transferred to adult care. One couple suggested this person could be a case manager who ensures appointments are

co-ordinated, and that information gets communicated between specialists to ensure their child “*doesn’t fall through the cracks*”. The parents suggested the case manager would be with them for a period of a year or two and that the role could be fulfilled by a nurse or a social worker. The parent recommended that the case manager could check in with them every few weeks. The parent explained how this would alleviate his/her stress as follows:

You know it would be really comforting for me to get a phone call from someone managing my – we understand you have transitioned, have you ever tried to – were you ever in a position where you tried to make an appointment and it took a very long time? And I would love to be able to say, yeah, it took nine whole months when he/she was in pain, and I didn’t know what to do. Instead of me calling them up, excuse me, my son/daughter is in pain, he/she hasn’t had an appointment for nine months, can you please bump him/her up on the list, or can you – do you know what I mean? I don’t want to be in a position of launching complaints or begging to have him/her seen earlier, or having to take him/her into Emergency. Because that’s what they always say, if you can’t get him/her in, take hi/her to Emergency. And you’re sitting there six hours in Emergency at a time when he’s/she’s in school, you have to pull him/her out of school, I have to take time out of my job.

Other parents concurred that this “*go to*” person should be someone who can answer your questions and help you deal with any problems. The person could also help navigate the adult healthcare world, and, as parents of two youths expressed, this person could give counselling on considerations for attending post secondary education or in getting a job. The parents felt the person should be knowledgeable about such things such

as entitlements, i.e.: grants that are available to provide tools to assist youth with their physical limitations, such as a computer for those who have difficulty writing by hand. This person could also inform the youth and their parents about the accommodations that are available at secondary and post secondary institutions to assist the youth in dealing with their physical limitations. Parents of one youth felt that HCPs should be able to provide information and answers on a variety of topics including the availability of, and funding of, infusions in other provinces.

Parents of a youth who had difficulty coping emotionally with his/her illness suggested it would be helpful to receive information on what his/ her youth may be experiencing psychosocially so that he/she may better understand what his/her youth is going through and offer support accordingly.

I think the strategies that they should teach to the parents- because I found this out in the very last appointment with the doctor, was that when a child is diagnosed with a chronic disease they have to go through stages. And I didn't know that. And one of the stages is grieving because they're grieving their childhood. I did not know that either. So I think that if they could – because obviously they know the stages because they see it. They know what the child is going to go through. If they could give you that kind of information at the get-go, that would mean the world – it would have meant the world to me because I did not know he/she was grieving. I didn't know children grieve. I didn't know that he/she felt like he/she lost his/her childhood, because you don't see it.

One parent couple disclosed their youth was not being compliant with personal health behaviors such as sleeping and eating well. These parents felt they would like the

HCPs to take a more active role in informing youth about what the youth could do to take responsibility for their own health. They suggested one means of doing this could be through an electronic newsletter. For these parents it was important that their youth make the connection between certain kinds of behaviors and the long term quality of their health.

Destiny Theme – Sustainability through Advanced Knowledge, Skills and Practices

In the destiny phase, interview questions were related to “what will be”. This phase looked at creating an achievable plan for HCPs. This plan would provide parents with effective support on a more consistent basis as their youth transitions, and state the networks and structures that would be in place in order to achieve this. In this phase parent responses revealed that HCPs required education and skills to carry out transition interventions and that a restructuring of services within the healthcare system had to occur in order to create and sustain the changes.

4.1 Healthcare professionals require education on topics related to transitioning.

At one point in the interview parents were asked “What are the innovative long lasting changes that you believe are necessary to better support parents in the transitioning of your adolescent from pediatric to adult care related to educating healthcare professionals?” Parents overwhelmingly identified that first and foremost healthcare professionals needed to be educated on the impact that transfer has on families and of the importance of carrying out transition interventions.

Parents of one adolescent suggested that HCPs need to be well informed about children's stages of development, especially through the teen years and apply this to what to they are capable of knowing and doing. They went on to say that it is important for the HCPs to be able to convey this information to the parents and tie it back to why they have certain expectations for youth at certain times. The parents use the following example to clarify this point:

They might just need to say it at that stage 12 and 13, okay, we're now working on – like they've never had to say that to us, but that might be something that as a routine with most of the parents say, okay, right now we're going to be working on empowering your child, so your child is going to have to answer more for themselves and X (child), we'd like you to answer your questions. I mean, when we went in for – the nurse takes him/her in, she'll/he'll say, now X (child), you need to tell me what you're on because you need to know, instead of your mother listing off all of your medications which is the right thing to do. So he/she was doing that already. Maybe it needs to be a bit more factual. .. That's what the parents need to be encouraged to know, that it's okay now. This is an appropriate time to – this is what at this age and stage is, they're able to – sometimes, you know – a lot of times it's just encouraging the parents that this is an appropriate time, I think.

Parents of two youth suggested that HCPs could benefit from some training in communication skills and how to address subjects such as teen health issues without making the youth feel like he/she was being grilled. Parents also agreed that HCPs needed to be educated on the resources that are available to parents and youth as they go

through the transition process so that they are able to provide these resources to the families. Parents felt it is also important for HCPs to understand how little many parents actually know about the healthcare system. Parents expressed a desire to have HCPs communicating with the families as much as possible and give them as much information as possible.

4.2 There needs to be a restructuring of services.

Nearing the end of the interview parents were asked “If you were to wake up tomorrow, what would be the one change you would like to see have happened within the current healthcare system related to transitioning from pediatric to adult healthcare?” Many of the parents stated that in order to get acquainted with adult care services and to have a more gradual transition process that they would like there to be some overlapping of services between pediatric and adult care. One parent gave the example of going to see the adult care rheumatologist as an introduction to their clinic but then still go back to the pediatric rheumatologist a few times before transfer of care officially took place. As explained by the parent, parents and youths could benefit from having a visit with the adult care rheumatologist in their facility, have a tour and meet the HCPs who will be caring for them and be interviewed by them so they know what your concerns are. The parent stated there is currently a focus on transitioning from one doctor to another but there needs to be a team approach. The parent emphasized this by stating, *“You need to transition to a new team of HCPs, not just the doctor.”*

One parent took these ideas a step further and suggested that there should be a care team specifically for young adults between the ages of 18 years and 23 years who specialize in the needs of young adults. This parent rationalized that they’re transitioning

not only in their healthcare but also into leaving the comforts of home and venturing out into the world. Another parent expressed concern that the changes between pediatric and adult care are significant in that the youth go from being pampered in pediatric care to feeling like the HCPs have no time for them in adult care. It would be beneficial if the youth had some extra support and attention for a time because they really aren't adults yet.

Parents of three youths suggested that some tools be developed to assist families through the transition process. One tool would be an on-line transition site. This would be a place where people can go to receive information, have questions answered and chat with other families who are going through the transition process as well. Another tool a parent suggested is a booklet that HCPs assist families in maintaining that included a running status of their health status, treatments and how the child responded to treatments. The parent explains that youth would not be able to recall this information from their early years and the youth could better inform their HCPs about their health history. The third tool suggested by a different parent would be a database of services that HCPs could access that would address or meet the various needs that youth could require.

One very concrete structural change that was a main priority for one parent was the creation of an adolescent waiting room. The parent had previously voiced how being in the same surroundings as crying babies and whiny children was enough to set her adolescent off and set the mood for the entire visit. This parent stated,

I know space is at a premium and all of that, but I even thought of an adolescent waiting room. I mean, I'm sure that's not anything new, but it's a huge age gap

from newborns to an 18 year old. And if it was an adolescent waiting room with, I don't know, a TV or a gaming system. Just something less childlike ...

Restructuring how youth move through the healthcare system, creating tools to assist with transition and possibly even restructuring physical spaces are suggestions the parents would like to see become reality. The parents did often state throughout their interviews that they realized gaps in care were often related to a lack in resources and that the clinics were very busy places.

4.3 Allocation of resources is key to success.

The last question that was asked of parents in the interview was in relation to the one change they would like to see happen within the current healthcare system. This question was “What would it take for this to happen?” Parents recognized that in order to sustain these changes that there needs to be a priority made for funding transition resources within the healthcare system. Parents feel that HCPs need to be allotted the dedicated time to focus on performing these strategies. They recognize that appointment times may need to be longer or that there would be dedicated personnel or case managers to help navigate the transition process both prior to and after transfer to adult care.

Parents recognized that in our current healthcare system that the HCPs are very taxed for time and that makes having these conversations around transitioning very difficult. Parents voiced this by stating:

I just think there needs to be something more in place, like an extra body .. but then you tell me how many kids are transitioning , and I'm thinking whoa, that's a lot. There's got to be kids who fall through the cracks. I know clinic days are a zoo. They're crazy. Maybe that's an issue. Maybe when it comes to the point that

they just don't have time to think outside of that weigh them, get their blood pressure...maybe that's an issue as well.

This parent thought that there should be a dedicated person who could help in navigating youth and parents through the transition process and that this would be extremely supportive. They voiced that they felt the resources in the current climate could limit what is currently being done. As they stated,

Ideally, if they could extend that kind of role, you know, person- I mean, I guess that I say this kind of laughingly because I know that our resources are so limited. I can't imagine they're actually doing this but you did say, ideal.

Parents in this study felt that money and time had to be spent on delivery of services. While this is true, it is definitely not unimaginable that change can happen with limited resources. HCPs need to have a mindset of performing transition support strategies while doing other tasks and health centres need to create a culture of providing transition care so that providing this support becomes second nature.

Summary

In the beginning of the interview it was evident that having a youth with a rheumatic disease created a loss of control in parents. Having an undefined transition process and not knowing what adult care would be like contributed to the loss of control. Parents play an important role in assisting their youth to develop the self management skills required to become independent but would like resources and support to do this more effectively.

Parents recognized the important role that HCPs play in supporting them. Parents were able to describe experiences they had with HCPs and tease out the interventions that

enabled things to work well. Parents also described experiences whereby interventions and support from HCP were at times lacking. Parents were able to identify areas of success to build on; areas that could be improved upon and had new ideas that could help support them through the transition process. Parents were able to take their initial thoughts and as the interview progressed refine them into detailed solutions. In the next chapter I will analyze these responses and tie them back to the findings in the literature review as well as any new literature that has surfaced.

Chapter 5 Discussion

Introduction

In healthcare, one approach that has received considerable attention in support of workplace change is Appreciative Inquiry (AI). AI is a means of data collection that effectively elicits narratives from research participants which focus on positive strategies for change (Cooperrider & Whitney, 2005). AI provided the framework for analysis for this study. The findings included: parental loss of control in caring for their youth with rheumatic disease; parents desire to have the knowledge and tools to do more in assisting their youth through transition; the need for an inclusive, defined, transition process; sustainability of changes through advanced knowledge, skills and practice. The usefulness of AI as a means of data collection will be explored and discussed.

The research questions for the study were:

1. How is the psychosocial health of parents affected as their youth transitions from pediatric to adult health care?
2. What are parents' perceptions of the process of transitioning from pediatric to adult health care for their youth with a rheumatic disease?
3. What strategies do health care professionals currently employ to assist and support parents in gaining the skills to promote self- care and independence in their youth and facilitate the transition process?
4. What strategies do parents believe healthcare professionals should employ to more effectively assist and support them in gaining the skills to promote self- care and independence in their youth and facilitate the transition process?

Study findings will be compared and contrasted with the literature to make note of similarities and differences between what is known and the findings of this study. Suggestions will be provided on possible implementation strategies to support transition. While undertaking this research project activities were initiated within the IWK Health Centre (pediatric services) and Capital District Health Authority (adult services) to promote and implement transition strategies and these will be highlighted.

Benefits of Using AI as a Data Collection Method

The use of AI as a data collection method proved to be a very effective way to elicit detailed, descriptive narratives from my research participants. The topic of transitioning from pediatric to adult care appeared to be a topic that participants were very passionate about as evidenced by their desire to be heard, the details of their narrative descriptions and the length of the interviews. In the initial *Discovery* phase of the AI 4-D cycle I was able to achieve an understanding of the world of the study participants as they described not only their values and experiences as parents of YSHCNs living with chronic illness and disability but their youth's attempts to achieve independence and self management skills as they transition to adult healthcare. Although the parents did not initially have a clear understanding of the differences between transition and transfer the manner in which the interview questions were asked and the explanations offered facilitated a greater comprehension of the distinction and led to a rich discussion of the topic.

As the interviews moved through the *dream* and *design* phases parents were asked what has worked well for them and what they envisioned could work well. Parents were able to evolve their experiences into what were initially broad suggestions and then build

on these suggestions until they came up with very detailed strategies which could be very useful in effecting change in the current transition process. In the *Destiny* phase parents articulated methods in which this change, through implementation of strategies, could be maintained.

The topic of transitioning to adult care was one that proved to cause some stress and anxiety in many of the parent participants; they voiced some of the negative experiences they had where good care was lacking. Through the use of positively framed questions and a goal of coming up with strategies to elicit positive change they were able to overcome these feelings and negativity and articulate strategies to create a transition process that supports both parents and their youth.

