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ELIMINATION DISORDERS IN A GROUP OF SOUTH AFRICAN CHILDREN

Firuzan Patel

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Science in the branch of Medicine (Neurodevelopmental Paediatrics).

Johannesburg, 2010

DECLARATION

I, Firuzan Patel, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Medicine in the branch of Neurodevelopmental Paediatrics, in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

…….

31st day of January, 2010

DEDICATION

In memory of

Dr K N Dastur (1917 – 1992)

and

Dr Harry Patel (1950 – 2006)

ABSTRACT

Background: Elimination disorders are childhood behavioural disorders. In South Africa these disorders fall within a neglected field of study when compared to physical illnesses. This report serves as formative research in order to address this neglect.

Aims: To identify and summarise the clinical presentations, age and gender distribution, associated comorbid disorders and psychosocial factors in our mainly black patients from Soweto, Johannesburg, South Africa.

Methodology: One hundred and sixteen children aged 4 – 14 years with these conditions were enrolled into a descriptive prevalence or survey study over a period of three years. An interview questionnaire was explained and responses recorded, from the caregivers and subjects.

Result: There were 72 males and 44 females and their mean age at presentation was 9 years. More males suffered from encopresis only and both elimination disorders than females. There was only one female with encopresis alone. More females had enuresis than males. A greater percentage of subjects had primary enuresis as compared to encopresis, which was predominantly secondary in nature. Mental retardation, learning disability and ADHD were common comorbid conditions.

Conclusion: The prevalence of elimination disorders in children attending an outpatient paediatric facility does justify the need for a specialised elimination disorder clinic. This clinic needs to be accommodated within an ambulatory paediatric unit such as the paediatric outpatients department of the Chris Hani Baragwanath Hospital.

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
CHBH	Chris Hani Baragwanath Hospital
CHC	Community Health Centres / primary health care clinic
CNS	Central nervous system
CSA	Child sexual abuse
E D	Elimination disorders
GP	General Practitioner or private primary care physician
H	Hour/s
L D	Learning disability / dysfunction
$L_1 - S_4$	Spinal segments lumbar 1 up to sacral 4
MR	Mental retardation
MSE	Mono symptomatic enuresis
MSNE	Mono symptomatic nocturnal enuresis
NA	Not applicable or not available
NMSE	Non mono symptomatic enuresis
NMSNE	Non mono symptomatic nocturnal enuresis
NVD	Normal vaginal delivery
ODD	Oppositional defiant disorder
POPD	Paediatric outpatients department
T	Toilet
UTI	Urinary tract infection/s

GLOSSARY OF TERMS

Elimination Disorders comprise disorders of voiding viz. encopresis, enuresis and both conditions occurring concomitantly whether functional or secondary to an organic problem.

DSMIV:

- Encopresis: the repeated passage of faeces, also known as soiling, into inappropriate places (clothing or floor) whether involuntary or intentional. This behaviour should occur at least once a month and for at least three months and the child's age should at least be four years or an equivalent developmental level. Furthermore this behaviour should not be due to the direct physiologic effect of a substance (e.g. laxative) or a general medical condition except through a mechanism involving constipation. (1)
- Classified as Encopresis with constipation and overflow incontinence. In this condition there is evidence of constipation.
- Encopresis without constipation and overflow incontinence. This condition is usually associated with psychological disturbances.
- Subtypes: Primary or secondary; diurnal, nocturnal or both. These subtypes describe the types and may indicate associated factors.
- Primary Encopresis: bowel control has never developed and is associated with a high rate of developmental disorders. (1, 2)
- Secondary Encopresis: soiling in a child who has previously been continent for at least six months and associated with higher rates of psychosocial risk factors. (1, 2)
- Diurnal Encopresis: soiling that occurs in the daytime while child is awake.
- Nocturnal Encopresis: soiling that occurs in the night while child is asleep.
- Diurnal and Nocturnal Encopresis: soiling that occurs in the day while the child is awake and during the night while the child is asleep.

- Enuresis**:** the repeated voiding of urine, also known as wetting, into inappropriate places, (clothing or bed) whether involuntary or intentional. The frequency of this behaviour should be at least twice a month for at least three months. The child's age should at least be five years or an equivalent developmental level. This behaviour

should be manifested by clinically significant distress or impairment in social, academic or other important areas of functioning. Further, this behaviour should not be due to the direct physiologic effects of substances (e.g. diuretics) or a general medical condition (e.g. diabetes, spina bifida or seizure disorder). (1)

- Subtypes: primary or secondary and nocturnal, diurnal or both.
- Primary Enuresis: the child has never developed urinary continence or has previously been dry for a period of less than six months.
- Secondary Enuresis: the child starts wetting, as a relapse, after a period of dryness lasting for at least six months.

International Children's Continence Society (ICCS):

Enuresis is just wetting while asleep and daytime incontinence is wetting while awake. (2)

- Subtypes: primary or secondary and mono-symptomatic or non-monosymptomatic.
- Mono-Symptomatic Enuresis (MSE): in this condition wetting occurs in the absence of bladder dysfunction symptoms. (2)
- Non-Monosymptomatic Enuresis (NMSE): in this condition wetting occurs in combination with other daytime, voiding symptoms such as increased frequency, urinary urgency, hesitancy, holding manoeuvres known as posturing and voiding postponement. (2)
- Combined voiding disorders are also known as elimination syndrome wherein wetting occurs in children with encopresis and vice versa soiling occurs in children with enuresis. (2)

CHAPTER ONE
INTRODUCTION

1.1 Background

Human beings have evolved a complex mechanism for waste disposal involving two separate organ systems viz. the lower gastro-intestinal tract for defecation and the genito-urinary tract for urination. These two organ systems share a common embryonic origin (endoderm) and anatomical space (abdomen and pelvis). In addition, they require an intact peripheral nervous system (sacral pelvic nerves/plexus/spine) and central nervous system to coordinate their activities. (3)

Elimination Disorders result from any affliction to the structure or function of the involved multi-systems. They encompass unique voiding patterns that may be due to structural abnormalities of the organ systems, neurological derangements or dysfunctional behaviour in the apparent absence of structural or neurological problems. These voiding patterns have significant aetiologic, diagnostic and therapeutic connections. Structural/anatomical and neurological problems lead to incontinence which is involuntary stool/urine voiding; while dysfunctional-behaviour problems involving these organ systems include encopresis and enuresis.

Encopresis and enuresis denote repeated, unintentional faecal or urinary voiding taking place at inappropriate, socially unacceptable places, after the child has attained an acceptable developmental age. These disorders are perceived to have multifactorial aetiology. Inherent factors within the child are biological, genetic and psychological. These internal factors constantly interact with external circumstances over a prolonged period of childhood development viz. physical environment, social, familial and school, resulting in more likelihood of expressing these disorders. Significant distress is experienced by the affected child and parent or caregiver. Evaluation of these disorders would have to incorporate these factors.

1.2 Literature Review

1.2.1 Epidemiology of encopresis, enuresis and combined voiding syndrome

Encopresis is prevalent in 2-4% of all boys and 1-2% of all girls. The male to female ratios are 3-4:1 denoting a male preponderance. (2) Nearly all encopretic children soil in the daytime and 50-60% of cases are secondary encopresis. (5)

It is believed that in South Africa, 2-3 out of 100 children suffer from this condition (M Kirsten, personal communication).

Nocturnal enuresis is present in about 10-20% of <7 year old children, 7-13% in the 7-10 year old children and 3-7% in the 10-15 year old children. Boys are 1.5-2 times more likely to have nocturnal enuresis without daytime incontinence. There is decreasing prevalence with increasing age. (2) Spontaneous remission rate is 15% each year from ages 5-19 years. (5)
Daytime incontinence is present in about 10% of < 7 year olds; 2-9% in the 7-10 year olds and 2-6% in the 10-15 year old children. (2) Daytime wetting is more common in girls than boys. (6) It is unclear if prevalence decreases with increasing age in this group as prevalence rises in the adult group especially in the female gender. (2)

In South Africa, Fockema M V, established an overall prevalence for NE at 16% in 5-10 year olds. (7)

The prevalence of wetting in encopretic children is 10-50% across all studies or one third of all encopretic children have wetting. (2) Daytime and night time wetting occurred at similar rates in encopretic children with or without constipation. This comorbidity (wetting) was more associated with the presence of constipation and 52% were successfully treated by managing the constipation. (2)

In a recent study, (8) the prevalence of encopresis in enuretic children was 12%. Eighty percent of these children had signs of stool retention. Daytime wetting was present in 24.6% and night time wetting was present in 5.5%. This comorbidity (soiling) was highly associated with bladder dysfunction. Soiling was most common in children with dysfunctional voiding (42.9%), voiding postponement (25%), urge incontinence (18.2%) and primary NMSNE. These children had more problems with relaxation of the pelvic floor and thickened bladder wall. They also displayed a higher rate of comorbid behavioural disorders such as oppositional defiant disorder (ODD) (45%) and emotional disorders (25%). Externalising behavioural patterns (disruptive, oppositional) were present in 50% while internalising patterns (anxious, depressed) were present in 40% of these children.

1.2.2 Aetiology

There is considerable overlap at presentation between incontinence due to anatomical/ medical disorders and dysfunctional voiding in the absence of identifiable disorders. Only after evaluation can the two main categories be identified viz.

- Incontinence secondary to anatomical pathology, medical disease or use of a substance.
- Dysfunctional voiding with unclear aetiology.

1.2.2.1 Encopresis

Encopresis is classified into:
(a)Encopresis with constipation and overflow incontinence and
(b)Encopresis without constipation and overflow incontinence.

(a)Encopresis with constipation and overflow incontinence
This condition results from chronic retention of stools in the distal colon. There are several triggers for stool retention such as avoidance of painful defecation in the presence of anal fissures, psychological toilet phobia and toilet refusal, repeated failure to obey the urge to defecate which may be a result of hyperactive disorder or just playfulness, a chaotic lifestyle

with absent daily routines and/or stressful life events. The initial urge to defecate is masked out (ignored) by paradoxically contracting the external anal sphincter until the urge to defecate abates. This, when repeated over time leads to habituation, conditioned aversion and altered colonic physiology. (9) Increasing amounts of hard stools accumulate in the colon leading to decreased sensitivity and peristalsis. The hard and dry faecal mass becomes difficult to expel while new liquid stools leak out from around this mass. Periodically, a portion of this mass just falls out of the anal opening. The resulting soiling causes interactional problems with the immediate family members and later on with the child's peers. Psychological effects of humiliation, decreased self esteem and anxiety are often a result of this condition on the child. This condition resolves with treatment of the constipation. Psycho-behavioural problems are greater in these children (30-50% more than those with incontinence due to organic causes) and need to be screened out and attended to for successful treatment outcomes. (2)

(b)Encopresis in the absence of constipation and overflow incontinence/Non retentive encopresis /Solitary encopresis

This condition is perceived to be a psycho- emotional disorder in the child. It may result from an impulsive act by the child and/or a manipulative act by the child expressing unconscious anger towards a parent in a disordered parent-child relationship. It may represent incomplete or disordered toilet training and learning by the child or be a consequence of child sexual abuse and sodomy. (4) Children from this group suffer interactional and psychological problems similar to the previous group. Comorbid psycho-behavioural and emotional problems are present in 30-50 % of children with non retentive encopresis. (2)

In its entirety, encopresis is an acquired, learned behaviour, resulting from a combination of inherited predisposition (e.g. constipation), unforeseen events (e.g. painful defecation), accidental practices (e.g. enemas), inappropriate situations (e.g. unavailable, filthy toilet) and misunderstandings (e.g. toilet fears). (4) This behaviour, once established, is reinforced by positive gains such as avoiding the toilet to continue with play, gaining more parental attention and avoiding painful defecation. Intrafamilial conflicts perpetuate this condition. (2)

Disorganisation and decreased communication styles within families were greater in one study. (10)

Psychological problems faced by these children can be subclinical and understandable reactions to the offending behaviour such as sadness, lack of self worth and social withdrawal. The presence of more severe psycho behavioural disturbances, such as Attention Deficit Hyperactive Disorder (ADHD), emotional problems, conduct disorder, oppositional defiant disorder (ODD), anxiety disorder and depressive disorders are significant in this group of children. A causal relationship with these comorbid conditions is unclear as they may precede or precipitate or result after the appearance of the encopretic events. They may also be a coexisting disorder or a manifestation of the same neurobiologic dysfunction. Behavioural disorders are more commonly found in children with encopresis as compared to enuresis. Internalising behavioural patterns (anxiety and depression) and externalising behavioural patterns (disruptive/oppositional behaviour and attentional difficulties) are common. Psycho behavioural disorders need to be screened for and treated before implementing treatment regimens. This is necessary for better compliance. The parents of these children need additional psycho-education to manage their affected children. (2)

Although these children are regarded to have normal intelligence or intelligence quotient (IQ) scores, their school performance is poor. Also, children with mental retardation and learning disabilities (LD) are more likely to have encopresis and this condition correlates directly with the degree of retardation/learning dysfunction. (2;11)

Genetics has been implicated in the aetiology, as higher rates of affected family members with similar problems have been found. (12) Furthermore, constipation has a higher genetic basis and more males are predisposed to this condition than females in childhood.

Recently, newer associations involving physiological factors such as high levels of post prandial pancreatic polypeptides, decreased motilin response, paradoxical contraction of the external anal sphincter during defecation and the interaction between the enteric and central nervous systems have been described. The effect of emotions on the gut and the converse,

affecting the psychological well being of the individual is being proved. Extensive interaction between the brain, gut and bladder are being implicated. (2)

1.2.2.2 Enuresis

Recent concepts, elucidating the pathogenesis of enuresis, comprise the following mechanisms.

1) Nocturnal polyuria as a result of decreased nephrologic response to circulating anti diuretic hormone / vasopressin.

2) Urodynamic factors involving detrusor instability and spontaneous contractility at a lower threshold capacity.

3) Inability to arouse from sleep to the stimulus of the micturition reflex.

4) Central nervous system (CNS) factors resulting in a lack of inhibition of the micturition reflex.

Each of these features has its own neuro-maturation course, expanding from birth to adulthood. Variations or alterations singly or combined in any of these features delay urinary continence. (2;13) More established factors identified in the pathogenesis of primary enuresis are genetic vulnerability, prematurity and neuro-maturational delay and constipation.

