

**University of Alberta**

Voiding Dysfunction and Quality of Life in Children

by

Betty Ann Thibodeau

A thesis submitted to the Faculty of Graduate Studies and Research  
in partial fulfillment of the requirements for the degree of

Master of Nursing

Faculty of Nursing

©Betty Ann Thibodeau  
Fall 2009  
Edmonton, Alberta

Permission is hereby granted to the University of Alberta Libraries to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only. Where the thesis is converted to, or otherwise made available in digital form, the University of Alberta will advise potential users of the thesis of these terms.

The author reserves all other publication and other rights in association with the copyright in the thesis and, except as herein before provided, neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatsoever without the author's prior written permission.

## **Examination Committee Members**

Committee Chair and Examiner	Dr. Priscilla Koop Associate Professor Faculty of Nursing
Supervisor	Dr. Katherine Moore Professor Faculty of Nursing
Committee Member	Dr. Peter Metcalfe Assistant Professor Faculty of Medicine Department of Pediatric Surgery

## Abstract

**Purpose:** The relationship between severity of voiding dysfunction and quality of life in children with daytime wetting was analyzed.

**Materials and Methods:** The relationship between age, gender, severity of voiding dysfunction (measured by DVSS) and quality of life (measured by PinQ) in the child with daytime wetting was analyzed. Twenty-four children (4 males, 20 females) aged 5-10 years ( $\bar{x}$  8.17 years, SD 1.37) and their parents completed the DVSS and PinQ.

**Results:** Parent and child total DVSS and total PinQ Scores had similar results with only a significant mean difference between the parent total DVSS scores based on gender. Only Gender with Parental Total DVSS Score ( $r = 0.462$ ,  $p = 0.023$ ) and Child Total DVSS Score with Parent Total DVSS Scores ( $r = 0.472$ ,  $p = 0.020$ ) were significant correlations.

**Conclusions:** Results illustrate the importance of early recognition and intervention to minimize the impact daytime wetting has on the child.

### **Acknowledgements**

I dedicate my thesis to all the children and families who participated in this research study. I would like to thank my family for the incredible support, patience and understanding through out the last 5 years. I would like to especially thank Rod Pittman and my son, Jason Thibodeau, for their tremendous encouragement without which, this thesis would not have been possible. I would also like to thank Dr. Katherine Moore, my thesis supervisor, as well as the members of my committee, Dr. Priscilla Koop and Dr. Peter Metcalfe, for their knowledge, support and collaboration through out this process.

Betty Ann Thibodeau

## Voiding Dysfunction and Quality of Life in Children

### Table of Contents

	Page Number
Examination Committee	2
Abstract	3
Acknowledgements	4
Table of Contents	5
List of Tables	8
List of Figures	10
Chapter 1 – Introduction	11
Background	11
Purpose of Study and Research Questions	12
Operational Definitions	13
Chapter 2 - Literature review	15
Voiding Dysfunction	15
Constipation	19
Behavioural Therapy	27
Quantifying Voiding Dysfunction and Incontinence in Children	31
Quality of Life	40
Pediatric Quality of Life	45
Pediatric Quality of Life Measures	49
Pediatric Urinary Incontinence Quality of Life	51
Pediatric Urinary Incontinence Quality of Life Measures	53
Implications for Research	56
Chapter 3 – Method	58

	Page Number
Research Design	58
Sample	58
Inclusion Criteria	58
Exclusion Criteria	59
Outcome Measures	59
Procedure	61
Data analysis	62
Chapter 4 – Results	64
Participant Demographics	64
Diaries and Pad Study Results	69
Scoring from the Dysfunctional Voiding Symptom Score (DVSS)	73
Scoring from the Pediatric Urinary Incontinence Quality of Life Instrument (PinQ)	80
Domains of the PinQ Instrument	83
The relationship between severity of daytime wetting (measured by DVSS), age, gender and quality of life (measured by PinQ)	91
The relationship between the parent and child’s scoring of the DVSS and the PinQ	93
DVSS	93
PinQ	94
PinQ Regression	96
PinQ Total Domain Score Correlations	98
Open Ended Question Data	103
Chapter 5 – Discussion	113
Defining Relationships Utilizing Correlational Statistics	115

	Page Number
What is the Relationship Between Severity of Daytime Wetting, Age, Gender and Quality of Life	117
Dysfunctional Voiding Symptom Score (DVSS)	118
What is the Relationship Between Severity of Daytime Wetting, Age, Gender and Quality of Life	119
Pediatric Urinary Incontinence Quality of Life (PinQ)	119
What is the Relationship Between the Parent and Child's Scoring of the DVSS and PinQ	124
Dysfunctional Voiding Symptom Score (DVSS)	125
Pediatric Urinary Incontinence Quality of Life (PinQ)	126
Family Coping Abilities	129
School Challenges	131
Limitations	134
Implications for Further Research and Recommendations	137
Conclusion	141
References	142
Appendixes	157
Appendix A – Study Information Tables from Articles	157
Appendix B – Dysfunctional Voiding Symptom Score (DVSS)	171
Appendix C – Pediatric Urinary Incontinence Quality of Life (PinQ)	174
Appendix D – Study Information Sheets and Consent Forms	178

**List of Tables**

		Page Number
Table 4.1	Comparison of Subject History with Diary	71
Table 4.2	Pad Study Results	72
Table 4.3	Child and Parent Responses to the DVSS	74
Table 4.4	Total DVSS Scores & Total DVSS Scores Based on Gender	75
Table 4.5	Mean Differences of Total DVSS Scores Based on Gender	76
Table 4.6	Comparison of Child and Parent Total DVSS Scores Based on Gender	77
Table 4.7	Child and Parent Responses to the PinQ	78
Table 4.8	Total PinQ Scores and Scores Based on Gender	81
Table 4.9	Mean Differences of Total PinQ Scores Based on Gender	82
Table 4.10	Comparison of Child and Parent Total PinQ Scores Based on Gender	82
Table 4.11	Questions Associated with Each Individual Domain	84
Table 4.12	Comparison of Child and Parent Domain Total Scores	85
Table 4.13	PinQ Self-Esteem Domain Total Scores	87
Table 4.14	Mean Differences of PinQ Self-Esteem Domain Based on Gender	87
Table 4.15	PinQ Family and Home Domain Total Scores	87
Table 4.16	Mean Differences of PinQ Family and Home Domain Based on Gender	88
Table 4.17	PinQ Social Relations with Peers Domain Total Scores	88
Table 4.18	Mean Differences of PinQ Social Relations with Peers Domain Based on Gender	89
Table 4.19	PinQ Mental Health Domain Total Scores	89
Table 4.20	Mean Differences of PinQ Mental Health Domain Based on Gender	90
Table 4.21	PinQ Independence Domain Total Scores	90
Table 4.22	Mean Differences of PinQ Independence Domain Based on Gender	90



		Page Number
Table 4.23	Comparison of PinQ Domain Mean Scores	91
Table 4.24	Correlations between Age, Gender, DVSS & PinQ	92
Table 4.25	Correlations of Child & Parent Responses to Individual DVSS Questions	93
Table 4.26	Correlations of Child & Parent Responses to Individual PinQ Questions	95
Table 4.27	PinQ Child Domain Regression Table	96
Table 4.28	PinQ Parent Domain Regression Table	97
Table 4.29	Correlations of Child & Parent PinQ Total Domain Scores	100
Table 5.1	Child DVSS Questions with Highest Response Rates	118
Table 5.2	Comparison of PinQ Studies	120
Table 5.3	Comparison of Child PinQ Mean Domain Percentages	121
Table 5.4	Child PinQ Questions with Highest Response Rates	122
Table 5.5	Comparison of PinQ Child Response Rates	123
Table 5.6	Comparison of Child and Parent Responses to DVSS	126
Table 5.7	Comparison of Child and Parent Responses to PinQ	128

**List of Figures / Charts**

		Page Number
Figure 4.1	Voiding Dysfunction & Quality of Life in Children Flow Chart	65
Figure 4.2	Subjects Age	66
Figure 4.3	Wetting History	66
Figure 4.4	UTI History	67
Figure 4.5	Voiding Frequency During the Day	68
Figure 4.6	Bristol Stool Scale	69
Figure 4.7	Child Total DVSS Score	73
Figure 4.8	Parent Total DVSS Score	75
Figure 4.9	Child Total PinQ Score	80
Figure 4.10	Parent Total PinQ Score	81
Figure 4.11	Partial Regression Plot Diagram of Child Mental Health & Child Self-Esteem	97
Figure 4.12	Partial Regression Plot Diagram of Parent Family & Home with Parent Self-Esteem	98
Figure 4.13	Partial Regression Plot Diagram of Parent Independence with Parent Self-Esteem	98

## **Voiding Dysfunction and Quality of Life in Children**

### **Chapter 1- Introduction**

#### ***Background***

Approximately 30 to 40 percent of the children seen in Pediatric Urology clinics have some form of voiding or urine storage abnormality (Farhat et al., 2000). Their symptoms may include urgency, frequency, diurnal incontinence, nocturnal enuresis and/or recurrent urinary tract infections (Robson & Leung, 2006). According to McKenna and McKenna (2004), 20 to 30% of children suffer from incontinence. Vemulakonda and Jones (2006) state that any evaluation of urinary incontinence in children must be based on the child's developmental age. Although some children may have symptoms into their teen years, the typical pediatric patient with lower urinary tract symptoms is 4-10 years of age with a normal healthy non-neurogenic bladder. In addition to being labor intensive for the health care provider and the child in the assessment and ongoing treatment of their symptoms (Berry, 2005) these children and families suffer from the effects of voiding dysfunction.

Children may develop abnormal voiding habits during or after toilet training. Some do not learn to relax their pelvic floor muscles to allow effective emptying. Others become so absorbed in computer games, television shows, play, or other activities, that they postpone or do not take the time to void. Many may delay voiding until the last minute, dance around, or will run in and out of the bathroom very quickly not taking the time to completely empty their bladders. Others develop abnormal posturing behaviors such as Vincent's curtsy (squatting

and compressing the perineum with the heel) to suppress bladder spasms and prevent inadvertent urinary incontinence. Problems with recurrent urinary tract infections (UTIs) and incontinence related to their abnormal elimination habits are potential consequences. Parents are often not aware of their child's elimination habits once the child is toilet trained unless the child has a severe problem (Berry, 2005; Schulman and Berry, 2007).

Pediatric voiding dysfunction and quality of life are indeed complex topics. It is important that we have a holistic approach when caring for these children. Although both voiding dysfunction and pediatric urinary incontinence quality of life have been studied, they have not been studied together. There have been no studies to date which compare the severity of voiding dysfunction with the child's and family's perception of the child's quality of life. As a result I would like to compare the severity of voiding dysfunction with a pediatric urinary incontinence quality of life measure in this study. By learning how voiding dysfunction impacts the child's quality of life, we may learn how to help the child and assist the family as well as the school teachers to respond appropriately to and help the child with voiding dysfunction. By becoming cognizant of the child's quality of life, "children will have a voice in their care" (Eiser, 2007, p. 380).

### ***Purpose of Study and Research Questions***

The purpose of this study was to determine the relationship between voiding dysfunction and quality of life in the pediatric patient. As voiding dysfunction encompasses a large number of abnormalities, for the purpose of this thesis

research study, only patients with daytime urinary incontinence were included. In children with daytime wetting the questions for this study were:

1. What are the relationships between severity of daytime wetting (measured by Dysfunctional Voiding Symptom Score, DVSS), age, gender and quality of life (measured by Pediatric Urinary Incontinence Quality of Life Instrument, PinQ)?
2. What is the relationship between the parent and child's scoring of the DVSS and the PinQ?

***Operational Definitions***

1. Voiding Dysfunction – abnormal urine storage and/or voiding pattern for the child's age (Hellerstein & Linebarger, 2003)
2. Dysfunctional Voiding – Habitually constricting the urethral sphincter while voiding (dyssynergia) resulting in a functional obstruction of urine flow (Neveus et al., 2006)
3. Urinary Incontinence – “uncontrollable leakage of urine” which may be continuous or intermittent (Neveus et al., 2006, p. 315)
  - a. Intermittent Urinary Incontinence – refers to discrete amounts of urine leakage during the day and/or night
  - b. Continuous Urinary Incontinence – refers to a continuous leaking or dripping of urine through out the day and night
4. Constipation – “A constellation of symptoms including infrequent passage of stool, difficulty passing stool, feces that are large and hard or in small pieces, abdominal pain, palpable stool in abdomen, stool in rectal vault, loading on x-

- ray or fecal soiling” for 2 weeks or more (Chase, Homsy, Siggard, Sit and Bower, 2004, p 2641)
5. Quality of Life – A multidimensional concept which measures the individual’s perception of his/her own well-being based on physical, emotional, social, psychological, and spiritual domains (Cohen, Mount and MacDonald, 1996; Connolly and Johnson, 1999)
  6. Pediatric Quality of Life – multidimensional concept which measures the child’s perception of his/her own well-being based on physical, emotional, social, psychological, and spiritual domains while incorporating the child’s age, development and language skills (Eiser, 1997)
  7. Pediatric Urinary Incontinence Quality of Life – the impact of the child’s urinary incontinence and/or voiding dysfunction on his/her life, self-esteem and perception of well-being (Bower, 2008)
  8. Dysfunctional Voiding Symptom Score (DVSS) – An measurement instrument developed to “quantify and grade the severity of abnormal voiding behaviors in children” (Farhat et. al., 2000, p. 1011)
  9. Pediatric Urinary Quality of Life Instrument (PinQ) – A urinary incontinence specific tool which measures the quality of life in children who have bladder dysfunction (Bower, 20008; Bower, Wong and Yeung, 2006)
  10. Proxy Respondent – A parent, guardian or individual who responds for the individual who is unable to respond for him/herself (Theunissen et al., 1998; Varni, Limbers, and Burwinkle, 2007).

## Chapter 2 - Literature Review

### *Voiding Dysfunction*

The purpose of this review was to examine the literature and research related to pediatric voiding dysfunction and quality of life from 1995 until 2009. The search engines CINAHL, PubMed, Medline and Embase with the search terms child, pediatric, daytime wetting, wetting, incontinence, urinary incontinence, dysfunctional elimination, dysfunctional voiding, constipation, quality of life as well as urinary incontinence quality of life were utilized. Articles related to adult urinary incontinence were excluded from this literature search.

The lower urinary tract is composed of the bladder, bladder neck, urinary sphincter and urethra. The lower urinary tract functions of storage and voiding are under complex neurological control. Stimulation of the sympathetic nervous system encourages urine storage whereas stimulation of the parasympathetic system acts in voiding, while the somatic nervous system controls contraction and relaxation of the external urethral sphincter and the pelvic floor muscles. As the bladder nears capacity, signals are sent to the Pontine micturation center in the brain through the spinal cord. Signals are sent back to both the urinary sphincter and bladder neck to relax, as well as back to the detrusor muscle of the bladder to contract. Urine expulsion from the bladder results from the complex coordination of urethral sphincter and bladder neck relaxation at the same time as bladder contraction. (Horowitz and Misseri, 2007).

In the infant urine storage and emptying is under reflex control and voiding is triggered when the bladder reaches its threshold capacity. As children age they gain voluntary control of their bowel and bladder through a sequence of stages: bowel control during the day, bowel control during the night, urinary control during the day and lastly urinary control overnight. By 3-4 years of age most children have gained control of their elimination processes. (Feldman & Bauer, 2006). “The impact of voiding control on social interaction and function evolves as a child progresses through their first years of life and is influenced by social, cultural and environmental factors.” (Vemulakonda and Jones, 2006, p. 551).

Dysfunctional voiding or voiding dysfunction are used interchangeably to describe abnormalities of urine storage and/or an abnormal voiding pattern for the child's age (Hellerstein & Linebarger, 2003). According to Vemulakonda and Jones (2006) “structural urinary incontinence refers to developmental, iatrogenic and traumatic anatomic abnormalities of the lower urinary tract that interferes with the urinary system’s ability to store or evacuate urine” (p. 552) whereas functional urinary incontinence refers to incontinence that is unrelated to any structural or neurological abnormality. The vast majority of children with incontinence fall into the functional incontinence category (Vemulakonda and Jones, 2006). In 2006, the International Children’s Continence Society (ICCS) developed standardized terminology to clarify abnormalities in pediatric lower urinary tract function (Neveus et. al., 2006) and dysfunctional voiding was defined as dyssynergia resulting in a functional obstruction. Dysfunctional voiding is only one of many conditions that children with abnormalities of storage



or voiding may have. Other conditions may include: intermittent nocturnal incontinence, enuresis, urge incontinence, overactive bladder, voiding postponement, under active bladder, urinary obstruction, vaginal reflux, giggle incontinence or extraordinary daytime urinary frequency (Neveus et. al., 2006). These symptoms are not mutually exclusive. For example, a child may experience intermittent nocturnal incontinence but also have symptoms of daytime enuresis with frequency and urgency. Ultimately the combination of day and night time symptoms dictates a different treatment modality than for the child who suffers from only one condition. For the purpose of this research, all forms of abnormal urinary elimination are considered as various forms of voiding dysfunction.

Although often unrecognized, voiding dysfunction remains prevalent within the young school age population. Abnormal voiding patterns and their effects have received modest attention but pediatric urinary incontinence quality of life has not been considered in many studies. A 1998 population based survey by Sureshkumar, Craig, Roy and Knight (2001b) showed that the overall prevalence of pediatric urinary incontinence in Australia was 19.2%; furthermore there was an increased incidence of urinary incontinence in female children who had a family history of daytime wetting or past emotional stress. Although the majority of children were wet once or twice during the previous 6 month period, 2.7% of children were wet at least twice per week. Moreover, the majority of parents surveyed did not seek medical attention for their child's daytime wetting and teachers only recognized 3% of the children in their care who actually suffered from daytime wetting (Sureshkumar et al, 2001b).

In a retrospective review of 226 medical charts of children who had abnormal voiding patterns by Hellerstein and Linebarger (2003), 76.4% of children were found to have detrusor instability (based on a history of urgency with or without frequency but not urodynamically confirmed), 8.7% with extraordinary daytime urinary frequency, 5.7% infrequent voiding and two had obstructive uropathy with renal damage. The authors also noted that 31% of the children with detrusor instability suffered from constipation. As well, 72% of children who utilized posturing maneuvers to prevent urinary incontinence developed recurrent UTIs in comparison to a 23% incidence in those who did not. Hellerstein and Linebarger (2003) postulated that the obstruction of the distal urethra during posturing maneuvers to prevent urinary incontinence during uninhibited bladder contractions led to intravesical reflux of bacteria into the bladder from the distal urethra resulting in UTIs.

The prevalence of daytime urinary incontinence was 6.3% in Kajiwara, Inoue, Usui, Kurihara, and Usui's (2004) population based study of 6,917 Japanese school children aged 7 to 12 years. In this study, 3.6% of children wet more than once per week, 1.2% of children were wet every day, 94.6% suffered from urgency, 23.8% suffered from frequency and 4.5% had stress incontinence in which they wet themselves during coughing, sneezing or laughing. A higher incidence of constipation and UTI's in children with daytime urinary incontinence was also found.

***Constipation***

A major contributor to voiding dysfunction and recurrent UTI is unrecognized constipation; assessment and treatment of constipation remains a basic practice standard in current practice. As the child's pelvis is small, a large amount of stool in the rectum can put excess pressure on the bladder not allowing it to fill or empty properly (Robson and Leung, 2006; Joinson, Heron, Von Gontard and ALSPAC Study Team, 2006). Yazbeck, Schick and O'Regan (1987) state that due to the close proximity of the posterior wall of the bladder to the rectum, any gross distension of the rectum results in compression of the bladder and bladder neck obstruction. Frequent detrusor contractions may be triggered by constipation as a result of stimulation of the stretch receptors in the bladder wall or colonic contractions related to a fecal mass (Franco, 2007). According to Halachmi and Farhat (2008) impacted stool in the rectum compresses the bladder, reduces the capacity and provokes an earlier voiding sensation. Fecal soiling or encopresis results from loose stool leaking around impacted stool in the distended rectum as the child tries to expel gas or the pelvic floor muscles which have been utilized to withhold the stool become fatigued. Voiding position may contribute to this fecal soiling as encopresis is more prevalent in boys than girls. As boys stand to void they unknowingly soil their underwear, whereas girls sit on the toilet and remove their underwear to void thus preventing inadvertent soiling (Halachmi and Farhat, 2008).

In a recent study by Joensson, Siggaard, Rittig, Hagstroem and Djurhuss (2008) to determine if transabdominal ultrasound was a useful diagnostic tool,

children who suffered from constipation were found to have significantly larger rectal diameters through transabdominal rectal ultrasound than the healthy children. In this study, 51 children from 4 to 12 years of age, of which 27 children had been previously diagnosed with chronic constipation and 24 healthy children who did not have a history of constipation, underwent rectal digital examinations, transabdominal rectal ultrasounds, urinalysis, uroflows, as well as bladder scans to assess post void residuals. Digital rectal exams revealed palpable fecal masses or fecal impaction in the rectums of 20 constipated children and 2 healthy children. Transabdominal ultrasound revealed that children with rectal impaction had significantly larger rectal diameters than the healthy children and that disimpaction and laxative treatment resulted in significantly smaller rectal diameters in these children. Although the rectal diameters were smaller after treatment in the constipated children, the rectal diameters were still significantly larger in comparison to the healthy children.

As early as 1973, Neumann, deDomenico and Nogrady reported in a random sample of 45 out of 131 children with recurrent UTI's, treatment of constipation resolved or decreased the frequency of UTI's in 80% of children. The only apparent cause of the UTI's in this sample of 45 children were abnormal bowel habits diagnosed by difficulty passing firm or hard stools, infrequent bowel movements, abnormally large bowel movements or fecal soiling. Radiological investigations prior to treatment showed in 30 children whose bladder was filled with contrast media, pressure from the full rectum resulted in a displaced bladder or an irregular shaped bladder wall. Barium enemas performed on 18 children

showed all children had dilated rectums and 10 had dilation of the descending and transverse colon as well. Constipation treatment during the study included dietary regulation, bowel training and medications. In the second year of the study 18 patients with recurrent UTI's and abnormal bowel habits received treatment for their UTI's only. The results show that only 20% of the patients that were treated for their constipation in comparison to 88% of the patients who were not treated developed another UTI within in a year. (Neumann, deDomenico and Nogrady, 1973).

A United States pediatric clinical group performed a retrospective chart review of children from 4-17 years of age, seen for health maintenance visits during a 6 month period in 2004 looking for urinary and fecal incontinence as well as constipation in their patient population (Loening-Baucke, 2007). The Iowa criteria was utilized to diagnose constipation which the patient must have met two or more of the following characteristics in the previous 8 weeks: less than three bowel movements per week, one or more episodes of fecal incontinence per week, large stools in the rectum or abdomen, passing of large stools which obstruct the toilet, retentive posturing and/or painful defecation. The results showed that out of their 482 patients, the prevalence of urinary incontinence was 10.5% of which 3.3% had daytime wetting only, 1.8% had day and night time wetting and 5.4% had wetting during the night only . The rate of constipation in their population was 22.6% of which 18% was considered functional in nature (no evidence of inflammatory, anatomic or metabolic disorder) and 4.6% was acute (less than 8 weeks in length) as well 4.4% of children suffered from fecal

incontinence in which 95% was associated with constipation. In 49% of the children, the constipation had started prior to 4 years of age. The prevalence of fecal and urinary incontinence in children was significantly associated with constipation in this population.

In a study evaluating behavioural characteristics of children with daytime wetting, Kodman-Jones, Hawkins and Schulman (2001) found that children who have daytime wetting and recurrent UTIs had a significantly higher rate of constipation (35%) as measured by comprehensive physical exams and standardized behavioural questionnaires, than children with only daytime wetting (25%,  $p < 0.02$ ). In girls, periurethral organisms colonize the urethra and the ascending urethra especially if there is persistently a large amount of stool in the rectum. In girls who are 'infrequent voiders', residual urine potentially becomes a medium for bacteria. Children who utilize their pelvic floor muscles during voiding may develop a "milk back phenomena" in which bacteria in the lower urethra are milked back into the bladder when the pelvic floor muscles are contracted (Ellsworth and Caldamone, 2008). Over time many of these children with voiding postponement behaviours and constipation develop symptoms of urgency, frequency, recurrent UTIs, daytime urinary incontinence and/or nocturnal enuresis (Berry, 2005; Feldman and Bauer, 2006; Schulman and Berry, 2007).

In a retrospective review of 226 medical charts of children with voiding dysfunction and urinary tract infections, Hellerstein and Linebarger (2003) found 55 (31%) children with detrusor instability (diagnosis based on a history of

urgency with or without frequency) were constipated; constipation was the primary cause of detrusor instability in 19 of these children (they developed normal voiding patterns with resolution of the constipation) and the consequence of detrusor instability in 36 children. The diagnosis of constipation was determined based on a history of fewer than 3 bowel movements per week, encopresis at least once per week, staining of the underwear or large bowel movements at least once per week. Hellerstein and Linebarger proposed that in order to control the uninhibited detrusor contractions, the children tightened their pelvic floor muscles, which in turn tightened the anus and rectum thereby preventing fecal evacuation and the detrusor contraction.

In a study prospectively evaluating 167 consecutive children from 5 to 10 years of age who presented to an enuresis clinic with day and/or nighttime incontinence, children were examined with uroflowmetry, ultrasound, electroencephalography as well as behavioural, intelligence and psychiatric diagnostic testing (Von Gontard and Hollmann, 2004). The results indicated that 20 children (12%) had a significantly higher incidence of encopresis, daytime incontinence, voiding problems, thickened bladder walls and EEG abnormalities. These children also had higher rates of UTI's, antibiotic prophylaxis, abnormal flow curves and post void residuals although these results were not significant. Of these 20 children, 16 had signs of stool retention diagnosed by abnormal ultrasounds and a palpable abdominal mass. Although the children did not differ in intelligence, 65% of these children with encopresis and enuresis had severe behavioural problems according to their parents. Of the 57 children with daytime

wetting, 14 children (24.6%) had encopresis in comparison to 110 children with nocturnal enuresis in which only 6 children (5.5%) had encopresis. Within the group of 57 children with daytime wetting, 7 children suffered from dyssynergia. Three of these children (42.9%) with dyssynergia had encopresis resulting in a higher incidence of encopresis within this group. As a result, Von Gontard and Hollmann (2004) suggest that “simultaneous contraction of the anal and urethral sphincter muscles, stool retention and rectal distention and common neurological-developmental factors” predispose children with day and/or night wetting to soiling (p. 2646).

In a study of 234 children with chronic constipation and/or encopresis, Loening-Baucke (1997) established that 46% of these children suffered from lower urinary tract symptoms in which 29% had daytime urinary incontinence, 34% had nighttime urinary incontinence, 17% had both day and nighttime incontinence and 11% had at least one UTI. Constipation was diagnosed based on a palpable abdominal mass and/or stool retention upon rectal examination. Encopresis was defined as fecal incontinence at least once per week over a 6 month period of time. Treatment of constipation consisted of disimpaction or bowel cleansing, prevention of reaccumulation of stool by the provision of a high fibre diet, stool softeners and laxatives as well as reconditioning of the bowel with timed evacuation and proper positioning on the toilet. Constipation was treated successfully in 52% of patients which resulted in the disappearance or reduction of daytime urinary incontinence by 89%, nocturnal enuresis by 63% and UTI's by 100% in children without structural anomalies. Children who had a partial



response to their constipation treatment had a decreased daytime urinary incontinence but did not have a significant decrease in their nighttime incontinence. Children who had persistent constipation despite treatment continued to have more frequent day and nighttime urinary incontinence.

Chase, Homsy, Siggaard, Sit and Bower (2004) also ascertained that treatment of constipation improves bladder functioning. O'Regan, Yazbeck and Schick (1985) studied 47 girls (mean age 8.2 years) with recurrent UTIs and urodynamically determined abnormal bladder contractility. Upon questioning of the parents, several children did have symptoms of chronic functional constipation but in 21 children, parents denied their child's constipation. Rectal examination and rectal manometry revealed large fecal reservoirs in these children. Symptoms of enuresis were present in 32 children while encopresis was present in 21. Aggressive treatment of the constipation resulted in dramatic symptomatic and psychological improvement of these children; 44 children no longer had UTI's, enuresis improved in 22/32 children and 20/21 children had resolved encopresis.

Constipation as an outcome may be difficult to determine. Although children may be capable of reporting infrequent bowel movements, 50% of parents deny their child's constipation (O'Regan, Yazbeck and Schick, 1985). Akyol, Adayener, Senkul, Baykal and Iseri (2007) studied 89 randomly selected children 4 to 14 years of age (mean age 7.4 years - 39 girls and 50 boys) who attended a urology clinic of which 65 children had urinary symptoms. Parents were given urinary symptom and bowel habit questionnaires at the initial

interview and 4 weeks later. 34 children with constipation and urinary symptoms were treated milk of magnesia for 2 weeks resulting in 20 children (62.5%) who were free of urinary symptoms, 11 children (34.5%) with partially resolved symptoms, no change in symptoms in only 1 child (3%) and 2 children lost to follow-up. Of the children who had improved 8/31, parents had previously reported normal bowel movements and the parents of 5/31 did not have any idea about their child's bowel habits. Lack of parental awareness regarding constipation was attributed to less parental monitoring of the child's elimination processes as the child ages as well as the perception that constipation must be severe before it affects the urinary tract.

A prevalence study in Australia showed that in 277 children aged 4.8 to 17.5 years with nocturnal enuresis, 36.1% were constipated by clinical assessment in comparison to only 14.1% of parents reporting their child was constipated (McGrath, Caldwell and Jones, 2008). Parental reporting of constipation was influenced by the frequency of their child's bowel movements and soiling rather than straining or stool consistency. For children greater than 4-5 year of age, unless bowel movements are painful or fecal soiling occurs parents are often not aware of their child's bowel habits (Halachmi and Farhat, 2008). This reinforces the fact that once children are toilet trained and independently voiding, parents are often not aware of their child's urinary or bowel habits. Based on the above review, assessment and treatment of constipation continues to be an important factor in the management of pediatric voiding dysfunction.

***Behavioral Therapy***

In addition to treating constipation, other common behavioural measures include: adequate hydration especially water (20-30ml/kg), avoiding proposed bladder irritants such as caffeine, chocolate, strong citrus juices and carbonated beverages, treating dysuria from perineal irritation, and timed voiding every two to three hours. According to Allen, Austin, Boyt, Hawtrey and Cooper (2007), timed voiding should be the first intervention utilized with any child who has daytime urinary incontinence. Timed voiding allows the child to empty their bladder on a regular schedule before they feel the need to void or before their bladder becomes too full resulting in accidents. Double voiding may need to be initiated in children with high post void residuals. Rewards or vibrating watches may be used as incentives to encourage compliance with behavioural modification and timed voiding. Glassberg and Combs (2009) state that “standard therapy” for children with voiding dysfunction includes:

Explanations to both parent and child regarding awareness of bladder fullness, understanding basic anatomy and bladder function, teaching proper toilet posture, avoiding holding maneuvers, normalization of fluid intake, prevention of constipation and the importance of regular or timed voiding... includes the use of bladder diaries, questionnaires and charts in order to document symptoms and frequency of incontinence (day or night) with regular follow-up to review progress (p. 412-413).

Weiner et al. (2000) showed that 60 % of patients improved daytime urinary control with simple behavioural therapy consisting of timed voiding, modification of fluid intake, pelvic floor exercises and the use of voiding diaries. Children who fail conservative measures will often need anticholinergic medications and/or biofeedback therapy to learn abdominal and pelvic floor muscle relaxation during voiding. The occasional child will continue to fail conservative management requiring further investigation to rule out any anatomic or spinal cord abnormality (Herndon and Joseph, 2006).

A number of studies have shown that prolonged pediatric voiding dysfunction may continue into adulthood. In a case control study (Minassian, Lovatsis, Pascali, Alarab and Drutz, 2006), an adult symptom survey as well as the Dysfunctional Voiding Symptom Score (DVSS) were applied to determine the effect of childhood dysfunctional voiding on adult women's incidence of lower urinary tract symptoms. The results showed that a number of subjects had a history of childhood voiding postponement, infrequent urination, urgency and stress incontinence. Bower, Yip and Yeung (2005) noted that 41.7% of the adult urogynecological patients they studied reported some form of urinary tract dysfunction as a child whether it was nocturnal enuresis, vesicoureteral reflux, recurrent UTIs, intermittent urine flow, frequency, urgency, incontinence or constipation. In 2006 Bower, Sit and Yeung established that unremitting nocturnal enuresis in adolescents and adults with voiding dysfunction was also associated with childhood lower urinary tract symptoms of recurrent UTIs, urgency, frequency, incontinence, voiding postponement and constipation.

Limitations to each of these studies include selection and memory or recall bias but they do reinforce the importance of treating voiding dysfunction in young children as their abnormal voiding habits could contribute to urinary problems or renal dysfunction into adulthood.