Affect on Parents' Psychosocial Health

Living with a Child with Chronic Illness

The parents in this study expressed that living with a child with a rheumatic disease meant living with a degree of uncertainty. Parents expressed a feeling of loss; loss of their healthy child and loss of control. The loss of control was attributed to the unpredictability of the disease. Loss of control also appeared to be attributable to a lack of clearly defined transition processes, including not knowing what to expect with adult care, not knowing their place in the transition process and fear over relinquishing care. Loss of control was found to be a source of concern within the research literature. In a qualitative study involving parents of youth with a neurological disorder who had transitioned to adult care, it was found that parents who had learned to cope with their child's condition over the years perceived a loss in stability, diminished levels of energy to deal with the associated stress of transition which combined to adversely affect their

emotional and physical well being (Davies et al., 2011). While parents in this study did not express any affects on their physical well being, they did express the frustration and stress they had experienced with the process of their youth transitioning to adult care. In some cases the everyday lives of all the family members were impacted. Time was spent at appointments or in hospital, as well, some siblings expressed worry over the well being of their sibling with rheumatic disease. Other concerns that were raised include financial struggles such as staying at home to care for the child as well as the associated cost of travel and treatments. It is important for HCPs to consider the impact of having a sibling or child with rheumatic disease on the entire family and not just the youth with special health care needs (YSHCNs).

Parents of four of the youths expressed that their youth at times exhibited anger and frustration over their condition as a result of associated pain and mobility issues as well as their inability to meet the developmental tasks of their peers. The frustration of the youth was also experienced by the parents as they struggled to help their youth cope. Parents of five of the six youth cited they had close bonds with their youth in part because of the struggles they have endured. Of young adults with JIA 40% are somewhat limited in their functional capacity and 10% are in need of assistance to manage daily routines (Minden, 2009). Parents require assistance and guidance from their HCPs in assisting their youth to manage their pain and cope with their disability. The importance of this will be revisited when suggested transitioned strategies are examined.

Parents' Role

The importance of the parent's role in managing their child's health care and in assisting their youth to be independent self managers of their health care was strongly

portrayed in the study outcomes. The literature supports the importance of the parent as the primary socializing agents for their children and as such may be the single most important influence in the lives of their youth (Pequegnat & Szapocznik, 2000; van Wel et al. 2002). Parents teach their children appropriate behaviour and a sense of responsibility for their own well being. This sense of responsibility extends to their family as well as others in their community and society. Children learn this through the examples their parents set and in the smaller family unit first. It is for this reason that parents should be included as contributors in planning transition care and in having their own transition needs met as well (Shaw et al., 2004).

All of the parent participants in this study recognized the importance of teaching their child self management skills and promoting independence in their child. In this study it was evident that the parents played a key role in supporting their children, teaching them to be self-advocates, and in helping them to make informed decisions. Despite recognizing the importance of building their youths' ability to be independent the parents still saw an active role in managing their youths' health care. This role included the importance of advocating for their youth when they felt that things weren't being done properly or when their youth wasn't voicing their needs clearly enough. Parents believed their youths already had a lot on their plates dealing with the limitations inherent in having a chronic illness; factoring in having to deal with the everyday tasks associated with normal life issues such as school work, parents felt a need to relieve some of this burden. Overseeing their youth's health by assisting them in identifying health issues and recognizing the need to manage them, as well as researching resources and assisting with time management were necessities which were identified by all parent participants. These

domains of support were also recognized in the literature and had varying degrees of continuity into adult care (Iles & Lowton, 2010). There are definite advantages to this parental support but caution must be exercised by parents so that they do not allow themselves to be consumed with anxiety or become over involved as this can be unsupportive to the adolescent and hinder their journey to independence (Iles & Lowton, 2010; Shaw et al., 2004).

Parents' Perceptions of the Transition Process

Transfer versus Transition

Parents in this study had a hard time differentiating between the terms “transfer” and “transition”. Parent participants of the two youth aged 15 years questioned why they were even being included in a study about transitioning as they explained their youths were not transitioning to adult care yet. This confusion could be attributed to the use of language in the Rheumatology Clinic at the IWK Health Centre. Youth attending pediatric clinic appointments immediately prior to the time of transfer attend what clinic staff refer to as a “transition clinic”. This is a misnomer as it is actually a transfer clinic that occurs immediately prior to the time of transfer. It is a common misinterpretation among HCPs and families to have transition synonymous with transfer (McDonagh & Kelly, 2003). Transition is a process that should commence when the youth is developmentally able, usually around 12 years of age, and should be done incrementally. During the transition process youth need to learn self-management skills, how to self-advocate and communicate effectively and concisely in order to be able to function independently in and navigate adult health care (Canadian Paediatric Society: Adolescent Health Committee, 2007).

Parent participants of youths who were in the process of transferring or who had transferred to adult care spoke of feelings of being abandoned and that transfer was thrust upon them with little or no preparation. The literature recognizes that while transition should be a well organized, smooth process, for most youth this has yet to become a reality with little done to assist and/or prepare them for entry into the adult world of medical care (Adam et al., 2005; Canadian Paediatric Society (CPS): Adolescent Health Committee, 2007). In 2011 clinicians approached the Chief Executive Officers of the IWK Health Centre and the Capital District Health Authority (CDHA) recommending that action be taken to address recognized gaps in transition care. Two years ago the IWK Health Centre and CDHA established a Joint Steering Committee on Transition Needs of Youth and Families. The steering committee produced a report titled “Transition of Medical Care from Youth to Adulthood: The Challenge for Capital Health and IWK”. Ten recommendations were made in this report and priority areas included communication, integration, transferring of patient information, physician engagement and clinical implementation. In 2012 resources were allocated to implement the recommendations established by the CDHA/IWK Steering Committee. At the IWK Health Centre a Master’s prepared nurse was hired into a one year term position to head the “Transition Project”. This position terminates in March 2015. A Masters of Health Administration Fellow who was doing an integrated fellowship at the CDHA and the IWK became the co-lead for this project but this fellowship concluded in October 2014. It is anticipated that the IWK and CDHA will provide permanent funding for professionals to lead the transition care work.

The “Transition Project” established two pilot teams, rheumatology and nephrology, to test transition care practice changes. Staff needs assessments were completed to look at the educational and support needs the teams have in order to be able to implement and sustain transition care. From the assessment it was recognized that HCPs wanted more education on adolescent health, including topics such as adolescent development, how to communicate with youth, strategies to assist HCPs with treatment compliance in youth, etc. Funding was acquired through the Nova Scotia Nursing Strategy Fund and the “Stay Connected Mental Health Project” to hold a one day education event for 200 HCPs from both CDHA and the IWK. This day will be held in February 2015. The plan is for the learning sessions to be recorded, developed into education modules and made available to HCPs both at the IWK and CDHA. Currently, the teams are testing tools that have been developed such as transition readiness checklists, transition care plans, and joint pediatric and adult care treatment plans. Transition practice within the two teams is being examined in an in-depth manner looking specifically at ways to improve transition care that are practical and sustainable.

As the interviews with study participants progressed they were able to recognize and identify transition strategies that were taking place in the pediatric rheumatology clinic. Even though transition strategies were occurring, there was a lack of formal discussion around the strategies or the transition process itself.

Transition Strategies Currently Employed

Youth Attending Appointments on their Own

A great deal of discussion during the interviews was dedicated to youth attending appointments on their own. Parents of five of the six youths were in agreement with the youth attending their appointments on their own and one had reservations surrounding this practice. Parents recognized the importance of the youth being able to communicate their health history and concerns to their care providers. They acknowledged that youth deserve their privacy and may discuss things with HCPs that they otherwise would not raise in their presence. One parent who had objections to this practice stated that her youth did not feel comfortable being alone with his rheumatologist. The literature findings recommend that Youth with Special Health Care Needs (YSHCNs) who are transitioning to adult health care spend time alone with their care provider prior to the formal transfer (Callahan et al., 2001; Canadian Paediatric Society: Adolescent Health Committee, 2007; Stinson et al., 2010; Tuchman et al., 2008). During this time it is important for HCPs to provide developmentally appropriate information and to teach the skills required to negotiate and communicate within the adult health care system (Adolescent Health Committee, Canadian Pediatric Society, 2007). Examples include a full understanding of their illness, and involvement in decision making, self-medication, and adherence to treatment regimes.

The parent who had concerns about her youth attending appointments on his/her own cited times when he/she used poor judgement in making decisions. To revisit this scenario, the youth had been suffering with pain in his knee and when given the option of having a joint injection the youth refused as he had plans for the day and didn't want to

be laid up all day. Rather than choosing an option with long term rewards, the youth chose an option with immediate gratification. Being unable to see the long term consequences of their decisions can be attributed to the late maturation of the prefrontal regions of the brain (Kauffman, 2006). Parents want the best for their children but they also need to consider the importance of learning from mistakes. This parent did recognize the value in this lesson and went on to talk about the next time when he/she was faced with this decision that he/she opted for a joint injection. Older adolescents are able to consider the choices, behaviors and outcomes that they experienced in the past and use these to inform their health-related choices (Wong, 1999 b).

Parents play the important role of medical care experts, co-ordinators of health care and advocates for their youth (Kieckhefer & Trahms, 2000; Newacheck & Kim, 2005). It is important a parent's concerns not be dismissed when voiced. A more in-depth discussion should take place focused on how the goals of achieving independence to speak for himself/ herself as well as maintenance of privacy can be achieved while still allowing the parent to have some input in decision making and ensuring that their youth is expressing their concerns effectively. This would also be an opportunity for HCPs to have a discussion with parents about the importance of youth being able to make their own decisions and learning from the consequences of those decisions.

Appointment with Pediatric and Adult Care Providers at Time of Transfer

As previously mentioned, youth in the rheumatology clinic who will continue to be seen in Halifax Regional Municipality are referred to a specific adult care rheumatologist with an interest in caring for adolescents. During this appointment the

youth and their parent have the opportunity to meet their new physician and a handover of care takes place between the pediatric and adult rheumatologist. The Provincial Council for Maternal and Child Health (2009) lists “ensuring excellent information transfer” (p.3) as one of their key principles of effective transitions that should underpin any transition program. While there are benefits to shared appointments they are medically focussed, essentially a hand over between physicians. There needs to be an opportunity for a more collaborative approach involving all HCPs involved in the youth and family’s care to provide input. Enhanced communication is needed between all pediatric and adult care providers, not just the physicians. Enhanced communication can be achieved through; having more exchange of knowledge and experiences through clinical lectures, patient rounds, internship and staff exchanges; holding consultation meetings about patients before and after transition; and setting up joint clinics (van Staa et al., 2011).

Assessment of Substance Use and Sexual Activity

In conducting interviews with the parents it was evident that conversations assessing the youths’ use of alcohol and illicit drugs as well as their sexual activity were taking place. Parents of two youth suggested that HCPs could benefit from some training in communication skills and how to address subjects such as teen health issues without making the youth feel like they are being grilled. One study designed, implemented, and assessed the impact of an office-based intervention designed to improve rheumatologists’ identification of risk behaviors, especially alcohol use and sexual activity, among adolescents and young adults with chronic rheumatologic conditions (Britto et al., 2000). This study found that HCPs who have been involved in caring for youth felt awkward

having discussions around sexuality, alcohol and drugs even after receiving education on how to address the topic. Other barriers to providing appropriate counseling on these matters included time, ambivalence of the doctor to the role of assessing risk taking behaviours and perceived lack of applicability (Britto et al., 2000). Doctors' decision to pursue screening was influenced by the length of time the physician had known the family and the level of risk associated with the medicines (ie, methotrexate and cyclophosphamide) that the adolescent or young adult was taking. Four of five physicians felt more comfortable doing this screening with patients they had known the longest and one felt less comfortable asking these questions of patients they had known the longest. Perceived lack of applicability meant that physicians used their judgement to screen or not screen based on the patient's presentation. Factors that influenced their impression were manner of dress, extent of school delinquency, mode of interaction with parents, family cohesion, and level of conservatism of the family.

HCPs at the IWK Health Centre and CDHA have identified learning how to have these discussions with youth as a need. When providing such counseling it is recommended that conditional confidentiality is explained to the parents and youth and that the discussion takes place with the youth in a setting that is conducive to confidentiality (Bagley, Shrier & Levy, 2014; McDonagh & Kelly, 2003). It is helpful if the HCP has a rapport with the youth as this can assist the youth in feeling more comfortable with the HCP (Bagley et al., 2014; McDonagh & Kelly, 2003). It should be explained to the youth that the use of standardized screening tools for risk taking behaviours such as drug and alcohol consumption and sexual activity minimizes the chance of omitting key questions and increases efficiency of the interview, while being

respectful of the adolescent's autonomy and choices (Bagley et al., 2014). One parent in the study stated her youth didn't understand why HCPs asked her questions about alcohol, drugs and sexuality every visit when she was not the type of person who would partake in those behaviours. HCPs need to explain to youth the necessity of asking these screening questions every visit and that they are asked of all youth. By having this explanation it could help youth understand that it is an important part of the assessment.