Genetic vulnerability was established in a clinical population that found a positive family history in 63.2% of families: 22.2% of affected fathers, 23.9% of affected mothers and 16.5% of affected siblings (2). Primary enuresis is more associated with genetic and developmental factors while secondary enuresis often followed stressful life events and is associated with psychiatric disorders. (13;14)

Parental separation and divorce, school problems and adaptation to new family structures are common stressors. Psychosocial stressors and traumatic life events such as family discord, broken homes, separation from parents, death of a close family member and child sexual abuse may contribute to secondary diurnal enuresis. These may potentiate and exacerbate this disorder. (4) Repeated exposure to stressful life events (four or more per year) and delayed

attainment of nocturnal urinary continence are known risk factors in the pathogenesis of secondary enuresis. (14;15)

Constipation and stool retention is believed to compress the urinary bladder resulting in obstruction, residual urine, infections and uninhibited bladder contractions. It is also presumed that voiding dysfunction and rectal dis-coordination often coexist. Treatment of constipation often results in resolution of enuresis. (2)

Children with primary nocturnal enuresis exhibit a lower rate of psycho-behavioural problems. They frequently display an externalising behavioural style. These include restlessness, easy distractibility, impulsivity, aggression, disobedience and oppositional behaviour. There may be ADHD, sleep terror and sleep walking disorder and conduct disorders. (4) Daytime incontinence is more frequently associated with psycho-behavioural disorders.

Daytime wetting syndromes have a high rate of detrusor instability which manifests as either over activity (urgency and frequency) or under activity (urgency with decreased frequency). Comorbid conditions such as urinary tract infections, asymptomatic bacteriuria, vesico ureteral reflux, pelvic pain syndromes and soiling have been implicated in the pathogenesis.
Voiding postponement that eventually leads to a 'lazy' bladder is interpreted as an oppositional symptom and a manifestation of externalising behavioural style. These children commonly display stubborn, oppositional and secretive tendencies. (2) Family dysfunction such as poor/rigid adaptability and a disengaged transactional style are common with this disorder. The disengaged transactional style involve emotional bonding, boundaries, roles, decision making, interests and recreation. (2)

1.2.3 Associated Factors

The resolution of elimination disorders, require an integrated approach that identifies factors which may promote as well as impact on these problems. Recognition of these factors aids

understanding and management of these conditions. (4) The factors associated with these disorders are described below.

Factors associated with elimination disorders are:

- Psychological factors
- Stressors and family functions
- Physical disabilities, mental retardation and comorbid conditions
- Neurodevelopmental dysfunctions
- Cultural beliefs and practices
- Physical environment.

1.2.3.1 Psychological Factors

The psychological factors associated with the elimination disorders are:

Temperament of the child

The 'difficult- child' is more prone to behavioural problems in early and mid childhood. They demonstrate negative withdrawal responses to new situations, slow adaptability and slower socialisation. (4) They are perceived as whiny and clingy by their caregivers. Emotional adjustment is slower in these children. It is more difficult to toilet train these children. These children often display a temperament of wanting to please their caregivers at all costs (M Naidoo, personal communication).

Toilet refusal syndrome (TRS) or diaper dependency is common with a difficult temperament and a risk factor for later development of encopresis. In this syndrome the child uses the toilet only for micturition and refuses to use the toilet for defaecation. (2)

Psychological Behavioural Styles

The 'externalising' or 'uncontrol' behavioural style has been linked to night-time wetting. These children display aggression, acting out and at times delinquent behaviours. The 'internalising' or 'overcontrol' behavioural style has been described more commonly with soiling. These children display over-anxious, withdrawn, overly quiet behaviours, secretiveness, stubbornness and inflexibility. Caregivers need considerable psycho-educational interventions in assisting these children particularly with the supervision required to comply with treatment regimens. (16)

1.2.3.2 Stressors

Emotional tension hampers both the parental role of toilet training and the child's role of toilet learning and mastery of this task. This could be a result of disruptive experiences and tensions at home during the early years of toilet training and learning. Over-bearing and punitive parents expecting immediate toilet learning from the child are counter productive. Conversely, extremely lax attitudes to learning cause confusion in the child as to expected behaviour. This is the 'interrupted learning theory.' Tensions promote inappropriate muscle dynamics, excessive pelvic floor contraction, poor relaxation and straining to void. These result in established retentive behaviour over time. (17) Tensions also distract the parent during the training period.

Constant and excessive environmental stress, beyond the child's capacity to cope, results in the child resorting to negative coping strategies and alienation from his/her social relationships. These negative defence strategies could take the form of behavioural regression or disorganization and/or overt psychopathology e.g. panic disorder, anxiety disorder & depression.

Examples of overwhelming stressors are learning disabilities in the face of academic demands, parental separation and abandonment of the child and child physical and sexual abuse. Traumatic life events often precede secondary encopresis and enuresis. (4;18)

1.2.3.3 Physical dysfunctions, mental retardation and comorbid conditions

Progressive favourable development in a child requires that the child perceive and learn from his/her environment. Optimal vision, hearing and cognition are necessary for preferential attention and learning. Mental retardation needs to be recognised in the child with elimination disorders. ADHD, depression and pervasive developmental disorders need to be identified as comorbid conditions. ADHD is often concomitant with these dysfunctions. The child with ADHD displays task impersistence, having difficulty in sitting still to complete tasks such as voiding. Furthermore, the urge to void may be overtaken by other thoughts before it can be acted upon.

These conditions need to be controlled prior to treatment of the voiding dysfunctions. (5)

1.2.3.4 Neurodevelopmental / Learning dysfunction

It is estimated that 5-15% of school aged children suffer from neurodevelopmental dysfunction such as deficiencies in attention, memory, language, temporal sequential and spatial - ordering, neuro-motor skills and social cognition. A learning dysfunction or disability results in poor scholastic performance, behavioural difficulties and social adjustment problems.

Social development is essential for a child to learn and master his environment. Task performance (play and work) and social competence (relationships) proceed developmentally as the child matures and learns. This learning should be a source of enjoyment for the child, for progressive development and a positive self-concept to develop. Successful learning enhances self-esteem and confidence in the child. (4) Social competence can be judged by the child's ability to enjoy playing with toys, members of the family and later on relationships with family members and peers.

1.2.3.5 Cultural beliefs and practices

Parental perceptions, attitudes and reasons for seeking help have clinical significance. Practices such as punishment and regular laxative use may be the cause or effect in these conditions.

Thirty percent of parents/caregivers have resorted to punitive means to cope with these conditions. They perceive the child's behaviour to be intentional 'naughtiness' or as a sign of 'laziness' to use the bathroom. Parental intolerance and resulting non accidental injuries to the child have been linked to increased rates of bed-wetting. (19)

Toilet training practices may be too rigid with punitive consequences for the child, resulting in decreased self-esteem. On the other hand, too much leniency or the lack of training may cause confusion in a child who needs to learn appropriate toileting practices. Toilet phobia or anxiety to use the toilet can be the result of too early toilet training in a child.

Regular laxative use is customary in certain cultures. These could be oral medicines or enemas. Irritant laxatives when used regularly have a propensity to weaken the colonic muscles leading to a type of atonic constipation. (20) Diarrhoeal encopresis may result from regular laxative use resulting in the child being unable to control the intestinal hurry. (4)

1.2.3.6 Physical environment

The child's type of residence and toilet influence these behaviours. Adverse experiences may be linked to poor living conditions. A communal toilet outside the house may be unavailable to a child when the urge to void appears, resulting in stool withholding. A pit latrine may be too scary for a little child to use without the fear of falling into. Cleanliness of the toilets may play a part in fastidious personalities who would avoid the filthy toilets at any cost. The school toilet, especially without doors, can be humiliating for a child to use.

1.2.4 Effects of elimination disorders

Elimination disorders pose a frustrating problem to the child (often confused), the parent (often annoyed) and the physician (often inadequately trained). (21) The younger child faces distressing physical and emotional repercussions while the older child suffers humiliation, guilt, social ostracism by peers, diminished self-esteem and avoidance of social activities. The diagnosis of enuresis requires a minimum frequency or presence of clinically significant distress or impairment in social, academic or other important areas of functioning. (1)

The usually supportive parent develops negative feelings of guilt, frustration and anger. Some resort to intolerance and punitive means (from 37- 42% in different cultures) while others reject the child. (22) Parental intolerance also has a negative impact on future successful treatment. (18)

A further effect is the economic drain on families, society and health services. Direct costs involve expenses on extra washing and drying, extra bed linen and the child's personal clothing, travel to consultations for treatment and the treatments themselves. Indirect costs involve time spent on extra house-work and consultations, with a loss of productivity in the parent. (22)

The primary care physician is unprepared to manage these disorders, especially in the face of insufficient training and limited resources. The result is that the child and his parent are shunted between facilities when and if they do present for help.

1.2.5 Diagnosis of elimination disorders

The diagnosis of elimination disorders is clinical. A detailed clinical interview that covers all the required diagnostic criteria is sufficient. As there is an overlap between incontinence

secondary to organic problems, relevant detailed clinical examination and investigations are necessary to rule these out.

The history should include details of the bladder and bowel symptoms, a 48 hour diet (types and amounts of fluid and fibre intake) and voiding (polyuria) diary (Appendix D), screening for comorbid conditions (emotional disorders, ADHD, anatomical pathologies, medical diseases and use of drugs), associated factors that impact on the child and family, attitudes, beliefs and practices.

Examination should include a general paediatric examination with anthropometry, blood pressure reading, abdominal examination (for faecal masses), genital and anal evaluation for abnormalities, evidence of sexual abuse including digital examination and detailed neurological (and developmental) assessment involving motor, sensory and reflex functions especially $L_1 – S_4$.

Investigations include urine analysis, abdominal ultrasound, plain x-ray abdomen. Blood and urine osmolalities may be required. Very rarely, voiding cysto-urethogram, urodynamic studies, ano-rectal manometry and barium studies may be required.

1.2.6 Management of elimination disorders

Recommended treatments, integrate behavioural and medical modalities. Initially education and demystification of these disorders is carried out. The interview which probes and explores the psycho-dynamic realms, provides insight into the conditions and associated factors. Acknowledging the difficulties and emphasising that the problem is not within the child's control, decreases the anxiety felt by both the parent and the child. Diagrammatic explanation of constipation, stool retention and overflow incontinence always increases the understanding by the parent and older child. Continued reassurance that treatment will help and recruiting prolonged commitment to comply with the tedious behavioural regimens is expected from the parent. (23)

Medical modalities for treating retentive encopresis require an initial disimpaction of an excessively loaded rectum using enemas. Maintenance of soft stools is then possible with mineral oils which are stool softeners. Dietary interventions to include and increase fibre and liquids in the diet may be recommended. Behavioural sitting schedules are taught and encouraged following meals. The parent ensures that the toilet is less fearful and more available for the child by providing cleanliness, a light source in the toilet and accompanying the child to the toilet. Positive reinforcement for desired behaviour is to be used in the form of star-charts and rewards. Biofeedback interventions such as strengthening the external anal sphincter and sensory discrimination training may be offered.

Non-retentive forms of encopresis also respond to regular toileting. However when accompanied by behavioural problems such as toilet refusal, apparent indifference of the child to his/her behaviour and retaliation they need to be referred to mental health practitioners.

The aim of treating nocturnal enuresis is for the child to learn to self-awaken in response to a full bladder. Behavioural techniques are preferred to enuresis alarms (prohibitive costs) and medications (high toxicity and relapse rates).

Fluids are restricted for 3 hours before bedtime and the bladder is emptied just before going to bed. An alarm clock is set for 3 hours after bedtime to awaken the child. Initially in response to the loud noise, sudden awakening from sleep and contraction of the pelvic floor muscles occurs. Later on spontaneous awakening to avoid the noise (avoidance conditioning) and conditioned reflex contraction of the pelvic floor muscles occurs. An increased expectation of success is anticipated with this technique. Over a prolonged period, the child functions autonomously and often awakens before the alarm rings. Teaching the child to be mindful and respond to bladder sensations is to be done concomitantly. The child and parent practice a sequence of 3 sets of exercises at bed time, every night. It begins with both lying down, closing eyes, pretending to perceive a full bladder in the middle of the night, feeling the ache (urge), getting up, running to the toilet, urinating and then returning to bed. This helps with voiding at bedtime and also, appeals to the child's magical thinking. Compliance with this technique and 'dry nights' are rewarded. (23)

Diurnal enuresis initially requires treatment of constipation and urinary tract infections (UTI) if present. Next regular voiding with adequate fluid intake is emphasised. Bladder exercises may be advised. Exercises for the overactive bladder (small bladder capacity) include stop and start of micturition and delaying micturition for ten seconds each time the urge appears. Anti-cholinergic medication may be used as a second line of treatment along with bladder training. Scheduled timed voiding for the 'lazy' bladder (urgency with infrequent urination) is recommended. Psychological interventions and family therapy may be necessary. (23)

Voiding dysfunction that presents with straining and staccato voiding, with a poor stream indicates poor relaxation of the pelvic floor. Biofeedback treatments are recommended for these disorders after the initial treatment of constipation and UTI. In the absence of available biofeedback therapies, conscious relaxation techniques and voiding at the first sign of urge are taught. Enuresis alarms have specific indications but the cost is prohibitive.

The services of a trained child care nurse, social worker, dietician, psychologist, child psychiatrist and specialist paediatrician are frequently required. At times the paediatric surgeon, urologist, neurologist are consulted. Currently, care for these patients is either not available or fragmented between various disciplines.

1.3 Statement of the problem

In the Republic of South Africa, there is a paucity of published data for elimination disorders. A description of the factors that influence the development of these disorders and the effects of these disorders on the child and parent are not available.

Accurate figures for prevalence are not available. Different researchers interpret and use varying definitions (e.g. ages and frequencies of occurrence) for these disorders. The age of continence is variable for different sexes, cultures, races and countries. (4) Underreporting and masking of these illnesses compound the issue.

1.4 Purpose of the study

A descriptive study of these patients presenting at the Chris Hani Baragwanath Hospital, the largest academic hospital in Gauteng, South Africa and Africa, will be performed. Also the influence of these disorders on the child and their caregivers will be described.