Although behavioural problems do not cause urinary incontinence, a number of authors have suggested that there may be an increased incidence of urinary incontinence in children with attention deficit disorders. These children can be particularly hard to treat due to their poor attention span. Joinson, Heron, VonGontard and the Avon Longitudinal Study of Parents and Children (ALSPAC) study team (2006) identified 643/8242 children (7.8%) suffering from daytime wetting. According to parent reports, in comparison to children without daytime wetting, those with wetting had twice the rate of conduct disorders, attention and activity problems as well as oppositional behaviours. Joinson, Heron, Emond and Butler (2007) utilizing the same sample as above, established that there was an increased incidence of attention, conduct and oppositional disorders in children who had both day and night time wetting (over twice the rate of children with no wetting problems) whereas children with bedwetting alone had an increased incidence of social fears as well as sadness and depression. Interestingly Joinson's study did not show a reduction in self-esteem in children who only suffered from bedwetting. Also from the ALSPAC study, risk factors associated with the development of daytime wetting and soiling in school-aged children were delayed development, difficult child temperament, and maternal depression or anxiety (Joinson et al., 2008). Chertin et al. (2007) studied 54

children with attention deficit hyperactivity disorder (ADHD) and nocturnal enuresis and found that there was a higher incidence of voiding dysfunction (mean score of 20/30 on DVSS) in children with ADHD. Kodman-Jones, Hawkins and Schulman (2001) studied 418 children with nocturnal enuresis or daytime wetting and/or UTI; a small sub sample of this group was randomly selected and studied for psychological conditions. The findings suggest an increased incidence of ADHD in children with daytime wetting with no UTI (21%) and nighttime wetting (16%) in comparison to the general population (3-5%). Parents of children in this study also described their children as more stubborn and secretive.

Many of the studies on pediatric voiding dysfunction have been retrospective reviews of cohorts rather than prospective or randomized studies which may have induced selection or recall bias to the results which consequently does not allow for generalizability to the population. Unvalidated outcome measures do not allow for consistent reliable results within and between the studies. But the literature reviewed identifies voiding dysfunction as a significant issue in young children that can proceed to adulthood. Despite this recognition, there has been little study on the impact voiding dysfunction has on either the child or the family. This is in part because of the challenge of measuring the impact of voiding dysfunction or quality of life in young children. Historically the quantification of voiding dysfunction and quality of life parameters within the pediatric population with urinary incontinence has been mistakenly absent

although there seems to be more recognition of this fact with an increased focus in this direction.

### ***Quantifying Voiding Dysfunction and Incontinence in Children***

Recently tools have been developed to assess the severity of pediatric urinary incontinence and voiding dysfunction. In 2000 Farhat et al. developed and validated the Dysfunctional Voiding Symptom Score (DVSS) at The Hospital for Sick Children in Toronto, Ontario. The DVSS was developed to quantify or grade the severity of abnormal voiding habits in children and provide a standardized reporting system for children from three to 10 years of age. The tool consists of 10 age appropriate urological questions with reference to urinary incontinence, voiding habits, urgency, posturing, bowel habits and stressful life events, graded on a scale of 0-3 with a total possible score of 30, with 30 being most severe voiding dysfunction. The initial sample of patients consisted of 104 patients from three to ten years of age who consecutively attended the Pediatric Urology Clinic at the Hospital for Sick Children. The control group consisted of 54 patients who were age matched cohorts from clinics outside of the urology department who had no history of urology complaints or fluid and electrolyte imbalances. Patients with Spina Bifida, posterior urethral valves or patients with neurogenic bladders were excluded from the study. The study group consisted of 83 females and 21 males (4:1) with a median score of 14 whereas the control group had 31 females and 23 males (1.3:1) with a median score of 4. The median scores between the groups were significantly different with females 2.93 times more likely to have voiding dysfunction than males. The data analysis showed

that the optimal threshold score for diagnosis of voiding dysfunction in males was 9.02 with a sensitivity of 80.95% and specificity of 91.30% whereas the optimal threshold score in females was 6.02 with a sensitivity of 92.77% and specificity of 87.09%.

In 2001 Farhat, McLorie, O'Reilly, Khoury and Bagli illustrated that changes in the DVSS were reflective of changes in voiding symptoms, in this case as a result of adherence to behavioural modification. In this study "compliance was defined as parent satisfaction with their child's cooperation with behavioural modification" (Farhat, et al, 2001, p.1403) as well as an improvement in the DVSS score whereas non-compliance with the bladder retraining program was defined as poor adherence to the behavioural modification program according to the child's parents and a lack of change in the DVSS score. Five months after their initial visit, 104 patients who were consecutively diagnosed with voiding dysfunction in the previous DVSS study in 2000 by Farhat et. al. were mailed the DVSS as well as a questionnaire to assess compliance with behavioural modification strategies. The child's treatment compliance was then correlated their DVSS score. Forty-six percent (48/104) of patients completed the survey. Group I consisted of 28/48 patients who were presumed to be compliant with behavioural modification based on parental response, with a male to female ratio of 1:5 and a mean age 7.1 years. Group II consisted of 20/48 patients who were presumed to be noncompliant with behavioural modification, with a male to female ratio of 1:5 and a mean age of 7.5 years. The mean scores for Group I and Group II were similar on initial evaluation but were significantly different on



follow-up evaluation. The scores in Group I were significantly lower on follow-up with a change from 15 to 6.5 ( $p < 0.0001$ ) whereas Group I scores only changed from 14.5 to 11 ( $p > 0.05$ ) (Farhat et. al, 2001).

In 2003, Upadhyay et al. noted that the change in the DVSS predicted the resolution of vesicoureteral reflux (VUR) associated with voiding dysfunction in children who had undergone successful behavioural modification. 58 children who had presented with dysfunctional voiding and UTI's, in the previous studies by Farhat, had abnormal voiding cystourethrograms (VCUG), of which 19 female children (mean age 6.7 years) had VUR only - 5 of these children had bilateral VUR. Baseline and follow-up DVSS scores were obtained in these 19 children who had behavioural modification therapy and were observed prospectively for 24 months for resolution of their VUR. The childrens' VUR grades varied from grades I – IV. The mean DVSS was 13.3 in children with normal VCUG and 11.7 in the VUR group. The DVSS score was then correlated with the changes in their VUR. Patient compliance with behavioural modification was assumed by the change in the DVSS over time, frequency of UTI's, and change in their VUR grade. 11 children had improvement (decrease of two or more grades) or complete resolution of their reflux with a change in the mean DVSS score from 9.6 to 3.7 by the end of the study whereas 8 children with persistent reflux only had a change in the DVSS from 14.4 to 11.1. According to Upadhyay et al., voiding dysfunction contributes to the delay in spontaneous VUR resolution.

Another tool is the Pediatric Daytime Urinary Incontinence (PDOI) questionnaire which utilizes parent reported data on their child's daytime urinary

incontinence (Sureshkumar, Craig, Roy and Knight, 2001a). During the pilot study of the PDOI questionnaire, the questionnaire was initially administered to 20 renal patients and then concordance of the responses was correlated with the child's history. Changes were made to the questionnaire based on parental responses to the questionnaire and suggestions. The questionnaire was then tested on another 20 subjects in a bladder clinic prior to the main pilot study. The questionnaire was then translated into a number of different languages to eliminate language bias. A randomly selected sample of kindergarten children from 5 randomly selected schools participated in the pilot study. Parents of 166 children from 3.5 to 7 years of age (mean 5.6 years) completed the questionnaire twice, 4 weeks apart. Most questions showed good test – retest reliability. The results show that the tool is useful in detecting detect voiding problems, severity and response to treatment in children with voiding dysfunction. According to Sureshkumar, Craig, Roy and Knight (2001a) the survey can be applied to any pediatric population or ethnic group. This questionnaire was then administered to the parents of 1419 children (728 boys and 689 girls with a mean age of 5.9 years) in a population based survey in Australia. The results showed that 19.2% of children were wet at least once in the previous 6 months, 4.2% were wet 2 or more times/month, and 0.7% of children were wet every day. Bedwetting was present in 11% of children and 4.3% of children had both day and nighttime incontinence. In a further study, Sureshkumar, Cumming and Craig (2006) conducted a parental survey to determine the incidence of urinary incontinence and UTIs in their children. The findings suggest that parents over reported the

incidence of UTIs by two fold but were able to accurately describe the severity of urinary incontinence in their children. Regardless of the parental report discrepancy in the incidence of UTIs in their children, the authors stated that the survey can accurately estimate the severity, frequency and risk factors associated with daytime urinary incontinence and UTIs in school children.

A third tool, the Dysfunctional Voiding and Incontinence Scoring System (DVISS) developed by Akbal, Gene, Burgu, Ozden and Tekgul (2005), grades voiding dysfunction and reflects therapeutic improvements in voiding dysfunction based on treatment. This survey included 13 questions related to daytime symptoms, night time symptoms, voiding habits, bowel habits and quality of life. The instrument was administered to the parents of two groups of children aged 4 to 10 years of which 86 children (mean age 7.6 years) had wetting and voiding difficulties and 256 children (mean age 7.8 years) with no urological complaints were the controls. Odds ratios were utilized to differentiate the patients from the controls and the strength of the questions. As a result some of the questions were excluded or modified based on the odds ratios and new scores were calculated. Although the total scores ranged from 0 to 35, the median scores for the two groups were significantly different with a score of 18.56 for the children with voiding dysfunction in comparison to 2.88 for the controls. Patients with a threshold score of  $\geq 8.5$  had voiding abnormalities with a sensitivity and specificity of 90%. Within this study, there were no statistically significant differences found between age and gender.

Tuygen et al. (2007) studied the role of the DVISS on children with voiding dysfunction; results showed that there was high sensitivity in predicting treatment effect but low specificity. 93 children with voiding dysfunction were divided into 3 groups; Group 1 - 40 children with wetting only (mean age 8 years), Group 2 - 18 children with wetting and UTI's (mean age 8.5 years) and Group 3 - 35 children with wetting, UTI's and reflux (mean age 7.5 years). The DVISS was administered and individualized treatments were given based on the child's diagnosis and symptoms. In Group 1 - 27 children (67.5%) had a complete response to treatment, 7 children partial response, 6 children had no response and 4 children had a reoccurrence of symptoms. In Group 2 - 16 children (88.8%) had a complete response to treatment, 2 had a partial response, and reoccurrence was seen in 6 children. Lastly in Group 3 - 30 children (85.1%) had a complete response to treatment, 5 had no response and reoccurrence was seen in 4 children. Of this last group 19 children had complete resolution of their reflux, 6 children had a decrease in their grade of reflux and 5 children had no change in their reflux. The specificity of the DVISS in predicting a complete response to treatment was 79% in group 1, 88% in group 2 and 100% in group 3 whereas the sensitivity in all groups was 100%. As a result Tuygen suggested that the DVISS could augment other methods of assessment in managing patients with voiding dysfunction.

In 2008, Schast, Zderic, Richter, Berry and Carr utilized the Pediatric Lower Urinary Symptom Score (PLUSS) formally called the DVISS along with the Emotional Functioning, Social Functioning, Daily Activities and Family

Relationship Scales of the Family Impact Module of the health related quality of life questionnaire (PedQL) to assess symptom scores and QOL of patients who attended their specialty urology clinic. 351 patients 5 - 17 years of age with a mean age of 9.5 years were included in the study. In this sample, 53% were female, 70% were Caucasian, 78% lived in a two-parent household, 21% came from household with a parental education of high school or less, 14% of patients had daytime wetting, 34% had nighttime wetting, 40% had combined day and nighttime wetting, 11% did not have any wetting at all and 38% had fecal incontinence. The average score of the PLUSS in this sample was 12.0 (range 0-29) with 29% of patients scoring below the clinical cut-off of 8.5. 80% of the respondents indicated that the child's family or social life was impacted by the child's urinary symptoms based on the QOL item on the PLUSS. The child's age was significantly correlated with the PLUSS as younger children had higher scores than the older children. Children of minority races presented with bedwetting or a combined day and nighttime incontinence as a result had higher PLUSS scores than Caucasian children. Children who scored at a below average levels in school had significantly higher symptom scores than those who were performing at average levels or higher. Fecal incontinence was significantly associated with higher PLUSS scores. Children with ADHD, learning or behavioral issues, on psychotropic drugs or mental health treatment had significantly higher PLUSS scores. Both the child's PLUSS symptom score and the child's symptomatology were negatively correlated with child and family QOL therefore as their PLUSS score and symptoms increased their QOL

decreased. Also according to the study, family QOL was most affected when children had both day and nighttime incontinence in comparison to just daytime or just nighttime wetting. Schast states that the PLUSS with its many clinical associations would be a useful tool to monitor clinical symptom resolution over time (Schlast et. al., 2008).

Finally, the Incontinence Symptom Index-Pediatric (ISI-P) was developed from the adult Incontinence Symptom Index and validated by Nelson et al. (2007) for children 11 to 17 years of age (mean age 14.4 years). Factor analysis was utilized to determine appropriate domains for the instrument which resulted in a self-administered 11-item instrument focused on impairment and symptom severity of voiding dysfunction with questions related to stress urinary incontinence, urge urinary incontinence, insensate urinary incontinence, nocturnal urinary incontinence and pad use. The ISI-P allowed researchers to quantify the urinary incontinence symptoms, adaptation, and psychological impairment of urinary incontinence for the older pediatric patient. The pilot survey was administered twice, two weeks apart, to 19 children with urinary incontinence who presented to a pediatric urology clinic and 19 similarly aged healthy children who attended a general pediatric clinic. Test-retest reliability of the instrument and discriminative validity of the instrument was good with a total severity score of 9.3 in incontinent children in comparison to 0.7 in the controls. The impairment scales and mean scores differed significantly between the groups except for pad use with the most significant difference in the urge urinary incontinence domain. Nelson concluded that the ISI-P could be utilized in

children from 11 – 17 years of age to measure patient reported urinary incontinence.

Urinary incontinence and dysfunction has also been quantified utilizing voiding diaries, voided volumes, voiding frequency and pad tests. In 1986, Hellerström, Andersson, Hjälrmås, and Jodal found that a 12 hour pad study was reliable in quantifying urinary incontinence in children. A positive test was considered more than 0.5 gram pad weight increase. The results show that 68% of the 50 children (39 girls and 11 boys) who participated in the pad study were positive for urinary incontinence and up to 80% were positive for urinary incontinence when fluid challenged. Bower, Moore, Adams and Shepherd (1997) found that the mean and standard deviation of voided volumes in frequency volume charts varied considerably between incontinent children and that the only factor which influenced the trends in voided volume was the child's age. Bael et al. (2007) found in the European Bladder Dysfunction Study that documentation in voiding diaries did not correspond to reported urinary incontinence, voided volumes and voiding frequency. Pad studies were also found to be unreliable with 64% sensitivity to self reported functional urinary incontinence symptoms but did show quantitative data with good specificity. Bael attributes the lack of positive data from the pad study to children trying to be continent during the study.

Although these instruments have all been developed to diagnose and quantify the severity of voiding dysfunction in pediatric patients, with the exception of the DVSS (Farhat et. al., 2000), most have been derived from adult

instruments and do not incorporate the child's age, cognitive development or language skills into their development. The child's ability to understand the concepts and questions in the tool as well as respond appropriately is dependent on his/her age and developmental state. As well a number of the instruments incorporate parent reports which may not correlate with how the child would respond. It is important that the tool we utilize is developmentally appropriate for the child, easy to understand and has been developed specifically for children.

### ***Quality of Life***

The "Quality of Life" concept has been developed over the last 40 years but remains an ambiguous term with no consistent theoretical definition or framework in the literature (Dijkers, 1999; Eiser and Jenney, 2007). Dijkers (2007) states that "many investigators do not bother to consider whether QOL is a construct they need to measure, and if so, what they mean by it" (p. 153).

Historically, the first reference to quality of life comes from Aristotle who spoke of a life of virtue resulting from happiness and good life (Anderson and Burckhardt, 1999). According to Meeberg (2001) the actual term "quality of life" was first introduced shortly after the Second World War but the actual "quality of life" construct did not come into vogue until the late 1960's or early 1970's. Since that time, quality of life has become an integral part of the literature but there have been many definitions of what quality of life and many ways to measure it. Lawford and Eiser (2001) state that "in the absence of a theoretical framework there is no way of distinguishing which factors are relevant to measurement, nor



of determining which variables moderate quality of life” (p. 213). It is difficult to measure a concept when we cannot define what it is.

In the early years a number of authors defined quality of life in terms of life satisfactions. During this time period the individual’s own reaction to the subjective indicators of happiness and satisfaction became measures of the individual’s reaction to their life experiences (Haas, 1999). According to Anderson and Burckhardt (1999), Cantril proposed in 1965 that

Each individual constructs a pattern of assumptions about self and environment that create conceptions of what is important to that individual. These subjective standards about what is important guide behavior and define satisfactions (p. 299).

Campbell (1976) explored life satisfaction and suggested that the 15 life domains of marriage, family life, health, neighborhood, friendships, housework, job, life in the United States, life in the city or country, non-work activities, housing, usefulness of education, standard of living, amount of education, and savings were influenced by the individual’s own characteristics and their perceptions of the domains importance (Anderson and Burckhardt, 1999). In 1982 Hörnquist described quality of life as the satisfaction of physical, psychological, social, activity, material and structural needs. In 1989 Hörnquist expanded his definition of quality of life to include the “perceived global satisfaction and satisfaction within a number of key domains with special emphasis on well-being” (p. 70) He went on to say that it is “primarily the individual’s own opinion of his life that

determines the that person's life quality" (p. 70). Satisfaction with one's own life became synonymous with quality of life.

Other authors have defined quality of life as a multidimensional concept. Tartar, Erb, Biller, Switala, and Van Thiel (1988) conceptualized quality of life as "a multifaceted construct that encompasses the individual's behavioral and cognitive capacities, emotional well-being, and abilities requiring the performance of domestic, vocational and social roles". Felce's (1997) framework incorporates the dynamic interaction of the three elements personal values, life conditions and personal satisfaction to determine the individual's quality of life. The overall model is multidimensional and interactive between the domains of physical well-being, material well-being, social well-being, productive well-being, emotional well-being and civic well-being (Felce, 1997). The model also incorporates objective life conditions, subjective personal appraisals and individual variability to define the individual's own quality of life.

In the 1980's individual authors began to define quality of life in terms of the "difference between one's present life circumstances and a standard to which one compared oneself" (Haas, 1999). Carr, Gibson & Robinson (2001) define the individual's perception of their quality of life as a difference between the individual's expectations and their experiences. Although the perception of quality of life within the individual is a dynamic, there is great variability between individuals in their perception of quality of life even though they may have the same clinical condition.

Although there are currently no consistent definitions or conceptualizations of what quality of life means, many current definitions have been derived from the World Health Organization's definition, "an individual's physical health, psychological states, level of independence, social relationships and their relationship to salient features of the environment" (Lawford and Eiser 2001, p. 210). In Connelly and Johnson's article (1999), quality of life is defined as "physical, social and emotional aspects of a patient's well-being that are relevant and important to the individual" (p. 606).

The term quality of life is often confused with the terms general health status, functional status or well-being (Eiser and Morse, 2001b). Although these terms are directly related to quality of life, each of these terms only incorporates one small aspect of the global concept of quality of life. Functional status refers to the "individual's ability to perform normal daily activities to meet their basic needs, fulfill usual roles and maintain health and well-being" (Eiser and Morse, 2001b, p. 9), whereas health status refers to the "individual's relative level of wellness & illness" (Eiser and Morse, 2001b, p. 9). Functional and general health status tend to focus on the negative aspects of the individual's health whereas the term well-being tends to focus on the more positive or holistic view of the individual's health status.

What remains consistent between different authors is that quality of life is a subjective experience to the individual and depends on the meaning the individual applies to the experience. Each individual has their own perspective of what quality of life is which relates to their own experiences, expectations, culture,

values, lifestyle, hopes, dreams and aspirations for the future (Eiser and Morse, 2001a; Eiser and Morse, 2001c). “Quality of life is what the individual experiences it to be...the subjective nature of quality of life means that it will vary greatly from person to person and even for a given individual over time in the same objective circumstances” (Cohen, Mount and MacDonald, 1996, p. 753).

Quality of life is a multidimensional concept which is difficult to measure and there are differences between individual people and their perceptions of their own quality of life. Quality of life is often measured on a continuum; it is not an absolute measure and the individual’s quality of life can change over time (Meeberg, 1993). Often people with similar illnesses and functional status can have very different perceptions of their own quality of life. (Beckie and Hayduk, 1997; Eiser and Morse, 2001a; Eiser and Morse, 2001b; Trajanovska and Catto-Smith, 2005).

In summary, the domains of quality of life often incorporate physical, emotional, psychosocial, social and spiritual functioning but can have great variability depending on what aspects of quality of life are being measured. Each domain can incorporate both objective perspectives which incorporate what the individual is able to do and subjective perspectives which incorporate the individual’s own perceptions or appraisal of their quality of life (Eiser and Morse, 2001a; Eiser and Morse, 2001b; Eiser and Morse, 2001c). Cohen, Mount, Tomas and Mount (1996) found that the domains of spirituality and existential wellbeing were paramount to terminally ill patients to their definitions of quality of life

(Beckie and Hayduk, 1997; Eiser and Morse, 2001a; Eiser and Morse, 2001b; Trajanovska and Catto-Smith, 2005).

### ***Pediatric Quality of Life***

An area of QOL research that has not been well addressed concerns pediatrics. The advancement of medical technology has increased the long term survival of many children who would have previously perished; as a result many of these children are left with long term chronic illnesses, physical or learning disabilities, or emotional problems which may compromise their quality of life (Eiser, 1997) and that of their parents. Survival alone can no longer be considered an adequate outcome measure; the focus must be redirected to the impact medical interventions have overall (Eiser, Mohay and Morse, 2000; Upton et al. 2005). The impact of long term survival in neonatal and pediatric oncology patients has guided pediatric quality of life research from its inception (Eiser, 1997; Eiser and Morse, 2001b).

Pediatric quality of life assessment is becoming more prevalent with measures being developed specifically for children. The historical perception that “children are merely small adults” has influenced a number of authors who have tried to transform adult quality of life measures into pediatric measures without success. As well, numerous authors have questioned whether children are reliable informants on their own quality of life but others have reinforced the belief that children are the best of proponents of their own quality of life. We now know that children’s views of the world and their perceptions of their quality of life are

very different than those of the adult population (Eiser, 1997; Eiser and Morse, 2001b).

Pediatric quality of life measures relevant to the young child such as the ability to play are very important to the child (Connelly and Johnson, 1999; Eiser, 1997). The different domains utilized for children should take into account the context in which the child lives. In the adult patient, the domain of physical functioning may mean the ability to climb the stairs whereas in the child it may mean the ability to play with friends (Eiser and Morse; 2001b). According to Eiser and Morse (2001b) pediatric quality of life domains should include cognitive functioning, autonomy, body image and family relationships over and above the domains of physical, social and psychological functioning.

Children's quality of life measures must take into account the child's age and developmental state. To complete quality of life tools, children must be able to understand the concepts behind the items utilized in the instrument (Cremeens, Eiser and Blades, 2006b). They also need basic understanding of health, self concept and emotions, are able to make social comparisons and recall personal events. A measure that was developed for a school age child may not be appropriate for a very young child, as the child's understanding and perceptions change with their age and cognitive development (Connelly and Johnson, 1999; Eiser, 1997; Eiser and Jenney, 2007; Eiser and Morse, 2001b; Gerharz, Eiser and Woodhouse, 2003). Although no lower age limit has been established in which a child can self report, literature has shown that children as young as 3.5 years can use psychological concepts and provide psychological information about

themselves when asked (Lawford, Volavka and Eiser, 2001). A child's ability to learn and comprehend may be compromised due to the impact of their chronic illness or their inability to attend school. Young children may not be able to progress through the normal developmental milestones due to their illness.

Children's peers and social relations change over time with their peers becoming more influential as the child ages and approaches the teen years. Adolescents may struggle with gaining independence and autonomy, are very egocentric in their perceptions of physical appearance and body image as a result any physical deformity or perceived physical deformity may negatively impact their quality of life (Eiser and Morse, 2001b).

Utilization of proxies or another person completing the quality of life survey for the child has been related to the child's inability to complete the measure due to their lack of cognitive and communicative development or severity of illness (Cremeens, Eiser and Blades, 2006b; Eiser and Morse, 2001b; Gerharz, Eiser and Woodhouse, 2003; Jenney and Campbell, 1997). Generally parents are the proxies and less frequently teachers and medical professionals are utilized. The concordance between the parent and child's interpretation of the child's quality of life is variable, as some research has shown excellent agreement but the majority of studies show major discrepancies between the child and parental views. Some studies show that there is good concordance in relation to observable behaviors such as physical activity and physical functioning but poor agreement in relation to non-observable factors such as social and emotional issues. Proxy respondents often underestimate quality of life in compared to their patients. Theunissen et al.

(1998) showed that children reported a significantly lower quality of life than their parents reported on their behalf. Parent's knowledge about their child's "disease related experiences may be limited" (Jokovic, Locker and Guyatt, 2004, p.1304) and they may have limited knowledge about their child's actual quality of life. The difference in concordance between parents and children may be as a result of differing life experiences as well as different perceptions of disease consequences or life events (Eiser and Morse, 2001b; Cremeens, Eiser and Blades, 2006b). Children may want to present themselves in a positive light or may not be aware of the potential restrictions of their disease. They will often report less impact on their quality of life from their illness or condition than their parents do (Eiser and Jenney, 2007). To date, the concordance between the child and an individual parent (mother or father) has not been studied (Eiser and Morse, 2001b).

Although parent and child perceptions may differ, patient and parent proxy ratings can be combined to gain differing perspectives on the child's quality of life (Eiser and Jenney, 2007; Cremeens, Eiser and Blades, 2006b). Sherifali and Pinelli (2007) state that "both child and parent reports allow us to more fully understand the complex and multidimensional construct of quality of life" (p. 96). Parent and child reports provide different views on the child's quality of life but both are important to obtain a comprehensive picture of how the child and family are impacted by disease (Raaijmakers, Mohangoo and Grootenhuys, 2006). Discrepancies are to be expected and that it is more important to look at the context of when parents are able to make accurate judgments of their child's quality of life than to



focus on the discordance (Eiser, 1997). From Connelly and Johnson's (1999) perspective, the utilization of proxies may prevent the loss of valuable information about the child's quality of life that would not otherwise been obtained although it may not actually reflect how the child is actually feeling or functioning. Cremeens, Eiser and Blades (2006c) showed that a lack of consistency between children and their parent's in the pediatric quality of life measure may be more related to the statistical method utilized to assess the data rather than a true discrepancy in the results. They also felt that the level of agreement may be affected by the particular domains studied as well as the child's age and the parents perception of their own quality of life. Although there continues to be controversy regarding the concordance between children and their parents, the utilization of proxies remains an important component of pediatric quality of life assessment.

### ***Pediatric Quality of Life Measures***

Pediatric quality of life measures have focused on generic health scales as well as disease specific measures. The generic health measures look at all domains of quality of life and can be generalized to the whole population, healthy or ill, and allows comparisons across groups; disease specific measures focus on specific domains that are impacted by the particular disease and can only be generalized to other patients who have the same clinical condition. Disease specific measures are able to quantify smaller changes in the individual's quality of life measures in relation to changes in their health status, whereas the generic measures are less sensitive to small changes in health status.

Generic health related quality of life measures can also be subdivided into health profiles or preference-based index measures. The health profile measures are divided into separate domains of health and functioning in which each domain can be compared across populations. The preference-based index measure gives a single total number which represents the net impact on physical, emotional and social functioning on quality of life; only the total score can be compared across populations (Connelly and Johnson, 1999; Eiser and Morse, 2001b).

To elicit meaningful responses, pediatric quality of life measures must incorporate the child's age, development and language skills for the targeted population. Children's ability to understand the concepts and questions in the tool as well as respond appropriately will be dependent on their age and developmental state. Quality of life tools which are targeted to the literate younger population need to be adjusted for the child who is unable to read. Younger children may have difficulty interpreting Likert or visual analogue scales but may be able to answer yes/no type questions. Children's recall is often better over shorter rather than longer periods of time therefore the quality of life measures must incorporate the child's understanding of the concept of time. Measures should be understandable to the child, have few questions, and have pictorial support. The use of computers and props may improve the child's understanding of the tool. (Cremeens, Eiser and Blades, 2007; Eiser and Morse, 2001b).

Quality of life measures may be utilized to evaluate the impact of medical interventions, aid decision making regarding particular treatment modalities,

evaluate clinical trials, or as a screening tool to identify children with particular problems (Eiser, 1997). Quality of life measures can also be used to assess outcomes in health related research (Davis et al., 2006). Quality of life measures may influence decision making when only small differences in clinical outcomes occur or by influencing decisions about resource allocations (Bower, Wong and Yeung, 2006). The use of quality of life "measures in clinical practice should lead to improved communication and enhanced patient satisfaction ...and provide a standard score against which change can be monitored." (Eiser, 2007, p. 379). Children have very different perceptions than adults, different cognitive and communication abilities as they grow, and unique life experiences that influence their quality of life. According to Grange, Bekker, Noyes and Langley (2007), there are currently no health related quality of life measures that are "conceptually and psychometrically robust for children" less than five year of age (p. 216).

### ***Pediatric Urinary Incontinence Quality of Life***

One area that affects QOL for both parents and children is incontinence and voiding dysfunction. Although the impact of urinary incontinence or voiding dysfunction on child's self esteem has been well documented in the literature, only recently has urinary incontinence related quality of life been addressed in children.

Children with voiding dysfunction often suffer from low self esteem and psychological distress as a result of their symptoms. Children who have special permission to leave the classroom due to urinary or bowel issues are often singled out as being "different" (Gerharz, Eiser and Woodhouse, 2003). Often these

children will be teased by school mates or siblings, are the targets of bullying behaviours and become social isolated (Theunis, Van Hoecke, Paesbrugge, Hoebeke and Vande Walle, 2002). According to Joinson, Heron, VonGontard and the ALSPAC study team (2006) "wetting pants in class was rated as the third most stressful of 20 different life events when school-age children were asked to grade them in terms of severity" (p. 1986). Children with voiding dysfunction will often avoid social activities such as sleep-overs or camps, fearing ridicule if others find out about their problem.

Incontinence affects both the child and the family socially, emotionally and behaviourally (Landgraft et al. 2004). According to Kelleher (1997) "inappropriate voiding may create social or educational problems, and parent/child or peer discord" (p. 73). In 1981 Hague et al., found that approximately one-third of parents punish their child for his/her incontinence and that parents with grade school education punished their children at twice the rate of high school or college educated parents. Parents may feel their child is lazy and immature or may be angry with the physical and financial costs associated with the child's incontinence such as laundry. Some parents must know where every bathroom is located whenever they go out as a result of their child's urgency and frequency, while others may be frustrated because they cannot leave the house because their child's need to void so frequently.

Incontinence is often a source of shame and embarrassment for the affected individual and those who have experienced treatment failure will have lower self-esteem (Hägglöf, Andrén, Bergström, Marklund and Wendelius, 1997; Landgraft

et al., 2004). Ultimately voiding dysfunction can have an immense impact on the child's self esteem and quality of life (Ward-Smith and Barry, 2006) which effective treatment can significantly improve (Hägglöf, Andrén, Bergström, Marklund and Wendelius, 1997).

### ***Pediatric Urinary Incontinence Quality of Life Measures***

Gladh, Eldh and Mattsson (2006) studied the quality of life of 359 neurologically healthy children in which 120 children (83 girls and 37 boys from 6 to 16 years of age) who attended the clinic with daytime incontinence, day and nighttime incontinence or therapy resistant nocturnal enuresis were compared to a control group of 239 age-matched school children. A self-rated quality of life questionnaire for children was modified from an adult quality of life instrument and then validated statistically. Validity testing of the instrument was able to show that the perceived difference in quality of life was as a result of incontinence but reliability of this instrument was not examined. This questionnaire was administered to the clinic children prior to their visit with the physician and to the school children in their classroom. Quality of life measures were rated lower in all age groups of the incontinent children in comparison to the control group except for the older adolescent children. The child's self esteem, self confidence and social situation were most influenced by the child's incontinence especially in the younger child. Interestingly 31 children (13%) in the control group had undiagnosed urinary incontinence, although these children were removed from the control group and the base analysis, their quality of life scores fell between the continent and incontinent children's scores.

Although importance of assessing quality of life in the pediatric population is recognized, only one published tool was found that has undergone reliability and validity testing for the pediatric population. Bower, Wong and Yeung (2006) developed a cross cultural pediatric specific urinary incontinence quality of life instrument called PinQ. The initial step in the development of the tool consisted of expert consultation with 33 continence clinicians in 13 countries. The tool was designed and administered to 156 children in 10 different countries within Europe, Asia, North America and Australia who were 6 years of age and older with bladder symptoms or a combination of bladder and bowel symptoms. The sample consisted of 54.5% males and 45.5% females, of which 88% of children had bladder symptoms alone and 22% had a combination of bowel and bladder symptoms. Psychometric testing of the tool was completed with a thorough item analysis, reliability and validity testing, and elimination of questions with ceiling or floor effects. At the completion of the survey development, none of the questions were highly correlated with each other. During the development of the survey, neither parents nor clinical specialists could predict key issues that were important to children. The domains included in the instrument are: social relations with peers, self-esteem, family and home, body image, independence, mental health and treatment (Bower, Sit, Bluysen, Wong, and Yeung, 2006; Bower, Wong and Yeung, 2006).