Emotional Support and Provision of Information

Parents revealed that they did, at times, receive emotional support and information from HCPs but these were not always offered consistently. The parents whose youth were in the process of transferring or had transferred to adult care received the majority of the transition support and information just as the time of transfer to adult care was approaching or during their last appointment in the pediatric setting. One means of addressing this “hit and miss” approach with information and emotional support is through the use of *Transition Checklists*. Other names that have been used for this tool are *Readiness Checklists* and *Autonomy Checklists*. These tools measure a youth's medical knowledge, autonomy and skills needed to self-manage health care (Amaria et al., 2011; Kennedy, Sloman, Douglass et al., 2007). Use of these tools could streamline the information and support that is being offered to the youth and parents as all HCPs can visualize what has been achieved to date. Documenting assessments of transition readiness and more specifically acquisition of skills related to transition and conversations that have taken place eliminate the assumptions that other HCPs have already done this. Use of these tools also serves as a reminder to families that they are striving towards independence for their YSHCNs. While these tools act more as a means

of assessing the acquisition of knowledge and skills related to transitioning, they could serve as a reminder to HCPs to do a check in with the parents and youths to also assess how they are doing on a psychosocial level and offer emotional support accordingly.

Posters Encouraging Transition Discussions

This past year the rheumatology clinic at the IWK Health Centre implemented the use of posters as a means to assist in fostering a culture of transition within the rheumatology clinic (Appendix G). The posters state “Talk with your Doc: Have you talked about transitioning into adult care? Talk early, talk often and prepare now.” These posters were created after viewing posters used by the *Good to Go Transition Program* at The Hospital for Sick Children in Toronto. The *Good to Go* poster was created to serve as a reminder that HCPs are preparing patients to transition out of the pediatric setting and to encourage discussions around transitioning to adult health care to take place (Amaria et al., 2011). The posters in the *Good to Go Program* were evaluated by the IWK Health Centre Youth Advisory Committee and they found the graphic design to be quite juvenile. The IWK rheumatology clinic posters were designed to appeal to the adolescent population and final approval for the designs was obtained from the IWK Youth Advisory Committee.

Only study participants of four of the youth would have been exposed to these posters. Of these parents two of them made mention of the posters. One of the parents explained that the poster urged her to have a discussion with her child’s rheumatologist about when transition would occur. Another parent saw the posters and wondered how they could be used more effectively by HCPs to initiate a discussion around transition. The parent’s suggestion of having the HCP draw attention to the poster and use it to

initiate a conversation around transition was a good one. HCPs need to be prepared to have this conversation in a meaningful manner, be versed in the pertinent information to supply the family and be prepared to follow up on this conversation in order to maximize the effectiveness of this tool.

Transition Strategies Suggested by Parents

Acknowledgement that Parents are Partners

Parent participants voiced that they wanted to have an active role, along with their youth and HCPs, in the planning and implementation of the transition process. Parents felt that as they knew their child best they could assist their youth in expressing their individual needs so that strategies and approaches could be tailored to their needs. Parents recognized they have an accountability to perform certain tasks with their youth in the transition process and to communicate with their HCPs, offer suggestions on how their youth copes and deals with situations and to ask questions when necessary. Parents also would like the HCPs to have accountability for performing their roles to the fullest as well.

Although it is important that, as the youth transitions to adult care and s/he learns to be an effective advocate for herself/himself there is still an important role for the parent (Reiss et al., 2005). Parents have managed their youth's healthcare for many years. If HCPs focus only on the youth they are excluding a key player who is able to share valuable knowledge with the existing and new health care team (Reiss et al., 2005). The literature demonstrated that parents expressed fear of leaving care providers who knew their children and situations well, where everything was familiar to them and where they felt in charge (van Staa et al., 2011). This fear and anxiety could lead to poor or less

effective coping among parents related to the transition process; in turn, their anxiety could be transferred to their youth (Iles & Lowton, 2010; Shaw et al., 2004). Treating parents as partners in the transition process could restore control to the parents (as well as the youth) and make the transition process a positive experience for all involved.

Formal, Defined Transition Process

Parents in this study expressed a strong desire to have a transition process that is clearly defined beginning with a formal discussion about the process before it started and allowing parents and youth to have their questions and concerns addressed. One parent expressed that much of their lives was spent with their pediatric health care team and that it was important that they be able to properly say good bye to everyone once they transfer out of pediatric care. The Provincial Council for Maternal and Child Health (2009) suggests that this should be taken one step further by framing departure from pediatric care as an achievement. The *Good to Go Transition Program* at the Hospital for Sick Children in Toronto awards youth with achievement certificates when they leave pediatric health care. This could also be done at the IWK Health Centre with involvement of all clinic staff and families and youth who have transferred once or twice a year. The rheumatology clinic holds what they currently refer to as “transition clinics” all on one day, it may be possible to gather all of those youth, their families and clinic staff together at one time during that day.

Parents expressed the importance of HCPs receiving the parent’s and youth’s input into how the process will unfold. Parents recommended that this process start early but ideas of the appropriate age to start varied from early teens to age 16 years. The Royal College of Nursing (2004) recommends that transition begin at 12 years of age and

be divided into three stages: early (12-14 years), middle (14-15 years) and late (15-16 years). The adolescent's cognitive and physical development, their emotional maturity and their state of health should all be considered when deciding on an appropriate timeline for transitioning. This step wise approach is important for several reasons. Youth need to gradually take ownership of the self management of their health and can learn and build on their abilities as they develop (Blum et al., 2005; The Royal College of Nursing, 2004). Starting with a simple task and practicing it gives them the confidence and ability to build on these skills over time. An example would be stating their diagnosis and reason for visit and expanding it to the point where they can recite their entire health history and make informed decisions about their treatment.

Currently at the IWK Health Centre Rheumatology Clinic youth are encouraged from as early as age twelve to begin giving some of their health history on their own and encouraged to have a list of their medications and to know what they are and their purpose.

Many of the parents stated that in order to get acquainted with adult care services and to have a more gradual transition process they would like to see some overlapping of services between pediatric and adult care. Some parents suggested that this could be implemented by having an appointment with the adult care rheumatologist in the adult facility prior to officially transferring. The benefits of this would include having a firsthand account of how their clinic runs, have a tour and meet the HCPs who will be caring for them and be interviewed by them so they know what one's concerns are. There was no mention of overlapping of services in this manner in the literature. It would be difficult to operationalize this process as the youths' health records would reside in the

pediatric facility and the youth would still be under the care of the pediatric facility.

However, there could be other means of achieving this same end. Parents and youth could be invited to come to the adult clinic, receive an introduction to the healthcare providers, and receive information on how the clinic operates as well as receive a tour. Transferring the entire team of HCPs and not just the physician was a need parents also expressed.

In implementing a successful transition process parents recognized that HCPs need to receive some formal education on transitioning. This education should take place not only within the work place but also within professional programs to properly prepare new HCPs to provide good transition care. This education should include the impact transfer has on families and the importance of carrying out transition interventions. Parents felt the other important area of education for HCPs is to be well informed about development, especially those relevant to the adolescent years and align these with expectations of age-appropriate knowledge, tasks, and relationships. They went on to say that it is important for the HCPs to be able to convey this information to the parents and link it back to why they have certain expectations for youth at certain times. HCPs involved in transition care for adolescents with Juvenile Idiopathic Arthritis (JIA) most frequently reported need was education on transition issues and informational resources (McDonagh et al., 2004). Research also shows that few primary care pediatricians had practice policies on transfer or employed transitioning strategies leaving researchers to conclude that there is a need for additional training and education of primary care pediatricians in the field of adolescent transitioning (Burke et al., 2008). If transition programs are to be successful it is important for organizations to commit to educating their HCPs.

Currently at the IWK Health Centre fact sheets concerning transitioning to adult services are being developed. There is potential for a fact sheet spelling out the transition process to be developed and given to youth and families at the appropriate time. This could be a mechanism for introducing the process; however to have a truly integrated transition process their needs to be a dedicated conversation on transition as well and commitment to keep the conversation going throughout the process. The Society of Adolescent Health and Medicine and the Canadian Pediatric Society recommendations for best practise in terms of transition care for youth include having a gradation of responsibility to the youth. In this model, HCPs employ anticipatory guidance to encourage a shift in knowledge and responsibility from the HCP to the parent and then finally to the adolescent as the adolescent matures. For example, in early transition the youth begins to be able to name their health condition, medications and healthcare team. The parents are still helping their youth with many things such as ordering prescriptions, making appointments, giving a health history, etc. As the youth ages they acquire more of these skills and take them over from their parent. This shift allows for the adolescent to ultimately assume responsibility for his/her care (Kieckhefer & Trahms, 2000). It could be useful to provide an explanation of this model to parents to give them the ability to visualize how, over time, they will be expected to relinquish more responsibility to their youths. This model is not rigid and allows for negotiation when circumstances dictate that a child requires parental assistance or support despite previously mastering a physical or cognitive task (Kieckhefer & Trahms, 2000). For parents to have the ability to envision the future and to envision their child growing up to be adult enabled parents to cope with the reality that one day it would be necessary for their youths to be independent self

managers of their care (Reiss et al., 2005). Transition conversations could start with parents and youth having a discussion about the future. Asking them questions such as “Where do you see your child in 6- 10 years time?” “Where does the child see themselves in 6-10 years time?” could serve as a starting point to chart the path to assist them in achieving those outcomes.

Parent and Adolescent Support Groups

Parent participants were unanimous in voicing the need to have support groups for either themselves or their youths. The need for a support group was strongly demonstrated during the focus group discussion. Two of the parents were particularly eager to attend the focus group. For the first time they would be able to have discussions with parents who were experiencing the same challenges as they were. In the end, one of those parents was unable to attend and she expressed that she was disappointed as she was also eager to speak with parents of youth who had already been transferred to adult care.

Parents felt that a support group would meet the following needs:

1. Having the ability to have an open discussion with others who understand what you are going through rather than internalizing everything.
2. To be able to hear others’ stories of what they have experienced in the trials and tribulations of having a child with rheumatic disease and know that you are not alone.
3. To share stories of transitioning, to find out what others have experienced and how they coped or were coping with the process.

4. To help alleviate their fears of the unknown, ie: not knowing what adult care looks like.

Having a parent focus group and encouraging parents to speak with other parents of adolescents who have successfully transitioned to adult care was found to be an effective approach (Betz, 1998; Kingsnorth et al., 2011). The literature described one study whereby a family facilitator who had YSHCNs with similar needs to study participants and was a strong advocate for these children facilitated a parent support group (Kingsnorth et al., 2011). The family facilitator was supported by a team of interdisciplinary health professionals. The authors concluded that the parent participants in the support group valued the facilitator role, benefitted from the social support they received from the group, and parents gained new knowledge which enabled them to become more active and future oriented in their transition planning. This is a model that could be implemented at the IWK Health Centre Rheumatology Clinic. Services such as this are often not implemented with “lack of resources” cited as the reason. Initial resources could be invested in training a parent volunteer to facilitate a focus group with ongoing costs associated with occasional support from HCPs. Illness/ disability focused support groups are aimed at providing assistance during acute periods of stress or change. The benefits of these support groups include reduced feelings of isolation and stress, validated emotions and experiences, exchange of information amongst participants and increased advocacy (Law, King, Stewart, et al., 2001; Nicholas & Keilty, 2007). Not addressing these needs could result in the parents and families experiencing anxiety, distress and decreased coping. This could result in further costs to the healthcare system if distress and anxiety

escalate to the point where they require the services of a social worker or psychologist and could potentially affect the transfer to adult care.

All of the parents expressed that it would provide them with a sense of relief and comfort to have their children have their own support group where they would feel comfortable to discuss teen-related concerns with their peers, decrease isolation and provide a sense of normalcy (others are living with similar health problems). One parent suggested that this group could be facilitated by a HCP. Such a group would also be beneficial by providing information on lifestyle choices, how to take ownership of their health and well-being. Some of these needs are currently being met for those youth who attend a weeklong camp for youth with arthritis called “Camp Join Together”. A few of the parents mentioned that in attending this camp their youth made friends and kept in touch with them throughout the year.

The internet has emerged as one of the top health information resources and means of social communication for youth (Gray, Klein, Noyce, Sesselberg& Cantril, 2005). In the literature many students reported that the internet was their primary general information source (Gray et al., 2005). One study examining 157 adolescents’ perceptions and experiences of using the internet to find information about health and medicines, in the context of the other health information sources that are available to them, recognised that young people have difficulties accessing traditional health services (Gray et al., 2005). Student participants of this study stated the internet offers them confidential and convenient access to an unprecedented level of information about a diverse range of subjects. With social media playing a large communication role for many adolescents and young adults, the development of a rheumatic disease chat room

might also serve to meet the needs of parents and youth. It would be important to have an online facilitator or site manager to ensure that confidentiality is maintained as well as provide accurate information to decrease misconceptions or misperceptions about issues such as treatment, life style choices, etc.

Systems Navigator

Throughout the interviews parents repeatedly made reference to the need for a case management or navigator role once the youth transferred to adult care. Parent participants suggested the roles of such a person could include the following:

1. To answer questions and help deal with any problems related to coordinating and receiving care in the adult facility (i.e.: help navigate adult care).
2. Give counselling on considerations for attending post secondary education or in entering the work force. This was further broken down into:
 - a. Offer knowledge about entitlements, i.e.: grants that are available to provide tools to assist youth with their physical limitations
 - b. Inform the youth and their parents about the accommodations that are available at secondary and post secondary institutions to assist the youth in dealing with their physical limitations.
 - c. Provide information and answers on a variety of topics including the availability of, and funding of, infusions in other provinces
3. Perform periodic check-ins with the youth and their parents to see how things are going and to utilize their feedback in improving the transition process.

