MOTHERS' EXPERIENCES IN LIVING WITH A CHILD WITH ENCOPRESIS: A PHENOMENOLOGICAL STUDY

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Mothers' Experiences in Living with a Child with Encopresis:

A Phenomenological Study

by

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Abstract

A phenomenological method of inquiry was used to explore the lived experience of mothers with a child with encopresis. Van Manen's Hermeneutic Phenomenology was used during data collection and analysis. Eight mothers participated in two or three audiotaped unstructured interviews. Throughout the interview process, participants were encouraged to speak freely and openly about their lived experience with a child who had encopresis.

Thematic statements formulated from the analysis of the narratives were identified: dealing with uncertainty, becoming frustrated with care giving, struggling to endure, and taking control. The interrelationship between these themes allowed the essence of the phenomenon to be captured as *rising to the challenge*.

There is a need for health care providers to reevaluate current approaches to assist parents in the effective management of children with encopresis. It is essential that parents be included in the management plan and their struggle recognized. The challenge to health care providers is to assist parents in increasing their resources and coping behaviors for managing the daily challenges and frustrations encopresis places on them. Community supports are also needed to assist them to develop diverse strengths and resources required to meet the needs of their children. Nursing has the resources to assist these mothers to help their children gain control over their elimination disorder.

This thesis is dedicated to my husband, Ed, and to my children, Scott and Angela, who encouraged and supported me throughout my studies in the masters program. I truly appreciated the many extra roles you all assumed so that I could devote more time to study. To my beautiful little granddaughters, Julia and Olivia, whose smiles and excitement were a welcomed reprieve from the many hours of study.

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CHAPTER 1

Introduction

Encopresis is a common pediatric problem (Landman, Rappaport, Fenton, & Levine, 1986). The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (1994) defines encopresis as involuntary bowel movements in inappropriate places, at a frequency of at least once a month for three months, in children 4 years of age and older, and not solely due to physiological factors. It is estimated that 3% of four year-olds and 1.6% of ten year-old children have this condition (Abi-Hanna & Lake, 1998), with an estimated ratio of 3 to 1 in males versus females (Nolan & Oberklaid, 1993).

Numerous labels have been coined to reflect the variant types and subtypes of encopresis. Functional encopresis, or cases without distinctive organic pathology, has been subdivided into primary (i.e., never mastered fecal continence), and secondary (i.e., bowel control for at least six months before reverting to incontinence) (Fielding & Doleys, 1988). Primary and secondary categories have been further subdivided into retentive (i.e., fecal incontinence during the day and night with clear evidence of constipation) and non-retentive (i.e., intermittent soiling of feces of a normal form or consistency) (Akande, 1993; American Psychiatric Association, 1994; Boon & Singh, 1991). The diagnosis has also been extended by several researchers to include fecal soiling which is the involuntary passage of fluid or semi-solid stool into clothing due to overloading in the rectum (Clayden & Agnarsson, 1991; Foreman & Thambirajah, 1996; Hatch, 1988).

Despite increased knowledge, it has been argued that encopresis continues to be underreported and misdiagnosed because health care providers fail to ask about soiling, or parents do not perceive soiling as a health problem (Sprague-McRae, Lamb, & Homer, 1993). There is some evidence to suggest that parents experience stigma for a child who manifests socially unacceptable bowel emptying (Becker, 1994; Buchanan & Clayden, 1992). Besides the potential adverse effects on the child's psychological development (Becker), feelings of shame and guilt prevent parents from admitting that their child may have a problem (Buchanan & Clayden; Clayden & Agnarsson, 1991). By treating the soiling problem as a secret, considerable stress is placed on the child and family. If left unchecked, encopresis can reduce family cohesiveness, impair communication, isolate family members from the community (Baird, 1974; Bernard-Bonnen, Haley, Belanger & Nadeau, 1993; Buchanan & Clayden, 1992), and increase the risk for ineffective coping and even physical abuse (Buchanan, 1990).

Although encopresis affects the entire family, mothers are more likely to assume the care giving responsibilities associated with this condition (Dworetzky & Davis, 1989). There is also some evidence suggesting that mothers may experience greater frustration and psychological and social burden (Buchannan

& Clayden, 1992; Gutsche & Walker, 1989). Although there is some reference to the importance of providing support and counselling to parents (Abi-Hanna & Lake, 1998; Akande, 1993; Buchanan, 1990; Nolan & Oberklaid, 1993; Turner, 1988), there are no specific recommendations on how to support parents, especially mothers. It is argued that before appropriate support measures can be identified information is needed on how parents experience living with and caring for a child with encopresis.

While it is acknowledged that having a child with encopresis raises issues and concerns for each family member, the decision to restrict the focus of this study on mothers' experiences was based on the fact that they are often the primary caregiver. The purpose of this study was to develop a greater understanding of what it is like for a mother to live with a child who has encopresis. Study findings have the potential to provide insightful information that will help nurses and other health care providers deliver timely and appropriate interventions to enhance mothers' coping abilities.

Background and Rationale

The etiological factors surrounding encopresis are controversial (Sprague-McRae, 1990) and multifactorial (i.e., physical disorders, psychological disturbances, environmental factors, or a combination of factors) (Buchanan, & Clayden, 1992). Several authors investigated the role played by physiological factors, such as abnormal defecation dynamics (Benninga, Buller, Heymans, Tytgat & Taminiau, 1994; Loening-Baucke, 1984; Loening-Baucke, Cruikshank & Savage, 1987; Loening-Baucke & Yamada, 1995) and constipation (Abrahamian & Lloyd-Still, 1984; Buchanan, 1990) in the onset and continuation of encopresis. There is also clinical and/or empirical support for the influence of psychosocial and behavioural factors (Benninga et al.1994; Boon, 1992; Gabel, Hegedus, Wald, Chandra, & Chiponis, 1986; Johnson & Wright, 1993; Landman et al, 1986), as well as familial factors (Akande, 1993; Baird, 1974; Becker, 1994).

There is also controversy in the research literature on the most effective treatment regimes for encopresis. A number of articles highlighted the effectiveness of using a single treatment approach to alleviate physical symptoms (Buluit & Tekant, 1991; Gleghorn, Heyman, & Rudolph, 1991; Loening-Baucke, 1993; Sprague-McRae et al., 1993) or behavioural problems (Feldman, Villanueva, Lanne, & Devroede, 1993; Fireman & Koplewicz, 1992; Gutsche & Walker, 1989; Ronen, 1993; Stark, Owens-Stively, Spirto, Lewis, & Guevremont, 1990; Wald, Chandra, Gable, & Chiponis, 1987). Several authors reported on the superiority of using multimodal, as opposed to single, treatment approaches (Abi-Hanna & Lake, 1998; Akande, 1993; Becker, 1994; Buchanan, 1990; Cox et al., 1994; Cox, Sutphen, Borowitz, Kovatchev, & Ling, 1998; Jannson, Diamond, & Demb, 1992; Loening-Baucke, 1990,1995; Nabors & Morgan, 1995; Nolan, Catto-Smith, Coffey, & Wells, 1998; Nolan, Debelle, Oberklaid, & Coffey, 1991; Stern, Prince, & Stroh, 1988). While the research findings suggest that better results are obtained when multimodal approaches are used to manage encopresis, limited attention has been placed on identifying effective strategies for prevention and health promotion (Papenfus, 1998; Rappaport & Levine, 1986; Stadtler, 1989; Taubman, 1997).