The PinQ was then retested on 40 Chinese and Dutch children aged 6-15 years of age at initial consultation and again 14 days later. Parents also completed a proxy version of the PinQ. The interclass correlation coefficient for comparison

between items showed very little variability in scoring and the overall proxy scores showed little variability between the child and parent. The PinQ survey was reliable under test and retest conditions (Bower Sit, Bluysen, Wong, and Yeung, 2006).

In phase 3 of the development of the PinQ, Bower (2008) the data from the previous study was analyzed to “generate an understanding of the child’s perception of the impact of bladder and bowel dysfunction on aspects of their life” (p. 617). The data obtained from 156 children (between 6 and 17 years) in 10 countries was reanalyzed measuring 6 domains in quality of life. Mean domain scores in descending order were self esteem (57%), mental health (52%), independence (48.5%), family (46%), social interaction (43%) and body image (39.5%). The PinQ total score was significantly correlated with the individual domain scores. Although there was no age related differences in total domain scores, older children were more nervous and perceived their parents as more angry about their bladder problems whereas younger children showed a greater impact on their sleep as a consequence of their bladder problem. The self-esteem domain showed a gender related difference with a significantly higher male mean score of 9.72 in comparison to the girls mean score of 8.44. The body image domain scores were significantly higher in boys with combined day and nighttime symptoms in comparison to both boys and girls with only nighttime symptoms. High total scores which reflected a greater impact on quality of life were associated with combined day and nighttime symptoms as well as male gender. When a bowel disorder was coexisted with a bladder dysfunction, all domain

scores were adversely affected and poor treatment efficacy was associated with impaired self-esteem and mental health scores. Poor treatment efficacy was also proportionally correlated with the cumulative score and the individual domain scores. Significant cultural differences were seen between the European and Asian children in relation to total domain scores with European children scoring higher on all domains except family. According to Bower, bladder and/or bowel related symptoms can have a significant impact on the individual child's quality of life as demonstrated by this PinQ study.

Although pediatric urinary incontinence quality of life has been discussed in the literature, it is only recently that a tool relevant to children has been developed. Past research has mainly focused on generic pediatric quality of life measures. To date the PinQ is the most robust tool which measures aspects of quality of life and impact of UTI in children.

### ***Implications for Research***

Learning about the impact of urinary incontinence on the individual child's self esteem and quality of life will help us to understand whether screening and early intervention is required. Teaching others to recognize the symptoms early is vital to minimizing the psychological suffering of the child as well as the coping ability of both the child and the family. Education geared towards schools and family physicians could improve understanding and enhance early intervention. Teaching families about urinary incontinence ultimately helps them understand that their child is not lazy and that their child may not have any control over their symptoms. Education about lifestyle changes to promote healthy bowel and



bladder functioning will help parents understand how they can assist their child to overcome their problems. Encouragement, patience and understanding on the part of the nurse will assist the patient and family to overcome the voiding dysfunction thereby improving the child's self-esteem and quality of life (Berry 2006; Berry, 2005; Schulman and Berry, 2007). Objective evaluation of the child's progress and recognition when the child is not improving is also important so that alternate strategies such as biofeedback may be implemented.

### **Chapter 3 – Method**

#### ***Research Design***

This correlational study determined the relationship between age, gender, severity of voiding dysfunction and quality of life of the pediatric patient with daytime wetting who attended the Pediatric Urology Clinics at the Stollery Children's Hospital from September 1, 2008 until June 1, 2009.

#### ***Sample***

The study utilized non-probability convenience sampling of consecutive potential participants who met the inclusion criteria. As the incidence of pediatric urinary incontinence in the general population is only ten to twenty percent, the likelihood of obtaining the appropriate sample selection from the larger general population using random selection is small since we are looking for a specific condition that is relatively uncommon in the general population. A sample size of at least 60 participants (10 per variable) was the recruitment goal for the study.

#### ***Inclusion Criteria***

1. Any child between 4 - 10 years of age referred to the Stollery Children's Hospital Pediatric Urology Clinic with symptoms of daytime urinary incontinence seen during a 9 month time period
2. The child and parent able to read and understand English
3. Live within 2 hours of the research centre to allow for visits from the research nurse if the data was unable to be obtained in the clinical setting

***Exclusion Criteria***

Any child:

1. With a neuropathic bladder or congenital anatomic abnormality
2. With cognitively impairment or developmental delay
3. With Grade II or greater hydronephrosis
4. With Grade III or greater vesicoureteral reflux
5. On prophylactic antibiotics for recurrent UTIs
6. On anticholinergic medications
7. Who has had previous bladder surgery

***Outcome Measures***

1. The Dysfunctional Voiding Symptom Score (DVSS) was utilized to quantify the severity of voiding dysfunction in the child. This tool utilized 10 age appropriate urological questions with reference to urinary incontinence, voiding habits, urgency, posturing, bowel habits and stressful life events which were graded on a scale of 0-3 with a total possible score of 30. A score of  $\geq 9$  in males (sensitivity 80.95%, specificity 91.30%) or  $\geq 6$  in females (sensitivity 92.77%, specificity 87.09%) indicated the child did have voiding dysfunction.
2. The PinQ (pediatric urinary incontinence quality of life instrument) was developed cross-culturally as a urinary incontinence quality of life tool with excellent test re-test reliability and validity (Bower, Sit, Bluysen, Wong and Yeung, 2006; Bower, Wong, and Yeung, 2006). In this study the PinQ was utilized to quantify the child's quality of life measure related to his/her urinary

- incontinence. This tool is made of 20 urinary incontinence quality of life related questions which are graded on a scale of 0-4 with a total possible score of 80. The total score indicated the impact urinary incontinence had on the child's quality of life with a higher score indicating a more significant effect.
3. 24 hour pad test to quantify urinary incontinence – A small sample of children were given a number of “good nites” or pads which they wore over a 24 hour period of time. The pads were weighed in grams both prior to the child wearing them and again afterwards. The pre-weight was subtracted from the post-weight to give the total volume of incontinence the child had during both the day and night. The time period that the pad or “good nite” was worn was indicated by the child or parent on the packaging so that the change in weight could be correlated with the day or nighttime wetting.
  4. Bladder and Bowel Diary – A bowel and bladder diary were sent home with the family to record the child's bowel and bladder habits. The volume and the frequency of the child's micturation and bowel elimination as well as any associated symptoms such as urgency, pain or incontinence are recorded on the diaries by the child and/or parent. The diaries were then mailed back for examination and comparison to the reported history and the symptom score.
  5. Open-ended Questions - The parent and child were asked three open ended questions during the initial interview to determine how the child's wetting (or voiding dysfunction) had impacted their lives.
    - a. Parent - Tell me what it is like to have a child with wetting or voiding dysfunction?

- b. Child - Tell me what it is like to have wetting?
- c. How do you manage?
- d. How does it impact your life?

***Procedure***

Consecutive patients who attended the Pediatric Urology Clinics at the Stollery Children's Hospital who met the inclusion criteria were recruited for the study. Potential participants were provided study information by the Pediatric Surgery Clinical staff during clinic registration and were asked to notify the Pediatric Urologists or Pediatric Urology Nurse Practitioner Intern if they wished to participate in the research study. Informed consent to participate in the study was obtained from the parent of the child as well as assent from the child prior to the study. An explanation of the study was provided to the child in developmentally appropriate language and terminology prior to obtaining assent from the child.

Ethical approval for the study was obtained from the Health Research Ethics Board at the University of Alberta Hospital and Stollery Children's Hospital. As the study involved direct patient participation, the Stollery Children's Hospital and Capital Health Authority also provided administrative approvals to proceed with the research study.

If either the child or the parent chose not to participate in the study, the child was not enrolled. Participants were informed that they were not obligated to participate, were free to withdraw from the study at any time and refusal to participate did not affect their child's care.

Every effort was made to maintain confidentiality and anonymity at all times by not utilizing the patient's name. All study information was coded, analyzed and reported as a unit with no reference to the patient name. All study information will be maintained in a locked cabinet for 7 years after completion of this study.

Data collection included the child's age, gender, DVSS score, PinQ score, the parent's scores on the DVSS and the PinQ, as well as a comprehensive urologic and bowel history. All children received standard conservative behavioural therapy of timed voiding, constipation treatment, and hydration. Severity of daytime wetting or voiding dysfunction (measured by DVSS) and quality of life (measured by PinQ) were assessed by administering the questionnaires to both the parent and child. If a child was unable complete the questionnaires due to lack of cognitive or communicative development, the researcher assisted the child in developmentally appropriate language to complete the survey rather than have their parent influence the responses. A subset was asked to do a 24-hour pad test to quantify their incontinence.

### ***Data Analysis***

Descriptive statistical measures of central tendency; frequency tables, mean, mode, median, and standard deviation as well as multivariate statistical analysis using correlation coefficients and regression were utilized for data analysis as six mutually exclusive variables were considered: age, gender, the child's response to the DVSS and the PinQ as well as the parent's responses to both the DVSS and the PinQ. If there was a lack of agreement between parent and child responses,

the data was analyzed to determine where and why the disagreement occurred as a number of studies have shown variable concordance between child and proxy perceptions quality of life. Also a comparison of the total scores of between the DVSS and the PinQ indicated whether severity of voiding dysfunction had an impact on quality of life.

All statistical analysis was accomplished utilizing SPSS version 17. The data was manually entered into the SPSS program ensuring accuracy as errors were minimized by a third party randomly double checking the data entry for any typographical errors. Ensuring the questionnaires were checked for completeness after they were finished helped to minimize the amount of missing data in the study. If missing data did occur, it was important to analyze why the missing data occurred and try to compensate for the missing data.

## Chapter 4 – Results

The purpose of this research study was to determine the relationship between the severity of voiding dysfunction (measured by the DVSS) and quality of life (measured by PinQ) in the child with daytime wetting as well as to compare the differential responses to the questionnaires between the child and his/her parent.

### *Participant Demographics*

Thirty-six consecutive neurologically normal children with no evident health problems apart from voiding dysfunction who attended the Pediatric Urology Clinic at the Stollery Children's Hospital between September 1, 2008 and June 1, 2009 were screened. Of these children, six did not have daytime wetting, four refused to participate in the research study after discussion with the research coordinator and two families took the questionnaires home without completing or returning them. Twenty-four children and their parents were enrolled in the study. Figure 4.1 shows the flowchart of the subject enrollment.

Twenty four children (4 males, 20 females) with an age range of five to ten years ( $\bar{x}$  8.17 years, median of 9.0 years, SD 1.37 years) participated in the Pediatric Voiding Dysfunction Study (Figure 4.2). The four males had an age range of seven to nine years ( $\bar{x}$  8.25 years, SD 0.957) whereas the 20 female children had an age range of five to 10 years ( $\bar{x}$  8.15 years, SD 1.461). Twenty two mothers, one father and one foster mother participated in the study with their children.



**Voiding Dysfunction and Quality of Life in Children Flowchart**

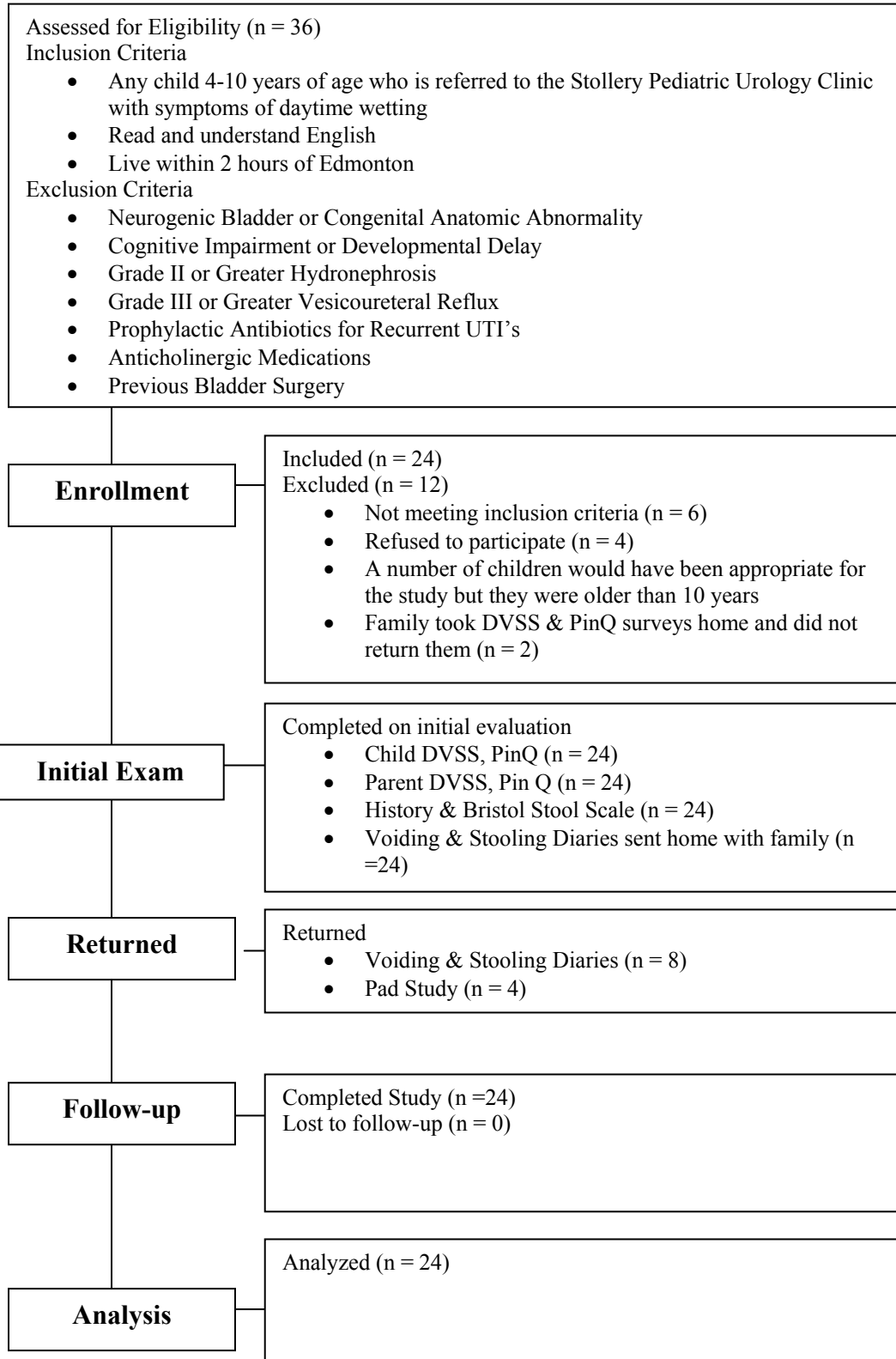


Figure 4.1. Voiding Dysfunction & Quality of Life in Children Flow Chart

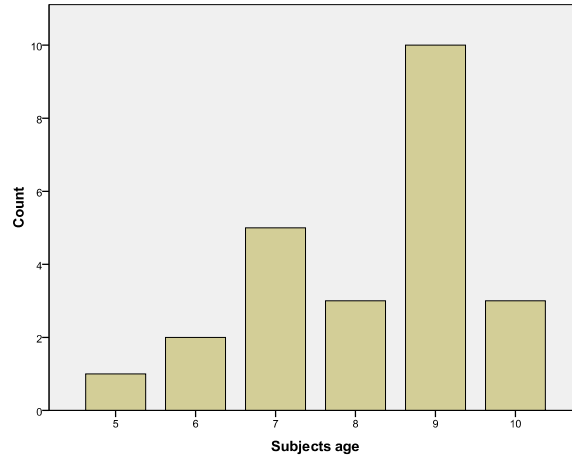


Figure 4.2. Age of Subjects

A detailed urological history and focused physical exam were completed during the child’s initial clinic visit. Three out of 24 (14%) suffered from daytime wetting exclusively while 21/24 (86%) suffered from both day and nighttime symptoms. Figure 4.3 shows the wetting history of the subjects. Of those with day and nighttime wetting combined 11/24 children were wet every night.

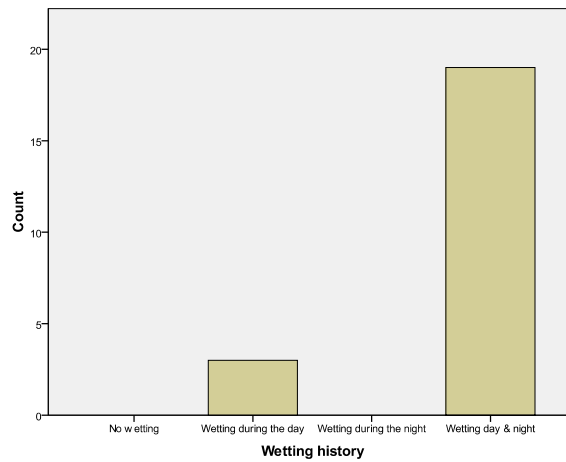


Figure 4.3. Wetting History

According to the voiding histories, 10/24 children usually had damp underwear, 4/24 children would soak through their clothes and 8/24 children

would alternate between damp and soaked underwear. Ninety percent exhibited some signs of urgency which often resulted in damp or soaked underwear.

Fourteen children would wet themselves or dribble in their underwear while on the way to the bathroom. Dancing around or voiding postponement techniques were utilized by 20/24 children to avoid or hold off going to the bathroom.

Posturing maneuvers such as squatting during urgency episodes were employed by 9/24 children; some of these children had to squat at least 30 – 60 seconds before they could move in effort to prevent soaking themselves.

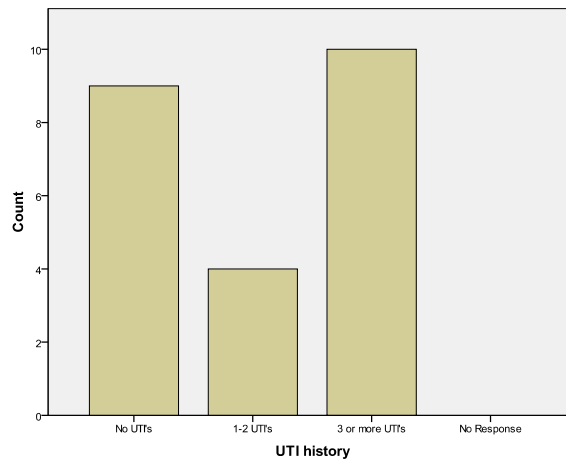


Figure 4.4. UTI History

Based on parent reports, 39% of children had no previous UTI history which was consistent with laboratory results. A previous history of one to two UTI’s was reported in 17.4% which was substantiated with positive laboratory results (positive leukocytes,  $\geq 10^8$  CFU/L *Escherichia coli* (*Ecoli*)). Based on parent, report 44% had 3 or more previous UTI’s, of these four had UTI confirmed by lab results (positive leukocytes, positive culture results). Each of these four children had a number of urine cultures all showing  $\geq 10^8$  *Ecoli*, while

one subject grew *Hafina alvei* and another subject grew  $10^7$  *Diphtheroids*.

Although one parent had reported that her daughter had four UTI's in eight months, this child only had 2/4 positive urine cultures. Figure 4.4 indicates the UTI incidence based on parent report. Malodorous urine, frequency, urgency, dysuria, and increased incidence of wetting were common symptoms; as well fever (4), gross hematuria (1), back or flank pain (2) were reported. Most were treated empirically with antibiotics based on their symptoms despite many of their urine cultures showing no growth, mixed cultures or contamination with *Staphylococcus*.

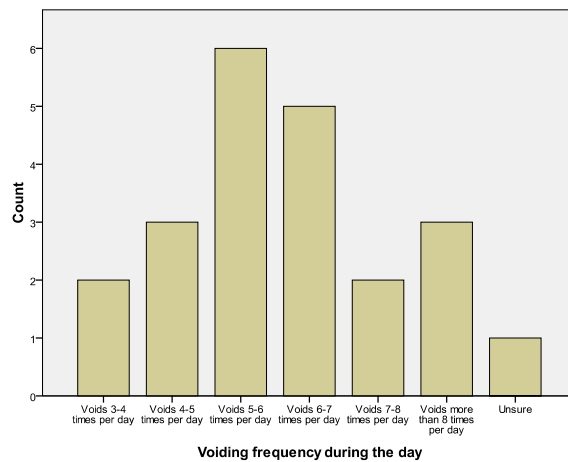


Figure 4.5. Voiding Frequency during the Day

According to the voiding history 50% of children voided an average of 5-7 times per day, 9% voided infrequently at 3-4 times per day and 14% voided more than 8 times per day. Figure 4.5 illustrates the voiding frequency of the research subjects.

Fifty-two percent of children stated they had a bowel movement every day whereas 29% had a bowel movement every other day and only 20% had more

than one per day. The study utilized the validated Bristol Stool Scale which has been correlated with bowel transit time to allow patient report of their bowel movements based the shape and consistency of the stools (Riegler & Esposito, 2001). Type 1 indicated severe constipation, Type II moderate constipation, Type III mild constipation and Type IV and Type V, normal. Type VI indicated mild diarrhea and Type VII demonstrated severe diarrhea. Sixty-one percent of children rated their bowel movements as type III on the Bristol scale, 14% type II, 10% Type I and only 14% rated their bowel movements as normal (Type IV) (Figure 4.6).

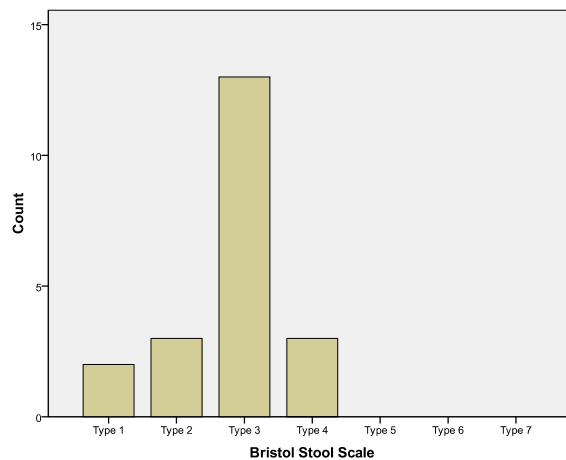


Figure 4.6. Bristol Stool Scale

***Diaries and Pad Study Results***

Each child was requested to keep a record their voids for three days and stools for two weeks, to be completed at home and returned to the research coordinator in a self-addressed envelope. Only seven complete diaries were returned and one diary was returned empty. Reasons for non-completion were the family moved, the family was too busy or forgetting to complete the diary.

Although only seven complete diaries were returned, analysis of the voiding diaries showed a discrepancy between the parents' report of the child's voiding frequency and the actual documented voiding frequency on the diaries, as 4/6 families over-estimated the frequency of their child's voiding habits during interviews. Table 4.1 compares the reported urological history with the diary responses. One child's urological history indicated a voiding frequency of five to six times per day but analysis of the voiding diary showed that the child had voided only three to four times per day and another reported a voiding frequency of six to eight times per day but based on the diary only voided two to four times per day.

All but two voiding diaries indicated the children had both day and nighttime incontinence. One child reported daytime incontinence during the collection but did not have any episodes while another described day and nighttime wetting but only reported nighttime during the diary data collection. Most children had some episodes of urgency. Each child drank water, milk and juice during this time period. No iced tea, carbonated drinks or other potential bladder irritants were recorded.

Analysis of the completed stooling diaries demonstrated that the family estimation of their child's bowel movement frequency was accurate but the Bristol Stool Scale ratings were variable with each child. Children's stool consistency varied from Type II (moderate constipation) to Type IV (normal) but most of their bowel movements were rated as Type II (moderate constipation) to

Table 4.1. Comparison of Subject History with Diary

<b>Comparing Subject History with Completed Diary</b>											
<b>Age</b>	<b>Gender</b>	<b>Voiding Frequency</b>		<b>Wetting History</b>		<b>Urgency History</b>		<b>Bowel Movement History</b>		<b>Bristol Stool Scale</b>	
		<b>Reported</b>	<b>Diary</b>	<b>Reported</b>	<b>Diary</b>	<b>Reported</b>	<b>Diary</b>	<b>Reported</b>	<b>Diary</b>	<b>Reported</b>	<b>Diary</b>
10	Female	6-8/day	2-4/day	Day & Night	Night	Urgency	Urgency	Every other day	Every other day	Type 3	Types 2-4
9	Female	4-5/day	7-8/day	Day & Night	Day & Night	Urgency	Urgency	More than once per day	More than once per day	Type 2	Types 2-3
6	Female	5-6/day	3-4/day	Day & Night	Day & Night	Urgency	Urgency	Daily	Daily	Type 3	Types 1-3
7	Female	6-7/day	6-7/day	Day & Night	Day & Night	Urgency	Urgency	Daily	More than once per day	Type 4	Types 3-5
9	Female	5-6/day	3-4/day	Day	None	Urgency	Urgency	Daily	Daily	Type 3	Types 3-4
9	Female	5-6/day	4-7/day	Day & Night	Day & Night	None	Urgency	Daily	Daily	Type 4	Types 1-4

Type III (mild) during the two week period stooling diary. Two children indicated severe constipation. Two of the children’s bowel movements were rated normal.

Pad weighing was attempted in order to quantify urine loss and correlate subject report with an objective measure. Ten children agreed to participate in the pad study but only four returned pads to the study coordinator. One male child and three female children aged six to ten years of age completed the pad study. One ten year old girl only returned her daytime pad and did not return the nighttime pad despite a number of reminders. Each of these children recorded history of day and nighttime incontinence as well as urgency during their initial visit. They had a voiding frequency of five to seven times per day and two had a history of recurrent UTI’s. The pad study cumulative totals are shown in Table 4.2.

Table 4.2. *Pad Study Results*

<b>Pad Study Results</b>				
<b>Age</b>	<b>Gender</b>	<b>Daytime Incontinence (grams)</b>	<b>Nighttime Incontinence (grams)</b>	<b>Total (grams)</b>
6	Female	34.5	52.9	87.4
7	Female	14.6	191.5	206.1
9	Male	3.8	293.3	297.1
10	Female	6.7	-	6.7

Correlating the pad test with the single score DVSS response allowed us to determine how well the survey correlated with the severity of voiding dysfunction. This comparison had not been done in any of the testing of the DVSS or the PinQ. This was difficult to obtain as most children with daytime wetting typically do not wear pads or pull-ups. The majority of children with



daytime wetting simply remain in their damp underwear throughout the day, as children who are wet at school, change their clothes during the day, smell of urine or wear pads or pull-ups are at risk of being teased or socially isolated from their peers.

***Scoring from the Dysfunctional Voiding Symptom Score (DVSS)***

The DVSS was utilized to measure the severity of voiding dysfunction. All twenty-four children and their parents completed the DVSS during their initial clinic appointment. Parents independently completed the DVSS and PinQ without consulting the child. Although the parent was in the room, children completed the survey with the only the researcher’s assistance. The child and parent responses to the DVSS instrument are summarized in table 4.3.

The child total DVSS responses are indicated in Figure 4.7 whereas the parental total DVSS scores are indicated by Figure 4.8. Parent Total DVSS Scores The ten age appropriate DVSS questions were each graded on a scale of 0 - 3 with a total possible score of 30 (10 x 3). More significant voiding dysfunction in indicated by a higher total score with 30 being most severe. Optimal threshold

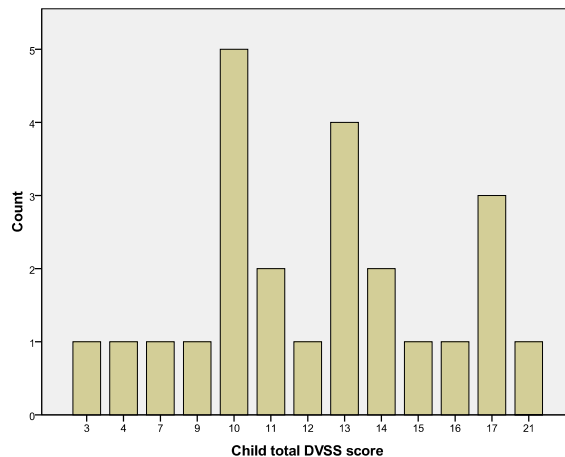


Figure 4.7. Child Total DVSS Scores

Table 4.3. *Child and Parent Responses to the DVSS*

<b>Child and Parent Responses to the DVSS</b>										
<b>Over the past month</b>	<b>Almost Never</b>		<b>Less than half the time</b>		<b>About half the time</b>		<b>Almost every time</b>		<b>Don't know</b>	
	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>
1. I have had wet clothes or wet underwear during the day	7 29.2%	3 12.5%	6 25.0%	4 16.7%	2 8.3%	2 8.3%	5 20.8%	13 54.2%	4 16.7%	2 8.3%
2. When I wet myself, my underwear is soaked	9 37.5%	8 33.3%	4 16.7%	1 4.2%	2 8.3%	7 29.2%	6 25.0%	8 33.3%	3 12.5%	0 0%
3. I miss having a bowel movement every day.	7 29.2%	10 41.7%	3 12.5%	3 12.5%	3 12.5%	4 16.7%	7 29.2%	3 12.5%	4 16.7%	4 16.7%
4. I have to push for my bowel movements to come out.	3 12.5%	6 25.0%	4 16.7%	3 12.5%	6 25.0%	6 25.0%	10 41.7%	6 25.0%	1 4.2%	3 12.5%
5. I only go to the bathroom one or two times each day.	14 58.3%	18 75.0%	5 20.8%	0 0%	3 12.5%	2 8.3%	0 0%	4 16.7%	2 8.3%	0 0%
6. I can hold onto my pee by crossing my legs, squatting or doing the "pee dance".	5 20.8%	2 8.3%	1 4.2%	8 33.3%	4 16.7%	7 29.2%	10 41.7%	4 16.7%	4 16.7%	3 12.5%
7. When I have to pee, I cannot wait.	2 8.3%	0 0%	3 12.5%	1 4.2%	8 33.3%	6 25.0%	10 41.7%	17 70.8%	1 4.2%	0 0%
8. I have to push to pee.	17 70.8%	13 54.2%	2 8.3%	2 8.3%	1 4.2%	1 4.2%	1 4.2%	1 4.2%	3 12.5%	7 29.2%
9. When I pee it hurts.	13 54.2%	18 75.0%	3 12.5%	3 12.5%	6 25.0%	3 12.5%	2 8.3%	0 0%	0 0%	0 0%
10. Parental response to stressful event	No 12 50.0%					Yes 12 50.0%				

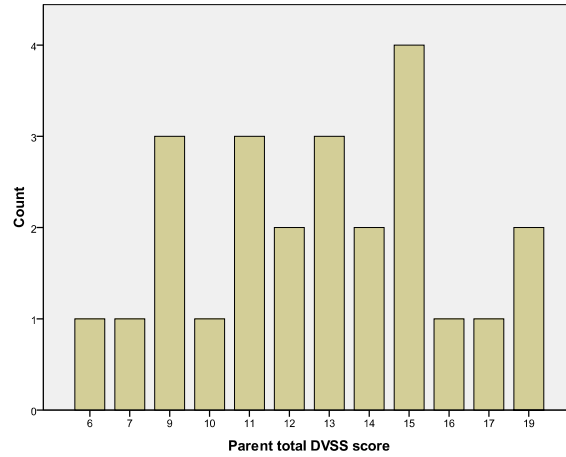


Figure 4.8. Parent Total DVSS Scores

scores to diagnose voiding dysfunction in females is 6.02 compared to 9.02 in males. Scores below the threshold denote a lack of voiding dysfunction.

Table 4.4 summarizes the child and parent total DVSS Scores. When comparing the total DVSS scores and the total DVSS scores based on gender, both parents and children show similar responses. Table 4.5 indicates that only the mean difference between the parents total DVSS score based on gender was statistically significant.

Table 4.4. *Total DVSS Scores and Total DVSS Scores Based on Gender*

<b>Total DVSS Scores</b>				
<b>Subjects</b>	<b>Range</b>	<b>Mean (<math>\bar{x}</math>)</b>	<b>Median</b>	<b>Standard Deviation (SD)</b>
Children	3 - 21	12.08	12.50	4.138
Parents	6 - 19	12.71	13.00	3.42
<b>Total DVSS Scores Based on Gender</b>				
4 male subjects	3 - 14	9.50	10.50	4.796
Parents of male subjects	6 - 13	9.25	9.00	3.304
20 female subjects	4 - 21	12.60	13.00	3.926
Parents of female subjects	9 - 19	13.40	13.50	3.068

Table 4.5. *Mean Differences of Total DVSS Scores Based on Gender*

<b>Mean Differences of Total DVSS Scores Based on Gender</b>					
<b>Subjects</b>	<b>Mean Difference</b>	<b>f</b>	<b>t</b>	<b>df</b>	<b>p</b>
Children	- 3.100	0.121	- 1.396	22	0.177
Parents	- 4.150	0.081	-2.443	22	0.023

When examining the male DVSS optimal threshold score of 9.02 to diagnose voiding dysfunction, only two male subjects exceeded this value with total DVSS scores of 12 and 14. When comparing the parental responses, the 7 year old boy who had a total DVSS score of 14 continued to exceed the threshold with a parental total DVSS score of 11 whereas a 9 year old boy whose child total DVSS score was 12 was scored below the threshold at 7 when scored by his parent and an 8 year old boy scored himself just below the threshold at 9 while his parent scored his total DVSS score at 13. Only one male subject consistently scored below the threshold score with a child DVSS total score of 3 and a parent total DVSS score of 6.