The literature described one transition program that utilized a systems navigator. The *Maestro Project System Navigator Model* was designed to target and alleviate the barriers adolescents face in obtaining treatment, with attention paid to primary reasons for dropping out of adult health care (Grant & Pan, 2011). This model employed an administrative coordinator (Maestro) who maintained contact via telephone and e-mail with the youth to provide assistance and support in overcoming barriers in navigating adult care (Grant & Pan, 2011). The *Maestro Project System Navigator Model* was evaluated in an initial study which demonstrated a lowering of adult care dropout from 40% to 11% among those who participated in the program compared to those who had not (van Wallegem et al., 2006).

Diabetes Care Nova Scotia recently received funding to hire their own navigator to mimic the *Maestro Project System Navigator Model* (N.Cashen & A.Ryer, personal communication, Sept. 26, 2014). This navigator could be a HCP or someone with a health promotion degree and the ability to communicate well with youth. Currently work is focused on transition from pediatric to adult care in the mental health field. This field is in the midst of a five year project to develop a transitions care pathway, and look at practices to offer peer and family support (N.Cashen & A.Ryer, personal communication, Sept.26, 2014). The mental health field is employing occupational therapists as case managers. The Oncology services in both pediatric and adult care utilize registered nurses as case managers/ navigators (Cancer Care Nova Scotia, 2014). The Brain Injury Team at the Nova Scotia Rehabilitation Centre (adult care) employs a Brain Injury Navigator who is an occupational therapist. The case managers in the oncology and brain injury services are for people of all ages, not just young adults. To my knowledge, there are no other

case manager roles or navigator roles in pediatric or adult care that facilitate transitions to adult care.

This role could be carried out by a number of HCPs or even a trained lay person. In the literature common functions of a navigator included assisting patients with accessing and coordinating services, providing emotional support and assisting with advocacy (Lemark, Johnson & Goodrick, 2004). The literature described studies that used case management to encourage routine diabetes care visits, provide information and emotional support, monitor adherence and foster problem-solving skills in patients with type 1 diabetes without offering medical advice (Sacco, Morrison & Malone, 2004; Svoren, Butler & Levine et al., 2003). In these studies case managers were not HCPs but were college graduates trained by the research and medical staff. In each study, the authors concluded that use of non-medical case management was a cost-effective approach to improving outcomes in their patients.

To implement this role would require a commitment of resources but could vastly improve our own outcomes of youth attrition from the adult care system. If a good relationship is not formed with the new healthcare providers young adults may avoid seeking care until they experience a medical crisis (Pywell, 2010; Tuchman et al., 2008).

Provision of Information

Parents expressed a strong desire to be kept informed throughout the transition process not only for themselves but for their youth. They offered suggestions on the type of information they would like to receive as well as ways, in which this information could be conveyed to them. The literature suggests that good transition care should include enhanced patient and parent preparation for differences between pediatric and adult

healthcare settings, such as adjusting to new roles that take into account self-management (van Staa et al., 2011). Parents further elaborated on what information they would like to receive, what the transition process would look like, the differences between pediatric and adult healthcare, how the roles of the parent and adolescents might change, and the HCPs the youth need to contact in the event of a major issue with their rheumatic disease.

In assisting their youth to cope, parents suggested it would be helpful to receive information on what their youth may be experiencing psychosocially so that the parent may better understand what their youths are going through and offer support accordingly.

Parents would like their youths to receive information on what they can do to help themselves and the importance of being accountable in promoting their health.

Parents offered strategies to implement this provision of information. These strategies included having an information packet, a one day seminar for families, or a web site. It was suggested the web site could be a place where you not only receive information but could post questions and have a chat room for parents to communicate with each other and youths could also communicate with other youths. A tool suggested specifically for youths was a booklet that HCPs assist families in maintaining which included a running account of their health status, treatments and how the child responded to treatments. The parent explained that such a tool would enable youth to communicate information from their early years that they otherwise may not remember, or may not have been aware of in the first place, enabling them to give a complete health history. The *Good to Go Transition Program* has a tool that serves some of these purposes called *My Health Passport* (Amaria et al., 2011). This is an on-line program that helps a young person to create a wallet-sized card with their important health information. This enables the youth

to be able to communicate this important information during consultations. The health passport could be useful tool to use and a link could be created for this tool on the health centre website. The tool the parent suggests is a good idea and would need to be initiated at the time of diagnosis as the intent is to contain a summary of the child's health history from that time. This is similar to the passport initiated in early 2000 in the cancer care program which helps patients keep track of treatment, responses to treatment, and other questions/concerns (Cancer Care Nova Scotia, 2014).

While this study has been underway work has occurred on meeting some of these needs. Fact sheets are in the process of being developed that address topics such as "What is transfer?" "What is Transition?", "What is my Role?" (N.Cashen & A.Ryer, personal communication, Sept. 26, 2014). Pamphlets have been designed specifically for the Rheumatology Clinic at the IWK Health Centre that address topics such as the services available in adult care and the youths role in being independent self-managers of their care but there is no funding currently available to pay for the cost of producing these pamphlets (L. Broderick, personal communication, Sept. 29, 2014). One way of avoiding the costs of producing hard copies of information would be to post these resources on the health centre web site. A transition site could be created on the web site and housing those documents there would prevent the possibility of the parent or youth losing or misplacing the information or not being able to find the information in a timely manner when they want to refer to it. In this day and age a large percentage of the population carry a smart phone or tablet with them and thus would always have this information at their finger tips. It would still be necessary to have these documents in hard copy or other forms for those who do not have access to electronic devices.

Parents also agreed that HCPs needed to be educated on the resources that are available to parents and youth as they go through the transition process so that they are able to provide these resources to the families. Parents felt it is also important for HCPs understand how little many parents actually know about the healthcare system. Parents suggested the creation of a data base of services that HCPs could access that would address or meet the various needs that youth could require. This is also a tool that is currently being created at the IWK Health Centre. Work is underway to create a tab on the health centre intranet site that would house transition tools, articles on transitioning and adolescent development as well as resources available to youths and their care givers (N.Cashen & A.Ryer, personal communication, Sept. 26, 2014).

Routine Check-Ins and Emotional Support

The evidence reveals that parents reported that the process of transitioning from pediatric to adult care was an extremely stressful time in their lives (Davies et al., 2011; Dupuis et al., 2011). Parents in this study indicated that HCPs could alleviate this stress by doing a check in on their emotional status. The purpose of this check in would be to see how they are doing, if there is anything they need, or any guidance the HCPs can give. Parents often feel that HCPs are very rushed during the clinics. They see the full waiting rooms and the HCPs bustling about. One study showed that the transfer from a specialized pediatric clinic to an adult healthcare setting can be marked by parents' emotional suffering and uncertainty that remained unexpressed to health care professionals (Dupuis et al., 2011). Professionals often ignore the family's emotional experience which in turn promotes parent's suppression of their fears regarding the disease (Dupuis et al., 2011). This suppression is often misinterpreted by HCPs as the

parents having come to terms with the disease and perpetuates a cycle of parents not expressing emotion and HCPs being oblivious to the parents' emotional experience (Dupuis et al., 2011). Having the onus on the HCP to perform this planned, purposeful check-in could prevent this avoidance of the subject and the assumption that all is well. This check in could also be utilized to have a discussion about the transition process, where things currently stand and next steps. While youth are being seen alone by the physician, another HCP such as a nurse or social worker could be carrying out these conversations with the parent. In initial conversations about transition HCPs could explain to parents that emotional distress is natural and encourage them to raise the issue as needed.

Adolescent Care Environment

The Rheumatology Clinic area at the IWK Health Centre shares its space with other services and there are children of all ages, many of them infants and young children, sharing the same waiting area. One parent voiced how their youth feels very out of place at the clinic and often gets frustrated with the crying and whining of young children. This was enough to set her youth off and set the mood for the entire visit. Another parent suggested that going from a pediatric centre where their youth was pampered to an adult care facility where they had to be more self-sufficient was a big change all at once and that a more gradual process in transfer of care was desired. Due to the late development of the pre-frontal regions of the brain youths have unique needs in comparison to adults aged from their mid to late twenties and onwards. The frontal lobe of the brain controls executive functions and as this area is not fully developed until as late as age thirty. The youth's ability to keep appointments, adhere to medication

regimes, communicate independently with health care providers and inhibit inappropriate emotional impulses can be impeded (Casey et al., 2000; Kaufman, 2006; Sowell et al., 1999; Steinberg, 2010). If, as the parents suggest, there was a care team specifically for young adults between the ages of 18 years to the mid twenties who specialize in the needs of young adults the youth could receive some extra support and attention for a time because they really aren't adults yet. Providing a clinic like this would be innovative and rather than the youth having to adapt to the current healthcare system, the healthcare system would adapt to meet the needs of the youth. The literature also cites the recommendation of "young adult clinics (Nakhla et al., 2009). Clinics for Young Adults with Rheumatic Diseases (YARD) are being offered in a number of Canadian centres (Grant & Pan, 2011). These clinics are for youth aged 18 and over and serve as a bridge between pediatric and adult care with the aim to transfer patients to adult care at age 22-24 years. In a systematic review to identify studies that evaluated health outcomes following one or more interventions in the period of transition between paediatric and adult services for youth with chronic disease, mental illness or disability, four studies were reviewed that looked at the effectiveness of a separate young adult clinic (Crowley et al., 2011). These clinics did not have a care team specifically trained to care for young adults but rather offered a time when young adults were seen separately from older patients with the purpose of making young people feel less out of place than in general clinics. Three of these clinics were found to be successful by the measure of improved health outcomes in the youth.

Discussions have taken place at the Rheumatology Clinic at the IWK Health Centre to try to create adolescent spaces, ie: having clinics take place for adolescents only

on certain days or have an adolescent only care area. The barriers that exist to carrying these ideas out is that the clinic shares it's space with other clinics, some of whom primarily serve the younger children and the lack of space within the health centre to create such spaces (Dr. E. Stringer, personal communication, Sept. 24, 2014).

Skills Parents Require

Most of the interventions parent participants recommended to enable them to assist their youth through the transition process centred on processes, structures and resources. Parents participants also recognized that while they were able to incite some independence in their youth that there were still skills they needed to acquire in order to promote self-care and independence in their youth.

Parent participants suggested it would be helpful to receive information on what their youths may be experiencing psychosocially so that the parent may better understand what their youths are going through and offer support accordingly. Additionally, parents want HCPs to teach them how to deal with their youth's feelings of anger and frustration. Another skill they wished to acquire was knowing how to assist youth to manage their pain and cope with their disability.

Parents also wished to have not only tools, but also to have an understanding of what approach to take to instill an appreciation of the importance of self-care in their youth. They want their youth to understand that they need to take good care of themselves not because their parent told them to, but because it may have a direct impact on their health outcomes.

Parents of youth who hadn't yet transferred to adult care also described the need to be skilled at case managing and in turn, be able to pass this skill on to their youth.

Parent participants explained that in pediatric care their youths' appointments are case managed to occur on one day. Parents felt they needed to know how to go about organizing appointments as this was a skill they would need to acquire in preparation for transfer to adult care. Parents believed in adult care, appointments would not be case managed.

One factor that may influence a parent's intention to perform a behaviour, (ie: having a discussion around coping in order to promote self-care and independence), is believing they have the skills necessary to engage in the behaviour (Hutchinson & Wood, 2007). The ability to manage pain and emotions were cited as skills necessary for youth to achieve in order to "let go" from parents and HCPs who had managed their illness and in "gaining control" over managing their arthritis independently (Stinson et al., 2008). While the literature supports appropriate attention and supports should be provided for family members to better facilitate a successful transition, there was little or no mention of skills parents need to acquire in order to facilitate self care and independence in their youth (American Academy of Pediatrics, 2011; Canadian Paediatric Society: Adolescent Health Committee, 2007; Iles & Lowton, 2010; Kieckhefer & Trahms, 2000; Kingsnorth et al., 2011; Provincial Council for Maternal and Child Health, 2009; Reiss et al., 2005; Rosen et al., 2003; van Staa et al., 2011; Viner, 2008).

Summary

Findings from this study suggest that parents have a significant role to play in the care of their youth with rheumatic disease and these youth have unique needs. Transitioning, or, more specifically, transfer to adult care experiences have been negative or lacking and for those whose youth have not yet transferred to adult care the thought

can provoke fear and anxiety. Through the AI 4D cycle interview process parent participants were able to get past their negative experiences and/or fear and anxiety and recognize some interventions that are currently working well in the pediatric facility and build on these and design interventions that could provide us with a more supportive, effective transition process.

There are changes that are currently taking place in both pediatric and adult care to attempt to improve transition care. These changes include having a designated persons appointed to work on transition care between the pediatric facility and adult facility for a one year period. As part of this project two service areas, nephrology and rheumatology, were chosen as pilot groups to examine how the transition process can be improved. To date there have been interfacility meetings with representative members of the health care teams to examine roles and processes. Some tools have been created including transition guidelines, transition readiness checklists, information sheets, compiled education articles for HCPs and compiled resources. The Youth Advisory Committee at the Health Centre has created 4 commercials which are all about transitioning from their perspective and are on the intra-hospital television channel as well as on You Tube.