The management of encopresis poses a challenge for families (Sprague-McRae et al., 1993). Levine (1992) suggested that encopresis is likely to instigate parental conflict over appropriate management techniques. Most treatment regimes focus on alleviating causes, with limited attention given to reducing parental stress (Abi-Hanna & Lake, 1998; Ronen, 1993). There is also the probability that parents will move from professional to professional and agency to agency seeking the elusive cure for their child (Buchanan & Clayden, 1992). The development of a knowledge base grounded in families' experiences with living with a child with encopresis is essential for the provision of quality care (i.e., prevention, health promotion, and treatment) by health care professionals.

Some authors emphasize that parents should understand the condition and the goals of treatment if they are to become active partners in facilitating the child's rehabilitation (Abi-Hanna & Lake, 1998; Ronen, 1993). However, limited information exists on how parents perceive encopresis and its treatment (Bernard-Bonnen et al., 1993). In particular, no studies were identified that examined the experiences of parents, especially mothers, who assume the responsibility of caring for children with this complex multifaceted problem. Further, while recognition has been given to the importance of supporting families during treatment (Nolan & Oberklaid, 1993; Turner, 1988), there is a dearth of information on this aspect of care.

Problem Statement

It is apparent from the review of relevant literature that there is limited information on how parents, especially mothers, experience living with a child with encopresis. The objective of the current study was to develop a greater understanding of the meaning of living with a child with encopresis from the perspective of mothers. With the focus restricted to mothers, study findings are limited as their perspectives do not necessarily reflect those of the entire family. When the focus is on meanings, the best approach is to conduct in-depth, thematic analysis of narrative descriptions gathered from those who are experiencing, or have experienced, the phenomenon. This information will help facilitate clinicians' understanding of the intrinsic, personal side of the experience, as well as provide useful insights into factors that help mothers cope with this condition.

Research Question

The current study was designed to address the following research question:

What is the lived experience of a mother who has a child with encopresis?

CHAPTER 2

Literature Review

This chapter presents a discussion of research and clinical findings on encopresis and relevant literature on the impact of chronic illnesses. The first section focusses on the risk factors involved in the onset and perpetuation of encopresis. The second section presents a discussion on the effectiveness of single versus multimodal strategies in the treatment of children diagnosed with encopresis. The final section discusses the literature dealing with the impact of a chronic illness on families, especially mothers who assume the primary responsibility for care giving.

Encopresis as a Disorder

The term *encopresis* was originally coined by Weissenberg in 1926 to describe an overt psychogenic soiling disorder in children (i.e., involuntary bowel movements in underwear and during socially unacceptable situations) (Becker, 1994). At that time, treatment was restricted to physical measures (i.e., laxatives, enemas, suppositories, or manual evacuation) to empty the bowel (Buchanan & Clayden, 1992). In the 1940's, the focus shifted to the psychopathology of encopresis and alternate treatment modalities. Burns (1941) recommended that all children with encopresis and obstipation (i.e., encopresis associated with constipation) receive psychological treatment.

A couple of early studies supported the benefits of psychotherapy and behavioural interventions. In a non-randomized control study of children with encopresis and obstipation ($\underline{n}$ = 30) and control subjects ($\underline{n}$ = 21), Pinkerton (1958) found that psychotherapy improved the symptoms of most (70%) treatment group subjects. Psychologists also demonstrated positive outcomes with behavioural interventions (Buchanan & Clayden, 1992). One such research study was by Anthony (1957) who examined the effectiveness of 'habit training' by a warm relaxed person in a happy environment. Although the children were successfully trained in three to five months, relapses occurred following exposure to stress.

Despite extensive clinical investigation into the causes of and treatments for encopresis over several decades, there is no universal agreement on the diagnostic criteria for this condition (Benninga et al., 1994; Boon & Singh, 1991). Support for a pathophysiological basis is found in studies which have used anorectal manometry and electromyography evaluations (Abrahamian & Lloyd-Still, 1984; Bulut & Tekant, 1991; Levine, 1982; Loening-Baucke, 1984; Loening-Baucke et al., 1987). Other researchers have reported that daytime urinary incontinence and urinary tract infections are part of the clinical profile, as well as vague abdominal pain (Loening-Baucke, 1993; Papenfus, 1998). With regard to psychosocial, behavioural, and family functioning factors, study findings suggest that children with encopresis and soiling have a higher incidence of problems in these areas than normative samples (Baird, 1974; Becker, 1994; Benninga et al., 1994; Gabel et al., 1986; Johnson & Wright, 1993; Landman et al., 1986; Loening-Baucke et al.,1987).

Risk Factors

A number of risk factors for encopresis were identified from a review of the theoretical, clinical and research literature. The most inclusive list of potential risk factors for encopresis at three critical developmental stages was presented by Levine (1982). In the early experience and predisposition stage (i.e., ≤ 2 years of age), risk factors include simple constipation, early colonic inertia, congenital anorectal problems, other anorectal conditions, parental overreaction, and coercive medical intervention. During the training and autonomy stage (i.e., 2 to 5 years), risk factors include psychosocial stressors, coercive or extreme permissive training, idiosyncratic toilet fears, and painful or difficult defecation. In the extramural function stage (i.e., early school years), avoidance of school bathrooms, prolonged or acute gastroenteritis, attention deficits with task inconsistency, food intolerance, (e.g., lactase deficiency, etc.), frentic lifestyles, and psychosocial stressors were identified as dominant risk factors. Levine argued that the presence and interaction of multiple risk factors at critical development periods greatly increases the child's susceptibility for encopresis.

Physical factors. Early colonic inertia, simple constipation, congenital anorectal problems, and other anorectal conditions, have been identified as significant etiological factors predisposing a child to develop encopresis. Despite the presence of empirical support for this assumption (Abrahamian and Lloyd-Still, 1984; Buchanan, 1990; Buluit & Tekant, 1991; Loening-Baucke, 1984; Loening-Baucke et al., 1987; Loening-Baucke & Yamada, 1995), there are contradictory findings (Benninga et al., 1994).

In a descriptive study, Loening-Baucke (1984) compared anal tone at rest and during air distention of a balloon in the rectum with children diagnosed with chronic constipation and encopresis ($\underline{n}$ = 20), children with constipation but no encopresis ($\underline{n}$ = 12), and healthy controls ($\underline{n}$ = 20). Study findings confirmed the existence of anorectal abnormalities in children with chronic constipation and encopresis. In a subsequent longitudinal, prospective study of children with encopresis ($\underline{N}$ = 38), Loening-Baucke et al. (1987) found additional support for these findings. Physiological status was evaluated with anorectal manometry and electromyography. The persistence of encopresis at 6 and 12 months follow-up was significantly related to the inability to defecate ($\underline{p} < .01$) and relax the external sphincter ($\underline{p} < .03$).

Using a descriptive-correlational study, Benninga et al. (1994) investigated the influence of chronic constipation on the onset of encopresis in a sample of children with constipation ($\underline{n}$ = 111) and with encopresis and/or soiling without constipation (n = 50). Data were collected by using colon transit time (CTT), orocecal transit time (OCTT), electromyography, and anorectal manometric profiles. Based on the anorectal manometry profiles, the findings indicated that defecation dynamics were abnormal in 59% of the children with constipation and 46% of those with encopresis. There were, however, no problems detected in either group with anal fissures, or the tone of the internal sphincter, or voluntary contraction of the external sphincter. Further, most OCTT and manometric parameters were comparable between the two groups, except for significantly higher threshold sensations in children with constipation. Finally, the total and segmented CTT were significantly more prolonged in children with constipation than those with encopresis.