1.5 Aims and objectives

1.5.1 Aims

To describe the health complaint, demographic features, psychological and social profiles and effects of these disorders on the child and parent/caregiver (henceforth used interchangeably).

1.5.2 Specific objectives

1) To describe the presenting complaints of children with encopresis and enuresis that present to a paediatric outpatient facility in Soweto.
2) To describe their demographic characteristics.
3) To determine the effects of the disorders on the children and their caregivers.
4) To determine the psychosocial factors affecting the child.

CHAPTER TWO
METHODOLOGY

The methodology for this study was determined by its aims and objectives.

2.1 Setting of the study

The study was conducted at the POPD of the CHBH, a designated central hospital situated in the Gauteng Province. The Hospital has an estimated capacity of 2700 beds. It is a public facility and also the main teaching hospital for the University of the Witwatersrand, Faculty of Health Sciences. The POPD manages all the medical paediatric problems presenting to the hospital. Among other things, the POPD is responsible for conducting periodic evaluation of its function and management of patients.

The subjects were from Soweto Township and its surroundings. Also included were referrals from regional 'cluster' hospitals, community health centres (CHCs) or clinics and general practitioners (GPs). The referrals were from varied medical and allied disciplines.

2.2 Scope of the study

The study investigated the patients presenting with elimination disorders. It also investigated their presenting symptoms, demographic features, behavioural profiles and psychosocial features. The report also looked at diagnosis of these patients.

2.3 Study design

The study design was a descriptive prevalence/survey study of the presenting symptoms and profiles of patients with elimination disorders referred to or self-referred to the POPD of the CHBH.

2.4 Study population and sampling

2.4.1 Study Population

The study population were patients (aged 4 years to 14 years belonging to both genders) presenting at the POPD of the CHBH with elimination disorders.

The study was conducted over a period of three years from July 2004 up to June 2007.

2.4.2 Sampling

All patients presenting to the POPD of the CHBH with elimination disorders during the study period and whose parents/caregivers consented to participate in this study, were included. As all the paediatric (medical) patients present first to the POPD, it is expected the sample includes all the patients who attended the CHBH during the study period.

2.5 Measurement tools

The data-collection tool was based on the previous experience of the researcher and her supervisor. The study instrument used in this study was a structured questionnaire (Annexure A). It was written in English only because it was expected that all doctors and nurses were able to comprehend English. Nurses were used as interpreters when patients and their parents/caregivers could not comprehend English.

2.6 Variables

The questionnaire included the variables referred to in Table 2.1.

Table 2.1 List of variables

Demographic profile	Age, gender, areas of referral
Description of conditions	Type of elimination disorder, subtype, severity, bowel and micturition function, ages at continence
Reasons for seeking help	Caregiver support, tolerance, effects on the child
Parental & child perceptions	Waits too long, feels toilet is too dirty, fears toilet, avoids toilet
Cultural practices	Punishment, purging, toilet training, breast feeding, help seeking behaviours
Birth and development	Pregnancy, birth and perinatal events, milestones
Medical history	Chronic illness, medications, upper airway obstruction (UAO), allergies,
Physical function	vision, hearing, cognition, clumsiness, activities of daily living
Trauma and stressors	Experience of traumatic events, child sexual abuse (CSA)
Difficult behaviours	Disobedience, destructiveness, aggression, habitual lying, self-destructiveness, running away from home, fearful and isolative
Social profile	Personality, enjoyment from playing with toys and family, best friend, social class
Housing conditions	Residential area, type of house, type of toilets
School function	Coping levels, concerns from teachers, toileting controls, school toilet doors, teasing by peers
Family profile	Relationships within family members, family roles, accountability, familial illnesses, substance and alcohol abuse in family
Clinical findings	Voiding diary, CSA, cerebral palsy, ADHD, UAO, radiological findings
Criteria for special clinic	Time taken for evaluation, personnel involved, disciplines involved

2.7 Data Management

2.7.1 Data collection

The researcher administered the questionnaires to all the subjects. It was written in English and a nurse-interpreter was used when the parents and children could not comprehend English.

Written, informed consent was obtained from the parent / caregiver (Appendix C). All children over 8 years of age were asked for written and informed assent (Appendix C). A two-day voiding-diary and dietary diary was completed by the primary caregiver before consultation (Appendix D). As part of gathering a thorough history, an interview questionnaire was completed involving the caregiver and child. (Appendix E). The questionnaire was designed based on the experience of the researcher and the supervisor. In addition, input was obtained from a child psychologist. (M Naidoo, personal communication) The problem was established including its details and the psycho-social background of the child. This provided a checklist as described in Table 2.1. A general paediatric examination was always done and a detailed neurological examination when necessary. Relevant investigations were carried out and the results documented.

2.7.2 Data analysis

Patient data was entered into a commercial spreadsheet (Microsoft Access) and coded. Statistical analysis was performed on the entire data set using a commercially available software package (NCSS 2000, Number Cruncher Statistical Systems, Kaysville, Utah, USA). Appropriate, Unpaired T- test, central tendency (mean) and spread (standard deviation) were calculated and expressed as Mean ± Standard deviation.

2.8 Ethical consideration

This project was approved by the Committee for Research on Human Subjects (Medical) Protocol No. M03-10-30) (Appendix A) and the Faculty Postgraduate Committee (Appendix

B1). It was also authorised by the Chief Executive Officer of the CHBH (Appendix B2). Names of respondents were not recorded anywhere in the questionnaire in order to ensure confidentiality. Participants were identified only with numbers. Informed consent was sought from the respondents.

CHAPTER THREE
RESULTS

The results obtained from the analysis of the data are described in this chapter.

3.1 Sample size

One hundred and sixteen children were enrolled into this study. None of the caregivers or patients refused to be enrolled in the study. The 'n' reflects the total number of complete responses obtained. The numbers vary when incomplete information is obtained.

3.2 Demographic characteristics

3.2.1 Gender

Sixty-two percent of the study subjects were males while 38% were females, giving a relationship of M: F = 1.6:1

3.2.2 Age

The mean age at consultation was 9.1 ± 2.2yr. Males = 9.1 ± 2 yrs and females = 9 ± 2.4 yrs with no statistical significance.

The mean age at which encopresis was noticed as being problematic was 5.6 yrs: Males 5.5 ± 1.8 yrs and females 6.2 ± 0.8 yrs. The mean age at which enuresis was noticed was 5.3 ± 2.4 yrs. There was no significant difference between males 5.3 ± 2.5 yrs and females 5.2 ± 2.2 yrs in the enuresis group.

The mean duration of the complaints was 43 months for both conditions.

Table 3.1 Distribution of age

Age in months	Total Mean ± SD	Male Mean ±SD	Female Mean ±SD	P value
Age at consultation	110 ± 27	110 ± 25	109 ± 29	0.39
Age at onset of enuresis	64 ± 29	64 ± 31	63 ± 27	0.39
Age at onset of encopresis	68 ± 20	66 ± 22	75 ± 10	0.12

3.3 Referral sources

The referral sources of the subjects are described in Figure 4.1 below:

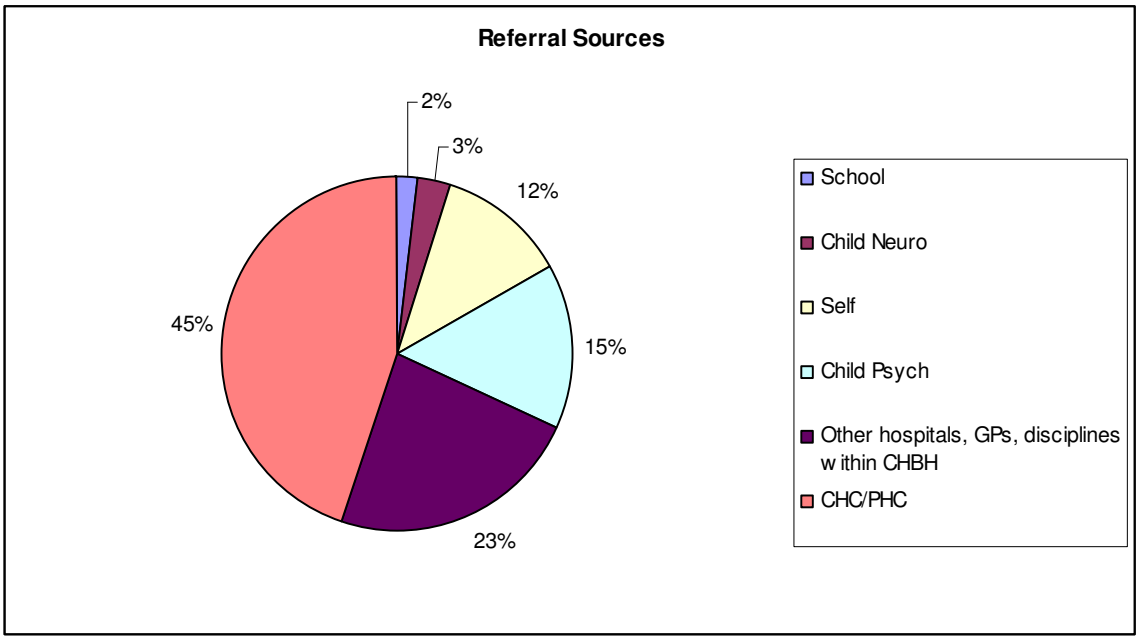

Figure 3.1 Referral Sources

3.4 Presenting conditions

More than forty percent (46.6%) of study sample suffered from enuresis only, while 21.6% suffered from encopresis only. More than thirty percent (31.9%) displayed both enuresis and with encopresis. Figure 3.2

The majority (62%) were males as compared to only 38% females. Only one female presented with encopresis.

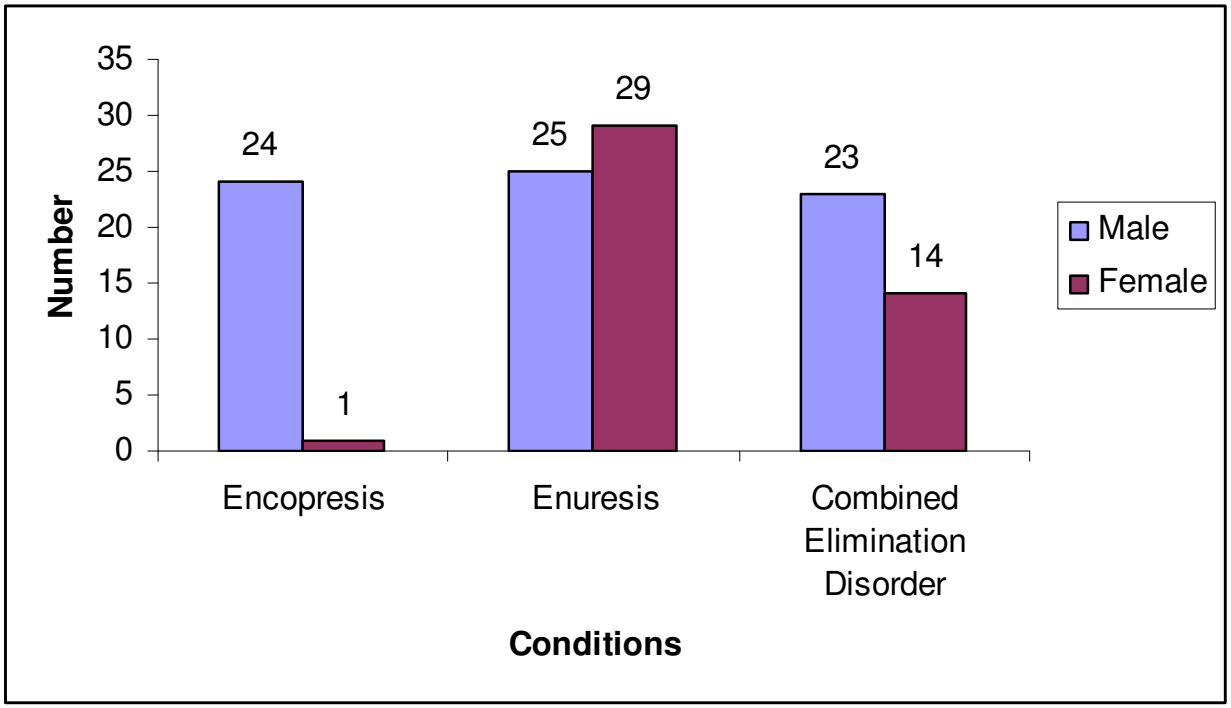

Figure 3.2 Frequency distribution of presenting conditions and gender

3.4.1 Encopresis

The distribution of various sub-types of encopresis is described below.

Out of a total of 62, primary encopresis comprised 11.2%, while secondary encopresis comprised 77.4%. Diurnal-only encopretics were 74% while none had nocturnal-only encopresis. Combined diurnal and nocturnal episodes comprised 25.8%.

More than one third (39.6%) had more than one episodes of soiling daily, while 12.1% had several episodes weekly. Twelve percent of the children soiled between 13H – 16H00 daily. More than twenty percent (20.5%) of the children soiled themselves at different time periods, between 10H-13H00, 13H-16H00 and 16H-20H00 in a day.

Over twenty percent (22.8%) of soiling was in the form of large stools in the underwear. Thirteen percent appeared as small pellets in the underwear. Fifty eight percent of the times there was a combination of large stool, pellets, liquid stools and stains on the underwear.

3.4.2 Enuresis

Out of a total of 91 patients, 47.2% had primary enuresis, 40.6% secondary and 12% were indeterminate (parent unaware if the child had ever been dry). The majority, 56% had only nocturnal enuresis while 36.2% had both nocturnal and diurnal enuresis followed by 7.6% with only diurnal enuresis.

A majority of 58.6% had several episodes per day, while 14.6% had several episodes per week. About 44% had several episodes of nocturnal enuresis per night while 21.5% had only one episode of nocturnal enuresis per night. Fourteen percent wet themselves between 03H-06H ; 12.3% wet between 24H-03H; 8.8% wet between 20-24H and 21,9% wet themselves at various times during one night.

Diurnal wetting was also noted at various different time periods of the day in 21.9% of the children.

3.4.3 Combined elimination disorders

Out of a total of 32 children with combined disorders, 31.2% were primary, 56.2% were secondary while 12.5% were indeterminate.