When examining the DVSS optimal threshold score of 6.02 for females all except one scored above this threshold score in both child and parental scoring of the DVSS. This female subject scored herself below the threshold at 4 and her mother scored her above the threshold at 13. Threshold scores were exceeded by 19/20 subjects (range 4 - 10 points).

When comparing the child and parent total DVSS scores, only one parent and child had the same score of 17 whereas 9 scored their child at least 1 to 3 points lower (two parents actually scored their child 5-6 points lower) and 10

parents scored their child higher by 1 to 3 points (one parent score her child higher by 5 points while two other parents scored their children higher by 9 points). Table 4.6 demonstrates a discrepancy in responses between child and parent for 4 boys and 19 girls.

Table 4.6. *Comparison of Child and Parent Total DVSS Scores Based on Gender*

<b>Male Total DVSS Scores</b>			
<b>Age</b>	<b>Child Total DVSS Score</b>	<b>Parent Total DVSS Score</b>	<b>Difference in Score</b>
7	14	11	- 3
8	9	13	+ 4
9	3	6	+ 3
9	12	7	- 5
<b>Female Total DVSS Scores</b>			
5	21	15	- 6
6	17	12	- 5
6	17	17	0
7	4	13	+ 9
7	14	19	+ 5
7	10	19	+ 9
7	10	9	- 1
8	16	15	- 1
8	10	11	+ 1
9	13	12	- 1
9	17	14	- 3
9	13	11	- 2
9	13	15	+ 2
9	7	10	+ 3
9	10	9	- 1
9	11	14	+ 3
9	11	9	- 2
10	10	13	+ 3
10	15	16	+ 1
10	13	15	+ 2

Table 4.7. *Child and Parent Responses to the PinQ*

Child and Parent Responses to the PinQ												
PinQ Questions	No		Hardly Ever		Some times		Often		All the time		Don't know	
	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent
1. I get shy because of my bladder problem.	5 20.8%	1 4.2%	2 8.3%	1 4.2%	9 37.5%	12 50.0%	4 16.7%	9 37.5%	3 12.5%	1 4.2%	1 4.2%	0 0%
2. People in my family treat me in a different way because of my bladder problem	12 50.0%	5 20.8%	3 12.5%	3 12.5%	6 25.0%	8 33.3%	1 4.2%	6 25.0%	1 4.2%	2 8.3%	1 4.2%	0 0%
3. I am worried that people might think my clothes smell of pee.	10 41.7%	1 4.2%	2 8.3%	10 41.7%	6 25.0%	5 20.8	3 12.5%	7 29.2%	3 12.5%	1 4.2%	0 0%	0 0%
4. I think that my bladder problem won't get better.	8 33.3%	3 12.5%	1 4.2%	3 12.5%	7 29.2%	10 41.7%	4 16.7%	3 12.5%	4 16.7%	3 12.5%	0 0%	2 8.3%
5. Mom and dad worry about me because of my bladder problem.	2 8.3%	0 0%	2 8.3%	0 0%	9 37.5%	5 20.8%	4 16.7%	11 45.8%	7 29.2%	8 33.3%	0 0%	0 0%
6. I would feel better about myself if I didn't have a bladder problem.	3 12.5%	1 4.2%	0 0%	3 12.5%	3 12.5%	9 37.5%	2 8.3%	10 41.7%	16 66.7%	1 4.2%	0 0%	0 0%
7. My bladder problem makes me feel nervous.	5 20.8%	1 4.2%	3 12.5%	4 16.7%	6 25.0%	13 54.2%	7 29.2%	5 20.8%	3 12.5%	1 4.2%	0 0%	0 0%
8. Mom or dad sometimes seem a bit cranky because of my bladder problem.	15 62.5%	5 20.8%	1 4.2%	5 20.8%	2 8.3%	8 33.3%	4 16.7%	6 25.0%	2 8.3%	0 0%	0 0%	0 0%
9. My bladder problem stops me from going on sleep-overs or holidays.	7 29.2%	4 16.7%	3 12.5%	2 8.3%	6 25.0%	8 33.3%	2 8.3%	9 37.5%	5 20.8%	1 4.2%	1 4.2%	0 0%
10. My bladder problem makes me feel bad about myself.	7 29.2%	1 4.2%	2 8.3%	5 20.8%	9 37.5%	10 41.7%	4 16.7%	7 29.2%	2 8.3%	1 4.2%	0 0%	0 0%
11. I wake up during my sleep because of my bladder problem.	10 41.7%	7 29.2%	3 12.5%	8 33.3%	7 29.2%	5 20.8%	3 12.5%	2 8.3%	1 4.2%	2 8.3%	0 0%	0 0%
12. I miss out on doing things because of my bladder problem.	8 33.3%	4 16.7%	3 12.5%	10 41.7%	9 37.5%	8 33.3%	3 12.5%	1 4.2%	1 4.2%	1 4.2%	0 0%	0 0%
13. I feel unhappy because of my bladder problem.	3 12.5%	0 0%	5 20.8%	5 20.8%	7 29.2%	12 50.0%	3 12.5%	5 20.8%	6 25.0%	2 8.3%	0 0%	0 0%

<b>Child and Parent Responses to the PinQ</b>												
<b>PinQ Questions</b>	<b>No</b>		<b>Hardly Ever</b>		<b>Some times</b>		<b>Often</b>		<b>All the time</b>		<b>Don't know</b>	
	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>
14. My bladder problem makes me feel sad.	7 29.2%	1 4.2%	5 20.8%	2 8.3%	6 25.0%	13 54.2%	3 12.5%	6 25.0%	3 12.5%	1 4.2%	0 0%	1 4.2%
15. I think about my bladder problem when choosing which sport to play.	11 45.8%	7 29.2%	3 12.5%	9 37.5%	7 29.2%	5 20.8%	1 4.2%	3 12.5%	2 8.3%	0 0%	0 0%	0 0%
16. I have to go to the toilet when I'm watching a movie.	2 8.3%	1 4.2%	2 8.3%	5 20.8%	7 29.2%	4 16.7%	4 16.7%	13 54.2%	9 37.5%	1 4.2%	0 0%	0 0%
17. If my bladder problem was fixed I would invite more friends to my house.	5 20.8%	9 37.5%	2 8.3%	6 25.0%	5 20.8%	5 20.8%	3 12.5%	2 8.3%	8 33.3%	2 8.3%	1 4.2%	0 0%
18. I choose hobbies that won't be spoiled by stopping to go to the toilet.	9 37.5%	10 41.7%	3 12.5%	8 33.3%	5 20.8%	3 12.5%	3 12.5%	1 4.2%	4 16.7%	1 4.2%	0 0%	1 4.2%
19. My bladder problem makes me feel different to other people.	4 16.7%	5 20.8%	2 8.3%	3 12.5%	7 29.2%	13 54.2%	7 29.2%	3 12.5%	4 16.7%	0 0%	0 0%	0 0%
20. I miss out on being with friends because of my bladder problem.	9 37.5%	6 25.0%	6 25.0%	4 16.7%	5 20.8%	11 45.8%	1 4.2%	1 4.2%	3 12.5%	2 8.3%	0 0%	0 0%

***Scoring from the Pediatric Urinary Incontinence Quality of Life Instrument (PinQ)***

The PinQ survey was recently developed to quantify Urinary Incontinence Quality of Life in children with voiding dysfunction (Bower, Sit, Bluysen, Wong and Yeung, 2006; Bower, Wong, and Yeung, 2006). The twenty PinQ questions are scored from 0 - 4 with a maximum total score of 80. The higher the total score on the PinQ, the greater the impact urinary incontinence has on quality of life.

The PinQ was completed during the initial clinic visit. Parents completed the PinQ independent of the child based on their own perceptions of their child’s voiding dysfunction and quality of life. Although the parent was in the room, children completed the PinQ survey with the only the researcher’s assistance. Table 4.7 summarizes the parent and child responses to the PinQ instrument. The child total PinQ responses are indicated in Figure 4.9 whereas the parental total PinQ scores are indicated by Figure 4.10.

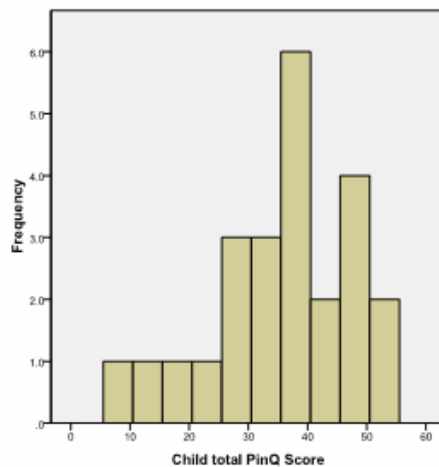


Figure 4.9. Child Total PinQ Scores



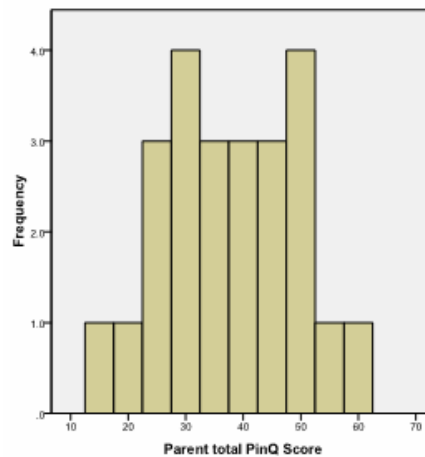


Figure 4.10. Parent Total PinQ Score

Total PinQ scores presented in table 4.8 show similar responses between parent and child. When examining the child’s total PinQ scores, 14 children scored above the mean score of 35.63 and 13 parents scored above the mean score of 37.58.

Table 4.8. Total PinQ Scores and Scores Based on Gender

<b>Total PinQ Scores</b>				
<b>Subjects</b>	<b>Range</b>	<b>Mean ( <math>\bar{x}</math> )</b>	<b>Median</b>	<b>Standard Deviation (SD)</b>
Children	8 - 55	35.63	37.50	12.086
Parents	15 - 61	37.58	37.50	11.447
<b>Total PinQ Scores Based on Gender</b>				
4 male subjects	29 - 55	43.00	44.00	10.801
Parents of male subjects	23 - 44	33.50	33.50	9.678
20 female subjects	8 - 53	34.15	36.50	12.027
Parents of female subjects	15 - 61	38.40	37.50	11.852

There was no statistically significant difference between the child and parent scores based on gender (Table 4.9).

Table 4.9. Mean Differences of Total PinQ Scores Based on Gender

Mean Differences of PinQ Scores Based on Gender					
Subjects	Mean Difference	f	t	df	p
Children	8.850	0.214	1.361	22	0.187
Parents	- 4.900	0.167	- 0.773	22	0.448

When comparing the male child and parent Total PinQ scores, all parent Total PinQ scores were lower than the child. Three parents scored their male child 2 to 6 points lower and one mother scored her child 27 points lower than the child score. For the female child and parent Total PinQ scores, 13 parent scores were 1 to 31 points higher than the child's and 7 parent scores were 4 to 35 points lower than the child's Total PinQ scores (see Table 4.10).

Table 4.10. Comparison of Child and Parent Total PinQ Scores Based on Gender

Male Total PinQ Scores			
Age	Child Total PinQ Score	Parent Total PinQ Score	Difference in Score
7	55	28	- 27
8	46	44	- 2
9	29	23	- 6
9	42	39	- 3
Female Total PinQ Scores			
5	48	51	+ 3
6	39	50	+ 11
6	47	32	- 15
7	35	43	+ 8
7	50	15	- 35
7	32	34	+ 2
7	13	44	+ 31
8	39	54	+ 15
8	38	20	- 18

<b>Female Total PinQ Scores</b>			
9	29	26	- 3
9	36	61	+ 25
9	21	32	+ 11
9	37	26	- 11
9	39	49	+ 10
9	53	37	- 16
9	8	39	+ 31
9	27	36	+ 9
10	31	32	+ 1
10	42	38	- 4
10	19	49	+ 30

### ***Domains of the PinQ Instrument***

The questions from PinQ Instrument can be divided into five separate domains: “Self-Esteem”, “Family and Home”, “Social Relations with Peers”, “Mental Health” and “Independence” (Bower et al., 2006). The total domain scores as well as a comparison of child and parent responses to the individual domains of the PinQ instrument were evaluated. Table 4.11 lists the questions associated with each individual domain and Table 4.12 provides a comparison of the individual domain total scores between each parent and child.

The Self-Esteem domain consisted of four questions (listed in Table 4.11) scored from 0 to 4, with a total possible score of 16. The higher the score, the greater impact the Self-Esteem Domain has on the individual’s quality of life. Analysis of the Self-Esteem Domain of the PinQ indicates that the children and parents had similar responses to the domain related questions. The Self-Esteem Domain results are summarized in Tables 4.13 and 4.14.

Table 4.11. *Questions Associated With Each Individual Domain*

<b>PinQ Domain Questions</b>				
<b>Self-Esteem</b>	<b>Family &amp; Home</b>	<b>Social Relations with Peers</b>	<b>Mental Health</b>	<b>Independence</b>
<ul style="list-style-type: none"> <li>• Q1: I get shy because of my bladder problem.</li> <li>• Q6: I would feel better about myself if I didn't have my bladder problem.</li> <li>• Q7: My bladder problem makes me feel nervous.</li> <li>• Question 10: My bladder problem makes me feel bad about myself.</li> </ul>	<ul style="list-style-type: none"> <li>• Q2: People in my family treat me in a different way because of my bladder problem.</li> <li>• Q5: Mom and dad worry about me because of my bladder problem.</li> <li>• Q8: Mom or dad sometimes seem a bit cranky because of my bladder problem.</li> <li>• Q11: I wake up during my sleep because of my bladder problem.</li> </ul>	<ul style="list-style-type: none"> <li>• Q3: I am worried that people might think my clothes smell of pee.</li> <li>• Q9: My bladder problem stops me going on sleep-overs or holidays.</li> <li>• Q12: I miss out on doing things because of my bladder problem.</li> <li>• Q16: I have to go to the toilet when I'm watching a movie.</li> <li>• Q17: If my bladder problem was fixed I would invite more friends to my house.</li> <li>• Q20: I miss out on being with friends because of my bladder problem</li> </ul>	<ul style="list-style-type: none"> <li>• Q4: I think that my bladder problem won't get better.</li> <li>• Q13: I feel unhappy because of my bladder problem.</li> <li>• Q14: My bladder problem makes me feel sad.</li> <li>• Q19: My bladder problem makes me feel different to other people.</li> </ul>	<ul style="list-style-type: none"> <li>• Q15: I think about my bladder problem when choosing which sport to play.</li> <li>• Q18: I choose hobbies that won't be spoiled by stopping to go to the toilet.</li> </ul>

Table 4.12. Comparison of Child and Parent Domain Total Scores

PinQ Domain Total Scores										
Age	Self-Esteem		Family & Home		Social Relations		Mental Health		Independence	
	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent
5	8	13	12	12	15	14	6	10	7	2
6	6	12	6	8	13	16	8	9	6	5
6	4	7	9	10	20	8	10	6	4	1
7	3	11	10	9	15	10	7	11	0	2
7	14	5	6	4	16	1	12	5	2	0
7	8	8	4	9	9	9	8	8	3	0
7	11	8	8	8	16	9	12	3	8	0
7	6	10	3	11	3	11	1	9	0	3
8	13	11	7	11	15	13	10	7	1	3
8	10	12	4	12	12	16	8	9	5	5
8	10	6	8	2	7	2	10	9	3	1
9	3	9	6	5	8	10	2	6	2	2
9	8	8	4	6	8	6	9	3	0	0
9	8	9	6	9	8	4	5	3	2	1
9	10	16	7	8	8	15	9	15	2	7
9	11	12	5	9	4	10	7	4	0	1
9	4	9	2	8	1	10	1	8	0	4
9	11	6	6	6	10	7	6	5	4	2
9	14	10	5	6	9	12	8	10	6	1
9	9	10	4	8	13	17	9	12	4	2
9	12	9	7	9	16	10	15	8	3	1

<b>PinQ Domain Total Scores</b>										
<b>Age</b>	<b>Self-Esteem</b>		<b>Family &amp; Home</b>		<b>Social Relations</b>		<b>Mental Health</b>		<b>Independence</b>	
	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>	<b>Parent</b>	<b>Child</b>
10	7	10	4	6	10	6	8	8	2	2
10	6	12	4	12	5	13	4	8	0	4
10	12	6	0	3	17	21	11	8	2	0
<b>Totals</b>	<b>208</b>	<b>229</b>	<b>137</b>	<b>191</b>	<b>258</b>	<b>250</b>	<b>186</b>	<b>184</b>	<b>66</b>	<b>49</b>

Table 4.13. *PinQ Self-Esteem Domain Total Scores*

<b>PinQ Self-Esteem Domain Total Scores</b>				
<b>Subjects</b>	<b>Range</b>	<b>Mean ( <math>\bar{x}</math> )</b>	<b>Median</b>	<b>Standard Deviation (SD)</b>
Children	3 - 14	8.67	8.50	3.319
Parents	5 - 16	9.54	9.50	2.604
<b>Self-Esteem Domain Scores Based on Gender</b>				
4 male subjects	8 - 14	11.50	12.00	2.646
Parents of male subjects	8 - 11	9.25	9.00	1.500
20 female subjects	3 - 14	8.10	8.00	3.194
Parents of female subjects	5 - 16	9.60	9.50	2.798

Table 4.14. *Mean Difference of PinQ Self-Esteem Domain Based on Gender*

<b>Mean Differences of PinQ Self-Esteem Domain Based on Gender</b>					
<b>Subjects</b>	<b>Mean Difference</b>	<b>f</b>	<b>t</b>	<b>df</b>	<b>p</b>
Children	3.400	0.436	1.987	22	0.60
Parents	- 0.350	1.261	- 0.240	22	0.812

The Family and Home domain consisted of four questions (listed in Table 4.11) scored from 0 to 4, with a total possible score of 16, with a higher score, indicating greater impact on quality of life. Children and parents had similar responses to the domain related questions. The Family and Home Domain results are summarized in Tables 4.15 and 4.16.

Table 4.15. *PinQ Family & Home Domain Total Scores*

<b>PinQ Family &amp; Home Domain Total Scores</b>				
<b>Subjects</b>	<b>Range</b>	<b>Mean ( <math>\bar{x}</math> )</b>	<b>Median</b>	<b>Standard Deviation (SD)</b>
Children	0 - 12	5.71	6.00	2.612
Parents	2 - 12	7.96	8.00	2.774

<b>Family &amp; Home Domain Scores Based on Gender</b>				
4 male subjects	4 - 8	6.00	6.00	1.826
Parents of male subjects	6 - 11	7.75	7.00	2.363
20 female subjects	0 - 12	5.65	6.00	2.777
Parents of female subjects	2 - 12	8.00	8.50	2.902

Table 4.16. *Mean Difference of PinQ Family & Home Domain Based on Gender*

<b>Mean Differences of PinQ Family &amp; Home Domain Based on Gender</b>					
<b>Subjects</b>	<b>Mean Difference</b>	<b>f</b>	<b>t</b>	<b>df</b>	<b>p</b>
Children	0.350	0.414	0.240	22	0.813
Parents	- 0.250	0.219	- 0.161	22	0.874

The Social Relations with Peers domain consisted of six questions (listed in Table 4.11) scored from 0 to 4, with a total possible score of 24. The higher the score, the greater impact on quality of life. Although there seemed to be a discrepancy in the male children and the parent scores, it was not statistically significant.

Children and parents had similar responses to the domain-related questions. The Social Relations with Peers Domain results summarized in Tables 4.17 and 4.18.

Table 4.17. *PinQ Social Relations with Peers Domain Total Scores*

<b>PinQ Social Relations with Peers Domain Total Scores</b>				
<b>Subjects</b>	<b>Range</b>	<b>Mean ( <math>\bar{x}</math> )</b>	<b>Median</b>	<b>Standard Deviation (SD)</b>
Children	1 - 20	10.75	10.00	4.928
Parents	1 - 21	10.42	10.00	4.800
<b>Social Relations with Peers Domain Scores Based on Gender</b>				
4 male subjects	8 - 16	12.00	12.00	4.082
Parents of male subjects	6 - 13	10.00	10.50	3.162
20 female subjects	1 - 20	10.50	10.00	5.135
Parents of female subjects	1 - 21	10.50	10.00	5.125



Table 4.18. *Mean Difference of PinQ Social Relations with Peers Domain Based on Gender*

<b>Mean Differences of PinQ Social Relations with Peers Domain Based on Gender</b>					
<b>Subjects</b>	<b>Mean Difference</b>	<b>f</b>	<b>t</b>	<b>df</b>	<b>p</b>
Children	1.500	0.293	0.547	22	0.590
Parents	- 0.500	0.719	- 0.186	22	0.854

The Mental Health domain consisted of four questions (listed in Table 4.11) scored from 0 to 4, with a total possible score of 16. The higher the score, the greater impact on quality of life. Although there seemed to be a discrepancy in the male children and the parent scores, it was not statistically significant. The children and parents had similar responses to the domain related questions.

Results are summarized in Tables 4.19 and 4.20.

Table 4.19. *PinQ Mental Health Domain Total Scores*

<b>PinQ Mental Health Domain Total Scores</b>				
<b>Subjects</b>	<b>Range</b>	<b>Mean ( <math>\bar{x}</math> )</b>	<b>Median</b>	<b>Standard Deviation (SD)</b>
Children	1 - 15	7.75	8.00	3.442
Parents	3 - 15	7.67	8.00	2.959
<b>Mental Health Domain Scores Based on Gender</b>				
4 male subjects	8 - 12	9.75	9.50	1.708
Parents of male subjects	3 – 10	5.75	5.00	3.403
20 female subjects	1 - 15	7.35	8.00	3.588
Parents of female subjects	3 – 15	8.05	8.00	2.800

Table 4.20. *Mean Difference of PinQ Mental Health Domain Based on Gender*

<b>Mean Differences of PinQ Mental Health Domain Based on Gender</b>					
<b>Subjects</b>	<b>Mean Difference</b>	<b>f</b>	<b>t</b>	<b>df</b>	<b>p</b>
Children	2.400	1.580	1.291	22	0.210
Parents	- 2.300	0.597	- 1.453	22	0.160

The Independence domain consisted of two questions (listed in Table 4.11) scored from 0 to 4, with a total possible score of 8. The higher the score, the greater impact. Although there seemed to be a discrepancy in the male children and the parent scores, it was not statistically significant. Children and parents had similar

Table 4.21. *PinQ Independence Domain Total Scores*

<b>PinQ Independence Domain Total Scores</b>				
<b>Subjects</b>	<b>Range</b>	<b>Mean ( <math>\bar{x}</math> )</b>	<b>Median</b>	<b>Standard Deviation (SD)</b>
Children	0 - 8	2.75	2.00	2.364
Parents	0 - 7	2.04	2.00	1.853
<b>Independence Domain Scores Based on Gender</b>				
4 male subjects	0 - 8	3.75	3.50	3.862
Parents of male subjects	0 - 3	1.00	0.50	1.414
20 female subjects	0 - 7	2.55	2.00	2.038
Parents of female subjects	0 - 7	2.25	2.00	1.888

Table 4.22. *Mean Difference of PinQ Independence Domain Based on Gender*

<b>Mean Differences of PinQ Independence Domain Based on Gender</b>					
<b>Subjects</b>	<b>Mean Difference</b>	<b>f</b>	<b>t</b>	<b>df</b>	<b>p</b>
Children	1.200	6.630	0.605	3.342	0.584
Parents	- 1.250	0.536	- 1.246	22	0.226

responses to the domain related questions. The Independence Domain results are summarized in Tables 4.21 and 4.22.

Comparison of child and parent PinQ Total Domain Mean scores showed similar responses in Self-Esteem, Social Relations with Peers and Mental Health domains but differences in Family & Home and Independence domains. The child overall domain ranking was Self-Esteem (54.2%), Mental Health (48.4%), Social Relations with Peers (44.8%), Family & Home (35.7%) and Independence (34.4%) whereas the parent ranking was Self-Esteem (59.6%), Family & Home (49.8%), Mental Health (47.9%), Social Relations with Peers (43.4%) and Independence (25.5%) (Table 4.23).

Table 4.23. Comparison of *PinQ* Domain Mean Scores

<b>Comparison of PinQ Total Domain Mean Scores</b>					
		Child		Parent	
	Maximum Total Score	Mean Score	Percentage	Mean Score	Percentage
Self-Esteem	16	8.76	54.2%	9.54	59.6%
Family & Home	16	5.71	35.7%	7.96	49.8%
Social Relations with Peers	24	10.75	44.8%	10.42	43.4%
Mental Health	16	7.75	48.4%	7.67	47.9%
Independence	8	2.75	34.4%	2.04	25.5%

***The Relationship between Severity of Daytime Wetting (measured by DVSS), Age, Gender and Quality of Life (measured by PinQ)***

Correlations between Age, Gender, Child Total DVSS Score, Parent Total DVSS Score, Child Total PinQ and Parent PinQ showed that only Gender and Parental Total DVSS Score correlations ( $r = 0.462$ ,  $p = 0.023$ ) as well as between

Child Total DVSS Score and the Parent Total DVSS Scores ( $r = 0.472$ ,  $p = 0.020$ ) were statistically significant. Consequently 21.34% of the variance in the Parent Total DVSS Score can be explained by the change in Gender whereas 22.28% of the variance in the Child Total DVSS Score can be explained by the change in the Parent Total DVSS Score. No statistically significant correlations were found between any other variables. Table 4.24 summarizes the correlation results

Table 4.24. *Correlations between Age, Gender, DVSS & Pin Q*

<b>Correlations Between Age, Gender, DVSS &amp; PinQ</b>			
<b>Variables</b>	<b>Pearson Correlation</b>	<b>Significance (p)</b>	<b>r<sup>2</sup></b>
Age with Gender	- 0.028	0.898	
Age with Child Total DVSS	- 0.347	0.097	
Age with Parental Total DVSS	- 0.276	0.191	
Age with Child Total PinQ	- 0.363	0.081	
Age with Parent Total PinQ	- 0.070	0.745	
Gender with Child Total DVSS	0.285	0.177	
Gender with Parent Total DVSS	0.462*	0.023	0.213444
Gender with Child Total PinQ	- 0.279	0.187	
Gender with Parent Total PinQ	0.163	0.448	
Child Total DVSS with Parent Total DVSS	0.472*	0.020	0.222784
Child Total DVSS with Child Total PinQ	0.135	0.528	
Child Total DVSS with Parent Total PinQ	0.344	0.100	
Parental Total DVSS with Child Total PinQ	- 0.299	0.155	
Parental Total DVSS with Parent Total PinQ	0.353	0.090	
Child Total PinQ with Parent Total PinQ	- 0.101	0.638	

\* Correlation significant at 0.05 level (two-tailed)

between age, gender, DVSS and PinQ.

***The Relationship between the Parent and Child’s Scoring of the DVSS and the PinQ***

***DVSS***

Correlations between the individual child and parent DVSS questions showed that only the parent and child responses to the questions “I have had wet clothes or wet underwear during the day” (r = 0.443, p = 0.030), “I miss having a bowel movement every day” (r = 0.601, p = 0.002) as well as “When I pee it hurts” (r = 0.576, p = 0.003) were statistically significant. Although Q10 was 1.000, the

Table 4.25. *Correlations of Child & Parent Responses to Individual DVS*

*Question*

<b>Correlations of Child &amp; Parent Responses to Individual DVSS Questions</b>			
<b>Question</b>	<b>Pearson Correlation</b>	<b>Significance (p)</b>	<b>r<sup>2</sup></b>
Q1. I have had wet clothes or wet underwear during the day	0.443*	0.030	0.196249
Q2. When I wet myself, my underwear is soaked	-0.172	0.421	
Q3. I miss having a bowel movement every day.	0.601**	0.002	0.361201
Q4. I have to push for my bowel movements to come out.	0.281	0.184	
Q5. I only go to the bathroom one or two times each day.	0.248	0.243	
Q6. I can hold onto my pee by crossing my legs, squatting or doing the "pee dance".	0.121	0.573	
Q7. When I have to pee, I cannot wait.	-0.327	0.119	
Q8. I have to push to pee.	-0.194	0.364	
Q9. When I pee it hurts.	0.576**	0.003	0.331776
Q10. Parental response to stressful event	1.000	0.000	

\* Correlation significant at 0.05 level (two-tailed)

\*\* Correlation significant at 0.01 level (two-tailed)

child response to question was taken from the parental response rather than the child answering the question independently. Consequently 19.62% of the variance in the child's score from Q1, 36.12% of the variance in the child's scores in Q3 and 33.18% of the variance in the child's scores in Q9 can be explained by the change in the parent scores. No statistically significant correlations were found between the parent and children responses to any other DVSS questions. Table 4.25 summarizes the correlations between the child and parent responses to the DVSS.

### *PinQ*

Analysis between the individual child and parent PinQ questions showed statistically significant differences only between the parent and child responses to the questions "I get shy because of my bladder problem" ( $r = 0.472$ ,  $p = 0.020$ ) and "I wake up during my sleep because of my bladder problem." ( $r = 0.557$ ,  $p = 0.005$ ). Twenty two percent of the variance in the child's score for Q1 and 31.02% of the variance in the child's score for Q11 can be explained by the change in the parent scores. No statistically significant correlations were found between the parent and children responses to any other PinQ questions. Table 4.26 summarizes the correlations between the parent and child responses to the individual PinQ questions.

Table 4.26. *Correlations of Child & Parent Responses to Individual PinQ Questions*

<b>Correlations of Child &amp; Parent Responses to Individual PinQ Questions</b>			
<b>Question</b>	<b>Pearson Correlation</b>	<b>Significance (p)</b>	<b>r<sup>2</sup></b>
Q1. I get shy because of my bladder problem.	0.472*	0.020	0.222784
Q2. People in my family treat me in a different way because of my bladder problem	0.057	0.790	
Q3. I am worried that people might think my clothes smell of pee.	0.182	0.395	
Q4. I think that my bladder problem won't get better.	-0.117	0.586	
Q5. Mom and dad worry about me because of my bladder problem.	0.164	0.443	
Q6. I would feel better about myself if I didn't have a bladder problem.	-0.142	0.508	
Q6. I would feel better about myself if I didn't have a bladder problem.	-0.142	0.508	
Q7. My bladder problem makes me feel nervous.	0.075	0.728	
Q8. Mom or dad sometimes seem a bit cranky because of my bladder problem.	0.277	0.191	
Q9. My bladder problem stops me from going on sleep-overs or holidays.	0.253	0.232	
Q10. My bladder problem makes me feel bad about myself.	0.060	0.782	
Q11. I wake up during my sleep because of my bladder problem.	0.557**	0.005	0.310249
Q12. I miss out on doing things because of my bladder problem.	0.305	0.147	
Q13. I feel unhappy because of my bladder problem.	-0.097	0.651	
Q14. My bladder problem makes me feel sad.	-0.160	0.454	
Q15. I think about my bladder problem when choosing which sport to play.	-0.220	0.301	
Q16. I have to go to the toilet when I'm watching a movie.	-0.011	0.959	

<b>Correlations of Child &amp; Parent Responses to Individual PinQ Questions</b>			
<b>Question</b>	<b>Pearson Correlation</b>	<b>Significance (p)</b>	<b>r<sup>2</sup></b>
Q17. If my bladder problem was fixed I would invite more friends to my house.	0.092	0.668	
Q18. I choose hobbies that won't be spoiled by stopping to go to the toilet.	-0.067	0.757	
Q19. My bladder problem makes me feel different to other people.	-0.133	0.537	
Q20. I miss out on being with friends because of my bladder problem.	-0.318	0.130	

\* Correlation significant at 0.05 level (two-tailed)  
 \*\* Correlation significant at 0.01 level (two-tailed)

***PinQ Regression***

Regression analysis of the PinQ Total Child Domain Scores indicates that only Child Mental Health has an impact on overall Child Self-Esteem [(beta=0.902), t=4.021, p=0.001]. Table 4.27 summarizes the PinQ Child Domain Regressions. Figure 4.11 shows a plot diagram of the regression equation.