In a descriptive correlational study, Loening-Baucke and Yamada (1995) investigated impairments in the rectal afferent pathways of children with constipation and encopresis (n = 15), ages 7 to 18 years, versus healthy children (n = 15), ages 8 to 17 years. Cerebral evoked potentials were measured by averaging the results of 100 rectal distentions, using 10, 20, and 30 ml of air. Prolonged latency was used to indicate defective afferent pathways. Study results revealed that children with chronic constipation and encopresis had prolonged latency, but not healthy children in the control group.

There is also evidence suggesting that constipation plays a significant role in the onset and persistence of encopresis. In a descriptive study, Abrahamian and Lloyd-Still (1984) reviewed the chart records of children (N = 186) diagnosed with constipation and soiling who had been followed at a gastroenterology clinic for seven years. The findings indicated that 55% of the children had a positive family history for constipation. Another significant finding was the presence of anal fissure/rectal prolapse in about 24% of the sample. In a quasi-experimental study examining the effectiveness of different interventions for children diagnosed with encopresis (N = 66), Buchanan (1990) found that 64% of the sample had a present or past history of constipation. Similar findings were reported by Buluit and Tekant (1991) who investigated predisposing factors in children, 4 to 12 years of age, diagnosed with encopresis (N = 50). Based on the data obtained from family history and physical examinations, the researchers found that although simple constipation (26%) and anal fissure/rectal prolapse (10%) were common factors, a significant percent of subjects (38%) had no identifiable predisposing factors.

From the reviewed literature, only one study was identified that investigated parents' understandings and perceptions of encopresis. Bernard-Bonnin et al. (1993) surveyed parents (N = 28) of children with secondary encopresis who attended a multidisciplinary clinic. Researcher-developed questionnaires were used to collect data on parent and child understandings of the causes and consequences of encopresis. The mean time since diagnosis was 3.5 years. The findings indicated that both parents and children had a good understanding of the pathophysiology of encopresis. Parents and children reported that the most important causes of the encopresis were intestinal dysfunction (53%) and painful defecation (46%). In terms of consequences, parents focussed on the child's low self-esteem and the burden of cleaning soiled garments, whereas children focussed on abdominal pain and pain on defecation. Further, only a small, but noteworthy, percentage of parents (10.9%) believed that the child's soiling behaviour was deliberate.

Psychosocial, behavioural and familial. A number of studies were identified that examined parents' perceptions of the presence of psychosocial and behavioural problems in their child with encopresis (Benninga et al., 1994; Buchanan, 1990; Gabel et al., 1986; Johnson & Wright, 1993; Sprague-McRae, 1993). The role of family dynamics in the onset and perpetuation of encopresis has also been examined (Baird, 1974; Becker, 1994). It is also apparent that there is some controversy over whether psychosocial and behavioural problems are responsible for, or a consequence of, encopresis (Borowitz, Cox, & Sutpen, 1999; Friman, Mathews, Finney, Christopherson, & Leibowitz, 1988; Loening-Baucke et al., 1987).

In a descriptive study, Gabel et. al. (1986) compared the behavioural characteristics of children diagnosed with encopresis ($\underline{n}$ = 55) with children referred for mental health services ($\underline{n}$ = 900) and a normative sample of non-referred children ($\underline{n}$ = 1400). All subjects were profiled by age and gender. A parent or parent guardian completed the Child Behaviour Checklist (CBCL), a standardized rating scale which contains 118 behaviour problem items and 20 social competence problem items. The CBCL generates four subscale scores: total behavioural, total social competency, and internalization (i.e., cluster of scales that measure functioning re schizoid/anxious, depressed, somatic complaints, and social withdrawal behaviours) and externalization (i.e., cluster of scales that assess hyperactivity, aggressive, and antisocial behaviours). The findings indicated that children with encopresis had a high incidence of behaviour problems, especially with such things as disobedience, difficulty concentrating and paying attention, and being argumentive. Comparatively, parents of children with encopresis reported more behavioural problems than those with children in normative samples, but less than those with children referred for mental health services.

Prior to testing the effects of different treatments on children with encopresis, Buchanan (1990) examined the presenting behaviour of three groups of children as described by parents - Hospital treated group (n = 18), Clinic group (n = 18) and Experimental group (n = 30). Study findings indicated that behaviour and school problems increased as the child became older. Behaviour problems were present in 39%, 61% and 30% of the hospital, clinic and experimental groups, respectively. Behaviour problems were categorized as neurotic type (i.e., shy, withdrawn, miserable, and tearful) and aggressive type (i.e., fighting, aggressive acts, stealing, fire lighting, and temper tantrums). School problems (i.e., teasing from peers, low self-confidence, and lowering of academic performance) were also presented to a lesser degree in the clinic (28%) and experimental (10%) groups.

In a four year prospective intervention study of children with encopresis, Sprague-McRae et al. (1993) assessed the behavioural profile of children (N = 136) referred to a health clinic. Levine's parental questionnaire, the Encopresis Evaluation System, was used to collect historical and demographic information (e.g., frequency of soiling, degree of stool retention, toilet training history, predisposing physiological and temperamental features, etc.), as well as information on associated problem behaviours (i.e., problems with hyperactivity and attention, antisocial and aggression, affective and dependence, physical concerns, and social isolation). Study findings revealed that parents reported a high percentage of toilet avoidance behaviours (i.e., spends limited time on the toilet - 77%, refuses to use toilet at school - 57%, dislikes sitting on toilet - 52%, avoids using toilet while out - 32%), and reactive and impact behaviours (i.e., family conflict due to soiling - 82%, unable to detect urge to have a bowel movement - 74%, hides dirty underwear - 67%, resists changing soiled clothes - 61%, not upset following an accident - 54%, teased by others - 48%, and denies having encopresis - 45%).

Johnston and Wright (1993) examined the prevalence of attentional dysfunction or hyperactivity in children (n = 167), ages 4 to 16, diagnosed with encopresis. The CBCL was used during data collection. Sample scores were compared to published normative scores. Study results revealed that 23.4% of children with encopresis had attentional disorders, an incidence ten times greater than the expected rate of attentional disorders in the general population.

Benninga et al. (1994) also examined the presence of behaviour problems in children with constipation (n = 111), and with encopresis and/or soiling without constipation (n = 50). The findings from the CBCL indicated that there were no significant differences in the behaviour scores of the two groups. However, when compared to normative sample data, the children from both groups had a significantly higher incidence of behaviour problems.

Only a couple of articles reported on the role played by family dynamics in the development of encopresis. Based on extensive clinical experience with children exhibiting encopresis, Baird (1974) stressed the importance of understanding illness meanings in order to successfully manage encopresis. This author identified the social environment as playing an important role in the development of this condition. Four co-existing interaction patterns were observed in the families of children with encopresis: withholding, infantilization, mishandled anger, and mis-communication. From the perspective of the family, the withholding pattern occurred when parents withheld valuable things such as praise, freedom to play, or gifts. Rather, these parents tended to use strategies such as, forced time sitting on the toilet or bribing for cooperation. Families were also viewed as interfering with the child's physiological capabilities and maturational development by using control tactics which only served to reinforce infantile behaviour. Repression or denial of anger was also seen as a predominant emotion in these families. The problems with withholding, infantilization and mishandled anger were enhanced in the presence of generally distorted family communication patterns. Baird recommended that assessing the family's interpersonal relationships and correcting dysfunctional patterns are important first steps prior to initiating treatment for the child with encopresis.