3.5 Reason for seeking help

The various reasons for seeking help are described as follows:

3.5.1 Caregiver support and tolerance

Almost all caregivers (99.1%) felt a need to support their children. However, 89.6% of caregivers were unable to tolerate their child's behaviour problem. They attributed the reason for their child's behaviour to naughtiness, laziness and playfulness. Some parents, (14.1%) attributed the cause to psychological problems relating to neglectful mothers, parental separation, parental demise, conflicts in the family and fear in the child; 3.5% suspected sodomy (anal penetration) of the child while 1.7% attributed the problem to bad genes.

3.5.2 Costs and expenses

Over eighty eight percent (88.7%) believed that there was a cost linked to their child's behaviour, while 11.2% were determined there was none. Seventy six percent agreed that extra washing, extra clothing were an added expense including the time spent on washing. Four percent included medical costs and transport to facilities as an added expense.

3.5.3 Effects on the child

About 67% of the children were worried about the smell emanating from themselves while 65.2% felt sad, ashamed and guilty as a result of their behaviour. Refer to Figure 4.3 for all the effects experienced by the subjects.

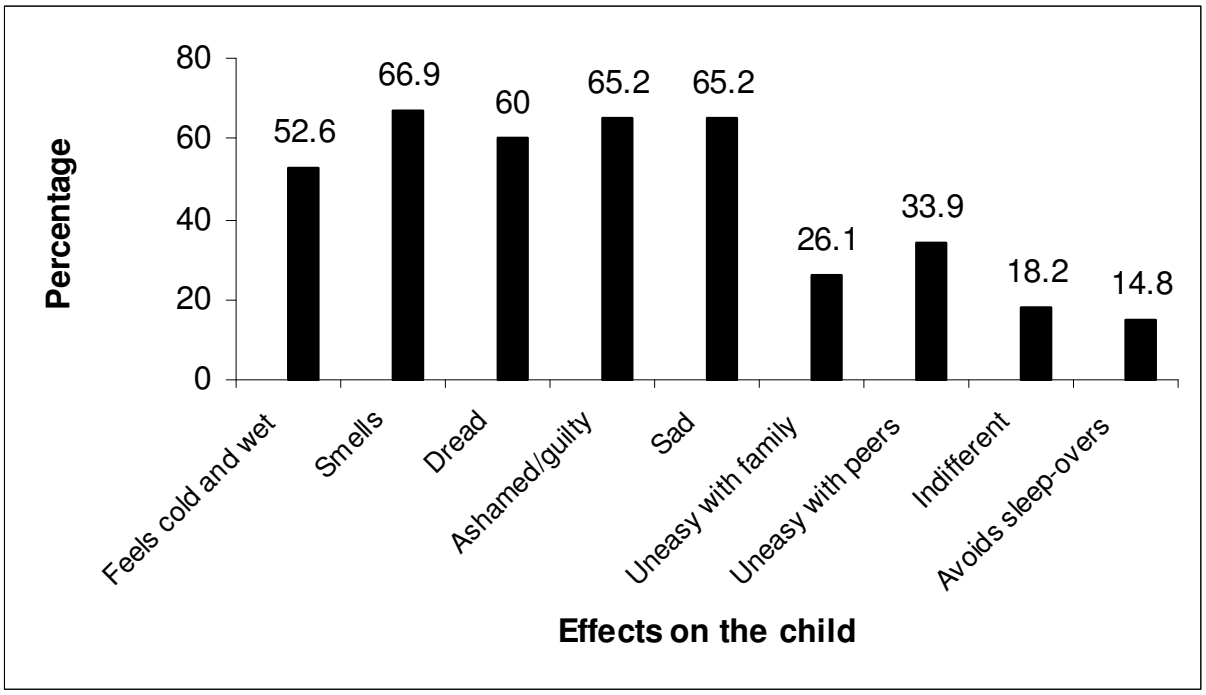

Figure 3.3 Effects on the child

3.6 Voiding Patterns

3.6.1 Bowel Habits

More than half of them (51.8%) had evidence of constipation which was reported as the passage of infrequent (<3/week) and hard stools.

3.6.2 Micturition habits

More than twenty two percent (22.8%) voided urine 7-10 times / day, while 43.8% voided less than that. Holding manoeuvres or posturing was reported in 64.9% whereas 55.2% displayed urgency with micturition.

3.7 Age at continence for stool and urine

The distribution of subjects that had achieved continence at various ages is described in Table

3.2 below. The majority of the subjects had achieved continence at less than three years of age. However, more than 40% subjects had not achieved urinary continence at night during the time of examination.

Table 3.2 Age of continence for stool and urine

	Total n	<3yr n (%)	>3yr n (%)	Not yet n (%)	Unsure n (%)
Continence for stool	116	66 (56.9)	27 (23.3)	8 (6.9)	15 (12.9)
Continence for urine in day	116	46 (39.6)	22 (18.9)	21 (17.2)	27 (23.2)
Continence for urine at night	115	36 (31.3)	14 (12.1)	48 (41.7)	17 (14.7)

3.8 Family member with enuresis

Around 60% of the subjects had a family member with enuresis. More than 20% (n=26) of the subjects' immediate parent had enuresis; in 7% a sibling had enuresis; in 28.9% there was another family member with enuresis.

3.9 Perception of toileting behaviour

Perception of toileting behaviour of the subjects is described in the Table 3.3. The majority of the subjects had multi-factorial reasons to postpone toileting.

Table 3.3 Perception of toileting behaviour

	Total n	Yes n (%)	No n (%)	Unsure n (%)	Other/NA n (%)
Waits too long	114	57 (50)	25 (21.9)	31 (27.2)	1 (0.8)
Prefers to play	114	79 (69.3)	18 (15.7)	14 (12.3)	3 (2.6)
Forgets	114	45 (39.4)	53 (46.5)	15 (13.1)	1 (0.8)
Fears home toilet	114	60 (52.6)	39 (34.2)	13 (11.4)	2 (1.6)
Fears school toilet	114	54 (47.3)	40 (35.1)	16 (14)	4 (3.5)
Feels toilets too dirty	114	69 (60.5)	41 (35.9)	3 (2.6)	1 (0.8)
School toilet has no door	112	17 (15.2)	92 (82.1)	2 (1.6)	1 (0.8)

3.10 Practices - punishment, purging and toilet training

The various practices and behaviours of caregivers for punishment, purging and toilet training are described below.

3.10.1 Practices of punishment

The methods of punishment are listed in Figure 3.4 The majority of the caregivers were punishing their children during assessment. Few of them had punished their children for this behaviour in the past.

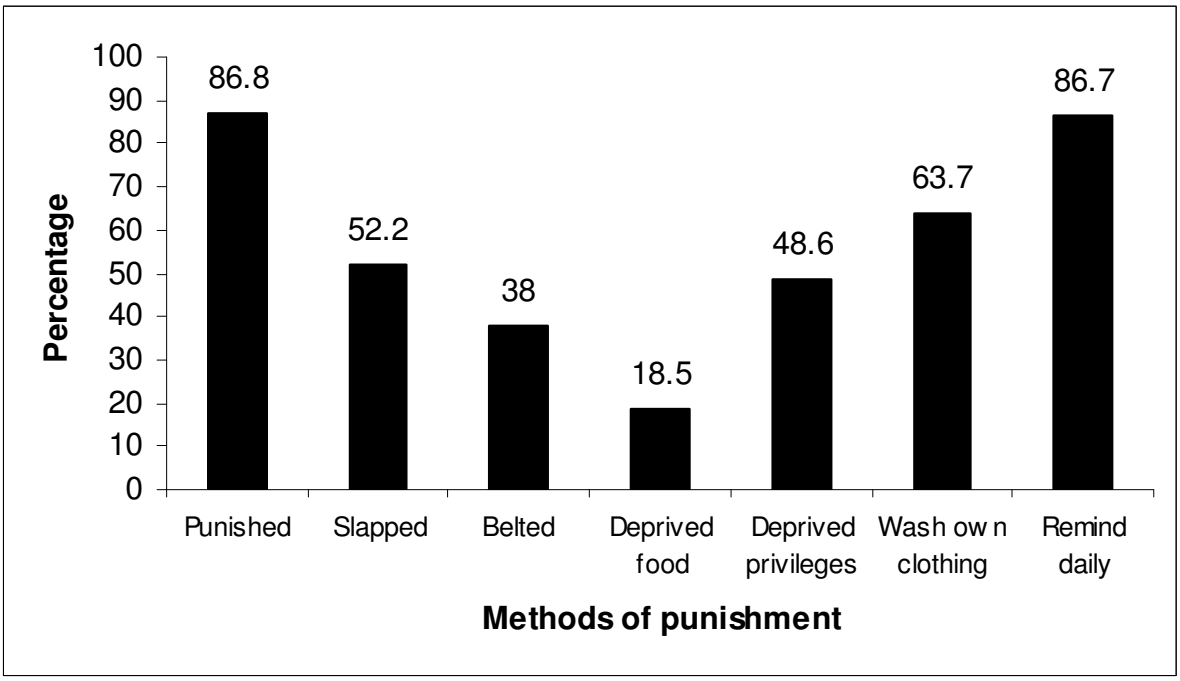

Figure 3.4 Methods of punishment

3.10.2 Practices of purging

Most of the subjects (84.9%) purged their children, a common custom in the study population. The majority of the subjects were purged regularly at 3-6 monthly intervals (45.1%) and they used various methods such as oral laxatives (56.6%), enemas (5.3%), and a combination of the two (24.7%).

3.10.3 Practices of toilet training

A regular potty was used for toilet training in 44.7% and a bucket in 37.7%. Toilet training was commenced <18 months in 31.8%; between 18-24 months in 25.6%, between 24 – 30 months in 23.8% and >30months in 4.4% subjects. Toileting at fixed intervals was the most utilized method (48.6%); 21.2% of subjects were taken to the toilet in response to cues/demand by the child. Only one caregiver admitted to not having toilet trained his/her child.

If there was no voiding, a significant number (47.7%) tried again later; 28% persisted by not allowing the child to get up, made the child push until they voided and used bribes and/or punishment.

3.10.4 Help seeking behaviour

Seventy eight percent of caregivers had sought professional assistance from the following health professionals:

- Primary health care clinics (26.5%)
- Private general practitioners (7.9%)
- Paediatricians (3.5%)
- Psychologists (7.1%)
- Traditional healers (1.7%)
- Combination (27.3%)
- No treatment (25.6%)

3.11 Pregnancy, delivery, breast feeding and immunisation

In the majority of cases (61.1%) the pregnancies were unplanned; in 25.6% they were planned. The mean age of the mother at delivery was 25.9 years (± 6.5 years). Ten percent were teen-age mothers. Most of them (70.7%) had normal deliveries. The majority of the subjects were born at term (85.8%). Few of them were premature (7.1%) and postdates (2.6%). A few, 9.7% had some form of birth asphyxia.

Eighty three percent of mothers breast fed their children. The reasons for not breast feeding were Human Immuno Deficiency Virus (HIV) disease in the mother, poor milk production, child refusal of the breast and abandonment by the mother. One mother left the child to join a school teaching traditional medicine while another child was hospitalised immediately after birth. More than 80% of the subjects were fully immunised.

3.12 Developmental milestones

Few subjects had delayed sitting after 6 months of age (16.8%), walking over 18 months (14.1%) and jabbering over 18 months (29.2%).

3.13 Past medical problems

Past medical problems of the subjects are listed below in the Table 3.4. Few of them had voiding problems with stool and urine within the first month of age (7.9%). A significant number (40.3%) had been hospitalised and 32.4% had a history of severe upper airway obstruction (UAO).

Table 3.4 Past medical problems

	Total n	Yes n (%)	No n (%)	Unknown n (%)
Voiding problem in first month	113	9 (7.9)	82 (72.5)	22 (19.4)
Admissions to hosp.	114	46 (40.3)	68 (59.6)	0
Surgery on child	114	11 (9.6)	103 (90.3)	0
UAO / snoring	114	37 (32.4)	77 (67.5)	0
Eczema	114	7 (6.1)	107 (93.8)	0
Rash on perineum	114	15 (13.1)	99 (86.8)	0
Allergy to foods, soap	114	3 (2.6)	111 (97.3)	0
Child on chronic meds.	114	25 (21.9)	80 (78.1)	0

3.14 Trauma and stressors

The majority of the subjects were exposed to multiple stressors, refer Table 4.5. Caregivers of 10.6% children were aware of past sexual abuse while 10.6% were suspicious of it.

Table 3.5 Trauma and stressors

	Total n	Yes n (%)	No n (%)	Unknown/NA n (%)	Suspect n (%)
Stress at onset	114	53 (46.5)	47 (41.2)	5 (4.4)	9 (7.8)
Stress at present	114	54 (47.3)	54 (47.3)	3 (2.6)	3 (2.6)
Child aware of stress	114	53 (46.5)	14 (12.2)	46 (40.3)	1 (0.8)
Experienced traumatic events	114	76 (66.6)	30 (26.3)	5 (4.4)	3 (2.6)
Child Sexual Abuse	113	12 (10.6)	79 (69.9)	10 (8.8)	12 (10.6)
Parental separation	112	53 (47.3)	55 (49.1)	4 (3.5)	0
Conflicts handled	112	54 (48.2)	54 (48.2)	4 (3.5)	0
Residential moves	114	62 (54.3)	52 (45.6)	0	0
School moves	112	38 (33.9)	64 (57.1	10 (8.8)	0
Teased at school	112	53 (47.3)	52 (46.4)	7 (6.1)	0
Rigid T practice school	112	38 (33.9)	69 (61.6)	5 (4.3)	0
School failure	112	23 (20.5)	75 (66.9)	14 (12.4)	0
Poor coping levels school	112	58 (51.7)	50 (44.6)	4 (3.5)	0
Recurring nightmares	113	23 (20.3)	85 (75.2)	5 (4.4)	0

3.15 Physical function, activities of daily living, difficult behaviours and social function

3.15.1 Physical function

Physical functions of the subjects were described in the Table 4.6. Few (10.4%) of the children suffered from or were suspected to have decreased vision and were referred to an appropriate

facility. Similarly, 9.6% were referred for a hearing dysfunction. A majority of 69.8% were perceived as cognitively challenged by their caregivers. Twenty three percent were considered clumsy.