To have effective transition care all HCPs must be committed and participate in acquiring skills and knowledge to implement transition strategies. Barriers to performing this transition care include a lack of resources, time and money. It is important for health services to commit permanent funds to this care rather than funding temporary projects for a few years only. In order to sustain change there needs to be dedicated people to drive the transition process. HCPs are taxed for time but they are still performing tasks that could be carried out by assistants or administrative staff. HCPs need to be working

to full scope of practice so that they are able to incorporate these transition strategies into their current practice.

Chapter 6 Conclusion

Introduction

The importance of providing good transition care to youth as they move from pediatric to adult health care is not a new concept to Health Care Professionals (HCPs). The importance of the parent's role in this process has also been acknowledged. What has not been clearly examined is the impact of caring for a child with rheumatic disease on the parents' psychosocial health, the scope of the parents' role, how their role and knowledge about transition can have an impact on the success of transition, and the kinds of supports they receive and require from HCPs to move through this process with their youth.

In this chapter the strengths and limitations of the study will be examined: clinical and research implications will be described; and, suggestions for future research offered. Finally, I will outline my plan for disseminating the study findings.

Strengths and Limitations of the Study

Embedding this study within a qualitative design that draws on Appreciative Inquiry (AI) aligns with the research questions for this study. The interview guide, which was based on the AI 4 –D cycle of *discovery, dream, design and destiny* elicited detailed, descriptive narratives from the research participants. The research participants were able to take their positive experiences and build on them to eventually suggest strategies to improve HCP support through the transition process which is the ultimate goal of AI.

Sample variability was a limitation of the study, particularly with regard to the socio-economic status and cultural diversity of the parents, which may have biased the results. I did attempt to increase the variability of the sample by attempting to recruit

parents with lower levels of socio-economic status, and different culture backgrounds or marital status without success. These groups may have different support needs and experiences and it would have been helpful to have their perspectives. At the same time, the sample reflected variability with regard to stage of transition. Parent participants included parents of 2 youth aged 15 years with whom transition had not yet been discussed, parents of 2 youth aged 17 and 18 years who were ready to transfer to adult care, and parents of 2 youth who had already transferred to adult care. Having this variability offered perspectives along the continuum of transition care. This highlighted the support needs of parents at the different stages of the transition process.

I had a sample size of 9 parents from one site: the Rheumatology Clinic at the IWK Health Centre. This number of participants is consistent with qualitative research (Morse, 2000) and allowed for the collection of rich, meaningful narratives of the phenomena of interest- the parents' perspective of transitioning from pediatric to adult health care. The findings shed light on transition- related processes and support received from HCPs as well as strategies for providing parents with support. In analyzing the data from this study several core themes emerged which were reflective of most parent participants. These findings may have relevance for other parents within the rheumatology clinic.

While the original intent was to have all study participants take part in the focus group only 4 of the 9 parents were able to attend due to scheduling conflicts. Focus groups of 4- 6 participants can be effective in eliciting rich information in an effective manner, particularly when the topic is emotionally charged or sensitive (Polit & Beck, 2008 d). Various perspectives were reflected from those participants who attended. The

participants in the focus group were parents of one youth aged 15 years, one youth who was very close to transferring to adult care and one youth who had transferred to adult care 2 years ago. Parents were very eager to talk with each other about their experiences; and, while they appeared to have benefitted from the opportunity to speak with each other it was difficult to remain on topic. Parents wanted to retell their stories and inquire as to what others had experienced. This would not be an unreasonable outcome given the lack of overall connectivity and community for the parents. Research evidence demonstrates that when people are undergoing acute periods of stress or change that they can benefit from talking with others in a similar situation. These benefits include reduced feelings of isolation and stress, validated emotions and experiences, exchange of information amongst participants and increased advocacy (Law, King, Stewart, et al., 2001; Nicholas & Keilty, 2007).

While I do not work in the rheumatology clinic, I am a nurse at the IWK Health Centre. As a result, participants may have been hesitant to disclose information which they may perceive as getting back to those on their healthcare team and thus compromising their youth's care in some manner. Alternatively, this could be viewed a strength since participants understood that I was interested in the wellbeing of their youth as well as the parents' leading to an increased willingness to share their stories with me in the hopes of effecting change.

Clinical and Research Implications

This study adds to an understanding of what parents of youth with rheumatic disease experience in caring for their youth on a daily basis and how it impacts their role and the supports they require. With limited sample variability the recommendations

should be considered as specific to the population researched. The recommendations from the study might still have relevance for all parents of youth with rheumatic disease as these should be considered the minimum standard of care. Including parents of lower socioeconomic status might bring to light further interventions needed to more effectively support this subset of parents not reflected in the current study.

Parents live with a degree of uncertainty in caring for their youth. Youth within this population have unique needs which are compounded during the transition phase as they prepare to move from pediatric to adult care. Parents described transition care as being undefined and, for some parents whose youth had not yet transferred to adult care, the thought of transferring provoked fear and anxiety. While parents play a strong role in supporting their youth through this process they look to HCPs to provide them with support. From this study HCPs and administrators may learn the importance of providing good transition care to youth and their families and the necessity of placing a priority on providing resources and services to implement this care. HCPs and administrators need to ensure that the transition process is clearly defined and that the parents and youth are an active part of the process with their input being sought and valued.

This study has generated knowledge on how HCPs can better support parents through the transition process. Parents recognized that there are strategies that HCPs employ that are helpful but there are also those that are needed but lacking. Parents were able to offer suggestions to build on areas of success and offered new strategies that HCPs could implement to help support them through the transition process. HCPs can utilize these strategies to attempt to better support parents. Evaluation of, and feedback on, these strategies is necessary to learn which strategies are effective and how HCPs felt

about implementing them. Education opportunities can be designed to focus on: the impact that transfer to adult care has on families, the importance of carrying out transition strategies, how to carry out transition strategies, learning about adolescent development, and learning how to effectively communicate with youth.

One need that I recognized as being important to all parents was the need to speak with other parents who had youth with rheumatic disease and to speak with other parents whose youth had transferred to adult care. Parents also expressed a desire for their youth to be able to meet with other youths with rheumatic disease. This need could be met through a support group for parents and a support group for youth. This need was highlighted during the focus group session when parents were eager to share their stories with each other and learn from each other's experiences. Support groups could be implemented even in a climate of limited resources. Volunteer facilitators could be trained by qualified HCPs and have a qualified HCP available as a resource to them. The groups would require a physical space (which could be a classroom at the health centre) and advertising of the meetings. The success of the support group could be measured by surveying participants before they started attending the support group and again, once they had attended the group several times.

Future Research

The findings and recommendations from this study may stimulate further research in the field of pediatric to adult transition care. Through the experiences of the parents, this study offers strategies to improve the support HCPs provide to parents in the transition process. These strategies will need to be implemented and evaluated for

effectiveness in HCPs support of parents of youth with rheumatic disease transitioning from pediatric to adult care.

Further research could be done to examine the specific educational and resource needs that HCPs require to perform effective transition care. In turn, this education could also be evaluated by examining HCPs ability and comfort in performing transition care strategies.

There is a population of youth who do not have parents or other care providers in their lives (i.e.: emancipated minors). When a youth is emancipated, the parent's legal obligations to the child are terminated. If the emancipated minor becomes unable to support himself/ herself this could create a cost to society to provide for the minor (J. Lerner, R. Lerner & Finkelstein, 2001). Such costs include the minor becoming financially dependent on provincial or federal monetary support as well as ensuring the well being of the youth. Additionally, there is a population of youth who live with their parents but their parents are not engaged in their care. It would be interesting to explore what the experiences and needs of the emancipated minor, as well as youth with unengaged parents, are in transitioning to adult care in light of the unique challenges they face without the support of their parents to assist and guide them through the process.

Another area of research that would be interesting to pursue is to examine if there are differences in the transition experience and needs of youth with rheumatic disease based on their gender.

Dissemination of Study Findings

When a research study is performed it is of vital importance to transfer the knowledge gained from the study otherwise the study has been conducted in vain. It is

important to convey the stories, experiences and recommendations of the research participants in order to improve the support parents receive from HCPs as their youth transitions from pediatric to adult care. The dissemination of my findings will be done in a variety of ways in order to reach different target audiences including: patients and families, health care professionals, senior leadership and researchers.

The parent participants who offered their time and shared their stories and thoughts will be e-mailed a copy of the thesis. I will also disclose to these parent participants how I intend to disseminate the study findings so that they are aware their voices will be heard by a vast audience.

My study findings can be shared directly with the Rheumatology Clinic at the IWK Health Centre as my sample was derived from parents of youth with rheumatic disease who attended this clinic. Study findings may also be transferable to other clinics both in pediatric and adult care and thus care providers from other clinics within the IWK Health Centre and the Nova Scotia Rehabilitation Facility and Queen Elizabeth Hospital will be invited to attend.

In order to effect change it is important to impose an awareness of the significance of study findings to Senior Executive Leadership as they make the decisions about priority areas for allocation of money and resources. I intend to offer a presentation of this study to this group as well.

I have applied to present a poster at the *Canadian Rheumatology Association (CRA) Annual Scientific Meeting* in February 2015 in Quebec City. Should my application be accepted the abstract will be published in the *Journal of Rheumatology*. Presenting the poster and having the abstract published in these forums will provide

HCPs who work in the rheumatology field an awareness of the study findings. An advantage of presenting a poster is that it can be done soon after the study is completed and offers opportunities for dialog among people interested in the topic.

I would also like to submit articles for publication in two journals, one that is rheumatology specific and one that focuses on adolescent care. Publishing articles in journals will reach a wider audience, can be easily accessed worldwide and, unlike a poster, will be available to refer to for all time.

Arts based knowledge translation (ABKT) initiatives are emerging as a unique way to address the complexities of context of research findings, engage audience members, promote dissemination within communities of practice, and foster new audiences interested in research findings (Rieger & Schultz, 2014). ABKT strategies operate from the premise that knowledge is socially situated, which demands acknowledging and engaging the learner within their context (Rieger & Schultz, 2014). Theatre, dance, photography, and poetry are art forms that are commonly used to communicate research findings to diverse audiences (Rieger & Schultz, 2014). Given the richness of the data of the lived experiences of the research participants these ABKT strategies could be yet another way to disseminate the study findings. A play could be presented on the experiences of parents as their youth moves through the transition process. Data from the interviews could be arranged into lines and stanza breaks to form a piece of poetry.

Summary

This study has provided a greater understanding of parental perceptions of the support they receive from HCPs as their youth with a rheumatic disease transitions from

pediatric to adult care. Parents play a significant role in the care of their youth with rheumatic disease. Furthermore parents recognize the important role that HCPs play in supporting them throughout the transition process. Parents were able to recognize strategies that are currently working well in transition care as well as areas that were lacking. They were able to build on transition strategies that were working well and offered improvements to these as well as new strategies that could help in supporting them through the transition process. In disseminating the findings of this study it is hoped that HCPs, administrators and researchers will utilize these findings to improve their current practice and perform further research in this field.

APPENDIX A 4-D Cycle



Cooperrider & Whitney (2005)

Study ID _____

APPENDIX B Consent Form for Participants

Research Title:

Examining Parents' Perceptions of Health Care Professionals Support in the Transition of their Adolescent with Rheumatic Disease from Pediatric to Adult Care

Researchers:

Jacqueline van Nieuwenhuizen
Principal Investigator (PI)
Master of Nursing Student
Dalhousie University
902-470-8790

Dr. Elizabeth Stringer
Supervising Investigator (SI)
Pediatric Rheumatologist
IWK Health Centre
902-470-8827

Dr. Brenda Sabo
Thesis Supervisor
Associate Professor
Dalhousie University
902-494-3121

Introduction:

To achieve success in seeking and receiving proper healthcare as an independent young adult, adolescents need to be gradually transitioned from pediatric to adult healthcare. Parents can play a pivotal role in this successful transition but require supports and guidance from healthcare professionals. The body of research that has focussed on the transition experience from the parent's perspective and the supports that have been offered to parents has been limited.

Purpose:

The purpose of this study is twofold:

1. To examine parents' perceptions of the process of transitioning from pediatric to adult health care for their adolescent with a rheumatic disease.
2. To examine parents' perceptions of the strategies that health care professionals employ or could employ that assist parents in gaining the skills enabling them to promote self-care and independence in their adolescent and facilitate the transition process.

Research Questions:

The questions this study will seek to answer are as follows:

1. What are parent's perceptions of the process of transitioning from pediatric to adult health care for their adolescent with a rheumatic disease?
2. What strategies do pediatric health care professionals currently employ to assist and support parents in gaining the skills to promote self-care and independence in their adolescent and facilitate the transition process?
3. How is the psychosocial health of parents affected as their adolescent transitions from pediatric to adult health care?
4. How is the psychosocial health of parents affected as their youth transitions from pediatric to adult care?

Description of the Research:

This voluntary research study will be carried with parents whose children attend or have attended the Rheumatology Clinic at the IWK Health Centre.

If you agree to participate in this study, you will be invited to attend one 60 minute interview about your positive experiences when you were engaged in the transition process of your adolescent from pediatric to adult care. Later on, when all the interviews are complete, you will be invited to attend a 90 minute focus group session. Consent will once again be obtained from you prior to participating in the focus group.