Based on clinical experiences at an encopresis clinic, Becker (1994) reported on the important role played by psychogenic factors in secondary encopresis. Disturbed mother-child relationships were highlighted as being especially common in children who had psychological problems. Clinical markers such as anxious, unreliable, emotional, overprotective and indulgent were used to describe these mothers. Becker also reported a link between encopresis and disturbed family relationships such as the presence of an uninvolved parent (i.e., usually the father), divorce, economic difficulties, and lack of family warmth. Similar to Baird (1974), Becker emphasized the importance of doing a comprehensive psychological assessment of children affected with encopresis, as well as their families. Psychological support for both parents and children was also identified as an essential component of the treatment program.

Although the preceding studies suggest that children with encopresis tend to have more psychological and behaviour problems than healthy children, there is some contradictory evidence. In a prospective study, Loening-Baucke et al. (1987) compared children with encopresis ($\underline{N} = 38$) to healthy norms on behavioural and social competency problems. Data were collected with the CBCL. The findings indicated that although children with encopresis had a higher incidence of social competence and behaviour problems than normative samples, their scores were not in the abnormal range. Further, boys did not evidence any social or behavioural abnormalities on the internalizing or externalizing subscales. However, girls were more likely to have a higher incidence of social withdrawal, hyperactivity, delinquency, or aggressive behaviours than healthy norms.

In a randomized controlled study, Friman et al. (1988) compared the presence of clinically significant behaviour problems in children with encopresis ($\underline{n} = 50$), children with behaviour problems ($\underline{n} = 50$), and children without encopresis or behaviour problems ($\underline{n} = 50$). Parents of all subjects completed a standardized behaviour checklist, the Eyberg Child Behaviour Inventory. The findings indicated that children with encopresis had similar scores to those from a normative sample, but significantly lower scores than those with behaviour problems ($\underline{p} < .00001$).

In a prospective, descriptive correlational study, Borowitz et al. (1999) compared the toileting habits of children diagnosed with chronic encopresis ($\underline{n}$ = 24) with asymptomatic siblings ($\underline{n}$ = 27) and nonsiblings ($\underline{n}$ = 35). Data were collected using the Automated Patient Symptom Monitoring system. The results revealed that children with encopresis experienced more soiling episodes but had similar toileting behaviours to those of asymptomatic siblings and nonsiblings. Children with encopresis also did not differ from these groups with regard to behaviour problems in school. In addition, the number of parents reporting learning disabilities, academic failures, attention-deficit hyperactivity disorder, and the use of Ritalin was comparable among the groups.

Summary

Despite the expansive research base in this area, much controversy exists about the etiology of encopresis. Given the descriptive-correlational nature of most study designs, it is difficult to determine whether associated factors are contributory or consequential. It seems that any number of physiological, psychosocial, behavioural or familial factors can precipitate, as well as perpetuate, this condition. The findings are also inconclusive as to the exact nature of behavioural, psychosocial, and familial problems. Importantly, parents must contend with the challenges posed by this condition regardless of the underlying etiology.

Encopresis: Treatment Modalities and Prognosis

With the etiology of encopresis somewhat elusive, there is limited agreement on the most effective management approaches. Empirical support has been found for the effectiveness of standard medical regimes (Bulut & Tekant, 1991; Gleghorn et al., 1991; Sprague-McRae et al., 1993; Wald et al., 1987), behavioural modification therapy (Fireman & Koplewicz, 1992; Ronen, 1993; Stark et al., 1990), biofeedback (Wald et al., 1987), play therapy (Feldman et al., 1993), and family therapy (Gutsche & Walker, 1989). There is also empirical support for the effectiveness of multimodal approaches (Buchanan, 1990; Cox et al., 1994; Cox et al., 1998; Jansson, Diamond, & Demb, 1992; Loening-Baucke, 1990; 1995; Nolan et al., 1991; Nolan et al., 1998; Stern et al., 1988).

Single Treatment Approaches

Standard medical regimes for children with encopresis focus on promoting normal bowel function. Prior to treatment, a complete history and physical examination is done to rule out organic causes (Sprague-McRae et al., 1993). Most children benefit from a treatment plan designed to alleviate fecal impaction, prevent future impaction, and promote regular bowel habits (Bulut & Tekant, 1991; Gleghorn et al., 1991; Loening-Baucke, 1993).

A couple of studies were identified from the literature that were designed to evaluate the effectiveness of medical regimes. In a prospective longitudinal study, Bulut and Tekant (1991) examined the effectiveness of different treatment interventions with children diagnosed with encopresis over a six-month period. One group of children (n = 13) were treated with mineral oil and glycerine suppositories twice a day in their own homes, whereas a second group (n = 37) received lactulose and rectal irrigation twice a day, in a hospital setting under the supervision of the surgeon and psychologist. Children in the latter group were placed on a low-fibre diet for a two-week period and were trained to sit on the toilet for ten minutes following irrigations. The findings indicated that an excellent success rate (88.9%) was achieved in both groups, with normal bowel control attained and fecal soiling completely resolved by six months. However, children receiving mineral oil and glycerine suppositories took longer to respond to treatment (i.e., 12.9 days) than those receiving lactulose and rectal irrigation (i.e., 4.8 days).

Gleghorn et al. (1991) conducted a retrospective chart audit of children (n = 45) treated for constipation and/or encopresis. All of the children received a large dose of oral mineral oil for initial fecal evacuation, a maintenance daily dose of mineral oil, a high fibre diet with increased fluid, and toilet training regimen. Study findings revealed that 98% of the clients had successful initial cleanouts without enemas. At six months follow-up, 93% continued to be free of constipation or encopresis.

In a four year prospective study of children with encopresis, Sprague-McRae et al. (1993) compared the efficacy of two treatment modalities. Subjects were randomly assigned to either the oral laxative group (n = 24) or the conditional rectal cathartics group (n = 37). Management consisted of an initial bowel evacuation, a high fibre diet, and a behaviour modification program. No significant difference was found between the two groups. At 6 to 12 months following treatment, 87% of subjects continued to be symptom-free.

In contrast to standard medical care, behaviorists view the fecal soiling that accompanies encopresis as socially inappropriate behaviour. The objective of behaviour modification therapy is to encourage children to respond to rectal distention cues with a visit to the toilet and to engage in frequent self-toileting, while discouraging withholding and fecal soiling (Cox et al., 1998; Lowery, Srour, Whitehead, & Schuster, 1985). In a descriptive study, Stark et al. (1990) investigated the efficacy of using behavioural strategies with children (n = 18) who had been treated unsuccessfully with medical interventions. The researchers used small treatment groups consisting of 3 to 5 parents and their children. Education on encopresis and treatment procedures (e.g., constipation and soiling relationship, importance of parental monitoring of child's dietary intake, factors involved in enema clean-out, how to increase dietary fibre, etc.) were the foci of six sessions held over a seven week period. Following the treatment period, there were notable increases in fibre intake (40%) and appropriate toileting behaviours (116%), and significant decreases in the frequency of soiling accidents (83%). Further, these results were maintained or improved at six month follow-up.