Table 3.6 Physical function

	Total n	Yes n (%)	No n (%)	Suspect n (%)	Unknown n (%)
Normal vision	114	99 (86.8)	6 (5.2)	6 (5.2)	3 (2.6)
Normal hearing	114	101 (88.6)	2 (1.7)	9 (7.9)	2 (1.7)
Normal cognition	113	75 (66.3)	29 (25.6)	7 (6.2)	2 (1.7)
Clumsy / accident prone	113	26 (23)	77 (68.1)	2 (1.7)	8 (7.1)

3.15.2 Activities of daily living

Low adaptive function with common day to day demands, e.g. personal care were revealed in 29.5% of the subjects.

3.15.3 Difficult behaviour

Difficult behaviours were reported in a significant number of subjects as occurring ‘most of the times’. Refer to figure 4.5. These behaviours indicate either a psycho-social maladjustment problem or co-existing psycho-pathology. These were identified and referred to the Child Psychiatry Department.

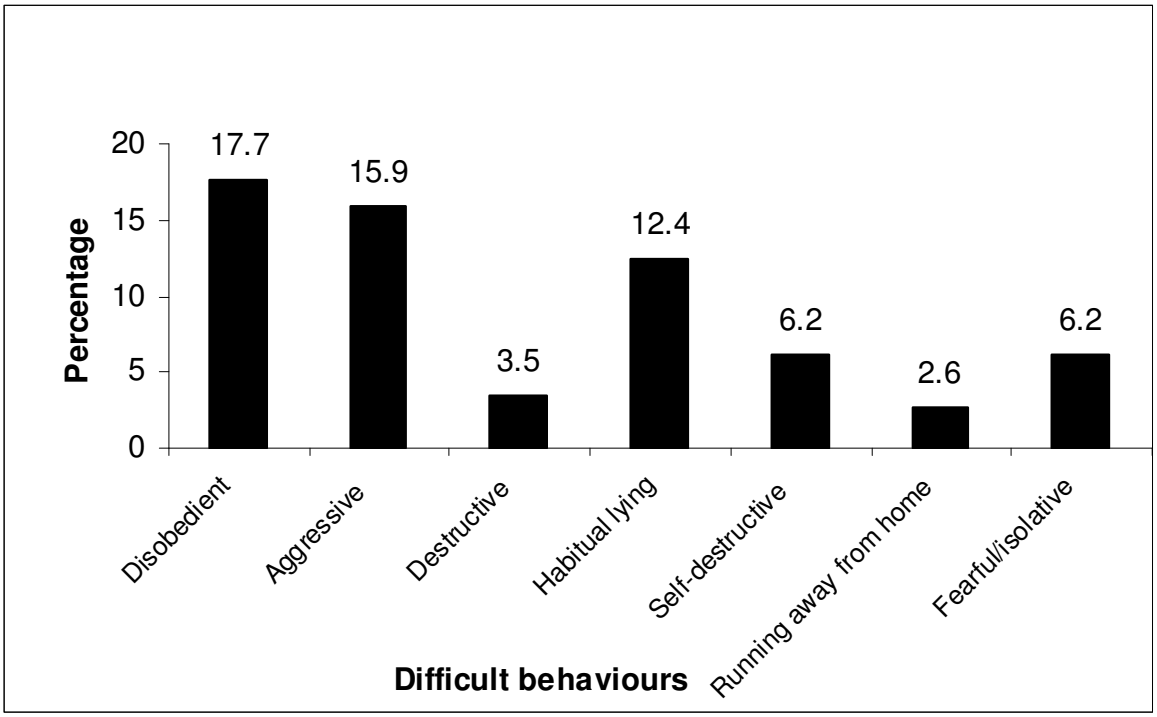

Figure 3.5 Difficult behaviour

Caregivers admitted that around half of the subjects' behaviour at school (49.5%) was of concern to their teachers. The key concerns were as follows:

- Slow (15%)
- Disruptive (12.3%)
- Aggressive (3.5%)
- Regular absenteeism (3.5%)
- Emotionally labile (2.6%)
- Sleepy and forgetful in class (2.6%)
- Shy and afraid (2.6%)
- Truancy and bullying (1.6%)
- Sexually acting out (0.8%)
- Substance abuse (0.8%)

3.15.4 Social function

Eighteen (15.9%) of the subjects displayed a 'whiny' temperament (n=113) in infancy while a similar number displayed a 'distant' temperament. Over thirty five percent (35.9%) of the subjects displayed a 'clingy' personality while 66.3% were excessively cooperative and wanting to please.

Few of the subjects did not enjoy playing with toys or family members (8.8%) and had no best friends (9.8%). A significant number of subjects had a foe (55.3%).

3.15.5 School function

The caregivers thought that nearly half of them (44.6%) were functioning below average while 41.1% were average and 10.7% were above average in their scholastic performance.

3.16 Socio economic condition

3.16.1 Social class

The social class of the care-givers is listed below: (24)

- Professional (1.7%)
- Intermediate (9.7%)
- Skilled non-manual (7.9%.
- Skilled manual (2.6%)
- Partly-skilled (41.5%)
- Unskilled (33.6%)
- Indeterminate (2.6%).

3.16.2 Dwelling

More than 75% resided in brick houses but 33 (29.2%) of the subjects lived in informal houses. Thirteen percent had residential moves during the early years (1-4 yrs) and 17.5% during the 4-7 years age period; 6.1% moved at later ages. Over fifteen percent had multiple residential moves. Almost half of them, 42.4% had moved residence at some time or the other.

3.16.3 Types of toilets

Nearly half of the children (52; 46%) had to share a communal outside flushing toilet with more than one family. 12.3% used an outside pit-latrine; 1.7% used an outside portable toilet, again shared by adults and children; 29.2% had a toilet inside the house that could flush; 8.8% had access to inside the house and outside the house latrines; less than 1% admitted to using a bucket for the children. See Figure 3.6 below. School toilets without doors for privacy were reported by 15.2% of the subjects.

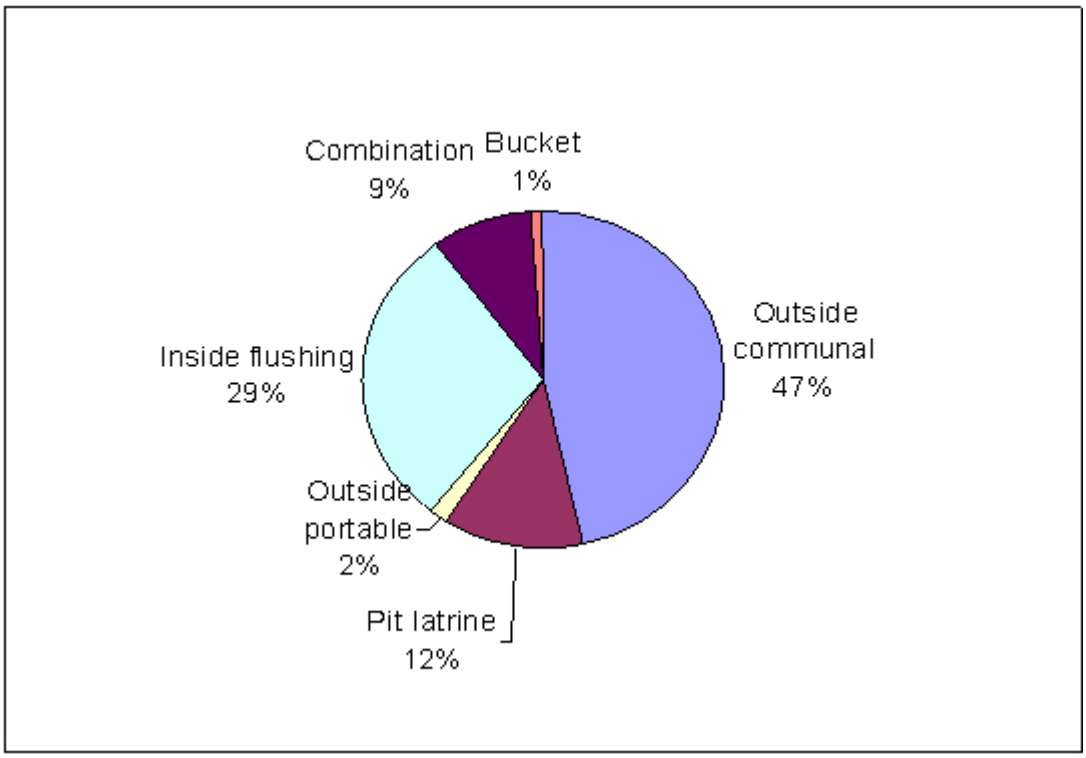

Figure 3.6 Types of toilets

3.17 Family history and habits

3.17.1 Family history of illness and habits

Family history of the subjects is listed in the Table 3.7

Table 3.7 Family history of illness and habits

	Total n	Yes n (%)	No n (%)	Unknown n (%)
Mental illness	112	20 (17.8)	83 (74.1)	9 (8)
Substance abuse	112	44 (39.2)	63 (56.2)	5 (4.4)
Habitual alcohol use	113	73 (64.6)	35 (30.9)	5 (4.4)
Mental retardation	113	41 (36.2)	64 (56.6)	8 (7.1)
Epilepsy	112	19 (16.9)	86 (76.6)	7 (6.2)

3.17.2 Family function and relationships

Family function of the subjects is listed in Table 3.8

Table 3.8 Family function

	Total n	Yes (%)	No n (%)	Sometimes n (%)	NA n (%)
Roles allocated	114	86 (75.4)	17 (14.9)	5 (4.4)	6 (5.2)
Accountability maintained	112	69 (61.6)	28 (25)	11 (9.8)	4 (3.5)
Has supportive member	112	107 (95.5)	3 (2.6)	0	2 (1.7)

Family relationship of the subjects is listed in Table 3.9

Table 3.9 Family relationships

	Total n	Yes n (%)	No N (%)	NA n (%)
Parent married	112	39 (34.8)	63 (56.2)	10 (8.9)
Parental new relationship	112	31(27.6)	31 (27.6)	50 (44.6)
Good relation with new spouse	112	63 (56.2)	10 (8.9)	39 (34.8)
Good relation with sibs	112	98 (87.5)	7 (6.2)	7 (6.2)

3.17.3 Child's age at separation

The ages of the children at separation of their parents were as follows:
16.1% were less than 2 years; 10.7% were between 2 to 4 years; 13.3% were between 4 and 6 years while 7.1% were over 6 years.

3.18 Clinical findings and diagnosis

Ninety eight subjects had completed the voiding diary. Over thirty eight percent (38.8%) had a urinary frequency of 4-6 per day while polyuria (7-10/day) was present in 19.4% of the subjects. Twenty four percent had symptoms of voiding dysfunction viz. urgency, posturing, abdominal pain and dysuria. There was a suspicion of constipation in 27.4% of the subjects.
The dietary diary was inadequately completed by the subjects.

Physical evidence of sexual abuse was present in 13.8% subjects out of 101 respondents. Of these, 9.9% were confirmed and 3.9% were suspected.

Neurological findings in 102 subjects examined were as follows; over twelve percent (12.7%) had clinical features of cerebral palsy (CP) while 10.7% had soft neurological signs. Significant café au lait spots (to fulfil the criteria for neurofibromatosis) were present on 4.9% subjects. One subject had a macrocephaly and one had microcephaly.

The Goodenough Draw a PersonTest. (25); was obtained in 46 subjects. Of these nearly half (47.9%) had inappropriate drawing for their chronological ages.

Of the 93 subjects evaluated for ADHD, it was confirmed in 11.8% of the subjects while it was suspected in 15%. In the confirmed ADHD group, 6 subjects were enuretic; 3 primary and 3 secondary enuresis; 1 had encopresis and 4 had combined elimination syndrome. Out of the 3 subjects with primary enuresis and ADHD, one had concomitant conduct disorder, one had a learning disability and the last one had a hemiplegia with psychosocial stressors. It is unclear if these are all part of the same neuro-biological dysfunction or a result of the CP.

On examination of the upper airways, 10% of the subjects of a total of 100 had evidence of tonsillar hypertrophy, allergic rhinitis and severe atopic features.

Hundred and two children were subjected to radiological investigations including ultrasonography. Evidence of faecal loading (excessive stool retention in part or whole of the large bowel) on plain X- ray of the abdomen was found in 47% of cases. Sixty four subjects had an ultrasound examination of the abdomen out of these; pathology was detected in 10.9%. These included absent kidney, horse-shoe shaped kidney, hydronephrosis, hydroureter, and residual urine in the bladder.
A radionuclear scan (DMSA) was booked in two cases and the subjects referred for further care. Voiding-cysto-urethrogarms (VCU) were booked on three subjects. An abdominal computerised axial tomography (CT) scan and one intravenous pyelogram (IVP) were booked. Blood and urine osmolalities were done on 14% of the patients. Urine cultures were positive in 10% of the subjects with ED.

Structural abnormalities relating to the renal system and the central nervous system were found in 6.3% of subjects.

Associated medical diseases were present in 38 subjects as follows:

- Epilepsy (7%)
- Cerebral palsy (12%)

- HIV Disease (5.4%)
- Foetal Alcohol Syndrome (0.9%)
- UAO (9%)

Of 110 subjects, mental retardation was suspected in 22.7% and learning disability in 18.2% respectively. Associated psycho-social difficulties were evident in 50% of the subjects.

Mono-symptomatic nocturnal enuresis (MSNE) was evident in 8.1% subjects. Out of these, 2 were secondary in nature while seven were primary subtypes.

Personnel required for conducting the interview were two people in 82.7% of cases, (the nurse interpreter and the researcher). Three personnel were required in only 14.5% of cases when specialised child abuse counsellors were involved.

Medical disciplines involved in assessing the cases were counted for each case (n= 108) e.g. nurse, researcher, radiology, laboratory, social worker, child psychiatry, paediatric renal, paediatric neurology etc. Two disciplines were utilised in 10 (9.2%) cases; three in 30.5%; four in 36.1%; five in 20.3% and six in 3.7%.

Time taken to conduct the interview was 120 minutes in 38 (34.2%) cases and the others ranged from 45 min to 225min. (n = 111).