You will be provided with an honorarium of \$40.00 for participation in the study to cover the costs of attending the interview and focus group. A private area within the hospital or at an alternative agreed upon location will be chosen for the interview location. The

information shared during interviews will be kept confidential, however it is requested that the information could be shared anonymously during the focus groups.

Potential Harms:

As you discuss your personal experiences there is potential for you to experience emotional distress. If your distress is not readily resolved, you will be encouraged to seek additional support through accessing a social worker, therapist or psychologist.

Potential Benefits:

While there are no direct benefits to participating in this study, you may benefit by knowing that your participation in this study may lead to positive changes in the transition process including:

1. Identifying what is working well in the transition of adolescents with a rheumatic disease from pediatric to adult care
2. Identifying ways to build on the support provided to parents or build on what is working well with the transition process itself.

Confidentiality:

All interviews and focus group sessions will be audio taped and transcribed. A research assistant will transcribe the interview and focus group data and sign a confidentiality agreement. Your privacy will be respected. No personal information or identifiers will be given to anyone or be published without your permission, unless required by law. Direct quotes may be used to strengthen the analysis of data; these quotes will not be linked with any personal information or identifiers.

Only the PI, SI, thesis supervisor, and IWK Research Ethics Audit Committee will have access to study records. No personal identifiers will be linked with the data. All tapes and transcriptions will be kept in a locked filing cabinet in the PI's office at the IWK. Audiotapes will be destroyed after transcription. Study information will be kept for 5 years after publication as per the guidelines for research services. Any published study results will not reveal your identity.

Participation:

Participation in this study is voluntary and it is your choice to take part in this study. You may withdraw from the study at any time. Withdrawal from the study will not affect your child's care in any way. Please contact the PI at 470-8790 if this option is anticipated.

Research Rights:

Signing and returning the consent form indicates that you have agreed to take part in this research study and have your responses used as data related to the research topic. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institution from their legal and professional responsibilities. If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Center at (902) 470-8765, Monday to Friday between 9:00am-5:00pm.

Conflict of Interest:

The PI, SI, and her thesis supervisor do not have any commercial or financial interest in this study.

Consent:

By signing this form, I agree that:

- 1) You have explained this study to me. You have answered all my questions.
- 2) You have explained the possible harms and benefits (if any) of this study.
- 3) I know that it is my right to choose to participate or not participate in this research study. I understand that I have the right to withdraw at any time. My decision about taking part in the study will not affect my employment status at the IWK Health Centre.
- 4) I am free now, and in the future, to ask questions about the study.
- 5) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
- 6) I agree, or consent, to take part in this study.

Printed Name of Subject

Subject’s signature & date

Printed Name of person who explained consent

Signature of person who explained consent & date

Printed Name of Witness

Witness’ signature & date

Study ID _____

APPENDIX C Demographic Data

Demographic Data of Participant:

Age: _____

Marital status: _____

Education: _____

Employment status: _____

Number of children and ages: _____

Do you live within metro Halifax? Yes _____ No _____

If no ___-KMs you live outside of Metro Halifax

Demographic Data of Adolescent with Rheumatic Disease of Participant:

Age: _____

Sex: _____

Type of rheumatic disease: _____

Age at time of diagnosis: _____

Education: _____

Employment status (working or in school): _____

Living arrangements: _____

If adolescent does not live with parents:

Do you live within metro Halifax? Yes _____ No _____

If no ___-KMs you live outside of Metro Halifax

If adolescent has transferred to adult services:

Age at transfer to adult services: _____

Year of transfer to adult services: _____

Study ID _____

APPENDIX D AI Interview Protocol (AIIP)

Phase	Questions	Field notes
<p style="text-align: center;"><i>Discover</i> <i>(the best of what is or has been)</i></p> <p>Interviewer needs to:</p> <ul style="list-style-type: none"> • Inquire • Explore • Appreciate <p>Prompts, examples</p> <p><i>How does it affect your daily life?</i></p> <p><i>What impact does it have on the family?</i></p> <p><i>How has it affected your child's day to day functioning?</i></p> <p><i>How has it affected your day to day functioning?</i></p> <p><i>What do you find the most meaningful about being a parent to _____ since he/ she was diagnosed with _____.</i></p> <p><i>What stories can you share that were the most memorable, challenging or exciting to you as a parent raising _____?</i></p> <p><i>What are some of the things that you value the most about yourself and your role as a</i></p>	<p><i>When you hear the word transfer what does that mean to you?</i></p> <p><i>When you hear the word transition what does that mean to you?</i></p> <p><i>Tell me what it is like to be a parent of a child with _____.</i></p> <p><i>What are your strengths in supporting your adolescent as he/ she transitions to</i></p>	

<p>parent to _____?</p> <p><i>What do you value and recognize as your role in engaging or involving your adolescent in learning the self management skills necessary to transition to adult healthcare?</i></p> <p><i>Can you describe a positive experience when you were involved in assisting your adolescent to become more independent?</i></p> <p><i>What self management skills does your adolescent perform (refilling prescriptions, making medical appointments, advocating for themselves at medical appointments, etc.</i></p> <p><i>Was there a time when someone said or did something that helped you and or your child with transitioning from pediatric to adult care?</i></p> <p><i>Were you taught any skills to help support your child?</i></p> <p><i>Were you linked with other parents who had been through the process?</i></p> <p><i>Were you encouraged to support your child in becoming more independent?</i></p> <p><i>Were you provided with any emotional support?</i></p>	<p><i>adult healthcare?</i></p> <p><i>What are your adolescent's strengths in transitioning to adult care?</i></p> <p><i>Talk about a shining moment when you felt that you were really supported by the healthcare team while moving through the transition process.</i></p>	
---	---	--

<p><i>Were you given any literature to review?</i></p>		
<p><i>Dream</i> <i>(what might be)</i></p> <p>Interviewer needs to work with parents to :</p> <ul style="list-style-type: none"> • co-construct a vision • a reason for achieving that vision • a strategic statement about how this might be achieved <p><i>Did you have knowledge in how best to do this? Was your adolescent prepared and willing to become more independent?</i></p> <p><i>Did you receive support, knowledge, or guidance from health care professionals?</i></p> <p><i>Were there processes in place within the health care system to make this possible?</i></p> <p><i>When did discussions about transferring initially take place?</i></p> <p><i>What skills were taught to assist in the transitioning process?</i></p> <p><i>What accommodations were made to prepare you and your child for the adult</i></p>	<p><i>What strategies work best for you in assisting your child to become more independent?</i></p> <p><i>How and in what way did healthcare professionals make you feel supported through the transition process from the pediatric to adult setting for your child?</i></p>	

<p><i>world?</i></p> <p><i>What processes would be in place? What types of things would healthcare professionals do?</i></p>	<p><i>What would the health care system look like if adolescents and their parents were always supported throughout the transition from pediatric to adult healthcare?</i></p>	
<p>Design <i>(what should be)</i></p> <p>Interviewer needs to focus on creating an ideal way that healthcare professionals can support parents in supporting their adolescent through the process of transitioning from pediatric to adult healthcare (this needs to be related to their own context and should be based on grounded experiences).</p> <p><i>What types of processes, programs, interventions/ strategies, supports and tools should be in place?</i></p>	<p><i>Now I would like you to think about what healthcare professional support to parents whose adolescent is transitioning from pediatric to adult healthcare should look like in the future.....</i></p> <p><i>If a healthcare professional asked how they could best support you in supporting your adolescent as he/she transitions to adult healthcare what would you describe as the most effective strategies?</i></p>	

	<p><i>How might your story help other parents facing similar experiences to yours?</i></p> <p><i>How might your story help healthcare professionals to better support parents during this time?</i></p>	
<p><i>Destiny</i> <i>(what will be)</i></p> <p>The interviewer needs to focus the participant to create ideal ways of providing healthcare professional support to parents as their adolescent transitions to adult healthcare.</p> <p>The participant should create networks and structures that can improve transition support.</p>	<p><i>What are the innovative, long lasting changes that you believe are necessary to better support parents in the transitioning of their adolescent from pediatric to adult care?</i></p> <p><i>.....related to educating healthcare professionals</i></p>	

	<p><i>...related to inter-professional and professional-parent roles and relationships</i></p> <p><i>...related to the healthcare system and the organization of services</i></p> <p><i>If you were to wake up tomorrow, what would be the one change you would like to see have happened within the current healthcare system? What would it take for this to happen?</i></p> <p>Adapted from the work of Lowther (2013).</p>	
--	--	--

Cooperrider & Whitney (2005)

APPENDIX F Focus Group Guide

After analyzing all the interview data, I have identified common threads or common ideas from your responses. I will talk about those ideas within the four phases of the methodology that I have used to help analyze the data. After reviewing the ideas, I would like for you as a group to come up with a phrase or a statement that summarizes that particular group of ideas.

*****Please note: Common threads and ideas will be written into focus group guide after the interview transcripts are analyzed. Examples of common threads for discussion may include (as in italics, but these are subject to change):**

In the **Discovery phase**, interview questions were related to “what works” in your environment (i.e., what is meaningful and valuable about your role as a parent, your healthcare team, and your healthcare organization).

The word transfer means.....to you.

The word transition means..... to you.

In describing what it is like to be the parent of a child with a special health care need you identified.....

Some of the things that you identified as strengths in supporting your adolescent as he/she transitions to adult healthcare were.....

Some of the things that you identified as your adolescents strengths in transitioning to adult care were.....,

Some of the shining moments when you felt that you were really supported by the healthcare team while moving through the transition process included...

In the **Dream phase**, interview questions were related to “what might be” (i.e., key positive aspects identified in the first phase are drawn out and expanded on).

Some of the strategies that worked best for you in assisting your child to become more independent were

Some of the ways healthcare professionals made you feel supported through the transition process from the pediatric to adult setting for your child were.....

If adolescents and their parents were always supported throughout the transition from pediatric to adult healthcare then the healthcare system would look like.....

In the **Design phase**, interview questions were related to “what should be” (i.e., processes and structures that need to be in place to make your dream a reality).

Healthcare professional support to parents whose adolescent is transitioning from pediatric to adult healthcare would look like this in the future.....

The key strategies you identified that healthcare professionals could utilize to offer you support as you support your child in transitioning from pediatric to adult care were...

Your story might help other parents facing similar experiences to yours by.....

Your story might help healthcare professionals to better support parents during this time by.....

In the **Destiny phase**, interview questions were related to “what will be” (i.e., achievable plan for healthcare professionals to provide parents effective support on a more consistent basis as their child transitions, and the networks and structures that would be in place in order to achieve this).

The innovative, long lasting changes that you believe are necessary to better support parents in the transitioning of their adolescent from pediatric to adult care are

....related to educating healthcare professionals are.....

...related to inter-professional and professional-parent roles and relationships are.....

...related to the healthcare system and the organization of services are.....

If you were to wake up tomorrow, the changes you would like to see have happened within the current healthcare system are.....

It would take..... for this to happen.

Adapted from the work of Lowther (2013).

APPENDIX F Transcriptionist Confidentiality Agreement

Study title: *Parents' Perceptions of Health Care Professionals Support in the Transition of their Adolescent with Rheumatic Disease from Pediatric to Adult Care*

I _____ have been employed to transcribe verbatim the audio file interviews from the study *Parents' Perceptions of Health Care Professionals Support in the Transition of their Adolescent with Rheumatic Disease from Pediatric to Adult Care*.

In transcribing these audio files I will substitute pseudonyms for the names of the participants and their friends. I will delete the copies of the transcriptions and audio files from my computer once I have given the transcriptions to Jacqueline van Nieuwenhuizen, the Principal Investigator (PI) for this study. I will not make or keep any copies of the audio files or transcriptions.

I realize that the information I learn through transcribing these audio recordings are of a confidential nature and I will not share any information that I have learned from transcribing these audio files to anyone.

Name of Transcriptionist (Print): _____

Transcriptionist Signature: _____

Date: _____

Time: _____

STATEMENT BY PERSON OBTAINING CONSENT

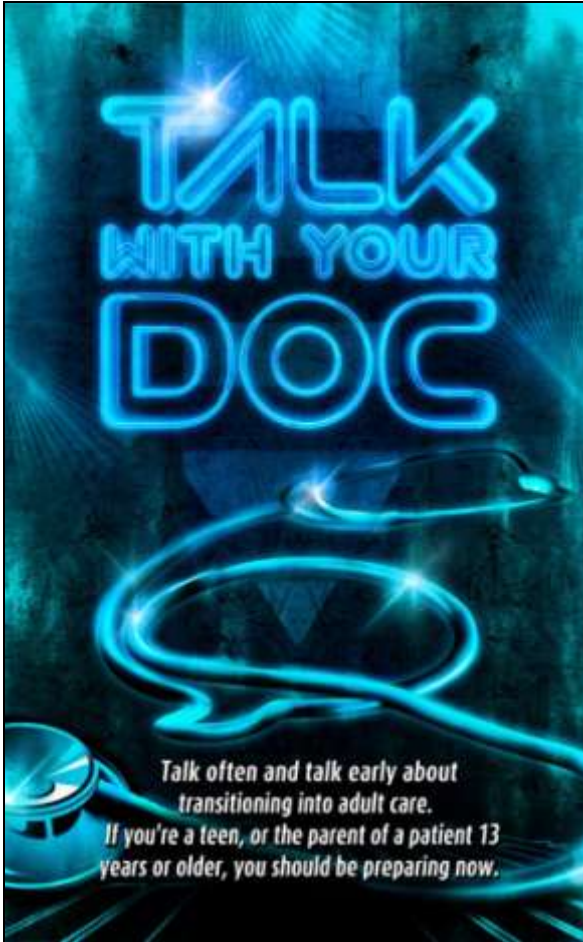
I have explained the nature of the consent form to the transcriptionist and judge that they understand the nature of confidentiality.