Fireman and Koplewicz (1992) treated children ($n = 52$) diagnosed with primary encopresis, according to a standardized protocol (i.e., physical examination to rule out organic causes; completion of a psychosocial history and mental status exam by a psychiatrist; and three appointments at one-week intervals with a behaviourally trained therapist). During the first session, the behavioural therapist conducted a detailed history and provided parents and children with relevant information (i.e., etiology and incidence of encopresis, and problems associated with living with encopresis). The second visit dealt with proper nutrition, developing a toileting routine and protocols to handle accidents, and instructing parents and children to maintain a daily record of toileting and soiling. The third visit focussed on reviewing the events of the first week of treatment and clarifying any misunderstandings. Weekly telephone calls were made after the third visit to facilitate compliance with treatment. The findings indicated there was a significant decrease in soiling during the first month ($p < 0.01$), with 84.6% of the children having no soiling accidents for 2 consecutive weeks. In addition, 78.8% of the children successfully completed an additional 7-week phase out period.

In a case study of a 6 year old boy with primary encopresis and failed medical intervention, Ronen (1993) reported success with a cognitive behavioural treatment approach (i.e., four weeks of treatment consisting of two one-hour sessions each week with the parents and child). The intervention consisted of skill elements (i.e., cleaning training and regular toileting practice) as well as cognitive (i.e., restructuring, self-monitoring of internal stimuli, self-instruction, and self-evaluation) and contingency (i.e., removal of attention, positive reinforcement for toileting practice, and social reinforcement) management. Ronen reported that soiling ceased and regular toileting behaviour was evident after two weeks, and continued up to six and twelve months follow-up.

Studies have also been designed to evaluate the effectiveness of using biofeedback to treat encopresis. In a prospective, randomized control design, Wald et al. (1987) randomly assigned children, 6 to 15 years of age, to either biofeedback ($\underline{n}$ =24) or conventional groups ($\underline{n}$ = 26) following rectal clean-out and anorectal manometry. An equal number of children ($\underline{n}$ = 9) from each group had abnormal patterns during stimulated defecation. With the biofeedback group, emphasis was placed on reinforcing normal responses of the external anal sphincter during contraction and simulated defecation. Children were also encouraged to practice these techniques at home. The conventional group received mineral oil to soften the stool, and information stressing the importance of regular defecation after breakfast and dinner. Reinforcement sessions were received by both groups at 2, 4 and 8 week intervals. The findings indicated that there were no significant differences in the clinical outcomes of both groups at 3, 6, or 12 months. However, at 6 and 12 month follow-up, children with normal defecation patterns responded better to conventional treatment, whereas those with abnormal patterns responded better to the biofeedback treatment.

Play therapy is another technique that has been used successfully with children who have encopresis. Feldman et al. (1993) discussed the use of play therapy with children (n = 6), aged 4 to 12, with constipation and encopresis who had not responded well to previous therapies (i.e., laxatives, enemas, high-fibre diets, and behavioural modification). Clay modeling was used to facilitate the child's expression of disgust or aggression, and the construction of symbolic structures. Brown clay was used because its color and messy consistency served as a metaphor for feces. The children played together for one hour a week for three months. The two psychologists were present in an observational capacity only (i.e., refrained from providing guidance or direction). The findings revealed that four of the children had no symptoms within three months of therapy and no relapses at one-year follow-up. One child improved significantly (i.e., stool frequency increased from bi-weekly to one stool every second day), and another failed to respond and withdrew from treatment.

Family therapy was also identified as an effective approach in treating encopresis. In a case study of an eight year old boy with encopresis, Gutsche and Walker (1989) reported on the benefits of having the entire family participate in the treatment plan. The family therapy approach involved educating family members about the physiology of bowel control and the toileting regimen, assessing the child's feelings about the soilings, helping the child externalize symptoms and feel in control of the soiling, engaging the child in fantasy (i.e., reframing the symptom of soiling as a villain), and involving the parents in assessing (i.e., strength and speed) and reinforcing the child's behavior, as well as recording any progress made by the child. The less involved parent, the father, was asked to assume greater responsibility, while the more involved parent, the mother, was asked to continue so that she could be assisted to overcome her sense of defeat. Siblings were also helped to address any conflict or competition issues. During the course of the program, soiling frequency decreased from 18 incidents within a 3 week period to 2 incidents within the same time frame. There was also evidence of reduced sibling conflict, increased cooperation with parents, improved school attendance and performance, and enhanced self-esteem. The authors attributed the program's success to family members' commitment to resolving encopresis, and the clinical team's ability to instill confidence in the child to deal with his problem.

Only one study was identified from the literature that focussed on parents' and childrens' perceptions of the benefits of different treatment regimes. Using a survey design, Bernard-Bonnin et al. (1993) examined perceptions of effective treatment protocols in a sample (N = 28) of parents and children with secondary encopresis who attended a multidisciplinary clinic for 3.5 years. Researcher-developed questionnaires were used to collect data on parent and child perceptions of treatment benefits. Data were also collected on recovery rates. The findings indicated that both parents and children reported on the benefits of treatment. However, parents were more inclined to report on the benefits of high fibre diet, whereas children highlighted the importance of establishing toileting routines. Significantly, despite parent and child exposure to a comprehensive management program, the recovery rate was only 35.7%, with no identifiable factors responsible for the persistence of encopresis.

Multimodal Treatment Approaches

Most current treatment plans for encopresis use multiple methods as opposed to a single method. Many of the studies reviewed in this section compared the efficacy of using multimodal versus single treatment approaches (e.g., standard medical treatment, behavioural, biofeedback, etc.). The findings suggest that the superiority of one form of treatment over another varies not only with the management plan but also targeted outcomes, especially short versus long term impact on decreasing the frequency of soiling accidents.

In a case report of an adolescent with primary encopresis, Stern et al. (1988) investigated the usefulness of medical and behavioural interventions when significant psychopathology was present in the child and family. The treatment plan consisted of a standard medical protocol (i.e., mineral oil, enemas, high fibre diet, routine toileting, and the use of rewards), simple behavioural interventions, and consideration of such areas of concerns as school problems. Following eight months of treatment the child had his first day without a stool or oil accident. There was also a significant improvement in family functioning and a reduction in behaviour problems. At two years follow-up the adolescent still had bowel continence.

Using a randomized controlled design, Loening-Baucke (1990) compared the effectiveness of biofeedback with conventional medical (BCM) treatment (n = 22) to conventional medical (CM) treatment alone (n = 19) in children ages 5 to 16 years with chronic constipation/encopresis or abnormal defecation dynamics. Both treatment groups were compared to a healthy group of controls of comparable ages (n = 16). The findings indicated that although children in both treatment groups experienced a significant decrease in soiling frequency by seven months, the BCM group had a much higher recovery rate than the CM group (i.e., 55% vs 5%). By 12 months follow-up, the recovery rate for the BCM group had decreased to 50%, whereas the CM group had increased to 16%. Further, at 7 and 12 months follow-up, significantly more children in the BCM group (77%) had learned to relax the external anal sphincter muscle than those in the CM group (13%).