CHAPTER FOUR
DISCUSSION

To my knowledge, this is the first series describing elimination disorders in a group of South African children. It documents the prevalence and service needs for these commonly occurring childhood conditions in a developing world. Inherent biological attributes within the child that constantly interact with his/her external environment were identified in order to understand the development of these disorders.

4.1 Epidemiology

The incidence and prevalence of elimination disorders (ED) in South Africa is not known. A study done by Fockema MW (7) was only for nocturnal enuresis. In that study the prevalence of MNE was 14.4% while that of combined MNE and NMNE was 12.3%. At the Steve Biko (Pretoria Academic) Hospital, there is a well established clinic for encopresis and constipation. Here, a prevalence of encopresis was established at 2-3 per 100 children (M Kirsten, personal communication).

My study was conducted over three years in the outpatients department with a turnover of 114,132 patients in the three year period; thus the prevalence of ED is roughly 0.1%. This is probably an underestimation of the problem as these disorders are regarded by many as not pathological and others face embarrassment when seeking help. There is also no specialised clinic with a multidisciplinary approach available for ED in CHBH. This is mainly due to time and physical space constraints.

The combined gender ratio for all three conditions was M:F = 1.6:1. One girl presented with encopresis only. Bellman (26) has quoted two studies done by von Harnack and Hallgren in which a number of encopretic boys were identified but no girls. It is unclear why boys are more prone to developmental problems.

It is difficult / impossible to compare the available figures from my study with other literature.

My study evaluates all elimination problems as they present at a facility. These included functional and organic problems whereas available studies are done around specific elimination disorders each fulfilling strict criteria for diagnosis. viz. enuresis, encopresis and both. Prevalence is also established for specific subtypes and specific age groups in population surveys whereas this study combines all subtypes and age groups on presentation to POPD. This study is a preliminary survey of the problem.

4.2 Familial Associations

There was a strong association with a heritable mode of transmission in these disorders in my study. Sixty percent of the subjects had a positive family history of enuresis. Twenty percent of whom were the immediate parent, 7% were siblings and 28.9% were other family members. A study done by von Gontard (2) examined a clinical population with nocturnal enuresis in whom a positive family history was available in 63.2%; 23.2% of these were the immediate parents while 16.5% were siblings. Although these percentages are comparable, a multigenerational history and a breakdown of the condition suffered by the index case would have elucidated the contribution of genetics more accurately in my study.

4.3 Constipation

The presence of constipation is subjective as it is perceived from a history. It is difficult to ascertain as neither parents and the subjects look at their stools consistently. In my study a history of stooling once every 2, 3 or 4 days was obtained in over half the subjects. A history of passing mostly hard stools was obtained in a third of the subjects. Palpable faecal masses on abdominal examination and faecal loading on x rays were present in about half (51.8%) the subjects. This is in keeping with retentive constipation which is implicated in the aetiology of these conditions.

This study compares well with those done by Van der Plas et al (27) and Benninga et al (28) in which encopresis with constipation ranged from 40-80%. Constipation associated with daytime urinary incontinence was 17% in a study by Hoebeke et al. (29) A breakdown of constipation occurring in individual ED was not possible in my study.

4.4 Urinary voiding patterns

Kajiwara et al (30) described increased frequency of voiding in 26.8% of daytime urinary incontinent children and urgency in the majority (90%) of day wetters. In my study, polyuria and urgency were present in less than a third of the patients and about a third of the subjects had daytime incontinence. No differentiation was available between these variables occurring within the different ED in my study.

Age at continence of urine at night was delayed in less than half of the subjects. This maturational delay has been identified as a risk factor for developing secondary enuresis by Fergusson et al. (15)

4.5 Infant Temperament, physical function, developmental delays.

A whiny or 'difficult' temperament was reported in 16% of the subjects while a distant or 'slow to warm' temperament was reported in a similar percentage. Approximately 36% were 'clingy' and difficult to separate from their parents. Two thirds displayed an excessively co-operative personality and wanting to please. These were observable visible behaviours as reported by their caregivers and a common personality trait observed in children with ED as communicated by M Naidoo (personal communication).

Thomas A and Chess S (31) recognised that 'difficult' children are more prone to develop behavioural disorders in early and mid childhood. Furthermore, learning and early socialisation of these children is more difficult. (4) More behavioural problems are encountered in 'difficult' children who may also have physical disabilities and mental retardation. In addition, these children are more prone to psychiatric disorders if their parent has a mental illness. (4;32)

In my study, physical dysfunctions were visual (10%); hearing (9%) and cerebral palsy (12%). Mental retardation was present in 22% and LD in 17%. Speech and language delay was present in 29% and 10% of the subjects had difficulties with socialisation. A history of mental illness in the family members was present in about 18% of the subjects. A correlation

between temperament, physical and mental and social difficulties, other behavioural problems and ED was not available in my study, but are definite risk factors to exclude.

4.6 Comorbid Conditions

ADHD is a common comorbid condition. In the literature, von Gontard et al (32) reported this co-occurrence in 9.3-13.5% of enuretic children. In my study ADHD was present in 11.8% and suspected in a further 15%. This is a very high figure which may be due to this study including all ED. It is essential that this condition needs to be screened for in all patients presenting with ED in our setting. There were an equal number of primary and secondary enuretics in this group of subjects as also reported by von Gontard et al. (32)

The boundaries between mental retardation and learning disabilities are considerably obscure. Both conditions are interpreted as poor cognition in the child by the caregivers. In my study, mental retardation (MR) was judged by an inability to perform activities of daily living while learning disability (LD) was judged from a history of slow learning in specific academic areas and a below average school performance. After evaluation, under a quarter of the subjects were assessed as mentally retarded but the degree/severity of MR was not evaluated. Out of these, 52% had combined elimination syndrome, 32% had encopresis and 16% had enuresis. In a population based study done by von Wendt et al (11) 38% of 7 year olds with MR had urinary incontinence and the risk of incontinence correlated directly with the severity of MR. Similarly, in this study, learning disability was found in 17.2% of the subjects and of these 36.8% had encopresis. Von Gontard (2) elaborates that in the same study by von Wendt et al, 35.5% of 7 year olds with moderate to severe LD soiled. Thus screening for LD and MR is an important aspect when investigating patients with ED.

Children with cerebral palsy often display urinary incontinence and detrusor over activity as established by Mayo (33). In my study, 69.2% of the CP subjects had urinary incontinence, 23% had combined elimination syndrome and 7.6% had faecal incontinence only. Therefore cerebral palsy is an important condition to exclude in children presenting with ED.

In various studies, von Gontard et al (2) and Benninga et al (28) reported behavioural problems in 20-30% of enuretics and 40-50% of encopretic children with constipation respectively. In my study 10% of children with ED screened positively for significant behavioural problems that required psychiatric intervention, but no formal detailed behaviour check lists were carried out on all the subjects. It is unclear if these were primary in nature or as a result of parental reaction to the elimination disorders. As formal behaviour checklists were not carried out on all the subjects this percentage was not comparable to published studies. Follow up evaluation notes were not available for these subjects on their consultation with the child psychiatry department.

The effects on the subjects and clinical distress have been well studied by von Gontard (2) who established that 32.1% enuretics felt cold and wet, 16.4% were sad and ashamed, 6.7% felt different from peers and 32.1% avoided sleep-overs. In my study 52.6% felt cold and wet on awakening in the mornings, 65.2% were sad and ashamed, 33.9% were uneasy with their peers and felt different from them and 14.8% avoided sleep-overs. The results compare inadequately as this study was collectively done for all elimination disorders, not only wetting. The variable, 'avoids sleepovers', was difficult to elucidate as it is not a culturally accepted practice in most of my study population.

4.7 Social environment

Parental perceptions and reasons for seeking help reveal their beliefs, attitudes and practices. In our study, almost all the parents wanted to support their child, but a similar number were intolerant of their child's behaviour, attributing it to a fault within the child and punishing them. Some (14.1%) attributed the cause to psychological problems within the child and 3.5% suspected sodomy (anal penetration) Shelov et al (34) established that 29% of parents attributed the cause to emotions while Haque et al (35) established this percentage at 35%.
Eighty eight percent of the parents felt there was a financial burden related to their child's problem. This parameter could possibly worsen the intolerance felt by most parents in my study.(36)

4.8 Cultural practices

In this study, punishing the child was employed by most of the caregivers (86.8%). This percentage compared well with the caregivers who admitted being intolerant of their child's behaviour (89.6%). Slapping or 'clapping' the child was the most frequent method and next was using a belt to hit the child. Rates of punishment differed in different studies from 5.6% von Gontard (2) to 35.8% Haque et al. (35) Forty two percent of Turkish children were slapped and 13% were beaten; a total of 40.6% were physically because of their enuresis. (37). It seems that the more financially challenged and poorly educated caregivers were more prone to use physical punishment. (35)

Purging was regularly practised in a majority of the subjects. This practice is common and passed down over generations in order to 'clean' the 'dirty' bowels (20). In my study the earliest method of purging was the use of enemas at the age of six weeks. Oral laxatives and enemas were commonly used individually or in combination. A causal effect between regular laxative use and constipation and/or encopresis is unclear, but compounds the problem and needs further investigation.

Toilet training should optimally occur without coercion or pressure and at a time when the child is developmentally ready to learn this complex skill. Over a quarter (28%) of caregivers admitted being coercive and putting pressure on their children if there was no voiding. Bellman described 31% of encopretic children who had undergone forceful/'demanding' and strict training. (26) Thus, forceful training is a risk factor for development of encopresis.

Family stability was judged by the perceived availability of a supportive family member in 95.4% of subjects, allocation of family roles and maintaining accountability in 61.6% of cases. However the destabilising factors were multiple and significantly more distressing to the subjects. These included frequent and multiple residential moves, school moves, habitual alcohol use, and substance abuse by family members. Kalo and Bella (38) reported that breast feeding and family stability appeared to be protective factors in NE. In my study, 83% of the subjects were breast fed, thus was not deemed protective.

4.9 Physical environment

Poor living conditions in informal dwellings were evident in a third of the subjects. Psychosocial factors that co-exist with nocturnal enuresis such as low socioeconomic status and large overcrowded families, have been cited by Butler (19). The poor state of toilets was evident in two thirds of the cases, contributing to toilet refusal by the subjects. These were outside, communal toilets that were mostly unavailable to the subjects. Pit latrines and portable toilets were a source of discomfort and fear among the subjects. School toilets without doors for privacy were a source of humiliation. Filthy toilets at home and at school were revealed in two thirds of subjects. The perpetuation of the myth about the toilet monster when combined with a child's propensity for magical thinking can also influence toilet avoidance and consequent stool retention. Fear of the toilet was reported frequently by the subjects. Over half the subjects feared going to the toilet because of the elusive toilet monster known as 'Pinky-Pink' or 'Tokoloshe'. Seven subjects had actually seen the monster, red eyed, half male and half female, black and short hanging from the roof of the toilet and at times under the bowl or inside the pit latrine! A further seven were fearful of the dark and being alone. Over two percent were afraid of adolescent gangsters that sodomise children in the toilet. Four percent were afraid of rats, spiders & dogs around the toilet, while one subject described 'Inkameleng-kameleng' the brown, large boot that walks around the school!

Thus, this is the most challenging aspect in our subjects. Effort put into addressing these factors can lessen the distress experienced by the affected children.

4.10 Traumatic events and stressors

Risk factors for secondary elimination disorders include an exposure to four or more stressful life experiences in one year. (15) Disruptive experiences such as parental separation and multiple residential moves were experienced by approximately half of the subjects and adjustment to new family structures by a third. Adverse experiences such as being teased and being regularly exposed to adults handling conflicts in their presence were experienced by

almost half the subjects, rigid toileting practices (children not being allowed to visit the toilet except during breaks) at school by a third. Researchers frequently describe a significantly higher percentage of psychological disorders in children with secondary NE. (39;40)

Sixty six percent of the subjects had witnessed traumatic events while stress at the onset of the disorders was perceived by almost half of the caregivers. Significant life events and stressors often coincide with onset or relapse of secondary enuresis. (39)

Sexual abuse was evident in 13.8% of the subjects. Out of these 43% had enuresis, 14.2% had encopresis and a similar percentage had combined elimination syndrome. All these disorders were secondary in nature. In a review of hospital records, Boon (41) had found that 16% of encopretic children were sexually abused, similar to this study. Thus, sexual abuse needs to be excluded in children presenting with ED.

A temporal relationship between the stressors and the ED was not obtained in most cases. A considerable number (11.2%) of caregivers were unaware or unsure of the child's exposure to stressful events. This is unique and frequently found in my study. There were greater socio-economic difficulties making the caregivers unavailable for their children. Also the extended family culture is expected to cover up for this unavailability. Most caregivers were unfamiliar with expected child rearing practices, compounding this problem.

Thus there are common similarities between available literature and this study but the unique factors in this study are the dwelling and toileting conditions, fears in the child, sexual abuse and the stressors affecting the subjects and their very extended families. Cultural practices such as purging and punishment being important considerations.

CHAPTER FIVE
CONCLUSION AND RECOMMENDATIONS

5.1 Conclusions of the study

The presence of encopresis, enuresis and combined elimination disorders were found in a significant number of patients during the study period. This may be the tip of the iceberg due to the secretive, embarrassing and self-effacing nature of these problems.

The extent of overlap between organic medical illnesses, psychiatric disorders, socio-familial and environmental difficulties requires parallel participation from medical, psychiatric and social worker teams to form a multidisciplinary team approach.

5.2 Limitations of the study

There were some limitations in this study. The prevalence was projected as there was a selection bias. The information supplied by the caregivers may have recall bias. Under or over-estimation by the caregivers, nurse interpreter and the researcher, allows for mis-assignment. The information gathered was not validated during the study period. Not all the information was available for every subject of the study cohort.