Table 4.27. *PinQ Child Domain Regression Table*

<b>PinQ Child Domain Regression</b>			
Dependent Variable – Child Self-Esteem			
<b>Model</b>	<b>Beta</b>	<b>t</b>	<b>Significance (p)</b>
constant		5.508	0.000
Child Family & Home	- 0.087	- 0.409	0.686
constant		4.170	0.000
Child Family & Home	- 0.236	- 1.030	0.315
Child Social Relations with Peers	0.344	1.502	0.148
constant		3.427	0.003
Child Family & Home	- 0.139	- 0.783	0.443
Child Social Relations with Peers	- 0.349	- 1.410	0.174
Child Mental Health	0.909	3.969	0.001
constant		3.602	0.002
Child Family & Home	- 0.194	- 1.088	0.290
Child Social Relations with Peers	- 0.445	- 1.763	0.094
Child Mental Health	0.902	4.021	0.001
Child Independence	0.251	1.373	0.186



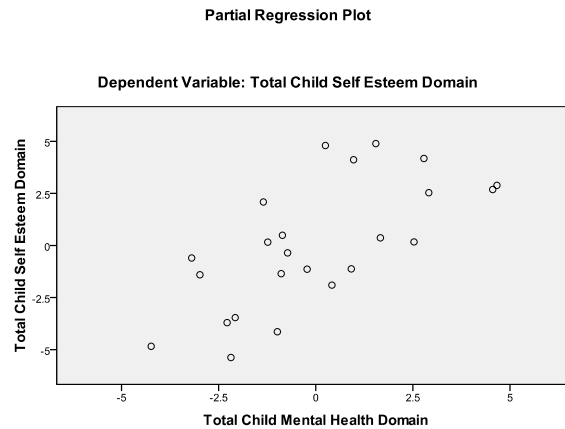


Figure 4.11. Partial Regression Plot Diagram of Child Mental Health & Child Self-Esteem

Table 4.28. *PinQ Parent Domain Regression Table*

<b>PinQ Parent Domain Regression</b>			
Dependent Variable – Parent Self-Esteem			
Model	Beta	t	Significance (p)
constant		3.723	0.001
Parent Family & Home	0.617	3.680	0.001
constant		2.845	0.010
Parent Family & Home	0.502	3.047	0.006
Parent Social Relations with Peers	0.352	2.140	0.044
constant		1.578	0.130
Parent Family & Home	0.521	3.547	0.002
Parent Social Relations with Peers	0.121	0.703	0.490
Parent Mental Health	0.419	2.550	0.019
constant		2.665	0.015
Parent Family & Home	0.385	7.712	0.014
Parent Social Relations with Peers	0.092	0.594	0.559
Parent Mental Health	0.202	1.179	0.253
Parent Independence	0.421	2.475	0.023

Regression analysis of the PinQ Total Parent Domain Scores indicates that

Parent Family & Home [(beta=0.385), t=7.712, p=0.014], and Parent

Independence [(beta=0.421), t=2.475, p=0.023] have an impact on overall Parent

Self-Esteem. Table 4.28 summarizes the PinQ Parent Domain Regressions.

Figures 4.12 and 4.13 shows plot diagrams of the regression equations.

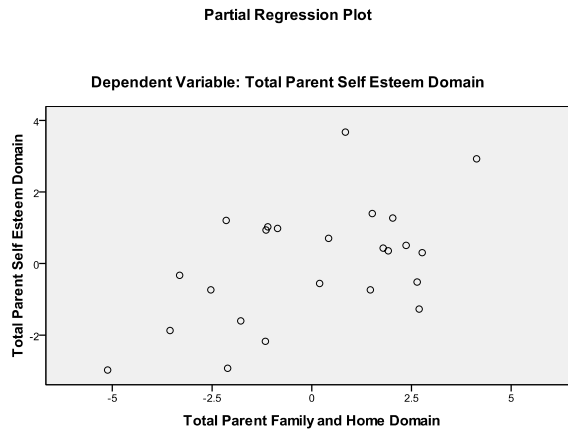


Figure 4.12. Partial Regression Plot Diagram of Parent Family & Home with Parent Self-Esteem

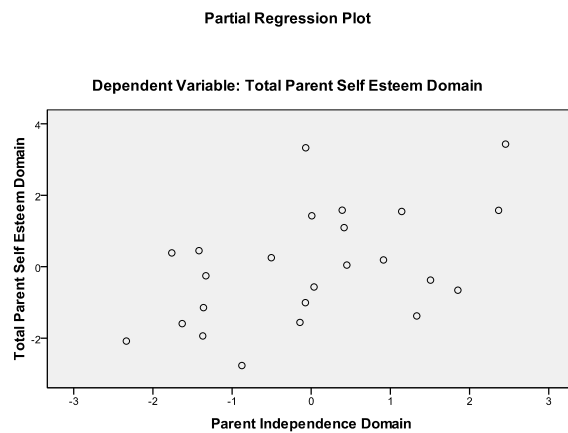


Figure 4.13. Partial Regression Plot Diagram of Parent Independence with Parent Self-Esteem

***PinQ Total Domain Score Correlations***

The PinQ Instrument questions were divided into five separate domains including “Self-Esteem”, “Family and Home”, “Social Relations with Peers”, “Mental Health” and “Independence” (Bower et al., 2006). The total domain

scores between the parent and child were correlated. (Table 4.29 summarizes the correlations).

Analysis of the PinQ showed statistically significant differences between the parent and child total domain scores: Child Self-Esteem with Child Mental Health ( $r = 0.628$ ,  $p = 0.001$ ), Child Family & Home with Child Social Relations ( $r = 0.433$ ,  $p = 0.034$ ), Child Social Relations with Child Mental Health ( $r = 0.716$ ,  $p = 0.000$ ), Child Social Relations with Child Independence ( $r = 0.495$ ,  $p = 0.014$ ), Parent Self-Esteem with Parent Family & Home ( $r = 0.617$ ,  $p = 0.001$ ), Parent Self-Esteem with Parent Social Relations ( $r = 0.517$ ,  $p = 0.010$ ), Parent Self-Esteem with Parent Mental Health ( $r = 0.555$ ,  $p = 0.005$ ), Parent Self-Esteem with Parent Independence ( $r = 0.743$ ,  $p = 0.000$ ), Parent Family & Home with Parent Independence ( $r = 0.415$ ,  $p = 0.044$ ), Parent Social Relations with Parent Mental Health ( $r = 0.537$ ,  $p = 0.007$ ), Parent Social Relations with Parent Independence ( $r = 0.453$ ,  $p = 0.026$ ) and Parent Mental Health with Parent Independence ( $r = 0.597$ ,  $p = 0.002$ ). No other statistically significant correlations were found between the parent and child PinQ total domain scores.

Thirty nine percent of the variance in Child Self Esteem can be explained by the change in Child Mental Health, 18.7% of the variance in Child Family & Home can be explained by Child Social Relations, 51.25% of the variance in Child Social Relations can be explained by Child Mental Health, 24.5% of the variance in Child Social Relations can be explained by Child Independence, 38.1% of the variance in Parent Self-Esteem can be explained by Parent Family & Home, 26.7% of the variance in Parent Self-Esteem can be explained by Parent

Table 4.29. Correlations of Child & Parent PinQ Total Domain Scores

PinQ Domain Total Score Correlations							
Variables	Pearson Correlation	Significance (p)	r <sup>2</sup>	Variables	Pearson Correlation	Significance (p)	r <sup>2</sup>
Child Self-Esteem with Child Family & Home	- 0.087	0.686		Child Social Relations with Parent Independence	- 0.294	0.163	
Child Self-Esteem with Child Social Relations	0.242	0.255		Child Mental Health with Child Independence	0.350	0.094	
Child Self-Esteem with Child Mental Health	0.628**	0.001	0.394384	Child Mental Health with Parent Self-Esteem	- 0.246	0.246	
Child Self-Esteem with Child Independence	0.272	0.199		Child Mental Health with Parent Family & Home	- 0.256	0.227	
Child Self-Esteem with Parent Self-Esteem	- 0.169	0.429		Child Mental Health with Parent Social Relations	- 0.036	0.869	
Child Self-Esteem with Parent Family & Home	- 0.252	0.235		Child Mental Health with Parent Mental Health	- 0.038	0.859	
Child Self-Esteem with Parent Social Relations	0.009	0.966		Child Mental Health with Parent Independence	- 0.360	0.084	
Child Self-Esteem with Parent Mental Health	- 0.092	0.671		Child Independence with Parent Self-Esteem	- 0.005	0.980	
Child Self-Esteem with Parent Independence	- 0.259	0.221		Child Independence with Parent Family & Home	0.025	0.908	
Child Family & Home with Child Social	0.433*	0.034	0.187489	Child Independence with Parent Social Relations	0.186	0.385	

Relations			
Child Family & Home with Child Mental Health	0.224	0.294	
Child Family & Home with Child Independence	0.389	0.060	
Child Family & Home with Parent Self-Esteem	0.190	0.373	
Child Family & Home with Parent Family & Home	0.226	0.288	
Child Family & Home with Parent Social Relations	- 0.257	0.226	
Child Family & Home with Parent Mental Health	0.071	0.741	
Child Family & Home with Parent Independence	- 0.024	0.910	
Child Social Relations with Child Mental Health	0.716**	0.000	0.512656
Child Social Relations with Child Independence	0.495*	0.014	0.245025
Child Social Relations with Parent Self-Esteem	- 0.223	0.295	

Child Independence with Parent Mental Health	0.068	0.751	
Child Independence with Parent Independence	- 0.067	0.756	
Parent Self-Esteem with Parent Family & Home	0.617**	0.001	0.380689
Parent Self-Esteem with Parent Social Relations	0.517**	0.010	0.267289
Parent Self-Esteem with Parent Mental Health	0.555**	0.005	0.308025
Parent Self-Esteem with Parent Independence	0.743**	0.000	0.552049
Parent Family & Home with Parent Social Relations	0.328	0.118	
Parent Family & Home with Parent Mental Health	0.136	0.526	
Parent Family & Home with Parent Independence	0.415*	0.044	0.172225
Parent Social Relations with Parent Mental Health	0.537**	0.007	0.288369

Child Social Relations with Parent Family & Home	- 0.014	0.950		Parent Social Relations with Parent Independence	0.453*	0.026	0.205209
Child Social Relations with Parent Social Relations	0.159	0.458		Parent Mental Health with Parent Independence	0.597**	0.002	0.356409
Child Social Relations with Parent Mental Health	- 0.009	0.967					

\* Correlation significant at 0.05 level (two-tailed)

\*\* Correlation significant at 0.01 level (two-tailed)

Social Relations, 30.8% of the variance in Parent Self-Esteem can be explained by Parent Mental Health, 55.2% of the variance in Parent Self-Esteem can be explained by Parent Independence, 17.2% of the variance in Parent Family & Home can be explained by Parent Independence, 28.8% of the variance in Parent Social Relations can be explained by Parent Mental Health, 20.5% of the variance in Parent Social Relations can be explained by Parent Independence, and 35.6% of the variance in Parent Mental Health can be explained by Parent Independence.

***Open Ended Question Data***

During the clinic visit, 15/20 child/parent dyads were asked three open ended qualitative questions to explore how the wetting impacted the child and the family. The responses were documented and analyzed by the researcher. The questions revolved around the following themes:

- a. Parent - Tell me what it is like to have a child with wetting or voiding dysfunction?
- b. Child – Tell me what it is like to have wetting?
- c. How do you manage?
- d. How does it impact your life?

In response, six parents expressed concern or worry about their child who had daytime wetting and the need to protect this child from others. One mother stated that if there was any way to fix her child's wetting, she would. One mother stated "I find it especially worrisome because I went through the same thing as a child...I know what it is like to be teased ...I know how it can destroy self confidence... it affects everything you do...you're not confident in any aspect of

your life...It affects how you deal with life in general". Concerns about the impact the wetting had on the child's feelings and self image were articulated by five parents. Three parents expressed anxiety about what others thought about their child because of his/her wetting. A consistent worry was "what would happen" when their child went over to a friends place? The potential for teasing as a result of the child's wetting was reiterated by four parents. Feelings of apprehension that others would be able to smell the pee on their child's clothes because they could smell it themselves were also expressed. One mother stated that "she feels bad when she notices the smell from her child and worries that others will notice the smell as well," while another parent described feeling embarrassment, anger and frustration for her child when she noticed her child was wet after they had gone somewhere. Another mother expressed her concern that other children at her child's school were starting to notice her daughter's odour.

Concerns about their child's feelings were expressed by ten parents. One mother stated that she worried about her daughter's feelings and the impact the wetting has on how her daughter feels about herself, while another parent expressed concern about how her daughter feels and what others think of her daughter. When speaking about her daughter's wetting, another mother stated that "It is not something that a child should have to worry about." Seven worried about their child feeling embarrassed as a result of his/her wetting. One mother stated that she felt bad for her child and worried about her child's embarrassment and another stated "I feel embarrassed for my daughter". One mother speaking from personal experience stated "If you pee your pants in school and it gets



noticed, it is devastating and follows you through out your school life... I don't want that for my girls". Yet another mother stated "I know that my daughter feels embarrassed when she has an accident at school."

Eight parents expressed feelings of anger and frustration with their child's daytime wetting. Although these parents felt bad for their child, believed the wetting was not their child's fault, understood that their child had a medical problem and tried hard not to get angry with their child, sometimes they could not help themselves. One mother stated that "initially it was very confusing – I wasn't sure whether I was overreacting or my daughter had a psychological problem but now I know that she has a medical problem." Another mother stated "I am angry at my daughter at times and I wonder - is it that she is lazy?" Frustration was uttered by one mother because her daughter would be standing right outside the bathroom door when she wet and she would ask her "why did you do that?" Another mother spoke about fighting her feelings of exasperation as well as guarding her emotions and reactions so that she did not take them out on her daughter. Another stated that although she feels frustrated with her daughter's wetting, she knows that "her daughter does not want to be like this".

Four parents stated that their child's wetting was always in the back of their minds while eight parents affirmed that they always had to be prepared. One mother commented that "you are always thinking about it – you always have to be on with certain things." Another mother said that "you always have to make sure that it is looked after." Most parents spoke about sending their child to the bathroom frequently during the day especially before they were going out as well

as the need to pack extra clothes for their child. Others parents talked about making sure they knew where every rest stop and bathroom was located wherever they were going. One mother stated "I am always reminding my girls to go to the bathroom... the last thing I say to them before they go out the door in the morning, don't forget to go to the bathroom.... I feel like I am always nagging them". One parent even made special trips to scout out the area first to find all the bathrooms prior to taking her child to a new location. Preparation was important to one family as they always took a potty seat in the vehicle to prevent accidents in the car when their daughter was younger because their daughter did not have any warning when she had to void - there was no "window of safety". As the child became older, the family bought a motor home with a bathroom in it so that the child would always have somewhere to go at a moment's notice.

Six parents spoke of the need to always have extra clothes on hand, at school or in the child's backpack for the child to change into if he/she wet him/herself. One parent changed the type of clothing that her daughter wore so that long shirts would cover the wet spots on her daughter's pants if her daughter had an accident. Another mother had bought five identical outfits and placed them in the school bathroom by the office in order that her daughter could change her clothes during the day without the other children realizing she had changed.

The impact on the child and family seemed to vary considerably as some families seemed to be more resilient and adapted while others struggled more. Seven parents stated that their child's wetting does not impact their family or their child's life very much and that they had involved the child in numerous sports

and/or physical activities. These parents also stated that they do need to be prepared and pack extra clothes in case of wetting. One mother stated “the wetting does not slow us down at all ... my son is involved in lots of things like Martial arts” while another stated that “it does not impact my daughter’s life...we go out and do things...she does everything like gymnastics.” Another mother stated that “they have tried to accommodate and cope in different ways but you learn to deal with it over time.”

Other families seemed to be less amenable to the wetting and were more impacted and bothered. “Everyone in the house is very aware that she is always wet ... we always have to tell her to go to the bathroom or that she is wet and to go change.” Another mother stated that they usually did not go anywhere because of their daughter's wetting and if they did happen to go somewhere, they certainly would not stay overnight. Four mothers expressed frustration regarding the extra laundry. One mother commented that there was “always lots of laundry and lots of years of pull-ups.” Another mother stated that in order to get the odor out of her daughter’s clothes, she had to wash her daughter’s clothes three times and hang the clothes on the line while at other times she just had to throw the clothes out because she could not eliminate the odor.

Six parents spoke about their child’s school and teachers. According to the parents, some schools tended to be more understanding than others. One parent stated that “the school has been wonderful and very supportive of my daughter ... in fact there is another child in my daughter's class with a similar problem and they support each other.” Another parent stated that “the teacher is aware of my

daughter's problems and that she always has spare clothes with her." One mother stated that her daughter's "classmates and friend have been there for her". Other schools and teachers have been less accommodating. One mother had a teacher complain about her daughter's odor and refused to let her daughter in class.

Another mother spoke about her frustration with her daughter's school "no matter how many clothes I buy and take to the school for my daughter ... I am always getting a phone call to bring more clothes to school." Another stated "I always speak to the teacher ahead of time but often when my daughter has to go to the bathroom they are busy and ask her to just wait". At a different school, one mother was regularly getting notes sent home from the teachers asking the mother what she is going to do about her daughters wetting. One family found that changing schools in response to the problems experienced at a previous school was their child's only option.

Four parents spoke about avoiding sleep-overs or allowing their child to only go to certain safe homes. One mother stated that they had to be very careful about sleep-overs as she could not tell everyone about her son's bedwetting. As a result he would only sleep over at his grandparents' home. Another mother spoke about making plans for sleepovers as well as providing reassurance to her daughter when she went to a friend's home for a sleep-over. Another parent stated that as a result of her daughter's wetting, they never went or stayed overnight at friends but they would stay with their immediate family who knew about the child's wetting. One young boy stated that he only slept over at a couple of families' homes who understood about his wetting.

A number of children would not elaborate about how they felt about their wetting while some other children were quite vocal about the impact their wetting had on them. Seven admitted that their wetting did indeed trouble them. One seven year old boy admitted that his wetting did bother him at times but he shrugged his shoulders and would not elaborate any further, while another nine year old boy stated "I hate my wetting and bedwetting ... I don't tell anyone about it". Another seven year old girl admitted that she did feel embarrassed at times but again would not elaborate any further with the researcher. One six year old girl stated that she felt frustrated because she always has to pee. Another nine year old girl stated "my wetting does not make me feel very good ... I always have to make a special trip to the bathroom I do anything ... I always have to leave the movie to go to the bathroom". Only two children in the study stated that their wetting did not bother them. One nine year old girl stated "I have other children in my class that wear pull-ups too ...it's really not that bad". Another nine year old stated that her wetting did not bother her much but she was teary and seemed embarrassed during her comprehensive voiding history questioning.

A number of children spoke about missing out on doing things, being embarrassed and teased by others. One seven year old stated that she missed out on having fun with her friends because her wetting prevented her from running, laughing or playing. This same young girl had been banished from a friend's home because she had previously leaked on their trampoline when she jumped on it. Although her good friends understood about her wetting, other children would not let her play with them once they learned about her problem. She was often

teased, laughed at and called names and spent great deal of time crying after school. This young girl changed schools due to the teasing and difficulty she encountered.

One nine year old boy was worried that classmates would notice the dark spot on his pants when he wet himself and people would gossip about it at school resulting in his embarrassment. He avoided going to the bathroom during class time to prevent others from noticing his need to go to the bathroom. Although he did admit that he would invite more people over to his home if his wetting was fixed, he worried that his friends would want to see what was in his "secret drawer" and tease him about wearing diapers while he is wearing his "Good Nites" as he stated that "his friends did not understand about wearing Good Nites". Consequently he would only sleep over at a couple of homes in which the family understood about his wetting.

Although one nine year old stated that her wetting and wearing pull-ups did not bother her as there were other children in her class that wore them, the majority of children either did not want to wear "Good Nites" or hid the fact to avoid being teased by others. One ten year old girl described putting on the "Good Nites" in another room so that her friends would not know when she is wearing them. Another young girl refused to wear any "Pull-ups or Good Nites" because someone had previously seen her wearing them while she was in Grade one and teased her about wearing diapers.

One nine year old girl with frequent recurrent UTI's indicated that she might only be wet three times a week on "good days" but that it could be up to

three times a day if she had a UTI. She would try to hide her accidents by wearing a sweater around her waist although sometimes the wetting still soaked through her clothes. She would get upset because she was afraid others would notice the wet spots on her clothes. At times she would avoid changing if she was wet because she was afraid that others would notice her different clothes, yet she admitted that she often developed rashes from her wet jeans or underwear rubbing against her skin. At times she would not notice that she had wet herself consequently her friends or her teacher would have to discretely inform her about the wetting.

A number of recurrent themes emerged from the subjective data as a result of the parental and the child responses. While many parents described worry and concern for their child as well as anger and frustration with their child's wetting, others spoke about the need to always be prepared, the impact the child's wetting had on their family as well as school attitudes towards their child's wetting. Although a number of children would not elaborate during questioning, some of children were quite vocal expressing concerns about being teased, feelings of embarrassment, others noticing the wetting or pull-ups and missing out on doing things as a result of their wetting.

In summary, 24 children and their parents completed questions on quality of life and voiding, as well as provided subjective data on the effect urinary incontinence has on their daily routines. The DVSS and PinQ questionnaire data demonstrated inconsistencies between the child responses and the parent perceptions of the problem. Recurrent themes of preparedness, worry, anger and

frustration, teasing, embarrassment and "missing out on things" were illustrated from the interview data and it was apparent that overall urinary incontinence affected family dynamics, child self-esteem as well as school and peer interactions.



## Chapter 5 – Discussion

The relationship between the severity of voiding dysfunction (measured by the DVSS) and quality of life (measured by the PinQ) in children with daytime wetting as well as the relationship between child and parent responses to the DVSS and PinQ were examined during this study guided by the following research questions:

1. What are the relationships between severity of daytime wetting (measured by Dysfunctional Voiding Symptom Score, DVSS), and age, gender and quality of life (measured by Pediatric Urinary Incontinence Quality of Life Instrument, PinQ)?
2. What is the relationship between the parent and child's scoring of the DVSS and the PinQ?

Comprehensive urological exams, voiding and stooling diaries, pad studies as well as three open ended questions regarding the impact of daytime wetting on the child and the family were incorporated into the research study.

Thirty-six children who attended the Stollery Pediatric Urology Clinics with daytime incontinence, urgency or frequency, urinary retention, bedwetting and/or recurrent UTI's were screened for the study. Six children did not meet the inclusion criteria, four children refused to partake and two families took the study information home without returning the questionnaires which resulted in 24 subjects (20 female and 4 male - ratio of 5:1) who participated in the study with their parents. Twenty-three of the parents or guardians, were female. All subjects and their parents completed the DVSS and PinQ instruments and the children had

a comprehensive urological exam during the clinic visit. Although all subjects were given voiding and stooling diaries, only seven completed diaries were returned. Ten children agreed to participate in the pad study but only four returned their pads or “Good Nites” to the research coordinator.

Analysis of the voiding diaries showed a discrepancy between the parent report and the actual documented voiding frequency of the child on the diaries, as 4/6 families over-estimated and 2/6 underestimated the frequency of their child’s voiding habits and/or incontinence during interviews. The voiding diaries may not have been accurate as the diaries were provided after the initial interview and children may have changed their voiding habits based on the information provided in the clinic visit, parents may not have recorded every void or bowel movement or families may have documented what they thought was appropriate for the study. Bael et al (2007) documented bladder diary discrepancies in the European Bladder Dysfunction study and reported that bladder diaries were not reliable in documenting outcome variables in children with dysfunctional voiding due to under and over reporting but may be utilized to document individual treatment.

Although the pad test was positive for each subject who returned the pads, it was difficult to interpret the pad study results when only four returned the pads to be analyzed. The literature provides conflicting evidence for pad studies as Hellerström et al. (1986) found that a 12 hour pad test was reliable in quantifying urinary incontinence in children but Bael et al (2007) found that pad studies were

unreliable in the European Bladder Dysfunction study suggesting that children may have been trying to be dry during the study.

Although this research study showed a large gender discrepancy with a ratio of 5:1 (20 females to 4 males) gender discrepancies are not uncommon as females seem to be more affected by voiding dysfunction than males. Farhat et al. (2000) reported a ratio of 4:1 (83 females to 21 males) subjects in his study of the DVSS, Wiener et al. (2000) a ratio of 3.8:1 (38 girls to 10 boys) in his study of the efficacy of simple behavioural therapy for daytime wetting and Bael et al. (2008) reported a ratio of 3.7:1 (159 females to 43 males) in the European Bladder Dysfunction Study. The cause of the gender discrepancy is uncertain but may be related to differences in urethral anatomy between girls and boys, an increased recognition of voiding dysfunction in girls rather than boys, an increased likelihood of parents bringing girls in for treatment, and/or an increased incidence of UTIs in girls which precipitates the onset of the child's voiding dysfunction.

Mothers as primary respondents for their children is also not uncommon in the literature. Kodman-Jones, Hawkins and Schulman (2001) documented that typically the mothers completed the questionnaires in their behavioural characteristics of daytime wetting study and 98% of respondents were mothers in the Avon Longitudinal Study of Parents and Children (Landgraft et al., 2004).

### ***Defining Relationships Utilizing Correlational Statistics***

In this study, data analysis included correlations between the variables DVSS, PinQ, age, and gender. Correlational statistics are utilized to define linear relationships between variables (Munro, 2005). The Pearson correlation

coefficient ( $r$ ) defines the strength of the relationship as well as how the variables interact with each other or the "strength and intensity of the relationship" (Polit, Beck & Hungler, 2001. p.342). Although correlational statistics may show that a relationship between two variables exists, it does not imply causality, consequently "the finding that two variables are related offers no evidence about which of the two variables - if either - caused the other" (Polit, Beck & Hungler, 200, p.408).

A correlational coefficient ranges from 1.0 (perfect) to 0.0 (no relationship). By convention a correlational coefficient that falls between 0.8 and 1.0 shows a strong relationship whereas a correlational coefficient that falls between 0.1 and 0.3 denotes a weak relationship between variables. A positive correlational coefficient denotes that the linear relationship of the variables moves in the same direction; as one variable increases the other has a corresponding increase; a negative correlation indicates an inverse relationship so that as one variable increases the other has a corresponding decrease (Munro, 2005). The percentage of the variability within the relationship is determined by squaring the correlational coefficient ( $r^2$ ) (Munro, 2005).

Although the correlational statistics may signify that there is a statistical relationship between the variables, the relationship is not necessarily clinically significant. If a study shows a statistically significant result but the outcome of the research cannot be utilized and translated into clinical practice the result is not clinically significant. Alternatively although a research study may show a non-

significant statistical outcome, the results may be clinically relevant and incorporated into practice despite the non-significant findings.

***What is the Relationship Between Severity of Daytime Wetting, Age, Gender, and Quality of Life***

In this study the relationships between the child ages, gender, total DVSS score, total PinQ score and parent total DVSS score and parent total PinQ score were analyzed. Only two of the variable combinations were found to have significant statistical correlations. Child's Gender correlated with the Parent's Total DVSS Score ( $r = 0.462$ ,  $p = 0.023$ ) and the Child's Total DVSS score correlated with the Parent's Total DVSS Score ( $r = 0.472$ ,  $p = 0.020$ ). The correlation between parent and child total DVSS scores implies that parents recognize signs of voiding dysfunction in children. The correlation between gender and parent DVSS score is difficult to interpret due to the gender discrepancy in the study. None of the other variable combinations analyzed showed any statistical significance. Further statistical analysis showed that only 21.34% of the change in the Parental Total DVSS score would be related to the change in the Child's Gender and only 22.28% of the change in the Child's Total DVSS Score would be related to the change in the Parental Total DVSS Score. These lower level correlation results may have occurred because of the large gender discrepancy in the study participants with a female to male ratio of (5:1) and a mainly female population in the parents.

***Dysfunctional Voiding Symptom Score (DVSS)***

The children's total DVSS scores ranged from three to 21 ( $\bar{x}$  12.08, median 12.50, SD 4.138) indicating that most children who participated in the current study had significant voiding dysfunction. When comparing by gender, the four male children had a total DVSS score which ranged from 3 to 14 ( $\bar{x}$  9.50, median 10.50, SD 4.796) and the 20 female children had a total DVSS scores which ranged from 4 to 21 ( $\bar{x}$  12.60, median 13.00, SD 3.926). Similar results were found by Farhat et al. in 2000, in which 104 children (83 females, 21 males) had a median DVSS score of 14. Farhat found that females were 2.93 times more likely to have voiding dysfunction than males.

Table 5.1. *Child DVSS Questions with Highest Response Rates*

<b>Child DVSS Questions with Highest Response Rates</b>	<b>Percentage*</b>
I have to push for my bowel movements to come out	41.7
I can hold onto my pee by crossing my legs, squatting or doing the "pee dance"	41.7
When I have to pee, I cannot wait	41.7
I miss having a bowel movement every day	29.2

\* Almost Every Time Response

According to Farhat et. al. (2000) the questions "I have to push for my bowel movements to come out", "I can hold onto my pee by crossing my legs, squatting or doing the "pee dance"", "when I have to pee, I cannot wait" and "I have had wet clothes or wet underwear during the day" are predictive of voiding dysfunction in both male and female children. Similar to Farhat's study, the response rates for these first three questions were high in the current study sample indicating that many of the children had significant voiding dysfunction. Table

5.1 summarizes the DVSS questions with the highest response rates in the current study.

Optimal threshold scores for voiding dysfunction as determined by Farhat et. al. (2000) are 6.02 for females and 9.02 for males. In the current research study 19/20 female participants exceeded the threshold score of 6.02 and 3/4 male participants exceeded the threshold score of 9.02. Although one female and one male child fell below the threshold scores when completing the DVSS themselves, their parents scored them above threshold. Only one male child consistently scored below the threshold score with both his and his parent's survey results. The children who scored below the threshold scores may have had lower scores because they really did not have voiding dysfunction, they did not feel their voiding dysfunction was a concern, they did not understand the questions in the survey or they were trying to make themselves look better while doing the survey. The majority of the children exceeded the threshold score by at least four to ten points.

***What is the Relationship Between Severity of Daytime Wetting, Age, Gender, and Quality of Life***

***Pediatric Urinary Incontinence Quality of Life (PinQ)***

The children's PinQ total scores ranged from 8 to 55 ( $\bar{x}$  35.63, median score of 37.50, SD 12.086). When splitting the results by gender, the four male children had a total PinQ score range of 29 to 55 ( $\bar{x}$  43.00, median 44.00, SD 10.801) and 20 female children had a total PinQ score range of 8 to 53 ( $\bar{x}$  34.15,

median 36.50, SD 12.027). Difference between the female and male scoring was not statistically significant.

Recently the PinQ instrument was translated and cross-culturally adapted into German by Bachmann et. al. (2009). In this study, 91 boys and 54 girls with non-neurogenic urinary incontinence and their parents completed the German PinQ, age range 6-18 years ( $\bar{x}$  9.3, SD 2.2 years) from July 2007 to August 2008,  $\bar{x}$  23.0 (boys) and  $\bar{x}$  23.9 (girls). Reliability and validity testing indicated that the German version was both valid and reliable. Age, sex, incontinence type and severity were not significantly associated with total scores of the German version of the PinQ. Table 5.2 compares the Voiding Dysfunction research with Bower (2008) and Bachmann (2009) studies.

Table 5.2. *Comparison of PinQ Studies*

<b>Comparison of PinQ studies</b>			
	<b>Voiding Dysfunction Study</b>	<b>Bower (2008)</b>	<b>Bachmann (2009)</b>
Age Range	5 – 10 years $\bar{x}$ 8.17 ± 1.37 years	6 – 17 years	6 – 18 years $\bar{x}$ 9.3 ± 2.2 years
Sample Size	24	156	145
Gender Mix	4 male 20 female	85 male 71 female	91 male 54 female
Wetting History	3 Daytime 21 Day & Night 0 Night Only	20 Daytime 64 Day & Night 72 Night Only	14 Daytime 111 Day & Night 20 Night Only
Female PinQ Score Range	$\bar{x}$ 34.15 ± 12.027	Domain scores only listed in article	$\bar{x}$ 23.9 ± 13.7
Male PinQ Score Range	$\bar{x}$ 43.00 ± 10.801	Domain scores only listed in article	$\bar{x}$ 23.0 ± 11



Comparison of the Bachmann et. al. (2009) study with the current Voiding Dysfunction study showed a considerable difference in the mean scores for both boys and girls between the two studies. These results may be related to the difference in sample size, gender ratio and cultures between the studies (Table 5.2).

The PinQ questionnaire was broken down into the domains presented by Bower (2008). The results in the current Voiding Dysfunction study differed slightly from the responses in the Bower (2008) study. Table 5.3 summarizes the mean domain score percentages in both studies. Although Self-Esteem and

Table 5.3. *Comparison of Child PinQ Mean Domain Percentages*

<b>Comparison of Child PinQ Mean Domain Percentages</b>		
<b>Domain</b>	<b>Current Study</b>	<b>Bower (2008) Study</b>
Self-Esteem	54.2%	57%
Family & Home	35.7%	46%
Social Relations with Peers	44.8%	43%
Mental Health	48.4%	52%
Independence	34.4%	48.5%
Body Image	0	39.5%

Mental Health have a significant impact on quality of life in both studies, it is difficult to directly compare the results as Bower's sample size was 156 children and utilized the twenty-eight question version of the PinQ whereas the current study utilized the twenty question version (Bower, Sit, Bluysen, Wong, and Yeung, 2006) with a sample size of 20.

The child's bladder problem had a substantial impact on their quality of life based on the question "I would feel better about myself if I didn't have a

bladder problem” (75.0% response rate). Forty-five percent of children felt different to others, 41.7% felt nervous and 37.5% felt unhappy because of their bladder problems. Thirty three percent of children thought their bladder problem wouldn’t get better. Fifty-four percent of children have to go to the toilet during a movie and 45.8% of children would invite more friends to their home if they did not have a bladder problem (Table 5.4).