Using a quasi-experimental design, Buchanan (1990) compared the effects of different treatment modalities on children with encopresis. Children assigned to the experimental group (n = 30) received the "whole child" treatment approach (i.e., emphasis on modifying psychological, physical, and social needs of the child in his/her environment). The comparison groups consisted of children who had been treated at a local hospital (hospital group) (n = 18) or a child guidance clinic (clinic group) (n = 18). Study findings revealed that the groups were similar with regard to no soiling for once a week or less following termination of treatment (hospital 78%, clinic 72%, experimental 87%). However, the experimental group (100%) had a significantly longer period of being clean following treatment than either the hospital (28%) or clinic (28%) group. As well, the experimental group (96%) evidenced greater improvements in quality of life indicators (i.e., fewer behavioural, school, and parent-child relationship problems) than the hospital (66%) and clinic (66%) groups.

Using a randomized block design, Nolan et al. (1991) compared the effectiveness of multimodal (MM) and behavioural modification (BM) therapies in children with encopresis, ranging in age from 3 to 16 years. Children referred to a pediatric clinic for treatment of encopresis were randomly assigned to the MM (n = 83) or BM (n = 86) groups, with an average follow-up time of 27 and 32 weeks respectively. The children in the MM group received a combination of behavioural therapy and laxatives. The stool retention rating record based on abdominal radiography was used to assess constipation, the CBCL assessed behavioural problems, and the fitness training card monitored progress on several factors (e.g., compliance with bowel training program, toilet defecation frequency, medication compliance, etc.). The findings indicated that compliance with toileting regimes and reduction in stool retention were comparable across treatment groups. Based on the adjusted gain scores for both the MM and BM groups, there was no evidence of a significant reduction in behavioural problems at 12 months. Although the MM group achieved remission significantly sooner than the BM group (i.e., 6 and 12 month rates were 49% and 51 % for MM group versus 30% and 36% for BM group), these significant differences disappeared when poor compliers with toileting regimes were excluded from the analysis.

Using a repeated measures design, Cox et al. (1994) compared the effectiveness of standard medical care (SMC) ($\underline{n}$ = 13) with external anal sphincter (EAS) electromyographic biofeedback combined with SMC ($\underline{n}$ = 13) in children with functional constipation and encopresis and abnormal defecation dynamics. The SMC group were given enemas, followed by laxative therapy, and finally high fibre diets. The biofeedback group also received enema/laxative therapy but were weaned within the first month. In addition, children in this group received training on EAS control and appropriate straining techniques and toileting behaviours, while parents were instructed to reinforce appropriate straining techniques and toileting behaviours with their children between treatment sessions. At sixteen months follow-up, study findings indicated that biofeedback parents reported significantly greater improvements in the incidence of constipation ($p < .01$) and encopresis accidents ($p < .04$). Further, when the pre and post-treatment reports of biofeedback were compared, significant reductions were noted in the number of painful defecations, use of laxatives, and number of soiling accidents.

In a quasi-experimental study, Loening-Baucke (1995) monitored the long-term outcomes of children with constipation/encopresis and abnormal defecation dynamics who received an average of six biofeedback sessions plus conventional treatment ($n = 63$) or conventional treatment alone ($n = 66$). The control group was comprised of healthy children ($n = 16$) who had undergone anorectal manometry. Conventional treatment included disimpaction with enemas, education on constipation and ways to prevent it (i.e., daily laxatives, increase in dietary fibre, and regular toilet settings after meals and following school), and instruction of parents and children to record bowel movements, fecal soilings, and medication use. Biofeedback treatment included education on abnormal/normal defecation dynamics, and instructions on how to increase intraabdominal pressure, to push as if defecating, and to inhibit contraction of the EAS to produce normal relaxations. Study findings indicated that soiling frequency decreased significantly in both treatment groups. Further, the long-term recovery rate (4.2 years ± 2.5 years) for biofeedback combined with conventional treatment (44%) was less than that observed with conventional treatment alone (62%).

In a randomized controlled study, Nolan et al. (1998) examined the effectiveness of using conventional medical treatment (CMT) or CMT in combination with biofeedback (BF) training with children with persistent encopresis and anismus (paradoxical contraction during attempted defecation). The children were randomized to receive either electromyographic BF and CMT (n = 14) or CMT alone (n = 15). Anorectal manometry was used to collect data at baseline and six months following randomization. Parents also completed the Child Behaviour Checklist (CBCL) before randomization and at follow-up. At six-months follow-up, the findings indicated that only two of the 14 children receiving BF/CMT and two of the 15 receiving CMT had laxative free remissions. However, overall improvements were observed in four children in the BF/CMT group and 6 of those in the CMT group. With regard to the six-month repeat anorectal manometry and EMG, six of the 13 in the BF/CMT group still demonstrated anismus and 11 in the CMT group.

In a randomized controlled study, Cox et al. (1998) compared the effectiveness of using different treatments with children with encopresis. Baseline assessment data were collected on toileting behaviours, number of painful defecations and soilings, and use of laxatives/enemas. A battery of psychological tests were completed, as well as physical and manometric examinations. One group of children (n = 29) received intensive medical care (IMC) with enemas and laxatives, a second group (n = 27) received enhanced toilet training (ETT) along with laxatives and enemas, and a third group (n = 31) received biofeedback along with toilet training, laxatives and enemas (BF). At three months follow-up, the findings indicated that ETT and BF produced comparable reductions in soiling (76% and 65%), but both were superior to IMC (21%).

There were a number of clinical articles identified from the literature that reported on the benefits of having family members involved in multimodal treatment plans. In a case study of a 9 year old boy with encopresis, Akande (1993) described the use of a multi-faceted treatment plan with extensive parent involvement in its implementation. The treatment, spanning a seven month period, included enema administrations, full cleanliness training (i.e., child instructed to wash underwear and to self-bathe after soiling), and token reinforcements at variable intervals. Parents were instructed to conduct periodic pant checks, maintain a diary of soilings, reduce the number of times they prompted the child to have a bowel movement, and provide token reinforcements for bowel movements in the toilet. During counselling sessions, the therapist worked to defuse the child's anger directed toward the parents, and to help him develop greater feelings of self-control and the need to assume more responsibility for toileting behaviours. Clinically significant behaviours (i.e., appropriate toilet use, full cleanliness, good bladder control, good behaviour to siblings, good social relations, obedience to parents, and positive attitude toward school work) were observed after seven sessions. The parents expressed appreciation for the support received from the therapist, reported that their son was happier, exhibited more understanding of his condition, and expressed feelings of control.

Becker (1994) described the effectiveness of using a multi-faceted treatment approach with families and children accessing an encopresis clinic. The first contact with the client involved a clinical and psychological assessment of the affected child, as well as an assessment of family members (i.e., parents and siblings). An educational video on encopresis (focussing on cause, treatment including how to administer an enema and the importance of family routine) was shown to all family members and followed by a group discussion. The treatment regimen consisted of diet modifications (raw bran at breakfast), daily enemas after breakfast followed by weaning until stool passage is spontaneous or the urge to defecate returns, confidence building with the child around the importance of empting the bowel and maintaining cleanliness, and psychological support for both the family and child. Follow-up was initially performed weekly and later on a monthly basis. After 9 years of working with this treatment plan, Becker reported that only about 3% of the children had total relapses one year following treatment and only 1.14% took longer than one year to be weaned successfully.