Name (Print): _____

Signature: _____ Position: _____

Date: _____ Time: _____

APPENDIX G Transition Posters



Bibliography

- Amaria, K., Stinson, J., Cullen-Dean, G., Sappleton, K., & Kaufman, M. (2011). Tools for addressing systems issues in transition. *Healthcare Quarterly (Toronto, Ont.), 14 Spec No 3*, 72-76.
- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley, W. C., & Sagerman, P. J. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 128*(1), 182-200. doi:10.1542/peds.2011-0969
- Appleton, J.V., & King, L. (2002). Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing, 40*(6), 641-648.
- Ajen, I., Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice Hall.
- Attride-Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research. *Qualitative Research, 1*(3). 385- 405.
- Bagley, S., Shrier, L., Levy, S. (2014). Talking to adolescents about alcohol, drugs and sexuality. *Minerva Pediatrica, 66*(1), 77-87.
- Baker, A., & Wright, M. (2006). Using appreciative inquiry to initiate a managed clinical network for children's liver disease in the UK. *International journal of Healthcare Quality Assurance, 19*(7), 561-574.
- Betz, C., & Smith, K. (2011). Measuring health care transition planning outcomes: Challenges and issues. *International Journal of Child and Adolescent Health, 3*(4), 463-472.
- Betz, C. L. (1998). Facilitating the transition of adolescents with chronic conditions from pediatric to adult health care and community settings. *Issues in Comprehensive Pediatric Nursing, 21*(2), 97-115.
- Betz, C. L. (2004). Transition of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing, 27*(3), 179-241. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2004190731&site=ehost-live>
- Betz, C. L. (2010). Approaches to transition in other chronic illnesses and conditions. *Pediatric Clinics of North America, 57*(4), 983-996. doi:10.1016/j.pcl.2010.07.017

- Blum, R., Garell, D., Hodgman, C. et al. (1993). Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 14*, 570-576.
- Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Britto, M.T., Rosenthal, S.L., Taylor, J., Passo, M.H. (2000). Improving rheumatologists' screening for alcohol use and sexual activity. *Archives of Pediatric and Adolescent Medicine, 154*(5), 478-483.
- Broderick, L. (Sept. 29, 2014). Personal communication, Rheumatology Clinic Nurse, IWK Health Centre, Halifax, N.S.
- Burke, R., Spoerri, M., Price, A., Cardosi, A. M., & Flanagan, P. (2008). Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. *Clinical Pediatrics, 47*(4), 347-354. doi:10.1177/0009922807310938
- Callahan, S. T., Winitzer, R. F., & Keenan, P. (2001). Transition from pediatric to adult-oriented health care: A challenge for patients with chronic disease. *Current Opinion in Pediatrics, 13*(4), 310-316.
- Canadian Institutes of Health Research Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans, December 2010.
- Canadian Paediatric Society (CPS), Adolescent Health Committee. (2007). Transition to adult care for youth with special health care needs. *Pediatric Child Health, 12*(9), 785-788.
- Canadian Paediatric Society (CPS), Adolescent Health Committee. (Nov.1, 2003, reaffirmed Jan.1, 2011). Position statement: Age limits and adolescents. Retrieved from: <http://www.cps.ca/documents/position/age-limits-adolescents>
- Cancer Care Nova Scotia. (Nov. 2014). Retrieved from: <http://www.cancercare.ns.ca/en/home/patientsfamilies/cancerpatientnavigation/default.aspx>
- Carter, B., Ruhe, M.C., Weyer, S., Litaker, D., Fry, R.E., & Strange, K.C. (2007). An appreciative inquiry approach to practice improvement and transformative change in healthcare settings. *Quality Management in Healthcare, 16*(3), 194-204.
- Cashen, N., Ryer, A. (Sept.26, 2014). Personal communication, Co-Leads, IWK Health Centre/ Capital District Health Authority Transition Project, IWK Health Centre, Halifax, N.S.

- Casey, B. J., Giedd, J. N., & Thomas, K. M. (2000). Structural and functional brain development and its relation to cognitive development. *Biological Psychology*, *54*(1-3), 241-257.
- Casillas, J., Kahn, K. L., Doose, M., Landier, W., Bhatia, S., Hernandez, J., Padres Contra El Cancer. (2010). Transitioning childhood cancer survivors to adult-centered healthcare: Insights from parents, adolescent, and young adult survivors. *Psycho-Oncology*, *19*(9), 982-990. doi:10.1002/pon.1650
- Cassidy, J. T. & Petty, R. E. (2011). Conditions of rheumatology. In *Textbook of Pediatric Rheumatology* 6th edn (pp.10-15). Philadelphia: Elsevier Saunders.
- Coooperrider, D.L., & Whitney, D. (1999). *Appreciative inquiry: Collaborating for Change*. San Francisco, CA: Berrett-Koehler Communications, Inc.
- Cooperrider, D.L., & Whitney, D. (2005). *Appreciative Inquiry: A Positive Revolution in Change* (2nd ed.). San Francisco, CA: Berrett-Koehler Publishers, Inc.
- Creswell, J. W. (2007). Philosophical, paradigm and interpretive frameworks. In J. W. Creswell (Ed.), *Qualitative inquiry and research design. Choosing among five approaches* (pp. 15-33). Thousand Oaks, CA: Sage.
- Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: A systematic review. *Archives of Disease in Childhood*, *96*(6), 548-553. doi:10.1136/adc.2010.202473
- Davies, H., N., Rennick, J., & Majnemer, A. (2011). Transition from pediatric to adult health care for young adults with neurological disorders: Parental perspectives. *Canadian Journal of Neuroscience Nursing*, *33*(2), 32-39. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2011286170&site=ehost-live>
- Dupuis, F., Duhamel, F., & Gendron, S. (2011). Transitioning care of an adolescent with cystic fibrosis: Development of systemic hypothesis between parents, adolescents, and health care professionals. *Journal of Family Nursing*, *17*(3), 291-311. doi:10.1177/1074840711414907
- Eastman, K. L., Corona, R., & Schuster, M. A. (2006). Talking parents, healthy teens: A worksite-based program for parents to promote adolescent sexual health. *Preventing Chronic Disease*, *3*(4), A126. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2009206768&site=ehost-live>

- Friedman, M.M., Connelly, K.M., & Williams, R.P. (1998). Family development theory. In Friedman, M.M., *Family nursing research, theory, and practice*. (pp 111-152). Los Angeles, California: Appleton and Lange
- Gerhardt, C.A., McGordon, K.D., Vannatta, K., McNamara, K.A., Taylor, J., Passo, M., Noll, R.B. (2008). Educational and occupational outcomes among young adults with juvenile idiopathic arthritis. *Arthritis & Rheumatology*, 59, 1385-1391.
- Gerrish, K., & Lacey, A. (2010). *The Research Process in Nursing* (6th Ed.). Oxford, UK: Wiley- Blackwell.
- Giarelli, E., Bernhardt, B. A., Mack, R., & Pyeritz, R. E. (2008). Adolescents' transition to self-management of a chronic genetic disorder. *Qualitative Health Research*, 18(4), 441-457. doi:10.1177/1049732308314853
- Grant, C., & Pan, J. (2011). A comparison of five transition programmes for youth with chronic illness in Canada. *Child: Care, Health & Development*, 37(6), 815-820. doi:10.1111/j.1365-2214.2011.01322.x
- Gray, N.J., Klein, J.D., Noyce, P.R., Sesselberg, T.S., Cantril, J.A. (2005). Information-seeking behavior in adolescence: The place of the internet. *Social Science and Medicine*, 60, 1467-1478.
- Guba, E., & Lincoln, Y. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 191-215). Thousand Oaks, CA: Sage.
- Hammond, S.A. (1998). *The thin book of appreciative inquiry*. (2nd ed.). Bend, OR : Thin Book Publishing.
- Hauser, E. S., & Dorn, L. (1999). Transitioning adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing*, 25 (5), 479. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2000012591&site=ehost-live>
- Havens, D.S., Wood, S.O., Leeman, J. (2006). Improving nursing practice and patient care. *Journal of Nursing Administration*, 36 (10), 463-470.
- Hazel, E., Zhang, X., Duffy, C.M., Campillo, S. (2009). High rates of unsuccessful transfer to adult care among young adults with juvenile idiopathic arthritis. *Pediatric Rheumatology Online Journal*, 8,2.
- Hersh, A.O., Pang, S., Curran, M.L., Milojevic, D.S., van Scheven, E. (2009). The challenges of transferring chronic illness patients to adult care: reflections from pediatric and adult rheumatology at a US academic center. *Pediatric Rheumatology Online Journal*, 7, 13.

- Hersh, A., von Scheven, E., Yelin, E., & Medscape. (2011). Adult outcomes of childhood-onset rheumatic diseases. *Nature Reviews.Rheumatology*, 7(5), 290-295. doi:10.1038/nrrheum.2011.38
- Huber, A. (Dec.1, 2011). Personal communication, Rheumatologist, IWK Health Centre, Halifax, N.S.
- Hutchinson, M. K. (2002). Sexual risk communication with mothers and fathers: influence on the sexual risk behaviors of adolescent daughters. *Family Relations*, 51, 238-247.
- Hutchinson, M. K., Jemmott, J.B., Jemmott, L.S., Braverman, P., & Fong, G.T. (2003). The role of mother daughter sexual risk communication in reducing sexual risk behaviors among urban adolescent females: A prospective study. *Journal of Adolescent Health*, 33, 98-107.
- Hutchinson, M. K., & Wood, E. B. (2007). Reconceptualizing adolescent sexual risk in a parent-based expansion of the theory of planned behavior. *Journal of Nursing Scholarship*, 39(2), 141-146. doi:10.1111/j.1547-5069.2007.00159.x
- Iles, N., & Lowton, K. (2010). What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services? *Health & Social Care in the Community*, 18(1), 21-29. doi:10.1111/j.1365-2524.2009.00871.x
- Kaufman, M. (2006). Role of adolescent development in the transition process. *Progress in Transplantation*, 16(4), 286-290. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2009361873&site=ehost-live>
- Kavanagh, T., Stevens, B., Seers, K., Sidani, S., & Watt-Watson, J. (2008). Examining appreciative inquiry as a knowledge translation intervention in pain management. *Canadian Journal of Nursing Research*, 40(2), 40-56.
- Kieckhefer, G. M., & Trahms, C. M. (2000). Supporting development of children with chronic conditions: From compliance toward shared management. *Pediatric Nursing*, 26(4), 354. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2000065809&site=ehost-live>
- Kingsnorth, S., Gall, C., Beayni, S., & Rigby, P. (2011). Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child: Care, Health & Development*, 37(6), 833-840. doi:10.1111/j.1365-2214.2011.01294.x

- Krause, M.L., Amin, S & Makol, A. (2014). Use of DMARDs and biologics during pregnancy and lactation in rheumatoid arthritis: what the rheumatologist needs to know. *Therapeutic Advances in Musculoskeletal Disease*, 6, 169-184.
- Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage Publications, p.60.
- Lavender, T., & Chapple, J.(2004). An exploration of midwives' views of the current system of maternity care in England. *Midwifery*, 20(4), 324-334.
- Law, M., King, S., Stewart, D. & King, G.(2001). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical Occupational Therapy in Pediatrics*, 21, 29-48
- Lawson, E.F., Hersh, A.O., Applebaum, M.A., Yelin, E.H., Okumura, M.J., von Sheven, E. (2011). Self-management skills in adolescents with chronic rheumatic disease: A cross-sectional survey. *Pediatric Rheumatology*, 9:35.
- LeBlanc, C.M.A., Lang, B., Bencivenga, A., Chetaille, A., Dancy, P., Dent, P., Tucker, L. (2012). Access to biologic therapies in Canada for children with juvenile idiopathic arthritis. *The Journal of Rheumatology*, 39, 1875-1879.
- Lemak, C.H., Johnson, C., Goodrick, E.E. (2004). Collaboration to improve services for the uninsured: exploring the concept of health navigators as interorganizational integrators. *Health Care Management Review*, 29 (3), 196-206.
- Lerner, J. V., Lerner, R. M., & Finkelstein, J. (2001). *Adolescence in America: ABC-CLIO*.
- Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. In Y. S. Lincoln & E. G. Guba (Eds.), *Naturalistic inquiry* (pp. 289-331). Newbury Park, CA: Sage.
- Lotstein, D. S., McPherson, M., Strickland, B., & Newacheck, P. W. (2005). Transition planning for youth with special health care needs: Results from the national survey of children with special health care needs. *Pediatrics JID - 0376422*, 115, 1562-1568.
- Lowther, S. (2013). Examining the conditions that facilitate parents' active engagement in non-pharmacological pain management strategies with their hospitalized child. (Master's thesis, Dalhousie School of Nursing, Halifax, NS).
- Madsen, W.C. (2009). Collaborative helping: A practice framework for family-centred services. *Family Process*, 48, 103-116.
- Manners, P.J., Bower, C. (2002). Worldwide prevalence of juvenile arthritis why does it vary so much? *Journal of Rheumatology*, 29, 1520-1530.