Table 5.4. *Child PinQ Questions with Highest Response Rates*

<b>Child PinQ Questions with Highest Response Rates</b>	<b>Percentages</b>
I would feel better about myself if I didn't have a bladder problem	75.0%
I have to go to the toilet when I'm watching a movie	54.2%
My bladder problem makes me feel different to other people	45.9%
Mom and dad worry about me because of my bladder problem	45.9%
If my bladder problem was fixed I would invite more friend to my house	45.8%
My bladder problem makes me feel nervous	41.7%
I feel unhappy because of my bladder problem	37.5%
I think my bladder problem won't get better	33.4%

\*combined "Often" & "All the Time" Responses

The results from the present study show substantial differences in some areas compared to the Bower (2008) study (Table 5.5). Although some of the responses are similar, a number of questions show a marked difference in responses. The questions “I would feel better about myself if I didn't have a bladder problem”, “Mom or dad seem a bit cranky because of my bladder problem”, “My bladder problem makes me feel nervous”, “I wake up during my sleep because of my bladder problem”, and “My bladder problem makes me feel different to other people” show considerable differences in responses and quality of life issues. This may be related to substantial differences in the sample

selection as the current research study utilized a small sample of 24 participants from a single country in comparison to Bower’s 156 children from 10 different countries. Gender mixes between the two studies also differed; the current study was comprised of 20 female and 4 male subjects; Bower’s study consisted of 156 subjects (85 males and 71 females). Bower’s sample had daytime symptoms, nighttime symptoms or combined day and nighttime symptoms whereas the current research study was focused on daytime wetting only.

Table 5.5. Comparison of PinQ Child Response Rates

<b>Comparison of PinQ Child Response Rates</b>		
<b>Question</b>	<b>Bower (2008)</b>	<b>Current Study</b>
I would feel better about myself if I didn't have a bladder problem	52.3%	75.0%
Mom or dad sometimes seem a bit cranky because of my bladder problem	51.3%	25.0%
My bladder problem makes me feel nervous	30.9%	41.7%
I wake up during my sleep because of my bladder problem	30.2%	16.7%
My bladder problem stops me from going on sleep-overs or holiday	29.7%	29.1%
I think that my bladder problem won't get better	29.5%	33.4%
My bladder problem make me feel bad about myself	28.4%	25.0%
My bladder problem makes me feel different to other people	28.2%	45.9%
My bladder problem makes me feel sad.	24.4%	25.0%

\* combined "Often" & "All the Time" Responses

The low level correlations as well as the DVSS and PinQ results may have occurred because only the children who had significant voiding dysfunction symptoms which impacted their life sought medical treatment or were referred to the Stollery Urology Clinic. Parents may not seek medical treatment for children

with mild symptoms or the child may be treated in the community by their primary family physician rather than referred to a specialty clinic. Parental lack of awareness of their child's wetting or elimination habits post toilet training (Alyol, Adayener, Senkul, Baykal and Iseri, 2007; Halachmi & Farhat, 2008) may contribute to families not recognizing or being concerned about the child who has mild wetting or voiding dysfunction symptoms. Parents may consider mild wetting or constipation normal for some children and those who are not soaking through their clothes may be able to conceal their symptoms from their family and friends. While some of these children may change their clothes spontaneously, others may be able to hide their wetting; as a result parents may be unaware of a problem unless there is excessive laundry.

***What is the relationship between the parent and child's scoring of the DVSS and the PinQ?***

When statistically analyzing the relationships between the child and parent responses to the DVSS only three questions had statistically significant correlations: "I have had wet clothes or wet underwear during the day" ( $r = 0.443$ ,  $p = 0.030$ ), "I miss having a bowel movement every day" ( $r = 0.601$ ,  $p = 0.002$ ) and "When I pee it hurts" ( $r = 0.576$ ,  $p = 0.003$ ). "I miss having a bowel movement every day" had a stronger relationship between the parent and child responses than the question "I have had wet clothes or wet underwear during the day" as this question has a higher correlational coefficient. Further statistical analysis shows that only 19.62% of the change in the child's response to the question "I have had wet clothes or wet underwear during the day", only 36.12%

of the change in the child's response to the question "I miss having a bowel movement every day" and only 33.18% of the change in the child's response to the question "When I pee it hurts" would be related to the change in the parent responses to the questions.

### ***Dysfunctional Voiding Symptom Score (DVSS)***

Comparison of the proxy scoring with the child's scoring on the DVSS indicated that only one parent/child dyad had identical scores while most parents scored their child one to three points higher or lower than the child. Consequently the total DVSS scores between the child ( $\bar{x}$  score 12.08) and parent ( $\bar{x}$  score 12.71) were similar. Gender comparison also resulted in similar outcomes between the children and their parents (male total DVSS score 9.50 & parent total DVSS score 9.25 vs female total DVSS score 12.60 & parent total DVSS score 13.40). Only the mean differences between the parent's total DVSS score based on gender (mean difference -4.150,  $f=0.081$ ,  $t=-2.443$ ,  $df=22$ ,  $p=0.023$ ) was statistically significant. Although previous studies on proxy scoring have shown some significant differences between parent and child scoring, the DVSS scoring during this research study did not confirm those results.

Evaluation of the "Almost Every Time" response to the DVSS instrument indicated that the questions "I have to push for my bowel movements to come out" (41.7%), "I can hold onto my pee by crossing my legs, squatting or doing the "pee dance""(41.7%), "When I have to pee, I cannot wait" (41.7%) and "I miss having a bowel movement every day" (29.2%) had the highest response rates from children in the study. The questions with the highest response rates for the

parents consisted of the questions: "When I have to pee, I cannot wait" (70.8%), "My child has had wet clothes or wet underwear during the day" (54.2%), "When my child wets, his/her underwear is soaked" (33.3%), and "My child has to push for his/her bowel movements to come out" (25.0%) (Table 5.6). Although there was a difference in the child and parent responses to the DVSS, parents may have responded in this manner because the child's wetting and urgency is more visible to them than the signs of constipation whereas the children responded in this manner based on the voiding dysfunction symptoms that they experienced.

Table 5.6. *Comparison of Child and Parent Responses to DVSS*

<b>Comparison of Child and Parent Responses to DVSS</b>		
<b>Questions with Highest Response Rates</b>		<b>Percentage*</b>
<b>Child Responses</b>	I have to push for my bowel movements to come out	41.7
	I can hold onto my pee by crossing my legs, squatting or doing the "pee dance"	41.7
	When I have to pee, I cannot wait	41.7
	I miss having a bowel movement every day	29.2
<b>Parent Responses</b>	When I have to pee, I cannot wait	70.8
	My child has had wet clothes or wet underwear during the day	54.2
	When my child wets, his/her underwear is soaked	33.3
	My child has to push for his/her bowel movements to come out	25.0

\* Almost Every Time Response

***Pediatric Urinary Incontinence Quality of Life (PinQ)***

When analyzing the relationships between the child and parent responses to the PinQ only two questions had statistically significant correlations: "I get shy because of my bladder problem" (r = 0.472, p = 0.020) and "I wake up during my sleep because of my bladder problem." (r = 0.557, p = 0.005). The question with

the higher correlational coefficient “I wake up during my sleep because of my bladder problem” has a stronger statistical relationship between the parent and child responses than the question “I get shy because of my bladder problem”. Further statistical analysis shows that only 22.28% of the change in the child’s response to the question “I get shy because of my bladder problem” and only 31.02% of the change in the child’s response to the question “I wake up during my sleep because of my bladder problem” would be related to the change in the parent responses to the questions.

Analyzing the PinQ total scores between the children ( $\bar{x}$  score 35.63) and parents ( $\bar{x}$  score 37.58) was not statistically significant. Gender comparison resulted in similar outcomes between the children and their parents as well (male total PinQ score 43.00 & parent total PinQ score 33.50 vs female total PinQ score 34.15 & parent total PinQ score 38.40). Neither the mean difference between children’s total PinQ scores based on gender (8.850,  $f= 0.214$ ,  $t = 1.361$ ,  $df= 22$   $p=0.187$ ) nor the mean differences between the parent’s total PinQ scores based on gender (-4.900,  $f= 0.167$ ,  $t= -0.773$ ,  $df=22$ ,  $p=0.448$ ) were statistically significant. Regression analysis of the PinQ child domain scoring indicated that only Child Mental Health had an overall impact on Child Self-Esteem. In contrast, Parent Family & Home as well as Parent Independence had an overall impact on Parent Self-Esteem.

Comparison of the responses to the top seven questions on the PinQ instrument between the child and the parents indicates that there are substantial differences in what both the children and parents consider important when

discussing pediatric urinary incontinence quality of life. Where children are more concerned about self-esteem and the social consequences of urinary incontinence, parents seem to be worried about their child, the child's self-esteem and the physical symptoms related to the urinary incontinence. Consequently the PinQ results suggest that urinary incontinence has a significant impact on the child's self-esteem and how they feel about themselves (Table 5.7).

Table 5.7. Comparison of Child and Parent Responses to PinQ

<b>Comparison of Child and Parent Responses to PinQ</b>		
	<b>Questions with Highest Response Rates</b>	<b>Percentage*</b>
<b>Child Responses</b>	I would feel better about myself if I didn't have a bladder problem	75.0
	I have to go to the toilet when I'm watching a movie	54.2
	My bladder problem makes me feel different to other people	45.9
	Mom and dad worry about me because of my bladder problem	45.9
	If my bladder problem was fixed I would invite more friend to my house	45.8
	My bladder problem makes me feel nervous	41.7
	I feel unhappy because of my bladder problem	37.5
<b>Parent Responses</b>	I worry about my child because of his/her bladder problem	81.8
	My child has to go to the toilet when he/she is watching a movie	58.4
	My child would feel better about himself/herself he/she did not have a bladder problem	45.9
	My child is shy because of his/her bladder problem	41.7
	My child's bladder problem stops him/her from going on sleep-overs or holidays	41.2
	My child worries that people might think his/her clothes smell of pee	33.4
	My child's bladder problem makes him/her feel bad about himself/herself	33.4

\* combined "Often" & "All the Time" Responses



### *Family Coping Abilities*

The subjective data from the current study demonstrates a significant difference in parental and family coping abilities between the study participants. Some families were able to acclimatize easily and adjust their routines to accommodate the child. Encouraging healthy bladder habits including timed voiding, adequate fluid intake, monitoring constipation as well as encouraging the child to void prior to going anywhere were an integral part of this routine. The child's urinary incontinence seemed to have little impact on these families as they tried not to treat the child any differently and involved the child in numerous extracurricular activities despite the wetting concerns.

Other families appeared to experience a higher degree of stress and struggled to adapt to the child's wetting, as they seemed to be embarrassed, angry and/or frustrated about the overall situation. The increase in clothing requirements, laundry, financial costs, restrictions associated with going out and stigma associated with the wetting seemed to compound this stress for these families. Egemen, Akil, Canda, Ozyurt and Eser (2008) reported that families face significant burdens related to time, effort and finances when dealing with their child's incontinence. Bachmann et. al. state "Incontinence places a particular strain on parents due to practical issues such as hygiene, and laundry, and to embarrassment and stigma in the social environment" (2009, p. 1997).

Families under stress who have difficulty coping may channel their anger and frustration towards the child. According to Butler, Redfern and Forsythe (1993) feelings of guilt and lowered self-esteem in the child result from parental

displeasure, family stress, and the belief that “the child is to blame”.

Consequently parental attitudes about the wetting strongly influence the child’s overall feelings of worth, self-esteem and their behaviours. Landgraft et al (2004) studied the coping abilities of families who had children with nocturnal enuresis and found that the children’s coping ability and parental perceptions about the impact of enuresis were influenced by the family’s frustration and overall cohesion.

In some family situations the availability of resources and support may lessen the stress and minimize the impact of the wetting. The single parent who is working multiple jobs to support the family may have more difficulty coping with the added burden of incontinence whereas the family who has the support of grandparents or a large extended family may be more accepting and able to address the consequences of the child’s wetting. The costs associated with the extra laundry, clothing, incontinence pads or “Pull-Ups” or “Good Nites”, bedwetting alarms, and/or extra mattresses may be prohibitive for the family who has very little financial resources, as a result migrants or families with low socioeconomic status may be less tolerant of the child’s wetting (Egemen, Akil, Canda, Ozyurt and Eser, 2008).

Often if a parent has lived through the experience of wetting themselves, they seem to be more tolerant of their child’s own situation, want to protect their child and prevent the suffering or the stigma associated with the wetting as they themselves had experienced as a child. This was particularly evident with one mother who had suffered through ridicule, embarrassment, humiliation, low self-

esteem and lack of confidence which resulted from her childhood wetting and did not want her children to have a similar experience.

"For the vast majority of children, the presence of diurnal and nocturnal enuresis is a source of shame and embarrassment. It profoundly affects the child's life socially, emotionally, and behaviorally and also impacts the everyday life of his/her family" (Landgraft et. al., 2004, p. 334). According to Theunis, Van Hoecke, Paesbrugge, Hoebeke and Vande Walle (2002) wetting can become a chronic stress which results in a negative impact on the child's self-concept and personality. Theunis goes on to state that children experience both social and emotional consequences from their wetting such as a loss of self-esteem, fear of being different than others, fear of discovery by others and they are more likely to be bullied.

### ***School Challenges***

The semi-structured question results indicate that some teachers seemed to be very supportive and understanding of the child with daytime wetting whereas others may not be responsive to the child's individual needs. Teachers supportive of the child with urgency and daytime wetting allowed free access to water and allow the child to leave the class at anytime if they had to use the bathroom. Some of these children had special prearranged signals which let the teacher know that he/she needed to leave the classroom while in other cases the teacher would discretely tell the child that he/she was wet and needed to change. Other teachers were not as accommodating or supportive and would not allow the child to leave during class time or free access to water. Some families really struggled with the

school environment as one teacher sent notes home to the parents to ask them how they are going to deal with the child's wetting, while another teacher refused to let a child into the classroom due to the child's odour.

Teachers face a number of challenges when teaching children who have voiding dysfunction. Although teachers may refuse to let children use the bathroom during class time because they suspect the child may not actually utilizing the bathroom as requested but rather stalling and trying to get out of doing their school work, children with daytime wetting often suffer from urgency and need to use the bathroom immediately or they will be wet. Many teachers do not receive any formal education regarding voiding dysfunction; as a result they may have difficulty dealing with these children in the schools. In an Australian population based survey, parents reported 19.2% of children suffered from urinary incontinence but teachers only recognized 3% of these children in their classes (Sureshkumar, Craig, Roy and Knight, 2001b). Boyt (2005) and Cooper, Abousally, Austin, Boyt and Hawtrey (2003) surveyed 467 elementary school teachers to evaluate their knowledge of elimination patterns in children. They report that most teachers were unaware of the consequences of abnormal elimination habits, that only 18% of teachers reported receiving information regarding voiding dysfunction, and only 17% suspected an underlying health problem if children suffered from urinary frequency. Thirty-three percent of teachers asked children to wait to use the bathroom, 80% of teachers had set times for children to use the bathroom and asked children to use the bathroom at these times only, 80% of teachers would only allow one child to go to the bathroom at a

time, only 40% would allow children to use the bathroom anytime and 42% of teachers were concerned about the bullying in bathrooms. Boyt (2005) and Cooper, Abousally, Austin, Boyt and Hawtrey (2003) suggest schools may actually contribute to a child's voiding dysfunction due to the large proportion of time children are in school, the limitation of bathroom access and the schools lack of healthy bladder habit support. Upadhyay, Mathai, and Reed (2008) suggests that the large percentage of time that children spend in school, school activities and low fluid intake during the day may interfere with a child's voiding habits which results in urinary accidents. As voiding dysfunction may be a learned behaviour, Cooper, Abousally, Austin, Boyt and Hawtrey (2003) suggests that limiting bathroom access and discouraging voiding in young children who have the urge to urinate may alter the normal bladder sphincter functioning and may contribute to voiding dysfunction.

Daytime wetting may be a foundation of shame, embarrassment and guilt for the child as he/she becomes the source of peer teasing and/or bullying. This potential for ridicule or embarrassment may prevent children from utilizing the bathrooms when necessary or from using incontinence products. Children may isolate themselves or fear that others will notice the wetting or associated odour. According to Joinson et al. (2008), peer ridicule and embarrassment as a consequence of the daytime wetting has been associated with emotional and psychological problems in school-age children.

Educating teachers about voiding dysfunction is paramount to improved understanding, enhanced early intervention and minimizing impact on the child's

self-esteem or quality of life. Teachers would be more supportive and understanding of the child who has difficulty with wetting with a familiarity about the nature of the problem and how to help the child. Teachers would be more willing to assist the child and recognize problems if they know normal elimination processes, the importance of proper bowel and bladder management, signs and symptoms of voiding dysfunction, the consequences of limiting bathroom access to children, as well as the social and emotional impact that incontinence has on the child and his/her family. Teachers may be more receptive to timed voiding, allowing free access to water and allowing bathroom access if they understood the normal treatment plan for these children.

### ***Limitations of the Study***

Limitations of the study include a small sample size, age, a large gender discrepancy, small return of diaries and pads as well as the lack of scoring for the PinQ instrument. The sample consisted of 24 children five to ten years of age with daytime wetting who attended the Pediatric Urology Clinics at the Stollery Children's Hospital from September 1, 2008 to June 1, 2009. The convenience sampling and the small number of participants in the research study does not allow generalizing results to the larger population of children with daytime wetting. A larger sample size may also minimize the discrepancies between the parent and child reports. Gender discrepancy may have resulted because more females suffer with daytime wetting than boys, female children are more likely to seek help for the problem in comparison to the male children or daytime wetting is more recognized or accepted in female children than male children.

The study was also limited by the age of the children (range 5 -10 years). No children less than five years of age participated in the research study as there were none seen in the clinic during this time period. A number of children who attended the Stollery Pediatric Urology clinic with significant day and nighttime wetting were older than the age cut off of ten years. Further research should also include children older than ten years of age with urgency, frequency, urinary incontinence, urinary retention and recurrent UTI's to determine if there is an age effect related to urinary incontinence quality of life.

Although all 24 subjects completed the DVSS and the PinQ, a number of the children in the study were unable to read; the research coordinator had to read the survey questions to the subjects without influencing their decisions. Some of the terminology in the DVSS was confusing for the younger children as many did not recognize the term "bowel movement" consequently the research coordinator had to define the term so that the child could complete the questionnaire.

Ambiguity of two of the DVSS questions seemed to confuse some of the younger children as they did not seem to have the cognitive skills to understand the concept of a double negative. "I miss having a bowel movement every day" as well as "I only go to the bathroom one or two times each day" were the two questions that the younger children seem to struggle with. Each of the younger children required a detailed explanation from the research coordinator about how to respond to the questions: i.e. "almost never" if they had a bowel movement daily or voided more than twice per day whereas respond "almost every time" if they had a bowel movement every other day or voided infrequently. Although the

younger children seemed to struggle with these questions, the older children with greater cognitive skills did not seem to have any difficulty answering these two questions. None of the children seemed to have any difficulty completing the questions in the PinQ Instrument.

Another limitation of the study was the lack of scoring for the PinQ Instrument. Although the author of the instrument had been contacted prior to the study, the scoring for the instrument was never made available. The PinQ instrument (Bower, Sit, Bluysen, Wong and Yeung, 2006) that was utilized was copied from a previous research article by the author. The response to each PinQ question was graded zero for “No”, one for “Hardly Ever”, two for “Sometimes”, three for “Often” and four for “All the time”. The scores for each question were then tabulated for the Total PinQ score. An assumption was made that the higher the score on the PinQ the greater the impact on the child’s quality of life but no categorization or grading related to the severity of impact on quality of life could be made (mild, moderate, severe) due to the lack of scoring. Also the lack of standardized results and scoring guidelines from the author of the PinQ as well as the lack of previous studies made it difficult to compare the current results with the literature.

The PinQ domains of “Self-Esteem”, “Family and Home”, “Social Relations with Peers”, “Mental Health” and “Independence” were taken from a PinQ research article by Bower, Wong, and Yeung (2006). Based on this article, the relevant questions were placed together and the responses tabulated for each domain. The Bower study utilized a 28 question version of the PinQ instrument



which resulted in the extra domain of body image whereas the PinQ instrument (Bower et. al, 2006) utilized in the current research study had 20 questions with the questions related to body image removed from the instrument. As a result it is difficult to completely correlate the results between the two studies due to the differences in PinQ instrument utilization.

It was difficult to obtain the 24 hour pad test as many children with incontinence do not typically wear pads, “Pull-ups” or “Good Nites”. Most children in the study refused to participate in this portion of the study and only those who normally wore incontinence products agreed. In fact a number of children would not have participated in the overall study, if they had had to wear the incontinence pads.

Lack of diaries and pads returned to the researcher limited the analysis of the actual elimination history and comparison to the reported elimination and wetting history of the children. Although only four children returned their pads and seven children returned their diaries completed, the results indicate that each of these children did have significant urgency and wetting which correlates with their individual histories but it is difficult to correlate the results with whole study due to the lack of response.

### ***Implications for Further Research and Recommendations***

The results of the study show that urinary incontinence does have a significant impact on both the child and the family. In an attempt to develop a homogeneous sample, a significant number of children with substantial urinary incontinence and voiding dysfunction were excluded due to their age or lack of

daytime wetting. Broadening the inclusion and exclusion criteria to include children of all ages who attend the Stollery Pediatric Urology Clinics with urgency, frequency, urinary incontinence, urinary retention and recurrent UTI's as well as including children with exclusive nighttime only wetting would enlarge the sample population and allow more generalizability.

As the Stollery Pediatric Urology Clinic is a tertiary referral clinic for Northern Alberta and the Northwest Territories modifying the inclusion criteria to allow all children regardless of where they live to participate in the study would gather more substantial data as a number of children were not recruited because they lived more than two hours away from the clinic. These children would be excluded from the pad study portion of the research project.

Difficulty in recruitment and the lack of participation in the study resulted in a small sample size. Participant recruitment only occurred when the researcher was present in the clinic and seeing patients with voiding dysfunction or recurrent UTI's. Setting up study reminders in the clinic for all research participants may help with the recruitment of potential subjects for the study. Although the charts of potential subjects were flagged and the study information sheets were placed in the potential charts, this information was not often given to the families to read prior to their appointment, despite reminding the registration clinic staff and flagging the chart that the information was in the file. A number of these families that did get the study information ahead of time did not meet the inclusion criteria based on the child's history while other families who did not get the information did meet the inclusion and exclusion criteria. Although recruitment posters were

put up in the waiting room, only two families responded to the poster (one child lived more than two hours away and the other child entered the study).

As the Stollery Pediatric Urology Clinic is a tertiary referral clinic, the involvement of pediatricians and family physicians may help to recruit children with less severe symptoms of voiding dysfunction and allow data collection from children with a variety of different voiding dysfunction levels. Also the recruitment of children without voiding dysfunction as a control group would allow comparison between the controls and the children with voiding dysfunction as well as evaluation of the differences between these groups.

Providing voiding dysfunction education for teachers and physicians would allow improve understanding, recognition and enhance early intervention for children who are wetting, thereby minimizing the impact on the child's self-esteem. Teachers and physicians would be more willing and receptive to assisting the child and recognizing problems if they know normal elimination processes, the importance of proper bowel and bladder management, signs and symptoms of voiding dysfunction, the consequences of limiting bathroom access to children, as well as the social and emotional impact incontinence has on the child and his/her family.

The development of a special Multidisciplinary Pediatric Voiding Dysfunction Clinic at the Stollery Children's Hospital would allow more comprehensive assessment and treatment of all children with voiding dysfunction. The utilization of a dietician would allow for comprehensive dietary evaluation and education, a pediatric psychologist would assist those children with complex

psychological issues, gastroenterological services would allow comprehensive assessment of constipation and bowel functioning, and social work would allow community and financial resource management for children and their families. As voiding dysfunction can have a significant impact on children, families and the school, research and education would play an integral part of the clinics mandate.

The provision of education for families would improve recognition and early intervention for the child with voiding dysfunction before it impacts his/her self-esteem and/or quality of life. As families may not recognize the child has a problem until it has become quite severe, early recognition would minimize the psychological impact and improve the coping abilities of both the child and the family. Teaching families about urinary incontinence ultimately helps them understand that their child is not lazy and that their child may not have any control over his/her symptoms. Promoting healthy lifestyle changes to encourage healthy bowel and bladder functioning would help parents understand how they can assist their child to overcome his/her problems.

### ***Conclusion***

In conclusion, 24 children with voiding dysfunction and their parents completed the Dysfunctional Voiding Symptom Score (DVSS) and the Pediatric Urinary Incontinence Quality of Life (PinQ) questionnaires to determine the relationship between age, gender, severity of voiding dysfunction, and quality of life. Although the children and their parents had similar total scores on the DVSS and PinQ even when comparing by gender, there were discrepancies between the parent and child responses to some of the individual questions of the DVSS and

the PinQ. The DVSS and PinQ questionnaire data demonstrated inconsistencies between the child responses and the parent perceptions of the problem. Only the mean difference between the parent total DVSS score based on gender was found to be statistically significant. Analysis of the PinQ domain total scores also showed some discrepancy between parent and child responses in the Family & Home as well as the Independence domains. Only the relationships between gender and Parental Total DVSS Score as well as Child Total DVSS Score and Parent Total DVSS Scores were found to be statistically significant. The subjective data of the study showed that urinary incontinence plays an important role in family dynamics as well as in child self-esteem, quality of life and peer interactions. The results of this study illustrate the importance of early recognition and intervention to minimize the impact urinary incontinence has on the child's overall and enduring self-esteem and quality of life.

### References

- Akbal, C., Genc, Y., Burgu, B., Ozden, E., & Tekgul, S. (2005). Dysfunctional voiding and incontinence scoring system: Quantitative evaluation of incontinence symptoms in pediatric population. *The Journal of Urology*, 173(3), 969-973.
- Alyol, I., Adayener, C., Senkul, T., Baykal, K., & Iseri, C. (2007). An important issue in the management of elimination dysfunction in children: Parental awareness of constipation. *Clinical Pediatrics*, 46(7), 601- 603.
- Allen, H. A., Austin, J. C., Boyt, M. A., Hawtrey, C. E., & Cooper, C. S. (2007). Initial trial of timed voiding is warranted for all children with daytime incontinence. *Pediatric Urology*, 69(5), 962-965.
- Anderson, K. L. & Burckhardt, C. S. (1999). Conceptualization and measurement of quality of life as an outcome variable for health care research and intervention. *Journal of Advanced Nursing*, 29(2), 298-306.
- Bael, A. M., Lax, H., Hirche, H., Gabel, E., Winkler, P., Hellstrom, A., Van Zon, R., Janhsen, E., Guntek, S., Renson, C., & Van Gool, J.(2007). Self-reported urinary incontinence, voiding frequency, voided volume and pad-test results: Variables in a prospective study in children. *British Journal of Urology International*, 100(3), 651-656.
- Bael, A., Winkler, P., Hildegard, L., Hirche, H., Gabel, E., Vijverberg, M., van Zon, R., Van Hoeke, E., & Van Gool, J. D. (2008). Behavior profiles in children with functional urinary incontinence before and after incontinence treatment. *Pediatrics*, 121(5), e1196-e1200.

- Bachmann, C., Lehr, D., Janhsen, E., Steuber, C., Gabel, E., Von Gontard, A,  
 Bachmann H. (2009). German version of the Pediatric Incontinence  
 Questionnaire for Urinary incontinence health related quality of life. *The  
 Journal of Urology*, 182(4), 1993-1999.
- Beckie, T. M. & Hayduk, L. A. (1997). Measuring quality of life. *Social  
 Indicators Research*, 42(1), 21-39.
- Berry, A. (2006). Helping children with nocturnal enuresis. *AJN*, 106(8), 56-63.
- Berry, A. (2005). Helping children with dysfunctional voiding. *Urologic Nursing*,  
 25(3), 193-200.
- Bower, W. F. (2008). Self-reported effect of childhood incontinence on quality of  
 life. *Journal of Wound, Ostomy and Continence Nursing*. 35(6), 617-621.
- Bower, W. F., Moore, K. H., Adams, R. D., & Shepherd, R. B. (1997).  
 Frequency-volume chart data from incontinent children. *British Journal of  
 Urology*, 80(4), 658-662.
- Bower, W. F., Sit, F. K. Y., Bluysen, N., Wong, E. M. C., & Yeung C. K.  
 (2006). PinQ: A valid, reliable and reproducible quality-of-life measure in  
 children with bladder dysfunction. *Journal of Pediatric Urology*, 2(3), 185-  
 189.
- Bower, W. F., Wong, E. M. C., & Yeung C. K. (2006). Development of a  
 validated quality of life tool specific to children with bladder dysfunction.  
*Neurourology and Urodynamics*, 25 (3), 221-227.

- Bower, W. F., Sit, F., K. & Yeung, C.K. (2006) Nocturnal enuresis in adolescents and adults is associated with childhood elimination symptoms. *The Journal of Urology*. 176(4 Pt 2):1771-5.
- Bower, W. F., Yip, S. K., & Yeung, C. K. (2005). Dysfunctional elimination symptoms in childhood and adulthood. *The Journal of Urology*, 174(6), 1623-1628.
- Boyt, M. A. (2005). Teachers' knowledge of normal and abnormal elimination patterns in elementary school children. *Journal of School Nursing*, 21(6), 346-349.
- Butler, R. J., Redfern, E. & Forsythe, W. I. (1993) The maternal tolerance scale and nocturnal enuresis. *Behaviour Research and Therapy*, 31, 433-6.
- Carr, A. J., Gibson, B., & Robinson, P.G. (2001). Measuring quality of life: Is quality of life determined by expectation or experience? *BMJ*, 322(7296), 1240-1243.
- Chase, J. W., Homsy, Y., Siggaard, C., Sit, F., & Bower, W. F. (2004). Functional constipation in children. *The Journal of Urology*. 171(6), 2641-2643.
- Chertin, B., Koulikov, D., Abu-Arafeh, W., Mor, Y., Shenfeld, O. Z., & Farkas, A. (2007). Treatment of nocturnal enuresis in children with attention deficit hyperactivity disorder. *The Journal of Urology*, 178(4 pt 2), 1744-1747.
- Cohen, S. R. (2001). Changes in quality of life following admission to palliative care units. *Palliative Medicine*, 15(5), 363-371.
- Cohen, S. R., Mount, B. M., & MacDonald (1996). Defining quality of life. *European Journal of Cancer*, 32A (5), 753-754.



- Cohen, S. R., Mount, B. M., Tomas, J. J. N., and Mount L. F. (1996). Existential well-being is an important determinant of quality of life; Evidence from the McGill quality of life questionnaire. *Cancer*, 77(3), 576-586.
- Connolly, M. A. & Johnson, J. A. (1999). Measuring quality of life in paediatric patients. *Pharmacoeconomics*, 16(6), 605-625.
- Cooper, C. S., Abousally, C. T., Austin, C., Boyt, M. A., & Hawtrey, C. E. (2003). Do public schools teach voiding dysfunction? Results of an elementary school survey, *The Journal of Urology*, 170(3), 956-958.
- Creameens, J., Eiser, C. & Blades, M. (2007). Brief report: Assessing the impact of rating scale type, types of items, and age on the measurement of school-age children's self-reported quality of life. *Journal of Pediatric Psychology*, 32(2), 132-138.
- Creameens, J., Eiser, C. & Blades, M. (2006a). A qualitative investigation of school-aged children's answers to items from a generic quality of life measure. *Child: Care, Health and Development*, 33(1), 83-89.
- Creameens, J., Eiser, C. & Blades, M. (2006b). Characteristics of health-related self report measures for children aged three to eight years: A review of the literature. *Quality of Life Research*, 15(4), 739-754.
- Creameens, J., Eiser, C. & Blades, M. (2006c). Factors influencing agreement between child self-report and parent proxy-reports on the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. *Health and Quality of Life Outcomes*, 4(58), 1-8.

- Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Graham, H. K., Mehmet-Radji, O., & Boyd, R. (2006). Paediatric quality of life instruments: a review of the impact of the conceptual framework on outcomes. *Developmental Medicine & Child Neurology*, 48(4), 311-318.
- Dijkers, M. (1999). Measuring quality of life: Methodological issues. *American Journal of Physical Medicine Rehabilitation*, 78(3), 286-300.
- Dijkers, M. (2007). "What's in a name?" The indiscriminate use of the "Quality of life" label, and the need to bring about clarity in conceptualizations. *International Journal of Nursing Studies*, 44(1), 153-155.
- Egemen, A., Akil, I., Canda, E., Ozyurt, B. C., & Eser, E. (2008). An evaluation of quality of life in mothers of children with enuresis nocturna. *Pediatric Nephrology*, 23(1), 93-98.
- Eiser, C. (2007). No pain, no gain? Integrating QoL assessment in paediatrics. *Archives of Disease of Childhood*, 92(5), 379-380.
- Eiser, C. (1997). Children's quality of life measures. *Archives of Disease of Childhood*, 77(4), 350-354.
- Eiser, C. & Jenney, M. (2007). Measuring quality of life. *Archives of Disease of Childhood*, 92(4), 348-350.
- Eiser, C., Mohay, H., & Morse, R. (2000). The measurement of quality of life in young children. *Child: Care, Health and Development*, 26(5), 401-413.
- Eiser, C. & Morse, R. (2001a). A review of measures of quality of life for children with chronic illness. *Archives of Disease of Childhood*, 84(3), 205-211.