In a case study of a 4 ½ year old boy with retentive encopresis, Nabors and Morgan (1995) reported on the usefulness of two-phase educational program for parents about encopresis and dietary modifications and behavioral techniques. Phase one consisted of a month of intensive treatment which focused on increasing daily fiber and fluid intake, and administering mineral oil. Parents were instructed to keep a daily record of the child's fluid and dietary fiber intake, laxative intake, and soiling incidents. As well, parents used techniques to help modify behavior (i.e., correction of soiling accidents, stimulus control training, and positive reinforcement). During the second phase, goals set in phase one were reviewed, reinforced, and modified as necessary. Monthly clinic and weekly phone contacts were maintained throughout both phases. After one year follow-up, the authors reported that diet modification combined with increased practice of appropriate toileting were associated with the elimination of laxatives, decreased soiling accidents, and increasing appropriate bowel movements.

Summary

It is apparent from the preceding discussion that conflicting findings exist on the effectiveness of different treatment modalities in resolving encopresis. Although the findings suggest that multiple treatment approaches are more effective than a single treatment approach, it is not clear which combination of approaches, in what doses and over what periods of time work best for different family situations. Conflicting study findings may be attributed in part to theoretical and methodological variations (i.e., nature and size of sample, outcomes selected for measurement, diverse data collection instruments with limited reliability and validity testing, type of interventions, etc.).

It was also apparent from the literature reviewed that limited attention has been placed on documenting parental and child perceptions of and experience with different treatment plans. This omission is rather puzzling given the key role played by parents in implementing recommended protocols. Certainly, the theoretical and clinical literature suggest that successful treatment of children with encopresis is highly dependent upon ensuring that adequate support mechanisms are in place for families.

Chronic Illness and Parenting

Chronic illness among the pediatric population creates special problems for the family (Williams, Lorenzo, & Borja, 1993). The burden of care lasts for a long period of time, and produces strain on the family's physical, financial, and emotional resources. Parents may experience guilt and anxiety related to the cause of the child's illness, or blame one another (Patterson, 1988). Feelings of guilt, generated from the anger and frustration of the care giving situation, can be overwhelming, and further enhanced when conflicting information is received from physicians and other health care providers (Anderson & Elfert, 1989; Lubkin, 1995). The extra burden of care giving almost always falls to the mother (Anderson & Elfert, 1989; Desquin et al. 1994). A number of studies have found that mothers of children with chronic conditions are at risk for poor mental or physical health (Fagan & Schor, 1993; Florian & Kruelik, 1991; Lubkin, 1995; Martinson, Davis, Liu-Chiang, Yi-Hua, Qiao, & Gan, 1995; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1995).

There is a growing research base that is directed toward understanding the special challenges faced by parents of children with chronic illness. A few of the studies reviewed that have some relevancy for the current study are summarized in this section. Particular attention is given to those studies which have assessed the support needs of families with childhood chronic illness (Florian & Krulik, 1991; Hamlett, Pellegrini, & Katz, 1992; Pelletier, Godin, Lepage, & Dussault, 1994) and parents' perceptions of the care giving experience (Anderson & Elfert, 1989; Horner, 1997; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1995).

In a five-year ethnographic study, Anderson and Elfert (1989) examined families' (N = 45) perceptions of caring for chronically ill children. A phenomenological approach was used to assess meanings of the child's illness within the context of everyday living. During the first phase of the study, participant observations and interview were used to collect data on illness meanings and management approaches. The data from phase one were used to facilitate the development of an interview schedule and identification of preliminary themes for enhancement and/or confirmation in phase two. The concept of competent mother was threaded throughout three dominant themes: 1) competence in doubt - the search for a cause - guilt and blame (i.e., continuously questioning what they had done to cause the child's illness), 2) constructing the caretaker role (i.e., internalizing society's notion that women are responsible for the providing and coordinating the care of ill children) and, 3) relationships with health professionals (i.e., professionals reinforced the notion that women were the principal family care givers).

Florian and Krulik (1991) compared loneliness and social support in mothers of chronically ill children with life threatening diseases (n = 33) and non-life threatening illnesses (n = 57) to a control group of mothers (n = 92) with healthy children. The UCLA Loneliness Scale was used to assess satisfaction with social relationships, and the Norbeck Social Support Questionnaire (NSSQ) measured functional and structural aspects of social support. Study findings revealed that although mothers of children with chronic life-threatening or non-life threatening illness had larger social networks and greater support than those with healthy children, they also reported greater loneliness.

Hamlett et al. (1992) examined family functioning and the degree of extrafamily social support available to mothers of children, aged 6 to14 years, with asthma (n =17) and juvenile diabetes (n =13), and without any health problems (n = 30). The CBCL measured psychological adjustment, the Family Environment Scale assessed family functioning, and the Interview Schedule for Social Interaction examined maternal social support. The child life events was measured with the Project Competence Life Events Questionnaire, and illness events were assessed through parental ratings of disease-specific checklists. The findings indicated that mothers of children with asthma perceived their support to be inadequate, had a great number of life stress events, and reported the presence of more internalizing behaviour problems in their children than mothers of healthy controls. However, no significant differences were observed in family functioning among the groups.

Pelletier et al. (1994) analysed the support needs of mothers (N= 213) of children with asthma or juvenile arthritis, 6 to 18 years of age. Data were collected using the Chronic Childhood Illness Support Scale, the Functional Status 111, and a sociodemographic questionnaire. Study findings revealed that mothers placed greater value on receiving support from spouses, professionals, and immediate family members. Further, the findings suggested that mothers wanted more support than actually received, especially in terms of appraisal, emotional, and informative support. Finally, during discriminant analysis, the probability of mothers receiving low support significantly increased when the chronically ill child was an adolescent, when the spouse had higher education level, and when the family income was in the low to middle range.

In a qualitative study, Jerrett (1994) investigated the ways in which families (N = 10) of children with juvenile arthritis experience their child's illness. Data were collected through explorative, and later focused, interviews. Study findings revealed that the experience of coming to know how to care for a chronically ill child involved turmoil and confusion, struggling to know, developing a different way of knowing, and finally taking charge. During the emotional turmoil and confusion stage, parents described feelings of sadness, anger, helplessness, conflict and tension. Most parents described feeling unprepared and overwhelmed by the care giving expectations as they struggled with an unfamiliar role. Parents' interpretation of the situation and their ability to cope with the illness often differed with health care professionals' expectations, thus increasing conflict, confusion and feelings of isolation. As well, coming to terms with the recommended care giving interventions added to the struggle. As parents gained more confidence in their ability they began to accept the fact that managing the child's illness involved a different way of knowing. All parents acknowledged the importance of managing their time effectively (using schedules) and being organized to carry out family responsibilities. Finally, the parents' world was reshaped as they took charge and integrated care giving activities with family life.

In a qualitative study design, Stewart et al. (1995) investigated how mothers experienced having a child with spina bifida (n = 30), diabetes (n = 30) and cystic fibrosis (n = 30). Semi-structured interviews focused on care giving during a typical day and a recent acute illness episode, the impact of the child's functional capacity and care giving demands on mothers' and families' activities, and the nature and usefulness of supports. The findings indicated that mothers' perceptions of the burden of care giving and quality of supports were comparable across the different chronic illness groups. All of the mothers reported feeling considerable isolation, receiving little support to help with care giving demands, and acknowledged the rigorous, time consuming, and unrelenting daily regime of treatment and management of symptoms. Mothers also reported that they experienced care giving burden beyond usual role expectations, and had stressful interactions with their partners and health care professionals.