- McDonagh, J. E. (2007). Transition of care from paediatric to adult rheumatology. *Archives of Disease in Childhood*, 92(9), 802-807. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2009687231&site=ehost-live>
- McDonagh, J. E., Kelly, D.A. (2003). Transitioning care of the pediatric recipient to adult caregivers. *The Pediatric Clinics of North America*, 50, 1561-1583.
- McDonagh, J. E., Southwood, T. R., Shaw, K. L., & British Paediatric Rheumatology Group. (2004). Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology (Oxford, England)*, 43(6), 737-743. doi:10.1093/rheumatology/keh163
- Miller, T., & Bell, L. (2002). Consenting to what? Issues of access, gate-keeping, and informed consent. In M. Mauthner, M. Birch, J. Jessop, & T. Miller (Eds.), *Ethics in qualitative research* (pp. 53-69). Thousand Oaks, CA: Sage
- Milne, J., & Oberle, K. (2005). Enhancing rigor in qualitative description: A case study. *Journal of Wound, Ostomy, and Continence Nursing*, 6, 413-420.
- Minden, K. (2009). Adult outcomes of patients with juvenile idiopathic arthritis. *Hormone Research in Paediatrics*, 72, (Suppl 1). 20-25.
- Moola, F., J., & Norman, M., E. (2011). 'Down the rabbit hole': Enhancing the transition process for youth with cystic fibrosis and congenital heart disease by re-imagining the future and time. *Child: Care, Health & Development*, 37(6), 841-851. doi:10.1111/j.1365-2214.2011.01317.x
- Morse J.M. (1991). Strategies for sampling. In *Qualitative Nursing Research: A Contemporary Dialogue* (Morse J.M. ed.), Sage, Newbury Park, California, pp. 127-145.
- Morse, J. (1995). The significance of saturation. *Qualitative Health Research*, 5(2), 147-149
- Morse, J. (2000). Determining sample size. *Qualitative Health Research*, 10(1), 3-5.
- Nakhla, M., Daneman, D., To, T., Paradis, G., & Guttmann, A. (2009). Transition to adult care for youths with diabetes mellitus: Findings from a universal health care system. *Pediatrics*, 124(6), e1134-41. doi:10.1542/peds.2009-0041
- Neergaard, M.A., Olsen, F., Andersen, R.S., & Sondergaard, J. (2009). Qualitative description-the poor cousin of health research? *BMC Medical Research Methodology*, 9:52, 1-5.

- Newacheck, P. W., & Kim, S. E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*, *159*, 10–17.
- Nicholas, D. & Keilty, K. (2007). An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance. *Social Work in Health Care*, *44*, 245-259.
- Ong, L. M., de Haes, J. C., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: A review of the literature. *Social Science & Medicine* (1982), *40*(7), 903-918.
- Packham, J.C., Hall, M.A. (2002). Long-term follow-up of 246 adults with juvenile idiopathic arthritis: social function, relationships and sexual activity. *Rheumatology*, *41*, 1440–1443.
- Pai, A. L., & Schwartz, L. A. (2011). Introduction to the special section: Health care transitions of adolescents and young adults with pediatric chronic conditions. *Journal of Pediatric Psychology*, *36*(2), 129-133. doi:10.1093/jpepsy/jsq100
- Patton, M. Q. (2002). Purposeful sampling. In *Qualitative research & evaluation methods*, (3rd ed., pp. 230-248). Thousand Oaks, CA: Sage.
- Pequegnat, W., & Szapocznik, J. (2000). The role of families in preventing and adapting to HIV/Aids: Issues and answers. In W. Pequegnat , & J. Szapocznik (Eds.), *Working with families in the era of HIV/AIDS* (pp. 3-26). Thousand Oaks, CA: Sage.
- Peter, N. G., Forke, C. M., Ginsburg, K. R., & Schwarz, D. F. (2009). Transition from pediatric to adult care: Internists' perspectives. *Pediatrics*, *123*(2), 417-423. doi:10.1542/peds.2008-0740
- Peterson, J.E. (2003). The Magic Power of Appreciative Inquiry. (Appreciative Inquiry Commons Website) Retrieved from <http://appreciativeinquiry.case.edu/research/bibPapersDetail.cfm?coid=3187>
- Polit , D.F. & Beck, C T. (2008 a). Generating research evidence ethically. In Polit, D.F. & Beck, C T. (Eds.), *Nursing research: Generating and assessing evidence for nursing practice* (pp.167-218). Philadelphia, PA: Wolters Kluwer /Lippincott Williams & Wilkins.
- Polit , D.F. & Beck, C T. (2008 b). Developing an approach for a qualitative study. In Polit, D.F. & Beck, C T. (Eds.), *Nursing research: Generating and assessing evidence for nursing practice* (pp.219-247). Philadelphia, PA: Wolters Kluwer/ Lippincott Williams & Wilkins.

- Polit , D.F. & Beck, C T. (2008 c). Developing a sampling plan. In Polit, D.F. & Beck, C T. (Eds.), *Nursing research: Generating and assessing evidence for nursing practice* (pp.337-364). Philadelphia, PA: Wolters Kluwer /Lippincott Williams & Wilkins.
- Polit , D.F. & Beck, C T. (2008 d). Collecting unstructured data. In Polit, D.F. & Beck, C T. (Eds.), *Nursing research: Generating and assessing evidence for nursing practice* (pp.392-413). Philadelphia, PA: Wolters Kluwer /Lippincott Williams & Wilkins
- Polit , D.F. & Beck, C T. (2008 e). Enhancing quality and integrity in qualitative research. In Polit, D.F. & Beck, C T. (Eds.), *Nursing research: Generating and assessing evidence for nursing practice* (pp.536-). Philadelphia, PA: Wolters Kluwer /Lippincott Williams & Wilkins.
- Provincial Council for Maternal and Child Health. (2009). Transition: A framework for supporting children and youth with chronic and complex care needs as the move to adult services.
- Pywell, A. (2010). ‘Transition: moving on well’ from paediatric to adult health care. *British Journal of Nursing*, 19, 652-656.
- Rabinovich, C.E. (2010, June 1). Juvenile Rheumatoid Arthritis. Retrieved from <http://emedicine.medscape.com/article/1007276-overview>
- Reed, J., Pearson, P., Douglas, B., Swinburne, S., Wilding, H. (2002). Going home from hospital- an appreciative inquiry study. *Health and Social Care in the Community*, 10(1), 36-45.
- Reiss, J., & Gibson, R. (2002). Health care transition: Destinations unknown. *Pediatrics*, 110(6 Pt 2), 1307-1314.
- Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics*, 115(1), 112-120. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2005089132&site=ehost-live>
- Rieger, K. & Shultz, A.S. (2014). Exploring arts-based knowledge translation: sharing research findings through performing the patterns, rehearsing the results, staging the synthesis. *Worldviews on Evidence- Based Nursing*, 11 (2), 133-139.

- Rosen, D. S., Blum, R. W., Britto, M., Sawyer, S. M., & Siegel, D. M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the society for adolescent medicine. *Journal of Adolescent Health, 33*(4), 309-311. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2004056335&site=ehost-live>
- Royal College of Nursing. (2004). *Adolescent transition care guidance for nursing staff*. London, United Kingdom.: Royal College of Nursing.
- Sable, C., Foster, E., Uzark, K., Bjornsen, K., Canobbio, M. M., Connolly, H. M. (2011). Best practices in managing transition to adulthood for adolescents with congenital heart disease: The transition process and medical and psychosocial issues: A scientific statement from the American Heart Association. *Circulation, 123*(13), 1454-1485. doi:10.1161/CIR.0b013e3182107c56
- Sacco, W.P., Morrison, A.D., Malone, J.I. (2004). A brief, regular, proactive telephone A coaching intervention for diabetes. Rationale, design, description and preliminary results. *Journal of Diabetes Complications, 18*,113–18.
- Sandelowski, M. (1995). Focus on qualitative methods. Sample size in qualitative research. *Research In Nursing and Health, 18*(2), 179-183.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.
- Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics, 115*(6), 1607-1612. doi:10.1542/peds.2004-0458
- Schuster, M. A., Corona, R., Elliott, M. N., Kanouse, D. E., Eastman, K. L., Zhou, A. J., & Klein, D. J. (2008). Evaluation of talking parents, healthy teens, a new worksite based parenting programme to promote parent-adolescent communication about sexual health: Randomised controlled trial. *BMJ: British Medical Journal (International Edition), 337*(7664), 273-277. doi:10.1136/bmj.39609.657581.25
- Schwartz, L., A., Tuchman, L., K., Hobbie, W., L., & Ginsberg, J., P. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: Care, Health & Development, 37*(6), 883-895. doi:10.1111/j.1365-2214.2011.01282.x
- Shaw, K. L., Southwood, T. R., McDonagh, J. E., & British Paediatric Rheumatology Group. (2004). Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: Results of a postal survey. *Rheumatology (Oxford, England), 43*(2), 211-219. doi:10.1093/rheumatology/keh018

- Sowell, E. R., Thompson, P. M., Holmes, C. J., Jernigan, T. L., & Toga, A. W. (1999). In vivo evidence for post-adolescent brain maturation in frontal and striatal regions. *Nature Neuroscience*, 2(10), 859-861. doi:10.1038/13154
- Steinberg, L. (2010). A behavioral scientist looks at the science of adolescent brain development. *Brain and Cognition*, 72(1), 160-164. doi:10.1016/j.bandc.2009.11.003
- Stinson, J. N., McGrath, P. J., Hodnett, E. D., Feldman, B. M., Duffy, C. M., Huber, A. M., White, M. E. (2010). An internet-based self-management program with telephone support for adolescents with arthritis: A pilot randomized controlled trial. *Journal of Rheumatology*, 37(9), 1944-1952. doi:10.3899/jrheum.091327
- Stinson, J. N., Toomey, P. C., Stevens, B. J., Kagan, S., Duffy, C. M., Huber, A., Feldman, B. M. (2008). Asking the experts: Exploring the self-management needs of adolescents with arthritis. *Arthritis and Rheumatism*, 59(1), 65-72. doi:10.1002/art.23244
- Street, R.L. (1991). Information giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Social Science and Medicine*, 32, 541
- Svoren, B.M., Butler, D., Levine, B., Laffel, L.M. (2003). Reducing acute adverse outcomes in youths with type 1 diabetes: a randomized controlled trial. *Pediatrics*, 112 (4), 914-22.
- Taylor, C., Mills, A., Schmied, V., Dahlen, H., Shuiringa, W., & Hudson, M. (2012). What works to engage young parents into services? Findings from an appreciative inquiry workshop. *Contemporary Nurse*, 42 (2), 258-271.
- Tuchman, L. K., Slap, G. B., & Britto, M. T. (2008). Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development*, 34(5), 557-563. doi:10.1111/j.1365-2214.2008.00844.x
- van Manen, M. (1990). Hermeneutic phenomenological reflection. In *Researching lived experience: Human science for an action sensitive pedagogy* (pp.77-109). London, Ont: The Althouse Press.
- van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J., M. (2011). Crossing the transition chasm: Experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health & Development*, 37(6), 821-832. doi:10.1111/j.1365-2214.2011.01261.x
- van Wallegem, N., MacDonald, C., & Dean, H., (2006). Building connections for young adults with type 1 diabetes mellitus in Manitoba: feasibility and acceptability of a transition initiative. *Chronic Diseases in Canada*, 27, 130-134.

- van Wel, F., ter Bogt, T., & Raaijmakers, Q. (2002). Changes in the parental bond and the well-being of adolescents and young adults. *Adolescence*, 37(146), 317-333.
- Viner, R. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood*, 81(3), 271-275.
- Viner, R. M. (2008). Transition of care from paediatric to adult services: One part of improved health services for adolescents. *Archives of Disease in Childhood*, 93(2), 160-163. Retrieved from <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2009777797&site=ehost-live>
- Watson, A.R. (2000). Non-compliance and transfer from paediatric to adult transplant unit. *Pediatric Nephrology*, 14, 469-472.
- Weiss, J.E., Ilowite, N.T. (2007). Juvenile idiopathic arthritis. *Rheumatic Disease Clinics of North America*, 33, 441-470.
- Westwood, A., Henley, L., & Willcox, P. (1999). Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *Journal of Paediatrics and Child Health*, 35(5), 442-445.
- Williamson, G. (2005). Illustrating triangulation in mixed methods nursing research. *Nurse Researcher*, 2005; 12 (4):7-18.
- Wong, D. (1999 a). Growth and development of children. In *Nursing care of infants and children*. (pp.133-134).St,Louis: Mosby,Inc.
- Wong, D. (1999 b).health promotion of the adolescent and family. In *Nursing care of infants and children*. (pp.896-897).St,Louis: Mosby,Inc.