- Eiser, C. & Morse, R. (2001b). Quality-of-life measures in chronic diseases of childhood. *Health Technology Assessment*, 5(4), 1-156.
- Eiser, C. & Morse, R. (2001c). The measurement of quality of life in children: Past and future perspectives. *Developmental and Behavioral Pediatrics*, 22(4), 248-256.
- Ellsworth, P. & Caldamone, A. (2008). Pediatric voiding dysfunction: Current evaluation and management. *Urologic Nursing*, 28(4), 249-258.
- Farhat, W., Bagli, D. J., Capolicchio, G., O'Reilly, S., Merguerian, P. A., Khoury, A., & McLorie, G. A. (2000). The dysfunctional voiding scoring system: Quantitative standardization of dysfunctional voiding symptoms in children. *The Journal of Urology*, 164(3 pt 2), 1011-1015.
- Farhat, W., McLorie, G. A., O'Reilly, S., Khoury, A., & Bagli, D. J. (2001). Reliability of the pediatric dysfunctional voiding symptom score in monitoring response to behavioral modification. *The Canadian Journal of Urology*, 8(6), 1401-1405.
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41(pt 2), 126-135.
- Feldman, A., & Bauer, S. B. (2006). Diagnosis and management of dysfunctional voiding. *Current Opinions in Pediatrics*, 18(2), 139-147.
- Franco, I. (2007). Overactive bladder in children. Part I: Pathophysiology. *Journal of Urology*, 178(3), 761-768.

- Gerharz, E. W., Eiser, C., & Woodhouse, C. R. J. (2003). Current approaches to assessing the quality of life in children and adolescents. *British Journal of Urology International*, 91(2), 150-154.
- Gladh, G., Eldh, M., & Mattsson, S. (2006). Quality of life in neurologically healthy children with urinary incontinence. *Acta Paediatrica*, 95(12), 1648-1652.
- Glassberg, K. I. & Combs, A. J. (2009). Nonneurogenic voiding disorders: what's new? *Current Opinion in Urology*, 19(4), 412-418.
- Grange, A., Bekker, H., Noyes, J., & Langley, P. (2007). Adequacy of health-related quality of life measures in children under 5 years old: systematic review. *Journal of Advanced Nursing*, 59(3), 197-220.
- Haas, B. K. (1999). A multidisciplinary concept analysis of quality of life. *Western Journal of Nursing Research*, 21(6), 728-742.
- Hägglöf, B., Andrén, O., Bergström, E., Marklund, L., & Wendelius, M. (1997). Self-esteem before and after treatment in children with nocturnal enuresis and urinary incontinence. *Scandinavian Journal of Urology and Nephrology*, 31(Supplement 183), 79-82.
- Halachmi, S. & Farhat, W. (2008). The impact of constipation on the urinary tract system. *International Journal of Adolescent Medicine and Health*, 20(1), 17-22.
- Haque, M., Ellerstein, N. S., Gundy, J.H., Shelov, S. P., Weiss, J. C., McIntire, M. S., Olness, K. N., Jones, D.J., Heagarty, M. C., & Starfield, B. H. (1981).

- Parental perceptions of enuresis: A collaborative study. *American Journal of Diseases of Children*, 135(9), 809-811.
- Hellerstein, S. & Linebarger, J. S.(2003). Voiding dysfunction in pediatric patients. *Clinical Pediatrics*, 42(1), 43-49.
- Hellerström, A., Andersson, K., Hjälmås, K., & Jodal, U. (1986). Pad tests in children with incontinence. *Scandinavian Journal of Urology and Nephrology*, 20(1), 47-50.
- Herndon, C. D. A. & Joseph, D. B. (2006). Urinary incontinence. *Pediatric Clinics of North America*, 53(3), 363-377.
- Hörnquist, J. O. (1989). Quality of life: Concept and assessment. *Scandinavian Journal of Social Medicine*. 18(1), 69-79.
- Hörnquist, J. O. (1982). The concept of quality of life. *Scandinavian Journal of Social Medicine*. 10(2), 57-61.
- Horowitz, M. & Misseri, R. (2007). Diurnal and nocturnal enuresis. In Docimo, S., Canning, D., & Khoury (Eds). *The Kelalis-King-Belman textbook of clinical pediatric urology*, 5<sup>th</sup> edition, 819-840, Informa Healthcare, London.
- Jenney, M. E. M, & Campbell, S. (1997). Measuring quality of life. *Archives of Disease in Childhood*, 77(4), 347-354.
- Joensson, I. M., Siggaard, C., Rittig, S., Hagstroem, S., & Djurhuss, J. C. (2008). Transabdominal ultrasound of rectum as a diagnostic tool in childhood constipation. *The Journal of Urology*, 179(5), 1997-2002.

- Joinson, C., Heron, J., Emond, A., & Butler, R. (2007). Psychological problems in children with bedwetting and combined (day and night) wetting: A UK population-based study. *Journal of Pediatric Psychology*, 32(5), 605-616.
- Joinson, C., Heron, J., Von Gontard, A., & the ALSPAC Study Team (2006). Psychological problems in children with daytime wetting. *Pediatrics*, 118(5), 1985-1993.
- Joinson, C., Heron, J., Von Gontard, A., Butler, U., Golding, J., & Emond, A. (2008). Early childhood risk factors associated with daytime wetting and soiling in school-age children. *Journal of Pediatric Psychology*, 37(8), 739-750.
- Jokovic, A., Locker, D., & Guyatt, G. (2004). How well do parents know their children? Implications for proxy reporting of health-related quality of life. *Quality of Life Research*, 13(7), 1297-1307.
- Kajiwara, M., Inoue, K., Usui, A., Kurihara, M., & Usui, T. (2004). The micturation habits and prevalence of daytime urinary incontinence in Japanese primary school children. *Journal of Urology*, 171(1), 403-407.
- Kelleher, R. E. (1997). Daytime and nighttime wetting in children: A review of management. *Journal of the Society of Pediatric Nurses*, 2(2), 73-82.
- Kodman-Jones, C., Hawkins, L., & Schulman, S. L. (2001). Behavioral characteristics of children with daytime wetting. *The Journal of Urology*, 166(6), 2392-2395.
- Landgraf, J. M., Abidari, J., Cilento, B. G., Cooper, C. S., Schulman, S. L., & Ortenberg, J. (2004). Coping, commitment, and attitude: Quantifying the

- everyday burden of enuresis on children and their families. *Pediatrics*, 113(2), 334-344.
- Lawford, J., Volavka, N., & Eiser, C. (2001). A generic measure of quality of life for children aged 3-8 years: Results of two preliminary studies. *Pediatric Rehabilitation*, 4(4), 197-207.
- Lawford, J. & Eiser, C. (2001). Exploring links between concepts of quality of life and resilience. *Pediatric Rehabilitation*, 4(4), 209-216.
- Loening-Baucke, V. (2007). Prevalence rates for constipation and faecal and urinary incontinence. *Archives of Disease of Childhood*, 92(6), 486-489.
- Loening-Baucke, V. (1997). Urinary incontinence and urinary tract infection and their resolution with treatment of chronic constipation of childhood. *Pediatrics*, 100(2), 228-232.
- McGrath, K. H., Caldwell, P. H. Y., & Jones, M. P. (2008). The frequency of constipation in children with nocturnal enuresis: a comparison with parental reporting. *Journal of Paediatrics and Child Health*, 44(1-2), 19-27.
- McKenna, L. S. & McKenna, P. H. (2004). Modern management of nonneurologic pediatric incontinence. *Journal of Wound, Ostomy and Continence Nursing*, 31(6), 351-356.
- McKenna, P. H. & Herdon, C. D. (2000). Voiding dysfunction associated with incontinence, vesicoureteral reflux and recurrent urinary tract infections. *Current Opinion in Urology*, 10(6), 599-606.
- Meeberg, G. A. (1993). Quality of life: A concept analysis. *Journal of Advanced Nursing*, 18(1), 32-38.

- Minassian, V. A., Lovatsis, D., Pascali, D., Alarab, M. & Drutz, H. P. (2006).  
Effect of childhood dysfunctional voiding on urinary incontinence in adult women. *Obstetrics and Gynecology*, 107(6), 1247-1251.
- Munro, B. H. (2005). *Statistical methods for health care research*. (5th. ed.). Philadelphia, PA. Lippincott Williams & Wilkins, 239-286.
- Nelson, C. P., Park, J. M., Bloom, D. A., Wan, J., Dunn, R. L., & Wei, J. T. (2007). Incontinence symptom index-pediatric: Development and initial validation of a urinary incontinence instrument for the older pediatric population. *The Journal of Urology*, 178(2 pt 4), 1763-1767.
- Neumann, P. Z., deDomenico, I. J. & Nogrady, M. B. (1973). Constipation and urinary tract infection. *Pediatrics*, 52(2), 241-245.
- Neveus, T., Von Gontard, A., Hoebeke, P., Hjalmas, K., Bauer, S., Bower, W., Jorgensen, T. M., Rittig, S., Vande Walle, J., Yeung, C., & Djurhuus, J. C. (2006). The standardization of terminology of lower urinary tract function in children and adolescents: Report from the standardization committee of the International Children's Continence Society. *The Journal of Urology*, 176(1), 314-324.
- O'Regan, S., Yazbeck, S. & Schick, E. (1985). Constipation, bladder instability, urinary tract infection syndrome. *Clinical Nephrology*, 23(3), 152-154.
- Polit, D. F., Beck, C. T., & Hungler, B. P. (2001). *Essentials of nursing research: Methods, appraisal, and utilization*. (5th. ed.). Philadelphia, PA: Lippincott, 342-343.



- Raat, H., Mohangoo, A. D., & Grootenhuis, M. A. (2006). Pediatric health-related quality of life questionnaires in clinical trials. *Current Opinion in Allergy and Clinical Immunology*, 6(3), 180-185.
- Riegler, G. & Esposito, I. (2001). Bristol Scale Stool form. A still valid help in medical practice and clinical research. *Techniques in Coloproctology*, 5(3), 163-164.
- Robson, L. M. & Leung, A. K. C. (2006). An approach to daytime wetting in children. *Advances in Pediatrics*, 53(1), 323-365.
- Schast, A. P., Zderic, S. A., Richter, M., Berry, A., & Carr, M. C. (2008). Quantifying demographic, urological and behavioral characteristics of children with lower urinary tract symptoms. *Journal of Pediatric Urology*, 4(2), 127-133.
- Schulman, S. L. & Berry, A. K. (2007). A simple, step-wise approach to the child with daytime wetting. *Contemporary Urology*, 19(1), 19-29.
- Schulman, S. L. & Berry, A. K. (2006). Helping the child with daytime wetting stay dry. *Contemporary Pediatrics*, 23(6), 64-80.
- Sherifali, D. & Pinelli, J. (2007). Parent as proxy reporting: Implications and recommendations for quality of life research. *Journal of Family Nursing*, 13(1), 83-98.
- Sureshkumar, P., Cumming, R. G., Craig, J. C. (2006). Validity and reliability of parental report of frequency, severity and risk factors of urinary tract infection and urinary incontinence in children. *The Journal of Urology*, 175(6), 2254-2262.

- Sureshkumar, P., Craig, J. C., Roy, L.P., & Knight, J. F. (2001a). A reproducible pediatric daytime urinary incontinence questionnaire. *The Journal of Urology*, 165(2), 569-573.
- Sureshkumar, P., Craig, J. C., Roy, L.P., & Knight, J. F. (2001b). Daytime urinary incontinence in primary school children: A population-based survey. *The Journal of Pediatrics*, 137(6), 814-818.
- Tartar, R. E., Erb, S., Biller, P. A., Switala, J. & Van Thiel, D. H. (1988). The quality of life following liver transplantation: A preliminary report. *Gastroenterology clinics of North America*, 17(1), 207-217.
- Theunis, M., Van Hoecke, E., Paesbrugge, S., Hoebeke, P., Vande Walle, J. (2002). Self-image and performance in children with nocturnal enuresis. *European Urology*, 41(6), 660-667.
- Theunissen, N. C. M., Vogels, T. G. C., Koopman, H. M., Verrips, G. H. W., Zwinderman, S. P., Verloove-Vanhorick, S. P., & Wit, J. M. (1998). The proxy problem: child report versus parent report in health-related quality of life research. *Quality of Life Research*, 7(5), 387-397.
- Trajanovska, M. & Catto-Smith, A. G. (2005). Quality of life measures for fecal incontinence and their use in children. *Journal of Gastroenterology and Hepatology*, 20(6), 919-928.
- Tuygun, C., Sertcelik, N., Bakirtas, H., Cakici, H., Cetin, K., & Imamoglu, A. M. (2007). Usefulness of a new dysfunctional voiding and incontinence scoring system in predicting treatment effect in children with voiding dysfunction. *Urologia Internationalis*. 79(1):76-82.

- Upadhyay, J., Bolduc, S., Bagli, D. J., McLorie, G. A., Khoury, A. E., & Farhat, W. (2003). Use of the dysfunctional voiding symptom score to predict resolution of vesicoureteral reflux in children with voiding dysfunction. *The Journal of Urology*, 169(5), 1842-1846.
- Upadhyay, V., Mathai, J., & Reed, P.W.(2008). Primary school children: Access to toilets. *Acta Paediatrica*, 97(11), 1546-1549.
- Upton, P., Maddocks, A., Eiser, C., Barnes, P. M. & Williams, J. G. (2005). Development of a measure of the health-related quality of life of children in public care. *Child: Care, Health & Development*, 31(4), 409-415.
- Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). How young can children reliably and validly self-report their health-related quality of life? An analysis of 8,591 children across age subgroups with the PedsQL 4.0 Generic Core Scales, *Health and quality of life outcomes*, 5(1), 1-13.
- Vemulakonda, V. M. & Jones, E. A. (2006). Primer: diagnosis and management of uncomplicated daytime wetting in children. *Nature Clinical Practice, Urology*, 3(10), 551-559.
- Von Gontard, A. & Hollmann, E. (2004). Comorbidity of functional urinary incontinence and encopresis: Somatic and behavioral associations. *The Journal of Urology*. 171(6 Pt 2), 2644-7.
- Ward-Smith, P. & Barry, D. (2006). The challenge of treating enuresis. *Urologic Nursing*, 26(3), 222-224.

Wiener, J. S., Scales, M. T., Hampton, J., King, L. R., Surwit, R., & Edwards, C.

L. (2000). Long-term efficacy of simple behavioral therapy for daytime wetting in children. *The Journal of Urology*, 164(3 pt 1), 786-790.

Yazbeck, S., Schick, E., & O'Regan, S. (1987). Relevance of constipation to enuresis, urinary tract infection and reflux. *European Urology*, 13(5), 318-321.

**Appendix A**  
**Study Information Tables from Articles**

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
<p>Akbal, Yasemin, Burgu, Ozden, &amp; Tegul</p> <p>Dysfunctional voiding and incontinence scoring system: Quantitative evaluation of incontinence symptoms in pediatric population</p>	<p>2005</p>	<p>Development and validation of symptom scoring system to quantitatively evaluate incontinence in the pediatric population (DVAISS)</p>	<ul style="list-style-type: none"> <li>• Developed symptom scoring questionnaire with 13 items (daytime symptoms, nighttime symptoms, voiding habits, bowel habits &amp; quality of life-QOL)</li> <li>• 1 QOL question (impact of voiding dysfunction on family, social or school life)</li> <li>• Administered to parents of 2 groups</li> <li>• Each group - female: male ratio = 1.5:1</li> <li>• Group 1 – 86 pts in clinic with daytime wetting various voiding problems</li> <li>• Group 2 – 256 pts who had no urological symptoms</li> <li>• Parents completed the questionnaire</li> <li>• Excluded pts with anatomic abnormalities</li> </ul>	<ul style="list-style-type: none"> <li>• Total score range 0 - 35</li> <li>• Modified to 13 question + 1 quality of life question</li> <li>• Group 1 mean score = 18.56</li> <li>• Group 2 mean score = 2.88</li> <li>• Patients with score of 8.5 or greater had voiding abnormalities (90% sens &amp; 90% spec)</li> <li>• No statistical difference between genders or age (4-7 yrs or 8-10 yrs)</li> </ul>	<ul style="list-style-type: none"> <li>• Parental Recall bias – parent report may not be the same as child</li> </ul>
<p>Bachman, Lehr, Janhsen, Steuber, Gabel, Von Gontard</p> <p>German version of the Pediatric Incontinence Questionnaire for urinary incontinence health related quality of life</p>	<p>2009</p>	<p>Reliability and validity testing of German translation and cross-culturally adapted PinQ questionnaire</p>	<ul style="list-style-type: none"> <li>• Translated and cross culturally adapted English version of PinQ into German</li> <li>• July 2007 – August 2008 the German version was evaluated</li> <li>• 91 boys, 54 girls with non-neurogenic urinary incontinence</li> <li>• Age range 6-18 years (mean 9.3 years, SD 2.2 years)</li> <li>• German questionnaire compared with DCGM-10/-</li> </ul>	<ul style="list-style-type: none"> <li>• Reliability testing – self-reported and proxy versions - cronbach's alpha 0.84 and 0.86</li> <li>• Inter-rater convergence with DCGM-10/-12 (self-report and proxy) ICC 0.81 and correlated r=-0.71 and -0.69</li> <li>• Mean scores 23.0 boys, 23.9 girls</li> <li>• Age, sex, incontinence type, and severity were not significantly associated with</li> </ul>	<ul style="list-style-type: none"> <li>• Abstract only not full article</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
			12	German version total scores • “German version of PinQ is valid and reliable outcome measure to assess health related quality of life in children and adolescents with urinary incontinence”	
Bower, Wong, & Yeung  Development of a validated quality of life tool specific to children with bladder dysfunction	2006	To develop a cross cultural tool to measure the psychological impact of bladder dysfunction in children (PinQ)	<ul style="list-style-type: none"> <li>• Tool was developed in 3 stages: expert consultation with continence clinicians, design and administration of child-completed questionnaire, &amp; item analysis, validity &amp; reliability testing resulting in design of new tool</li> <li>• 6 domain questionnaire developed to assess psychological impact of bladder dysfunction developed from 33 experts from 13 countries with family feedback</li> <li>• Questionnaire was administered to children in 10 countries (Hong Kong, Japan, Australia, US, Italy, Turkey, Germany, Holland, Belgium &amp; Denmark</li> <li>• 156 child questionnaires returned</li> <li>• Age range 6-17yrs (38% younger than 8yrs, 50% 9-12yrs, 12% older than 12yrs)</li> <li>• 54.5% boys, 45.5% girls</li> </ul>	<ul style="list-style-type: none"> <li>• 54% European, 29% Asian, rest from North American or Australian</li> <li>• Incontinence - 46% nighttime only, 13% daytime only, 41% day &amp; nighttime</li> <li>• 88% bladder only, 22% bowel &amp; bladder problems</li> <li>• Variables expected to be higher by clinicians were rated lower by children (social, family &amp; body image)</li> <li>• Mental health &amp; independence rated 2 &amp; 3 by children</li> <li>• Self-esteem most impacted domain by clinicians &amp; children</li> <li>• Ceiling &amp; floor effect questions removed, individual items did not correlate with each other</li> <li>• Tested for structural validity, internal validity &amp; reliability</li> </ul>	<ul style="list-style-type: none"> <li>• Individual translation of questions by clinicians in different countries</li> <li>• Education level of child may impact understanding of questions</li> <li>• Low parent literacy may also skew results - Tool designed at primary school level</li> <li>• Socioeconomic factors may impact the scale – data was not collected</li> </ul>
Bower, Sit, Bluysen, Wong, & Yeung  PinQ: A valid, reliable and	2006	Test retest reliability testing on PinQ – Pediatric urinary incontinence quality of life tool	<ul style="list-style-type: none"> <li>• PinQ was translated and back translated from English to Chinese &amp; Dutch to check linguistic appropriateness or</li> </ul>	<ul style="list-style-type: none"> <li>• Intraclass correlation coefficient (ICC) between total scores &amp; factor scores showed excellent agreement</li> </ul>	<ul style="list-style-type: none"> <li>• Scoring of measure not available in article – have contacted author (W. Bower) and will send in future</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
reproducible quality-of-life measure in children with bladder dysfunction			ambiguity <ul style="list-style-type: none"> <li>• 40 Dutch &amp; Chinese children completed the questionnaire and then again 14 days later</li> <li>• Ages 6-15 yrs (mean age 9.18 yrs)</li> <li>• No new treatment was implemented between the two time periods</li> <li>• Parents completed proxy version of PinQ on 1<sup>st</sup> visit</li> <li>• Results analyzed to test retest validity</li> </ul>	<ul style="list-style-type: none"> <li>• Individual items showed excellent agreement in 5 cases &amp; moderate agreement in 14 cases</li> <li>• Overall proxy scores varied little from child report scores</li> <li>• 4 items showed poor agreement between parent &amp; child – worried about smell of urine on clothes, parents worry about problem, feel better without bladder problem, unhappy because of bladder problem</li> <li>• Total scores &amp; factor sub scores show excellent test retest reliability</li> <li>• Data shows that the negative effect of bladder dysfunction on the child's sense of worth may be poorly understood by parents &amp; children are adversely affected by the worry the bladder problem causes their parents</li> </ul>	<ul style="list-style-type: none"> <li>• Education level of child may impact understanding of questions</li> <li>• Low parent literacy may also skew results - Tool designed at primary school level</li> <li>• Socioeconomic factors may impact the scale – data was not collected</li> </ul>
Bower Self-reported effect of childhood incontinence on quality of life	2008	To generate an understanding of the child's perception of the impact of bladder and bowel dysfunction on aspects of the child's quality of life	<ul style="list-style-type: none"> <li>• Questionnaire was administered to children in 10 countries (Hong Kong, Japan, Australia, US, Italy, Turkey, Germany, Holland, Belgium &amp; Denmark)</li> <li>• 156 child questionnaires returned</li> <li>• Age range 6-17yrs (59-38% younger than 8yrs, 78-50% 9-12yrs, 18-12% older than 12yrs)</li> <li>• 54.5% boys, 45.5% girls</li> </ul>	<ul style="list-style-type: none"> <li>• Total score for each domain significantly correlated with individual domain scores</li> <li>• Significant correlation between poor treatment outcome with cumulative score &amp; individual domain scores</li> <li>• Self-esteem &amp; mental health significantly correlated with poor treatment outcome</li> <li>• Mean domain scores in descending order: self-</li> </ul>	<ul style="list-style-type: none"> <li>• Verbal administration of questionnaire by treating clinician</li> <li>• Presence of parent during questionnaire administration may have influenced child's answers</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
			<ul style="list-style-type: none"> <li>• 46% nighttime only, 13% daytime only, 41% day &amp; nighttime sx</li> <li>• 82% urinary sx only, 18% bowel &amp; bladder sx</li> </ul>	<p>esteem 57%, mental health 52%, independence 48.5%, family 46%, social interaction 43% &amp; body image 39.5%</p> <ul style="list-style-type: none"> <li>• Difference in self-esteem: boys <math>\bar{x}</math> 9.72 vs girls <math>\bar{x}</math> 8.44</li> <li>• Older children more nervous about bladder and anger of parents related to bladder problem whereas younger children had impact on sleep</li> <li>• All domain scores differed significantly if child had day, night or combined sx &amp; coexisting bowel problems</li> <li>• Body image scores were sig higher in boys with combined day and night sx in comparison to boys &amp; girls with only night sx</li> <li>• All domain scores higher if bowel sx reached sig with domains of self-esteem &amp; independence</li> <li>• More severely impaired QOL scores in boys with both day &amp; night urinary sx</li> <li>• Sig cultural differences in total domain scores in European &amp; Asian children</li> <li>• European scored sig higher in all domains but family</li> </ul>	
<p>Farhat, Bagli, Capolicchio, O'Reilly, Merguerian, Khoury, McLorie</p> <p>The dysfunctional voiding scoring system: Quantitative</p>	<p>2000</p>	<p>Development and testing of the pediatric dysfunction voiding symptom score (DVSS) to quantify or grade the severity of voiding dysfunction in children</p>	<ul style="list-style-type: none"> <li>• 10 pediatric age appropriate voiding dysfunction parameters modified from the I-PSS</li> <li>• Assigned scores of 0-3 with a total score ranging from 0-</li> </ul>	<ul style="list-style-type: none"> <li>• Group 1 had median symptom score of 14</li> <li>• Group 2 had median symptom score of 4 which significantly different (<math>p &lt; 0.0001</math>) –</li> </ul>	<ul style="list-style-type: none"> <li>• Possibility of interpretative bias with the utilization of a pediatric urology nurse assisting the child and family to complete the questionnaire</li> </ul>



Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
<p>standardization of dysfunctional voiding symptoms in children</p>			<p>30</p> <ul style="list-style-type: none"> <li>• DVSS was completed by 2 groups</li> <li>• Group 1 - 104 patients 3-10 yrs of age with female to male ratio 4:1 who presented to the pediatric urology clinic with hx of urinary incontinence, UTI, or abnormal voiding habits</li> <li>• Group 2 - 54 age matched cohort with no history of urological complaints presenting to other clinics in hospital</li> </ul>	<ul style="list-style-type: none"> <li>• Dysfunctional voiding odds ratio was 2.93 for females compared to males</li> <li>• Threshold score was for females was 6.026 (sen 92.77% &amp; spec 87.09%) &amp; 9.02 for males (sen 80.77% &amp; spec 91.30%)</li> <li>• Females with a score &gt;6 and males with a score &gt;9 are most likely to have dysfunctional voiding</li> </ul>	
<p>Farhat, McLorie, O'Reilly, Khoury &amp; Bagli</p> <p>Reliability of the pediatric dysfunctional voiding symptom score in monitoring response to behavioral modification</p>	<p>2001</p>	<p>Investigating whether the DVSS reflects compliance with behavioral modification</p>	<ul style="list-style-type: none"> <li>• 104 patients 3-10 yrs of age with female to male ratio 4:1 who were previously diagnosed with voiding dysfunction from previous study</li> <li>• Completed DVSS at initial diagnosis</li> <li>• Behavioural modification therapy taught at first visit</li> <li>• 5 months after initial visit sent DVSS survey in mail as well as questionnaire to assess compliance of behavioural modification</li> <li>• Compliance defined as parent satisfaction with child's cooperation with behavioural modification</li> <li>• 48/104 completed the second survey</li> <li>• Change in symptom score correlated with compliance or noncompliance</li> </ul>	<ul style="list-style-type: none"> <li>• Group 1 – 28/48 who were presumed to be compliant with behavioral modification (male:female ratio = 1:5, mean age 7.1 yrs with a mean follow-up of 4.8 months)</li> <li>• Group 2 – 20/48 pts who were presumed to be noncompliant (male:female ratio = 1:5, mean age 7.5 yrs with a mean follow-up of 4.6 months)</li> <li>• Group 1 &amp; 2 scores were similar on initial evaluation</li> <li>• Group 1 – change from 15 to 6.5 (p&lt;0.0001)</li> <li>• Group 2 – change from 14.5 to 11 (p&gt;0.05)</li> <li>• Group 1 scores were significantly lower on follow-up evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• DVSS may have decreased for reasons other than compliance to behavioural modification</li> <li>• Recall bias (parents over assessment of subjective information) – questions on DVSS designed to minimize effect of recall bias</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
<p>Gladh, Eldh &amp; Mattsson</p> <p>Quality of life in neurologically healthy children with urinary incontinence</p>	<p>2006</p>	<p>To develop further knowledge about how urinary incontinence influences the child's wellbeing</p>	<ul style="list-style-type: none"> <li>• Self rating quality of life questionnaire for children developed from an adult questionnaire</li> <li>• Quality of life instrument which included questions on urinary incontinence</li> <li>• Validity of questionnaire was statistically analyzed</li> <li>• 359 children divided into two groups</li> <li>• Group I – 120 children (83 girls &amp; 37 boys: 6-16 yrs) referred to clinic due to day and/or nighttime incontinence</li> <li>• Group II (control group) – 239 age matched school children (118 each boys &amp; girls + 3 unanswered questionnaire)</li> <li>• Group I – questionnaire administered in clinic prior to seeing physician</li> <li>• Group II – questionnaire administered in school classroom</li> </ul>	<ul style="list-style-type: none"> <li>• 31 children in the control group representing all age groups had day and/or nighttime incontinence (were excluded from the analysis)</li> <li>• No significant difference between boys &amp; girls in any domain in the control group</li> <li>• Patient group had significantly lower index both with and without items related to incontinence in comparison to the control group (p&lt; 0.0001)</li> <li>• Highly significant differences between the two groups in most domains (patient group scored lower)</li> <li>• Significant differences between the scoring of the continent and incontinent children in the control group</li> <li>• When comparing the patient group with the incontinent control group the patient group scored lower in a number of indices than the incontinent control group</li> <li>• The incontinent control group scored lower than the continent control group but higher than the patient group</li> <li>• Total and subtotal indices in age related subgroups were significantly lower in the patient group except for the older adolescent children</li> <li>• Social situation, self-esteem and self confidence were</li> </ul>	<ul style="list-style-type: none"> <li>• Questionnaire was developed from an adult instrument</li> <li>• No perfect QOL instrument for all purpose</li> <li>• Analysis based on total indices rather than individual domains</li> <li>• Types of incontinence not investigated between the control and patient groups (historically children with both day and nighttime incontinence have lower self-esteem than child with just nighttime wetting) which may have affected the results</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
				<p>domains most influenced especially in the younger children</p> <ul style="list-style-type: none"> <li>• Greatest differences in QOL domains were in the younger children</li> <li>• Patients scored lower in basic &amp; intellectual functioning, social relations, as well as actual well-being and self-esteem</li> </ul>	
<p>Misassian, Lovatsis, Pascali, Alarab, &amp; Drutz</p> <p>Effect of childhood dysfunctional voiding on urinary incontinence in adult women</p>	<p>2006</p>	<p>To determine whether childhood dysfunctional voiding hx is associated with urinary incontinence in adulthood</p>	<ul style="list-style-type: none"> <li>• Case control study</li> <li>• Surveyed patients presenting with and without urinary incontinence in tertiary urogynecology clinic</li> <li>• Controls- patients who were referred to general gynecology clinic</li> <li>• 84 cases &amp; 86 controls with similar baseline characteristics except for body mass index and incidence of pelvic surgery</li> <li>• Administered validated childhood questionnaire about dysfunctional voiding to patients (score of 6+ in girls is indicative of dysfunctional voiding)</li> </ul>	<ul style="list-style-type: none"> <li>• Dysfunctional voiding score in cases = 7.3 &amp; controls = 5.0 (p=0.001)</li> <li>• Difference in number of patients with dysfunctional voiding within the two groups was not significant (47 vs 36)</li> <li>• When all patients were combined there was a higher prevalence of childhood dysfunctional voiding in women with or without current urinary frequency (p=0.004), urgency (p=0.03), stress incontinence (p=0.01), &amp; urge incontinence (p=0.009)</li> </ul>	<ul style="list-style-type: none"> <li>• Recall bias - patients with current urinary incontinence may be more sensitized to remembering urinary problems in childhood</li> <li>• Dysfunctional voiding symptom score validated in children only</li> <li>• Referral filter bias - patients with lower urinary tract symptoms selected from urogynecology clinic are different from general population</li> <li>• Questionnaire study completed by patients without presence of research coordinator resulting in missing data or improper responses</li> </ul>
<p>Nelson, Park, Bloom, Wan, Dunn &amp; Wei</p> <p>Incontinence symptom index-pediatric: Development and initial validation of a urinary incontinence instrument for the older pediatric population</p>	<p>2007</p>	<p>Development &amp; validation of patient reported severity of urinary incontinence, symptom measurement &amp; bother survey</p>	<ul style="list-style-type: none"> <li>• Incontinence Symptom Index – Pediatric is an 11 item instrument covering 2 domains (impairment &amp; symptom severity)</li> <li>• Survey was self administered twice – 2 weeks apart</li> </ul>	<ul style="list-style-type: none"> <li>• Internal consistency by item scale correlations</li> <li>• Convergent validity with excellent correlation of symptom severity scale &amp; impairment scale (r = 0.818 p&lt; 0.0001)</li> <li>• Reliability for symptom</li> </ul>	<ul style="list-style-type: none"> <li>• Small sample size of 24</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
			<ul style="list-style-type: none"> <li>• Children completed the survey independently</li> <li>• Face validity confirmed by panel of pediatric urologists</li> <li>• Language adjusted to grade 5 reading level</li> <li>• Validity testing – 19 pts (aged 11-17 yrs, mean age 14.4 yrs) who attended pediatric urology clinic with complaint of urinary incontinence &amp; 19 pts with similar ages presenting to pediatric clinic for well checks</li> <li>• Convergent validity established by correlating symptom severity with impairment</li> </ul>	<p>severity score was high – impairment scale was lower</p> <ul style="list-style-type: none"> <li>• Discriminate validity was good with a significant difference between the total scores of the incontinent children (9.3) &amp; the controls (0.7) <math>p &lt; 0.0001</math></li> <li>• The impairment scale differed by 2.2 points (<math>p &lt; 0.0001</math>)</li> <li>• 24 subjects completed 2 surveys showing excellent test retest reliability (symptom severity score differed by 2 or fewer points &amp; the impairment scale differed by 1 or fewer in 92% of subjects)</li> </ul>	
<p>Schast, Zderic, Richter, Berry &amp; Carr</p> <p>Quantifying demographic, urological and behavioral characteristics of children with lower urinary tract symptoms</p>	<p>2008</p>	<p>To examine the voiding and behavioral characteristics of children referred to specialty voiding clinic including the impact of incontinence on the child and family</p>	<ul style="list-style-type: none"> <li>• 351 patients (5-17 years of age) referred to specialty voiding clinic</li> <li>• 53% female, 70% Caucasian with mean age of 9.5 years</li> <li>• 78% living in 2 parent household</li> <li>• 21% came from household with parental high school education or less</li> <li>• 25% dx with mental or behavioral health problem</li> <li>• Background information, demographics, medical history, standardized voiding questionnaire, school history, questions about child &amp; family QOL completed prior to initial appointment</li> </ul>	<ul style="list-style-type: none"> <li>• Mean urological symptom score of PLUSS was 12 (range 0-29) which is above clinical cut-off of 8.5 – 29% had score &lt; cut-off</li> <li>• 14% of children had daytime wetting, 34% nighttime wetting, 40% combined day &amp; nighttime wetting, 11% were not wet</li> <li>• 40% frequency or infrequent voiding, 59% urgency &amp; 41% constipation</li> <li>• 1/3 patients used holding maneuvers, had to void again after voiding or had wetting on way to BR</li> <li>• PLUSS score was significantly related to age (younger children &gt; older)</li> </ul>	<ul style="list-style-type: none"> <li>• Parents asked to consult with children regarding toileting habits but not sure whether they did – report of voiding symptomatology may be under reported</li> <li>• Data from parent or guardian so data is from only one perspective</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
			<ul style="list-style-type: none"> <li>• PLUSS (Pediatric Lower Urinary Symptom Score) previously Dysfunctional Voiding Symptom Score – 14 item measure to measure symptoms of voiding dysfunction</li> <li>• Emotional Functioning and Social Functioning Scales + The Daily Activities and Family Relationships Scales of the Family Impact Module of the PedsQL</li> </ul>	<p>children)</p> <ul style="list-style-type: none"> <li>• Children with minority race had higher PLUSS scores than Caucasian children &amp; were referred for bedwetting or day &amp; nighttime wetting</li> <li>• Children functioning at average school level had significantly lower symptom scores than peers who were failing or functioning at below average level</li> <li>• 24% of children had chronic medical condition – not associated with elevation of PLUSS score</li> <li>• Fecal soiling (38% of children) associated with higher PLUSS score</li> <li>• 20% of children had at least one UTI – not associated with PLUSS score</li> <li>• 25% dx learning or behavioral condition, 13% ADHD, 4% autism, 11% psychotropic drugs, 13% mental health counseling</li> <li>• Children with ADHD, learning or behavioral issues, or on psychotropic drugs had sig higher PLUSS scores</li> <li>• Families indicated good QOL (higher score indicates better QOL) – average scores for child items 82.8 (0-100) &amp; family functioning scale 82.9</li> <li>• PLUSS score negatively</li> </ul>	