5.3 Recommendations

5.3.1 Setting up a special clinic for elimination disorders

In Soweto, the primary care physician is inadequately trained to manage these conditions. Furthermore there are limited resources to investigate these disorders at a primary care level. Presently, the varied referral sources clearly indicate that there is a need for this service to be available in an ambulatory, general paediatric facility. Available care is fragmented and ill defined. The child psychiatrists rarely consider these conditions to be solely psychological in origin and there is a need to rule out medical and/or structural anatomical pathology. The

paediatric neurologists, urologists and surgeons require time to invest into gathering a psychosocial history. Once assessed by the paediatrician, input may be required from the above specialists. The convenience of having all investigative facilities and specialists in one place, such as the Chris Hani Baragwanath Hospital make it desirable to assess these cases in the paediatric out-patients department. However the time spent on each case, mostly 120 minutes, requires that a special clinic be allocated for these conditions, within the busy paediatric outpatients department.

5.3.2 Further research

A community based survey is necessary to determine the true prevalence and associated factors of these 'neglected' disorders, which this study highlights among its cohort. Once a clinic is established, further studies regarding more specific details of these conditions, management and long term outcome can be planned.

5.4 Summary and conclusion

In summary the study was a description of elimination disorders in children attending the Chris Hani Baragwanath Hospital over a three year period. A lengthy, time consuming interview and assessment was necessary in order to rule out structural anatomical or medical diseases and identify the factors that may potentiate these behaviours.

Understanding of the associated psychosocial factors and child characteristics enabled positive interaction with the respondents. Both parent/caregiver and child were allowed to express their problems. Assistance to navigate environmental difficulties e.g. allaying fears and phobias, counselling over cultural practices and their effects, offering the child an opportunity to understand (the meaning of stressful and traumatic events) and cope with challenges. When necessary, child psychiatrists, urologists and neurologists were consulted in the management.

A specialised clinic at the CHBH is essential, for these children to be managed by a multidisciplinary team.

APPENDICES

APPENDIX A: ETHICS CLEARANCE CERTIFICATE

APPENDIX B (1): FACULTY APPROVAL AND
APPENDIX B (2): PERMISSION FOR RESEARCH

APPENDIX C (1): INFORMATION SHEET
APPENDIX C (2): CONSENT FORM
APPENDIX C (3): ASSENT FORM

APPENDIX D (1): 24 HOUR VOIDING DIARY
APPENDIX D (2): 24 HOUR DIETARY DIARY

APPENDIX E: INTERVIEW QUESTIONNAIRE

Appendix A

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

COMMITTEE FOR RESEARCH ON HUMAN SUBJECTS (MEDICAL)
Ref: R14/49 Patel

CLEARANCE CERTIFICATE **PROTOCOL NUMBER** M03-10-30

PROJECT Elimination Disorders in a Group of South African Children

INVESTIGATORS Dr F Patel

DEPARTMENT School of Clinical Medicine, CH Baragwanath Hospital

DATE CONSIDERED 03-10-31

DECISION OF THE COMMITTEE Approved unconditionally

Unless otherwise specified the ethical clearance is valid for 5 years but may be renewed upon application
This ethical clearance will expire on 1 January 2003.

DATE 03-11-21 CHAIRMAN.....(Professor P E Cleaton-Jones)

* Guidelines for written "informed consent" attached where applicable.

c c Supervisor: Prof U Kala
Dept of School of Clinical Medicine, CH Baragwanath Hospital
Works2\Iain0015\HumEth97.wdb\M 03-10-30
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DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10001, 10th Floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress form. I/we agree to inform the Committee once the study is completed.

DATE 02/12/03 SIGNATURE F. PATEL U.K. Kala

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B (1)

Faculty of Health Sciences
UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
7 York Road PARKTOWN Johannesburg 2193 Telegrams WITSMED Telex 4-24655.SA
FAX 643-4318 TELEPHONE 717-2075/2076
E-MAIL healthpg@health.wits.ac.za

DR FH PATEL
PO BOX 11006
KIASHA PARK
1829

APPLICATION NUMBER 0009186E
STATUS (DEG 21) (MM044) PZZ

2004-06-09

Dear Dr Patel

Approval of protocol entitled Elimination disorders in a group of South African children

I should like to advise you that the protocol and title that you have submitted for the degree of Master Of Science In Medicine (Part-Time).(Coursework) have been approved by the Postgraduate Committee at its recent meeting. Please remember that any amendment to this title has to be endorsed by your Head of Department and formally approved by the Postgraduate Committee.

Prof UK Kala has/have been appointed as your supervisor/s. Please maintain regular contact with your supervisor who must be kept advised of your progress.

Please note that approval by the Postgraduate Committee is always given subject to permission from the relevant Ethics Committee, and a copy of your clearance certificate should be lodged with the Faculty Office as soon as possible, if this has not already been done.

Yours sincerely

S Benn (Mrs)
Faculty Registrar
Faculty of Health Sciences

Telephone 717-2075/2076

Copies - Head of Department____Supervisor/s

Appendix B (2)

Gauteng Department of Health

CHRIS HANI BARAGWANATH HOSPITAL

PERMISSION FOR RESEARCH

DATE: 01 September 2003

NAME OF RESEARCH WORKER: Dr F. Patel

TITLE OF RESEARCH PROJECT Elimination Disorders In A Group of SA children

OBJECTIVES OF STUDY (Briefly or include a protocol): requirements for MSc-NeuroDevelop. Paeds.

METHODOLOGY (Briefly or include a protocol): Descriptive Study - re incidence, demographic details, probable causes.

CONFIDENTIALITY OF PATIENTS MAINTAINED: YES.

COSTS TO THE HOSPITAL: none

APPROVAL OF HEAD OF DEPARTMENT: obtained

APPROVAL OF CRHS OF WITS UNIVERSITY:

SUPERINTENDENT PERMISSION:

Signature: (DR A. NAIDOO) Date: 2003/09/02

Subject to any restrictions: * Ethics Approval

* No financial implication to Hospital

APPENDIX C (1)

INFORMATION SHEET

Dear Parent / Care giver / Guardian

I am Dr F Patel. I work in the Paediatric Outpatients Department of the Chris Hani Baragwanath Hospital. I am conducting a research to identify children who wet / & / or soil their underclothes inappropriately.

The inability to control urination and/or passing stools has serious effects on a child & his/her parent /caregiver. The child suffers embarrassment and feels shame as other children tease him/her. This hampers his/her social development and school performance.

The parent / caregiver in turn are frustrated at the time and money spent on the extra care of his / her child.

The reason for doing this study is to identify the number of these children, to describe the possible cause of their problem and to describe the treatments that help them. These children require specialized care and at present there is no such facility available for them.

As part of this study you will be asked a detailed history & questions, which may take up to two hours sometimes. I would also request you to complete a diary about your child's bowel and bladder habits. The examination of your child will include a complete examination of the nervous system and genitalia (private parts). The investigations and treatment of your child will carry on in a normal manner.

There will be no risks to you or your child, however at times sensitive issues may be exposed, in which case, counseling will be made available to you and your child. These issues sometimes may require referral to social workers and people concerned with the well being of your child.

The information obtained will be used without using your child's name and other personal information, at any time. Participation in this study is voluntary. If you refuse to be part of the study, your child's management will not be affected in anyway. You can also withdraw from the study at anytime and this will not prejudice any future treatment of your child.

I am available for your questions at Tel No.: (011) 933 8633 / 933 8231 (working hours)

Your help with this study will be appreciated.

Thank you,

Dr F H Patel

APPENDIX C (2)

CONSENT FORM

I, _____(parent/guardian/caregiver) give permission to Dr F Patel to let my child, _____, be part of the above study.

I have been satisfactorily informed of my involvement in and the purpose of the study. I understand that it involves answering questions regarding my child's disorder. Further, that there is no direct benefit to my child or me; but it will help the researchers to understand and describe the disorder.

I also understand that I am free to withdraw this consent and discontinue participation in this study at any time and this will not affect the care of my child.

I have been offered a copy of the Information Sheet and this consent form.

Parent / Guardian / Caregiver Name: _____

Relationship to child: _____

Signature: _____

Date: _____ Address: _____

Contact Telephone No.: _____ _____

Person obtaining consent:

Name & Designation: _____

Signature: _____

Date: _____

Witness' Name & Designation: _____

Signature: _____

Date: _____

STUDY CODE NUMBER:

APPENDIX C (3)

ASSENT FORM

I, _____ agree to participate in this study which is going to describe the disorder that I have. My parent / guardian has been informed of the process and details by Dr F Patel and they also agree.

I understand that Dr F Patel is going to ask my caregiver / parent and myself questions describing my problem and details of my family and school life. She will ask me to complete a diary of how many times I void urine & stools in a day. Then she will examine my body and my private parts to look for signs of any illness. She will then do investigations like X rays and advise us treatment.

Dr Patel is doing this study to help children who have similar problems as myself, by obtaining information about our illness. I understand that there will be no direct benefits to me, nor any risks. However, counseling will be made available to me if there is a need.

I also understand that I may refuse to participate in this study at any time and that it will not prejudice my ongoing treatment.

Signature of child: _____

Name in capitals: _____

Date: _____

Parent / caregiver's Signature: _____

Witness' signature: _____

APPENDIX D (1)

24 HOUR VOIDING DIARY

INSTRUCTIONS FOR COMPLETION OF 24 HOUR VOIDING DIARY

Please record all 'urination' & 'defecation' events on the sheet provided. The left hand columns are for urination events while the right hand columns are for defecation events.
Record with a √ every time the child either urinates or defecates alongside the time the event happens. Try to measure the amount of urine passed in the cup(c) measure provided. The stools passed may be recorded as large, medium or small amounts. The measured amounts are to be entered alongside the time column.
If your child displays any of the following symptoms while voiding, please enter the symbols as follows:
Associated symptoms while 'urinating'

(d) = dysuria = pain in the genital urinary passage, while passing urine.
(u) = urgency = inability to hold urine before getting to the toilet.
(p) = posturing = abnormal postures when urge to urinate appears
(a) = abdominal pain = pain in the lower abdomen while urinating

Associated symptoms while 'defecating'

(a) = abdominal pain = pain in the abdomen while defecating
(p) = pain in the anal passage while defecating

APPENDIX D (1)

24 – HOUR VOIDING DIARY

	URINE			**STOOLS**	
Time of day		**Associated symptoms?**		**Amount Small? Large? Medium?**	**Tick alongside Time of day**
06H00					
07H00					
08H00					
09H00					
10H00					
11H00					
12H00					
13H00					
14H00					
15H00					
16H00					
17H00					
18H00					
19H00					
20h00					
Nighttime					
1st third 20-24H00	**Damp? Or Soaking?**				
2nd third 24-03H00	**Damp? Or Soaking?**				
3rd third 03-06H00	**Damp? Or Soaking?**				
		Urgency(u)	**Abd. Pain(a)**		
		Dysuria(d)	**Anal pain (p)**		
		Postures(p)			
		Abd. Pain(a)			

APPENDIX D (2)

24 – HOUR DIETARY DIARY

INSTRUCTIONS FOR COMPLETING THE DIETARY DIARY

Please include all foods, snacks and drinks that your child eats & drinks from the time s/he wakes up till s/he sleeps.

Record only one food/drink per line.

Record the amount consumed alongside the item in teaspoon(t), tablespoon(T), slices(s), cups(c).

Time of day	Item	Amount
On waking up		
Mid morning (1st break)		
Lunch (2nd break)		
Afternoon		

APPENDIX D (2)

24 HOUR DIETARY DIARY CONTINUED

Late afternoon		
Supper		
After supper		

APPENDIX E: INTERVIEW QUESTIONNAIRE

ELIMINATION DISORDERS IN A GROUP OF SOUTH AFRICAN CHILDREN

INTERVIEW - QUESTIONS

Date | | | | | 2 | 0 | | | Study No ELIM | | | |

Time started | | | | | | Time finished | | | | | |

PERSONAL

Date of birth | y | y | m | m | d | d | Age | y | Y | m | m |

Sex | Male=1 | Female = 2 | |

2. MAIN COMPLAINT

2.1 Does your child wet his underclothes inappropriately? | Yes=1 | No=2 | |

2.1.1 At what age was it noticed? | y | y | m | m |

2.2 Does your child soil his underclothes? | Yes=1 | No=2 | |

2.2.1 At what age was it noticed? | y | y | m | m |

2.3 Does your child wet & soil his underclothes inappropriately? | Yes=1 | No=2 | |

2.3.1 At what age was the wetting noticed? | y | y | m | M |

2.3.2 At what age was the soiling noticed? | y | y | m | M |

3. REASON FOR SEEKING HELP

3.1	Do you wish treatment to support your child?	Yes=1	No=2		
3.2	Can you tolerate this behaviour?	Yes=1	No=2	Sometimes=3	
3.3	Are their costs/expenses you have to bear due to this behaviour?	Yes=1	No=2		
3.3.1	If yes, please specify				
3.4	Does your child suffer from any physical distress such as feeling cold/wet on waking?	Yes=1	No=2		
3.5	Does your child worry over the bad smell	Yes=1	No=2		
3.6	Is your child indifferent to the results of his/her behaviour?	Yes=1	No=2		
3.7	Does your child feel ashamed as a result of his/her behaviour?	Yes=1	No=2		
3.8	Does s/he feel guilty & blames him/herself for the behaviour?	Yes=1	No=2		
3.9	Does he feel different from his peers?	Yes=1	No=2		
3.10	Is s/he fearful of his behaviour happening at any time?	Yes=1	No=2		
3.11	Does his/her behaviour make him/her sad?	Yes=1	No=2		
3.12	Is your child uneasy with his/her sibs?	Yes=1	No=2		
3.13	Is your child uneasy with his / her peers?	Yes=1	No=2		
3.15	Is your child threatened by his/her sibs?	Yes=1	No=2	Unknown=3	
3.16	Is your child threatened by his/her peers?	Yes=1	No=2	Unknown=3	

3.17	Do the adults including yourself threaten your child?	Yes=1	No=2	Sometimes=3	
3.18	Does anybody use this behaviour as a means to make your child obey their wishes?	Yes=1	No=2	Sometimes=3	
3.19	Does your child avoid sleepovers at his peers?	Yes=1	No=2		

4. ENCOPRESIS HISTORY

4.1	Did the child ever have total bowel control?	Yes=1	No=2		
4.1.1	If so at what age was it attained?	before 3yrs	after 3 yrs	not yet	
4.1.2	If so was it for > 3 - 6mths?	Yes=1	No=2		

4.2 Bowel habits

4.2.1	Does your child pass stool daily?	Yes=1	No=2		
4.2.2	If no, how often?	once in 2d =1	once in 3 d =2	once in 5d =3	
4.2.3	The amount of stool at each void is?	small =1	large = 2	not known = 3	
4.2.4	The consistency of stool is	hard=1	soft=2	semi-formed=3	Watery=4
4.2.5	Do the soiling episodes occur in the	day =1	night = 2	both = 3	
4.2.6	*At what time do they usually occur*	06 to 10 h =1	10 to 13 h =2		
		13 to 16 h = 3	16 to 20 h =4		
		20 to 06 h next day =5			

4.2.7 Number of episodes per day

4.2.8 Number of episodes per week

4.2.9 Number of episodes per month

4.2.10 How much stool is passed during the Encopretic episodes?

stains =1	little liquid =2
small pellets = 3	large=4

5. ENURESIS HISTORY

5.1 Has your child ever been 'dry' for >3 - 6 mths

Yes=1	No=2

5.2 Does your child wet him/herself during the

Day only =1	night only = 2	both = 3

5.3 How often do these episodes occur during the day

several times daily =1	at least once a day =2
at least once a week = 3	at least once a month=4
less than once a month =5	

5.4 How many episodes occur during the night

once=1	More than once = 2	unknown = 3

5.5 Timing of episodes

5.5.1 Approximately at what times does your child wet in the day?

1st	2nd	3rd

5.5.2 Are the underclothes

damp=1	wet = 2	soaked = 3

5.5.3	Approximately at what times does your child wet in the night?	20h-24h=1	24h03h=2	03h-06h=3	
5.5.4	Are the pyjamas	damp=1	wet = 2	soaked = 3	

6. Micturition history :

6.1	How many times per day does s/he urinate?	4-6 times =1	7-10 times = 2	unknown = 3	
6.1.2	Is your child unable to hold urine when the urge appears?	Yes=1	No=2	Sometimes=3	
6.1.3	Does your child adopt funny postures & strain when urinating?	Yes=1	No=2	unknown=3	
6.2	Does your child wake up after wetting @ night?	Yes=1	No=2	unknown=3	

Family History of Enuresis :

7.1	Were there enuretics in your family/s?	Yes=1	No=2	unknown=3	
7.1.2	If yes, were they	parent=1	sibling=2	other=3	
7.1.3	At what age was s/he dry during the day?	<3y=1	>3yr=2	unknown=3	
7.1.4	At what age was s/he dry during the night?	<7y=1	>7yr=2	unknown=3	

Parental Perception

8.1 What in your opinion is the cause of this problem?

8.1.1	S/he waits too long?	Yes=1	No=2	unknown=3
8.1.2	S/he prefers to play?	Yes=1	No=2	unknown=3
8.1.3	S/he forgets?	Yes=1	No=2	unknown=3
8.1.4	S/he feels that the toilet is too dirty?	Yes=1	No=2	unknown=3
8.1.5	S/he fears the toilet?	Yes=1	No=2	unknown=3
8.1.6	Family member had similar problem?	Yes=1	No=2	unknown=3
8.1.7	You don't know	Yes=1	No=2	
8.1.7	If no, please specify			

9. What methods have you tried, to assist your child so far?

9.1	Punishment as discipline?	Yes=1	No=2	
9.1	If yes, please specify			
9.1.1	'Clap' the child?	Yes=1	No=2	sometimes=3
9.1.2	'Belt' the child?	Yes=1	No=2	sometimes=3
9.1.3	Deprive food?	Yes=1	No=2	sometimes=3
9.1.4	Deprive privileges?	Yes=1	No=2	sometimes=3

9.1.5	Wash own clothing?	Yes=1	No=2	sometimes=3

9.2	Do you have to remind your child daily about voiding appropriately?	Yes=1	No=2	sometimes=3

9.3	Have you seen a health professional? If so, who?	GP =1	PHC clinic =2
		Paediatrician = 3	Traditional healer =4
		Psychologist =5	Other =6

9.3.1	If other, please specify

9.4	What treatment did they use?	medication =1	herbs =2
		nappies = 3	plastic/protection sheets =4
		alarms =5	regular supervised toileting =6
		Waking schedules =7	prayer =8
		other =9	

9.4.1	If other, please specify
9.4.2	Please specify, which aspect of the intervention helped?
9.4.3	Please specify, which aspect of the intervention was troublesome?

10. Toilet training :

10.1	What did you use to potty train?	Bucket =1	'potty' =2

	Regular toilet with support = 3	regular toilet without support =4
	Other =5	

10.1.1	if other, please specify	

10.2	When did you start potty-training?	before 18 mths. =1	Between 18-24 mths.=2
		between 24-30 mths = 3	after 30 mths.=4
		don't remember=5	Other=6

10.2.1	if other, please specify	

10.3	What method/s did you use?	toileting@fixed times =1	on demand of child=2
		reward = 3	Punishment =4
		Imitation =5	don't know =6
		Other =7	

10.3.1	if other, please specify	

10.3.2	What did you do if there was no voiding?	persisted until void =1	let him/her push =2
		used a bribe=3	Punished =4
		Tried again later=5	don't remember =6
		Other = 7	

10.3.2	if other, please specify

11. BIRTH HISTORY :

11.1	Was your pregnancy planned?	Yes=1	No=2	

11.1.2 What was your age then?

Y	y	m	m

11.2	Your delivery was	NVD=1	Other=2	

11.2.1	if other, please specify

11.3	The period of gestation was?	full-term=1	pre-term=2	post-term =3	

11.4	Did your child cry immediately?	yes=1	no=2	unknown=3	

11.4.1	If no, please specify the immediate perinatal problem	

11.5	Did your child have any bowel or urine problems in the first month?	yes =1	no =2	unknown =3	

11.5.1	If yes, please specify	

11.6	Did you breast feed your child?	yes=1	no=2	

11.6.1	if no, please specify the reason

12. DEVELOPMENTAL MILESTONES :

12.1	At what age did your child first smile at you ?	< 2 mths. =1 / > 2 mths = 3	@ 2 mths. =2 / don't remember=4
12.2	At what age could s/he sit up unaided?	< 6 mths. =1 / later = 3	@ 6 mths. =2 / don't remember=4
12.3	At what age could s/he walk alone?	< 1 yr. =1 / later = 3	12-18 mths. =2 / don't remember=4
12.4	At what age could s/he imitate 1-2 words? / jabber?	@ 1 yr. =1 / later = 3	12-18 mths. =2 / don't remember=4
12.5	At what age could s/he name few body parts?	@ 2 - 2,5yr. =1 / later = 3	> 3 yrs. =2 / don't remember=4

12.6 At what age did he/she start Grade 1 of school?

Y	y	m	m

13. Immunisations

13.1	Are your child's immunisations complete?	yes=1	no=2

13.1.1	if no, please specify the reason

14. Past History :

14.1	Did your child have any serious illnesses requiring admission to a hospital in the past ?	yes=1	no=2

14.1.1	if yes, please specify the details

14.2	Were any surgical manipulations / operations done to the perineum?	yes=1	no=2	

14.2.1	if yes, please specify the details

14.3	Does your child suffer from severe blocked nose / snoring ?	Yes =1	No =2	Unknown =3	

14.4	Does your child have eczema?	yes=1	no=2	

14.4.1	if yes, please specify details

14.5	Does your child suffer from irritation of the perineum?	yes=1	no=2	

14.5.1	if yes, please specify details soap?/nylon?/worms?

14.6	Is your child on any chronic medication?	yes=1	no=2	

14.6.1	if yes, please specify which ones

14.7	Is your child allergic to any foods or drinks?	yes=1	no=2	

14.7.1	if yes, please specify details

15.	Do you regularly purge your child ?	yes=1	no=2	

15.1	How frequently do you do this?	Fortnightly=1	monthly=2	Other=3	

15.1.2	if other, please specify how often
	age of child when started?

15.2	What method/s do you use?	oral laxative.=1	Enemas=2	
		oral emetic= 3	digital manipulation=4	
		Other=5		

15.2.1	if other, please specify

16.	Do you think that your child has been sexually abused?	yes =1	no =2	unknown =3	

16.1	If yes, please specify details	

17. Home Conditions :

17.1	Is your present house in	Residential area =1	informal settlement=2	Other=3	

17.2	If you moved house, how old was your child then?	< 1yr. =1	1 - 4 yrs.=2	
		4 - 7 yrs = 3	Other=4	

17.2.1	if other, please specify when

17.3	What is the type of toilet?	inside flushing=1	outside flushing=2	
		outside portable= 3	pit latrine=4	
		Other=5		

17.3.1	if other, please specify

18. Daily Routine, Physical Function & Difficult Behaviour/s

18.1 Describe a typical day in your child's life

_____

_____

_____

Physical Functioning

18.2.1 Is your child's vision normal?	yes=1	no=2	unknown=3	
18.2.2 Is your child's hearing normal?	Yes=1	no=2	unknown=3	
18.2.3 Is your child's understanding normal?	Yes=1	no=2	unknown=3	
18.2.4 Do you think your child is clumsy & accident prone?	Yes =1	no =2	unknown =3	
18.2.5 Does your child get recurrent dreams/ nightmares?	yes =1	no =2	unknown =3	

18.3. Does your child exhibit the following difficult behaviors at home?

18.3.1 Disobedience?	Sometimes=1	not at all=2	most of the times=3	
18.3.2 Destructiveness?	sometimes=1	not at all=2	most of the times =3	
18.3.3 Aggression?	Sometimes=1	not at all=2	most of the times=3	
18.3.4 Habitual lying?	Sometimes=1	not at all=2	Most of the times=3	
18.3.5 Self-destructive behaviour, [nail-biting / hair plucking]	sometimes=1	not at all=2	Most of the times=3	

18.3.6 Running away from home?	sometimes=1	not at all=2	Most of the times=3	
18.3.7 Fearful & isolative behaviour?	Sometimes=1	not at all=2	Most of the times=3	

19.Temperament & Sociability

19.1 How would you describe your child's personality?	Jolly =1	Whiny =2	
	Distant= 3	did not show feelings=4	

Do you think your child was clingy & constantly wanting to be carried?	yes =1	no =2	unknown =3	
Was s/he excessively cooperative & wanting to please you all the time?	yes =1	no =2	unknown =3	
Did your child enjoy toys & playing with family members?	Yes =1	no=2	Unknown=3	

19.3 Is / was your child fearful of his/her environment?	yes=1	no=2	

19.3.1	if yes, please specify details

20. Social History

20.1 How old was the child when there was a change in care-giver/s?	< 6 mths =1	6 – 12 mths =2	
	1 – 4 yrs. = 3	other =4	

20.2 What was the child's reaction to a change in the care-giver/s?

sad / longed for =1	angry =2
Avoidant = 3	no reaction=4

20.3 What was the child's relationship with the day caregiver ?

good & enjoyable =1	bad & disliked =2
indifferent &/or tolerant = 3	

Were there any stresses in the family at the time this problem started / was noticed?

yes =1	no =2	unknown =3

20.5 Are there any stresses facing the family at present?

yes=1	no=2

20.5.1 Is your child aware of them?

yes=1	no=2

20.6 Has your child experienced a traumatic event?

yes=1	no=2

20.6.1

if yes, please specify details

20.7 Does your child have a best friend?

yes=1	no=2

20.8 Does your child have a foe?

yes=1	no=2

20.9 Social class?

professional =1	Intermediate =2
skilled non-manual= 3	skilled manual=4
partly skilled=5	Unskilled=6

21. Family History & Function

21.1 Is there family history of mental illness?	Yes=1	no=2	unknown=3	
21.2 Is there family history of substance abuse?	Yes=1	No=2	Unknown=3	
I21.3 Is there mental retardation in the family?	yes=1	No=2	Unknown=3	

21.4 Is there habitual alcohol use in the family?	yes=1	no=2	
21.5 Are there any epileptics in the family?	yes=1	no=2	

21.6 Who is the bread-winner? _____

21.7 Who makes decisions? _____

21.8 Who maintains discipline? _____

21.9 Are familial roles clearly allocated?	yes=1	no=2	
21.9.1 If yes, is accountability maintained?	yes=1	no=2	

22. What is your marital status at present?	married =1	Single =2	
	separated/divorced= 3	widowed=4	

22.1 What was the age of your child when separated/ widowed?	< 2 yr =1	2 – 4 yrs =2	
	4 – 6 yrs.= 3	> 6 yrs.=4	

22.1.1 Are you in a permanent relationship at present?	yes=1	no=2	
22.1.2 Is the relationship of your child with your spouse good?	yes=1	no=2	

22.2	Are there any conflicts handled in the child's presence?	yes=1 / no=2	
22.3	Have you been in previous marriages/relationships?	yes=1 / no=2	
22.3.1	If so, was the child and his problem in any way the reason for dissolution?	yes=1 / no=2	
22.4	Does your child share a normal relationship with his/her siblings?	yes=1 / no=2	

22.4.1	if no, please specify

How is quality time spent as a family? give one answer

_____

22.6	Does your child have a supportive family member to turn to in times of trouble?	yes=1 / no=2	

23. School History and Function.

23.	Have you made your child move schools?	yes=1 / No=2	

23.1	If yes, please specify details & reasons for moves	

Is your child's teacher aware of his/her problem?	yes=1	no=2	Unknown=3	
Does your child's class teacher / school set rigid toileting-behaviour controls?	yes =1	no =2	unknown =3	
Are the school toilets clean?	yes=1	no=2	Unknown=3	
23.3.1 Do the school toilets have doors?	Yes=1	no=2	unknown=3	

Is your child teased at school as a result of his/her behaviour?	yes =1	no =2	unknown =3	

23.5	Has your child had previous failure?	yes=1	no=2

23.5.1	If yes, please specify details	

Do you think s/he is coping?	average=1	Below average=2	above average=3	

23.6	In your opinion, your child's behaviour at school is ?	shy/lacks confidence =1	Cheeky =2
		Disobedient=3	Disruptive=4
		Restless=5	prone to emotional outbursts=6
		Other=7	

23.6.1	if other concerns from school, please specify	

23.7	Who assists child with home-work?	mom/dad =1	grandparent =2	
		elder sib = 3	Friend=4	
		self study=5	other=6	

Name 2 things your child does well

_____

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