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
				<p>correlated with degree of social and emotional difficulty related to sx (higher score associated with lower QOL)</p> <ul style="list-style-type: none"> <li>• Degree of symptomatology was negatively correlated with family QOL</li> <li>• Symptom score sig associated with degree of symptoms interfered with daily functioning</li> <li>• Children seriously affected by sx had higher scores than those sometimes or not affected</li> <li>• Family QOL suffered most when child wet both day &amp; night compared to day or night only</li> <li>• Children wet day &amp; night experienced more social &amp; emotional distress</li> </ul>	
<p>Sureshkumar, Cumming &amp; Craig</p> <p>Validity and reliability of parent report of frequency, severity, and risk factors of urinary tract infection and urinary incontinence in children</p>	<p>2006</p>	<p>Development and testing of questionnaire designed to determine frequency, severity and risk factors for UTI &amp; daytime urinary incontinence in primary school children</p>	<ul style="list-style-type: none"> <li>• Questionnaire was developed &amp; pilot tested with 10 parents of children with incontinence &amp; 10 parents in consultation with investigator – changes were made to the questionnaire and then retested on 5 parents</li> <li>• Questionnaire was translated into Arabic, Chinese &amp; Korean</li> <li>• Content validity – questionnaire was developed by experts in field</li> <li>• Criterion validity – Parental report of UTI correlated with</li> </ul>	<ul style="list-style-type: none"> <li>• Criterion validity – 2 fold variation between parent report of UTI &amp; culture results – parent reported UTI at 15% &amp; culture results 8% (sen 100% &amp; spec 68.5%)</li> <li>• Construct validity – 52 parents completed bladder diary &amp; questionnaire for same time period</li> <li>• Construct validity – 22% daytime urinary incontinence, 2% spots of urine on underclothes, 6% damp underwear, 8% wet soaking through clothes, 6%</li> </ul>	<ul style="list-style-type: none"> <li>• Small number of children with severe daytime urinary incontinence so instrument may not be valid for these pts</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
			bacteriological results (100 children randomly selected from primary school children – 50 with hx of UTI & 50 without hx of UTI) <ul style="list-style-type: none"> <li>• Criterion validity - Mean age 7.0 yrs (age range 4.6-9.8yrs)</li> <li>• Construct validity (compared retrospective questionnaire results with 3 month bladder diary)</li> <li>• Construct validity - mean age 6.6yrs, range 5.2 to 8.2</li> <li>• Reliability – Questionnaire administered to parents of 150 children &amp; repeated in 4 weeks</li> <li>• Reliability – mean age 7.8yrs (range 5.1-10.6yrs)</li> </ul>	puddle on seat or floor <ul style="list-style-type: none"> <li>• Construct validity – excellent agreement between bladder diary &amp; questionnaire</li> <li>• Reliability – 106 parents responded to questionnaire, substantial agreement between the 2 occasions of questionnaire administration</li> <li>• Tool had excellent test retest reliability, content &amp; criterion validity but parents over reported the incidence of UTI by almost 2 times</li> <li>• Questionnaire measures daytime urinary incontinence by frequency, severity of leakage, &amp; symptoms of daytime urinary incontinence &amp; UTI in children</li> </ul>	
Sureshkumar, Craig, Roy & Knight  A reproducible pediatric daytime urinary incontinence questionnaire	2001	Developed and tested the reliability of parent administered questionnaire to determine the prevalence and risk factors for daytime urinary incontinence in children - administered to parents twice 4 weeks apart	<ul style="list-style-type: none"> <li>• 16 questions relate to daytime and nighttime urinary incontinence, voiding habits, family history of daytime urinary incontinence &amp; socioeconomic status</li> <li>• Administered questionnaire to parents of 212 kindergarten children 3.5-7 yrs of age (54% boys) from randomly selected schools within 25km radius of New Children's Hospital in Westmead Australia -</li> </ul>	<ul style="list-style-type: none"> <li>• 78% response rate - 166 responded to questionnaire</li> <li>• Mean subject age 5.6 yrs</li> <li>• Overall there was substantial agreement between the 2 questionnaires for most questions</li> <li>• In 12 cases the answers for the question on daytime wetting differed between the 1<sup>st</sup> &amp; 2<sup>nd</sup> questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• No age effect but the results cannot be extrapolated to older children</li> <li>• Discrepancy in agreement with daytime wetting question may be related to change in symptoms over the 4 week period</li> </ul>
Tuygen, Sertcelik, Bakirtas, Cakici, Cetin, & Imamoglu  Usefulness of a new dysfunctional voiding and	2007	To assess the role of the dysfunctional voiding and incontinence scoring system (DVAISS) in children with voiding dysfunction	<ul style="list-style-type: none"> <li>• DVAISS composed of 13 questions &amp; 1 quality of life question which have a total score range of 0-35</li> <li>• Total score of ≥9 indicates</li> </ul>	<ul style="list-style-type: none"> <li>• Group 1 – 27 pts complete response (67.5%), 7 pts partial response, 6 pts no response, recurrence seen in 4 pts</li> </ul>	<ul style="list-style-type: none"> <li>• The sensitivity of the DVAISS is higher in predicting treatment effect but specificity is decreased</li> </ul>

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
<p>incontinence scoring system in predicting treatment effect in children with voiding dysfunction</p>			<p>voiding dysfunction, score of &lt;9 indicates absence of voiding dysfunction</p> <ul style="list-style-type: none"> <li>• 93 children with voiding dysfunction were divided into 3 groups: 40 pts with wetting only (mean age 8 yrs, range 6-11yrs), 18 pts with UTI's &amp; wetting (mean age 8.5 yrs range 6-12 yrs), 35 pts with Reflux, wetting &amp; recurrent UTI (mean age 7.5 yrs, range 5-12 yrs)</li> <li>• Male:female ratio: Group 1 = 1.6, Group 2 = 0.3, Group 3 = 0.35</li> <li>• Follow up: Group 1 = 15 months (range 9-22), Group 2 = 17 months (range 10-24) &amp; Group 3 = 15.5 months (range 12-25)</li> <li>• Children with bedwetting or anatomic abnormalities were excluded</li> <li>• Initial exams include hx, PE, voiding symptoms, voiding diary, ultrasound, uroflow, &amp;/or VCUG</li> <li>• Individualized treatment was given to the patients based on diagnosis</li> <li>• Patients were followed every 3-6 months for 2 yrs &amp; reevaluated on DVAISS, voiding diary, urinalysis</li> <li>• Outcomes were graded complete response (reduction of wetting by 90%), partial response</li> </ul>	<ul style="list-style-type: none"> <li>• Group 2 – 16 pts complete response (88.8%), 2 partial response, recurrence seen in 6 pts</li> <li>• Group 3 - 30 complete response (85.1%), 5 no response, recurrence seen in 4 pts, complete resolution of reflux in 19 pts, decreased reflux grade in 6 pts, 5 pts no change in reflux</li> <li>• The severity &amp; frequency of wetting episodes of pts in group 3 was significantly less than the other groups at the start of treatment</li> <li>• Resolution of reflux more common in pts who undergone failed STING procedures previously</li> <li>• The specificity of the DVAISS in predicting complete response for Group 1 = 79%, Group 2 = 88% &amp; Group 3 = 100%</li> <li>• The sensitivity was 100% in all groups</li> <li>• The sensitivity of the DVAISS is higher in predicting treatment effect but specificity is decreased</li> <li>• Recommend use as an auxiliary diagnostic tool in voiding dysfunction</li> </ul>	



Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
			(reduction of wetting by 50-90%) or no response (less than 50% reduction) • Group 3 was also graded on complete resolution of reflux or 2-grade decrease in reflux grade • Recurrence graded as increase of symptoms on follow-up after improvement or resolution of symptoms		

Author(s) & Title	Year	Study Objectives	Sample / Study Information	Findings	Limitations
<p>Upadhyay, Bolduc, Bagli, McLorie, Khoury, Farhat</p> <p>Use of the dysfunctional voiding symptom score to predict resolution of vesicoureteral reflux in children with voiding dysfunction</p>	<p>2003</p>	<p>Utilization of the dysfunctional voiding symptom score (DVSS) to evaluate the association of dysfunctional voiding with vesicoureteral reflux (VUR)</p>	<ul style="list-style-type: none"> <li>• 114 pts with dysfunctional voiding were placed on behavioral modification in 1998</li> <li>• 58/114 pts (51%) presented with UTI – 27 pts (47%) had abnormal VCUG including 19 with reflux only</li> <li>• Baseline &amp; follow up DVSS score were obtained for the 19 pts</li> <li>• 19 pts underwent prospective observation &amp; behavioral therapy</li> <li>• All pts were female with mean age of 6.7 years with grades I-V reflux and a mean follow up of 24 months</li> <li>• 5 pts had bilateral VUR</li> </ul>	<ul style="list-style-type: none"> <li>• Dysfunctional voiding score was similar between the groups with a mean DVSS of 13.3 in 31 pts with normal VCUG and 11.7 in 19 pts with reflux (p=0.06)</li> <li>• Overall 11 pts had a significant decrease in their DVSS with concomitant resolution or improvement of their reflux</li> <li>• Reflux completely resolved in 7 pts</li> <li>• No improvement of reflux was noted in 8 pts who had a initial mean DVSS of 14.4 and post score of 11.1 (not statistically significant p=0.18)</li> <li>• 2 pts had worsening of their reflux &amp; DVSS</li> <li>• 4 pts had breakthrough UTI with no improvement of reflux required corrective surgery</li> <li>• Significant difference in UTIs between those with persistent vs resolved or improved reflux (p&lt;0.02)</li> </ul>	<ul style="list-style-type: none"> <li>• Small cohort of patients with VUR</li> </ul>

**Appendix B**  
**Dysfunctional Voiding Symptom Score - Child Form**

Name: \_\_\_\_\_ Date: \_\_\_\_\_ Date of Birth: \_\_\_\_\_  
 Male     Female    Completed by:  Child     Parent

Over the last month	Almost Never	Less than half the time	About half the time	Almost every time	Don't know
1. I have had wet clothes or wet underwear during the day.					
2. When I wet myself, my underwear is soaked.					
3. I miss having a bowel movement every day.					
4. I have to push for my bowel movements to come out.					
5. I only go to the bathroom one or two times each day.					
6. I can hold onto my pee by crossing my legs, squatting or doing the "pee dance"					
7. When I have to pee, I cannot wait.					
8. I have to push to pee.					
9. When I pee it hurts.					
10. Parents to answer. Has your child experienced something stressful like the example below? <ul style="list-style-type: none"> <li>• New Baby</li> <li>• New Home</li> <li>• New School</li> <li>• School Problems</li> <li>• Abuse (sexual / physical)</li> <li>• Home Problems (divorce / death)</li> <li>• Special Events (Birthday)</li> <li>• Accident / Injury</li> <li>• Others</li> </ul>	No			Yes	
<b>Total Score</b>					

Farhat, W., Bagli, D. J., Capolicchio, G., O'Reilly, S., Merguerian, P. A., Khoury, A., & McLorie, G. A. (2000). The dysfunctional voiding scoring system: Quantitative standardization of dysfunctional voiding symptoms in children. *The journal of urology*, 164(3 pt 2), 1011-1015.

**Dysfunctional Voiding Symptom Score - Parents Form**

Name: \_\_\_\_\_ Date: \_\_\_\_\_ Date of Birth: \_\_\_\_\_  
 Male  Female Completed by:  Child  Parent

Over the last month	Almost Never	Less than half the time	About half the time	Almost every time	Don't know
1. My child has had wet clothes or wet underwear during the day.					
2. When my child wets, his/her underwear is soaked.					
3. My child misses having a bowel movement every day.					
4. My child has to push for his/her bowel movements to come out.					
5. My child only goes to the bathroom one or two times each day.					
6. My child can hold onto his/her pee by crossing his/her legs, squatting or doing the "pee dance"					
7. When my child has to pee, he/she cannot wait.					
8. My child has to push to pee.					
9. My child complains of pain when he/she pees.					
10. Has your child experienced something stressful like the example below? <ul style="list-style-type: none"> <li>• New Baby</li> <li>• New Home</li> <li>• New School</li> <li>• School Problems</li> <li>• Abuse (sexual / physical)</li> <li>• Home Problems (divorce / death)</li> <li>• Special Events (Birthday)</li> <li>• Accident / Injury</li> <li>• Others</li> </ul>	No		Yes		
Total Score					

Farhat, W., Bagli, D. J., Capolicchio, G., O'Reilly, S., Merguerian, P. A., Khoury, A., & McLorie, G. A. (2000). The dysfunctional voiding scoring system: Quantitative standardization of dysfunctional voiding symptoms in children. *The journal of urology*, 164(3 pt 2), 1011-1015.

**Scoring Sheet for the Dysfunctional Voiding Symptom Score (DVSS)**

Over the last month	Almost Never	Less than half the time	About half the time	Almost every time	Not available
1. I have had wet clothes or wet underwear during the day.	0	1	2	3	NA
2. When I wet myself, my underwear is soaked.	0	1	2	3	NA
3. I miss having a bowel movement every day.	0	1	2	3	NA
4. I have to push for my bowel movements to come out.	0	1	2	3	NA
5. I only go to the bathroom one or two times each day.	0	1	2	3	NA
6. I can hold onto my pee by crossing my legs, squatting or doing the "pee dance"	0	1	2	3	NA
7. When I have to pee, I cannot wait.	0	1	2	3	NA
8. I have to push to pee.	0	1	2	3	NA
9. When I pee it hurts.	0	1	2	3	NA
10. Parents to answer. Has your child experienced something stressful like the example below? <ul style="list-style-type: none"> <li>• New Baby</li> <li>• New Home</li> <li>• New School</li> <li>• School Problems</li> <li>• Abuse (sexual / physical)</li> <li>• Home Problems (divorce / death)</li> <li>• Special Events (Birthday)</li> <li>• Accident / Injury</li> <li>• Others</li> </ul>	No (0)			Yes (3)	
<b>Total Score</b>					

Questions predictive of Dysfunctional Voiding in both males and females: 1, 4, 6, 7

Threshold Score for Dysfunctional Voiding: Females = 6 Males = 9

Farhat, W., Bagli, D. J., Capolicchio, G., O'Reilly, S., Merguerian, P. A., Khoury, A., & McLorie, G. A. (2000). The dysfunctional voiding scoring system: Quantitative standardization of dysfunctional voiding symptoms in children. *The journal of urology*, 164(3 pt 2), 1011-1015

**Appendix C**

**PinQ: Impact of Bladder Function, Dysfunction and Treatment on the Quality of Life of Children with Bladder Dysfunction - Child Form**

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Child's Age: \_\_\_\_\_ years    DOB: \_\_\_\_\_    Gender:  Male  
 Female

Child's Symptoms:

Daytime Only     Night Only     Day and Night     Bladder Only   

Bladder and Bowel

Length of treatment at time of interview: \_\_\_\_\_ months

1. I get shy because of my bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
2. People in my family treat me in a different way because of my bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
3. I am worried that people might think my clothes smell of pee.  
 No     Hardly Ever     Sometimes     Often     All the time
4. I think that my bladder problem won't get better.  
 No     Hardly Ever     Sometimes     Often     All the time
5. Mom and dad worry about me because of my bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
6. I would feel better about myself if I didn't have a bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
7. My bladder problem makes me feel nervous.  
 No     Hardly Ever     Sometimes     Often     All the time
8. Mom or dad sometimes seem a bit cranky because of my bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
9. My bladder problem stops me going on sleep-overs or holidays.  
 No     Hardly Ever     Sometimes     Often     All the time
10. My bladder problem makes me feel bad about myself.  
 No     Hardly Ever     Sometimes     Often     All the time
11. I wake up during my sleep because of my bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time

12. I miss out on doing things because of my bladder problem  
 No    Hardly Ever    Sometimes    Often    All the time
13. I feel unhappy because of my bladder problem.  
 No    Hardly Ever    Sometimes    Often    All the time
14. My bladder problem makes me feel sad.  
 No    Hardly Ever    Sometimes    Often    All the time
15. I think about my bladder problem when choosing which sport to play.  
 No    Hardly Ever    Sometimes    Often    All the time
16. I have to go to the toilet when I'm watching a movie.  
 No    Hardly Ever    Sometimes    Often    All the time
17. If my bladder problem was fixed I would invite more friends to my house.  
 No    Hardly Ever    Sometimes    Often    All the time
18. I choose hobbies that won't be spoiled by stopping to go to the toilet.  
 No    Hardly Ever    Sometimes    Often    All the time
19. My bladder problem makes me feel different to other people.  
 No    Hardly Ever    Sometimes    Often    All the time
20. I miss out on being with friends because of my bladder problem.  
 No    Hardly Ever    Sometimes    Often    All the time

Bower, W. F., Sit, F. K. Y., Bluysen, N., Wong, E. M. C., & Yeung C. K. (2006). PinQ: A valid, reliable and reproducible quality-of-life measure in children with bladder dysfunction. *Journal of Pediatric Urology*, 2(3), 185-189.

**PinQ: Impact of Bladder Function, Dysfunction and Treatment on the Quality of Life of Children with Bladder Dysfunction - Parent Form**

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Child's Age: \_\_\_\_\_ years

DOB: \_\_\_\_\_

Gender:  Male

Female

Child's Symptoms:

Daytime Only     Night Only     Day and Night     Bladder Only   

Bladder and Bowel

Length of treatment at time of interview: \_\_\_\_\_ months

1. My child is shy because of his/her bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
2. I treat my child in a different way because of his/her bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
3. My child worries that people might think his/her clothes smell of pee.  
 No     Hardly Ever     Sometimes     Often     All the time
4. My child thinks that his/her bladder problem won't get better.  
 No     Hardly Ever     Sometimes     Often     All the time
5. I worry about my child because of his/her bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
6. My child would feel better about himself/herself if he/she didn't have a bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
7. My child's bladder problem makes him/her feel nervous.  
 No     Hardly Ever     Sometimes     Often     All the time
8. I sometimes seem a bit cranky because of my child's bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
9. My child's bladder problem stops him/her going on sleep-overs or holidays.  
 No     Hardly Ever     Sometimes     Often     All the time
10. My child's bladder problem makes him/her feel bad about himself/herself.  
 No     Hardly Ever     Sometimes     Often     All the time
11. My child wakes up during his/her sleep because of his/her bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time
12. My child misses out on doing things because of his/her bladder problem



- No     Hardly Ever     Sometimes     Often     All the time  
 13. My child feels unhappy because of his/her bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time  
 14. My child's bladder problem makes him/her feel sad.  
 No     Hardly Ever     Sometimes     Often     All the time  
 15. My child thinks about his/her bladder problem when choosing which sport to play.  
 No     Hardly Ever     Sometimes     Often     All the time  
 16. My child has to go to the toilet when he/she is watching a movie.  
 No     Hardly Ever     Sometimes     Often     All the time  
 17. If my child's bladder problem were fixed he/she would invite more friends to our house.  
 No     Hardly Ever     Sometimes     Often     All the time  
 18. My child chooses hobbies that won't be spoiled by stopping to go to the toilet.  
 No     Hardly Ever     Sometimes     Often     All the time  
 19. My child's bladder problem makes him/her feel different to other people.  
 No     Hardly Ever     Sometimes     Often     All the time  
 20. My child misses out on being with friends because of his/her bladder problem.  
 No     Hardly Ever     Sometimes     Often     All the time

Bower, W. F., Sit, F. K. Y., Bluysen, N., Wong, E. M. C., & Yeung C. K. (2006). PinQ: A valid, reliable and reproducible quality-of-life measure in children with bladder dysfunction. *Journal of Pediatric Urology*, 2(3), 185-189.

**Appendix D**  
**VOIDING DYSFUNCTION AND**  
**QUALITY OF LIFE IN CHILDREN STUDY**  
**INFORMATION SHEET FOR PARENTS**



You and your child have been asked to take part in a research study about wetting in children. Please read this sheet before signing the consent for this study.

**PURPOSE OF STUDY**

This study is to see how wetting affects children..

**LENGTH OF STUDY AND NUMBER OF VOLUNTEERS:**

This study will sign up at least 60 kids with wetting who attend the Stollery Pediatric Urology Clinics during a 4 month time period.

**STUDY PROCEDURES**

If your child is enrolled in the study, both you and your child will be asked to fill out two questionnaires about your child's wetting. The questionnaires will be filled out during your clinic appointment. They should take 10 – 15 minutes to fill out. You will also be given a voiding diary and a stooling diary to be filled out at home. The voiding and stooling diaries will be mailed back to the research nurse in the envelopes provided. Your child may also be asked to wear a pull-up or pad for 24 hours. Your child does not have to wear the pads or pull-ups if he/she does not want to wear them. This will help us learn more about your child's wetting.

If the questionnaires cannot be filled out in the clinic, the research nurse will need to come to your home to fill out the questionnaires for the study.

**VOLUNTARY PARTICIPATION & CONSENT**

This study will not occur without your consent or your child's assent. You and your child do not have to take part in this study. If you or your child chooses not to take part in the study, it will not affect the medical care your child receives in the Pediatric Urology Clinic. Both you and your child are free to withdraw from this study at anytime.

**CONFIDENTIALITY**

All personal records from this study will be kept completely confidential. All research data collected about your child will not identify him/her by name, only by initials and a coded number. Every effort will be made to maintain confidentiality and anonymity at all times. Any report published about the data collected in this study will not identify your child by name. All study information will be maintained in a locked cabinet for 7 years after the study is finished.

For this study, the study nurse or doctor may need to access your personal health records for health information such as past medical history and test results. The health information collected as part of this study will be kept confidential unless release is required by law, and will be used only for the purpose of the research study. By signing the consent form you give permission to the study staff to access any personally

identifiable health information which is under the custody of other health care professionals as deemed necessary for the conduct of the research.

**BENEFITS OF PARTICIPATING IN THIS STUDY:**

It is not possible to predict whether any personal benefit will result from taking part in this study. Taking part in this study may help other children with wetting.

**RISKS OF PARTICIPATING IN THIS STUDY:**

There is no anticipated harm from completing the questionnaires. Every effort will be made to prevent upset to your child. Wetting can be upsetting to your child's sense of worth and self esteem as well as to your family's quality of life. Many children who wet themselves may be teased by other children. If you feel your child requires more support to cope with his/her wetting, the research nurse will refer you to an appropriate source.

**FURTHER DATA ANALYSIS**

The information obtained during this study may be looked at again during future studies. Ethical approval will be obtained prior the use of this data in future studies.

**WHOM TO CONTACT:**

Please contact the nurse below if you have any questions regarding this study:

<b>Betty Ann Thibodeau Pediatric Urology Nurse Practitioner Intern, Study Coordinator, MN Student University of Alberta Faculty of Nursing</b>	Phone (780) 407-7010 Pager (780) 445-2880
--	--

If you have concerns about your rights as a study participant, you may contact the Patient Relations Office of Capital Health at 407-1040 or Dr. Christine Newburn-Cook, Associate Dean for Research, Faculty of Nursing, University of Alberta at 492-3769. This office has no affiliation with the study investigators.



**VOIDING DYSFUNCTION AND  
QUALITY OF LIFE IN CHILDREN STUDY**

**INFORMATION SHEET FOR CHILDREN (4- 6 YEARS OF AGE)**

You as well as your mom or dad have been asked to answer some questions about your wetting. The nurse or your mom or dad will read this paper to you before you take part in this study.

**REASON FOR STUDY**

To learn about kids who wet and how to help.

**WHAT WILL YOU HAVE TO DO**

If you want to take part in this study, you will be asked about your wetting and how it makes you feel. You may also be asked to wear a pad or pull-up on a weekend. We want to see how much wetting you have.

**CAN YOU QUIT?**

You can say “no” that you don’t want to be in the study. You can stop anytime. No one will be mad at you if you decide you don’t want to do this. If you want to stop, tell the doctor or nurse.

**WHO WILL KNOW?**

The only your mom or dad and the nurse will know you are in the study.

This study may help other kids with wetting.

**DO YOU HAVE MORE QUESTIONS?**

You can ask your mom or dad about you do things you do not understand. You can also talk to the nurse about the study if you are unsure:

<p><b>Betty Ann Thibodeau</b>  <b>Pediatric Urology Nurse Practitioner Intern, Study</b>  <b>Coordinator</b>  <b>MN Student University of Alberta Faculty of Nursing</b></p>	<p>Phone (780) 407-7010                  Pager (780) 445-2880</p>
--	---

If you or your parents are worried about being in this study, you may contact the Patient Relations Office of Capital Health at 407-1040 or Dr. Christine Newburn-Cook, Associate Dean for Research, Faculty of Nursing, University of Alberta at 492-3769. These people are not part of this study.



**VOIDING DYSFUNCTION AND QUALITY OF LIFE  
IN CHILDREN STUDY**

**INFORMATION SHEET FOR CHILDREN (7-10YEARS OF AGE)**

You have been asked to take part in a study looking at wetting in kids. Please read this paper before taking part in this study.

**PURPOSE OF STUDY**

To learn about kids who have wetting and how it affects them.

**WHAT WILL YOU HAVE TO DO**

If you agree to take part in this study, both you and your parents will be asked to fill out two questionnaires. You may also be asked to wear a pad or pull-up for 24 hours over a weekend. We want to see how much wetting you have. Only your parents and the nurse will know that you are wearing the pad or pull-up.

The nurse may have to come to your home, if the questionnaires cannot be filled out in the clinic.

**CAN YOU QUIT?**

You don't have to take part in the study. You can stop at any time. No one will be mad at you if you decide you don't want to do this, or if you decide to stop part way through. You should tell the doctor or nurse that you want to stop.

**WHO WILL KNOW?**

No one except your parents and the nurse or doctor will know you're taking part in the study unless you want to tell them. Your name and your chart won't be seen by anyone except the doctors and nurses during the study.

**FURTHER DATA ANALYSIS**

The information from this study may be used in future studies of kids with problems peeing.

**DO YOU HAVE MORE QUESTIONS?**

You can ask your mom or dad about anything you do not understand. You can also talk to the nurse about the study:

<p><b>Betty Ann Thibodeau</b>  <b>Pediatric Urology Nurse Practitioner Intern, Study</b>  <b>Coordinator</b>  <b>MN Student University of Alberta Faculty of Nursing</b></p>	<p>Phone (780) 407-7010  Pager (780) 445-2880</p>
--	---

If you or your parents are worried about being in this study, you may contact the Patient Relations Office of Capital Health at 407-1040 or Dr. Christine Newburn-Cook, Associate Dean for Research, Faculty of Nursing, University of Alberta at 492-3769. These people are not part of this study.

**PARENT CONSENT FORM**



**Title of Project: Voiding Dysfunction and Quality of Life in Children**

**Principal Investigator: Katherine Moore**

**Phone Number: (780) 492-1541**

**Co Investigators: Priscilla Koop  
Dr. Peter Metcalfe**

**Phone Number: (780) 492-2962  
Phone Number: (780) 407-3867**

**Research Nurse: Betty Ann Thibodeau**

**Phone Number: (780) 407-7010**

**Part 2 (to be completed by the research subject):**

	<u>Yes</u>	<u>No</u>
<b>Do you understand that you and your child have been asked to participate in a research study ?</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Have you read and received a copy of the attached Information Sheet?</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Do you understand the benefits and risks involved in taking part in this research study?</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Have you had an opportunity to ask questions and discuss this study?</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Do you understand that you are free to withdraw your child from the study at any time, without having to give a reason and without affecting your child's future medical care?</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Do you understand who will have access to your child's records, including personally identifiable health information?</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Do you want the investigator(s) to inform your child's family doctor or pediatrician that your child is participating in this research study? Doctor's name _____</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Who explained this study to you? _____</b>		

**Child's Name** \_\_\_\_\_

I agree for my child to take part in this study: YES  NO

Signature of Parent or Guardian \_\_\_\_\_ Date & Time \_\_\_\_\_

(Printed Name) \_\_\_\_\_

Signature of Witness \_\_\_\_\_ Date & Time \_\_\_\_\_

Signature of Investigator or Designee \_\_\_\_\_ Date & Time \_\_\_\_\_

**THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT**

**VOIDING DYSFUNCTION AND QUALITY OF LIFE IN CHILDREN  
INFORMATION SHEET AND ASSENT FORM  
(CHILDREN 4- 6 YEARS OF AGE)**



Principal Investigator(s): Katherine Moore, Associate Dean of Graduate Studies,  
University of Alberta Faculty of Nursing

Co-Investigator(s):  
Priscilla Koop, Associate Professor University of Alberta Faculty of Nursing  
Dr. Peter Metcalf, Pediatric Urologist, University of Alberta Faculty of Medicine  
Betty Ann Thibodeau, RN, MN Student, University of Alberta Faculty of Nursing

In this study we would like to learn about kids who wet and how to help them. You as well as your mom or dad have been asked to answer some questions about your wetting.

What will you have to do? If you want to take part in this study, you will be asked about your wetting and how it makes you feel. You may also be asked to wear a pad or pull-up on a weekend. We want to see how much wetting you have.

Can you quit? You can say “no” that you don’t want to be in the study. You can stop anytime. No one will be mad at you if you decide you don’t want to do this. If you want to stop, tell the doctor or nurse.

Who will know? Unless you tell people, only your mom, dad, doctor or nurse will know you are in the study. Your information will not be seen by anyone except the doctors and nurses in the study. The information you give may be used again in studies about kids with wetting.

Your signature: We would like you to sign this form to show that you agree to take part. Your mom or dad will be asked to sign another form agreeing for you to take part in the study.

Do you have more questions? You can ask your mom or dad about anything you don’t understand. You can also talk to Betty Ann Thibodeau. Her phone number is 407-7010.

I agree to take part in the study.

Name of Research Participant	Signature of Research Participant	Date
Name of Witness	Signature of Witness	Date
Name of Investigator	Signature of Investigator	Date