Using a time series longitudinal design, Knafl et al. (1996) investigated management styles of families (N = 63) of children with chronic illnesses (i.e., diabetes, juvenile rheumatoid arthritis, asthma, and renal). Data were collected using unstructured techniques and structured guides based on the Family Management Style conceptual framework (i.e., individuals were asked how they defined their situations, what management behaviors were used, and the sociocultural factors influencing their response to the illness situation). Study findings revealed the presence of five management styles: thriving, accommodating, enduring, struggling, and floundering. With the thriving management style, normalcy was the dominant theme as parents expressed confidence in their abilities to manage the illness, used a proactive management approach, and a shared sense of mutuality with each other. In the accommodating style, although normalcy was the overriding theme, parents found the adherence to doctors' orders, the close monitoring of symptoms, and the treatment regimen more burdensome than parents in the thriving group. In the enduring family management style, parents focused on the illness and protecting the child from possible harm as they struggled with adhering to treatment regimes, managing the illness, and the child's self-care deficiencies. Conflict over management was the overriding theme in the struggling family group. Mothers viewed their situation more negatively than did fathers, and felt they received little support from their spouses. In the floundering style of management, confusion was the underlying theme. Parents' negative view (i.e., an ominous situation or a hateful restriction) of the illness was enhanced by the uncertainty about how to best manage the illness. Parents described illness management as a burden and often focused on feelings of inadequacy and conflict with the ill child over complying with the treatment intervention.

Using a grounded theory design, Horner (1997) conducted in-depth interviews with mothers (N = 12) caring for young children with asthma during illness episodes and prior to a diagnosis. Study findings revealed that the prediagnosis phase was the most difficult for mothers as they struggled with unanswered questions. Groping in the dark was the core variable coined to describe the mothers' experience with their childrens' asthma episodes during the prediagnosis phase. This variable consisted of two components - unending illness and searching for answers. Unending illness was described in the mothers stories as 'just not knowing or unknowing', watching the struggle, and wearing out. Searching for answers reflected the mothers' increasing efforts over time through questioning, trying alternatives, and demanding attention.

Summary

The above discussion sheds some light on the significant impact that a child's chronic illness has on the family unit. Research efforts are continuing to uncover the challenges experienced by parents as they attempt to cope with childhood chronic illness. Study findings acknowledge the rigorous, time consuming daily regimen of treatment. Even though responsibilities for care giving lie with both parents, it seems that mothers feel unprepared and overwhelmed by care giving demands during a chronic illness. Although some mothers' may feel that they do not receive adequate support from spouses and other family members, others report receiving inadequate informational and appraisal support from health care professionals. The findings suggest that future research efforts should be directed toward expanding the current knowledge base on the challenges, as well as the support needs, of families caring for a child with a chronic illness.

Discussion

The primary focus of research studies on children with encopresis has been on identifying possible etiological factors and effective treatment regimes. Research into the etiology of encopresis suggest that there are multiple factors responsible for this condition. Given the complexity and multidimensional nature of encopresis, it is not surprising that study findings are inconsistent regarding the effectiveness of different treatment modalities. Against this background of multiple causes and variant treatment successes, the management of encopresis is proving to be quite a challenge for health care providers and the families of children with this condition.

What is readily apparent following a comprehensive review of the research literature are the significant information gaps on how families, especially mothers, experience an ill-defined condition for which there is no standard treatment protocol. Although case studies did provide some insight into how families were involved in implementing treatment protocols, only fleeting reference was made to the frustrations and struggles experienced by parents and the affected child. Without such information, how can health care providers ensure that adequate support mechanisms are available to meet family needs?

Qualitative studies would help provide greater insight into how parents experience living with a child who has encopresis.

CHAPTER 3

Methodology and Methods

This chapter presents a discussion on the methods used during data collection and analysis. The first section presents a brief overview of the research method used in this study, hermeneutic phenomenology as described by van Manen (1990, 1997), and the rationale for using this approach to data collection and analysis. The remaining sections of the chapter describe how the chosen phenomenological approach was used to explore how mothers experience living with a child with encopresis.

Hermeneutic Phenomenology as a Research Method

Phenomenology is a rigorous, systematic method which aims to describe particular phenomenon, or the appearance of things, as lived experience (Streubert & Carpenter, 1995). The purpose of this method is to acquire a deeper understanding of the meaning of everyday experiences pre-reflectively (van Manen, 1990). The researcher must be always cognizant of the importance of grasping and then rendering the logic of lived experiences without distorting them.

The decision was made to use van Manen's (1990, 1997) hermeneutic phenomenology method to capture the lived experience of mothers who have children with encopresis. The choice of this particular phenomenological method over others was based on the emphasis given to interpreting participants' descriptions of particular experiences with a phenomena through the process of phenomenological describing. The following steps, as proposed by van Manen, were taken by the researcher during this study:

(1) turning to the phenomena of interest and becoming committed to the research (i.e., orientating to the phenomena, formulating the phenomenological question, and explicating assumptions and pre-understandings about the phenomena of interest);

(2) investigating the experience as lived by participants as opposed to researcher conceptualizations (i.e., use of alternate sources, such as personal experiences, etymological sources, idiomatic phrases, experiential descriptions from others to facilitate understanding of the experience);

(3) identifying essential themes inherent in the phenomenon (i.e., total emergence with descriptions of the phenomenon while using a line-by-line approach to grasp themes and their meanings and, ultimately, conveying this understanding in words);

(4) describing the phenomenon through the art of writing and rewriting;

(5) maintaining a strong and oriented relation to the phenomenon (i.e., staying focussed on the research question and purpose while trying to capture meanings in the written text); and

(6) balancing the research context by considering parts and whole (i.e., being cognizant of the essence of the total lived experience while attending to the individual themes defining it).

These six activities were followed throughout this study. Although a certain order is implied, the researcher did not perform one activity in isolation of another. In the actual research process, various activities may be undertaken intermittently or simultaneously (van Manen, 1990). A more detailed discussion of these steps is presented in the data analysis section.

Population and Sample

The target population was all mothers in Newfoundland who were living with a child with encopresis. The accessible population was mothers in the Corner Brook area who lived within a one-hour radius of the city. Sample sizes in qualitative research are typically small because of the large volume of data generated from intensive and prolonged contact with subjects (Sandelowski, 1995; Streubert & Carpenter, 1995). Although it was anticipated that about ten participants would be needed, a sample size of eight was sufficient for this study as dictated by the themes emerging during data analysis.

The eight study participants met the following inclusion criteria: (1) had a child between the ages of 5 to 13 years with a primary diagnosis of encopresis without any comorbid neuromuscular disorders (e.g., spina bifida, muscular dystrophy, etc), (2) lived with the child's illness for at least one year (i.e., adequate time to ensure understanding and acceptance of the illness), (3) the child had received medical treatment for encopresis, (4) fluent in English, and (5) willing to allow audiotaping of the interviews.

Procedure

The researcher initiated telephone contact with pediatricians' offices in the Corner Brook area to gain access to mothers who had a child with encopresis. This initial contact was followed by a letter that outlined the study's purpose and proposed methodology. Letters of support were received from two pediatricians who were currently providing care to children with this condition (see Appendix A).

All of the study participants were identified with the assistance of the two pediatricians who agreed to act as intermediaries. The intermediaries informed mothers about the study, ascertained their interest in participating, and sought permission for the researcher to contact them. The names and telephone numbers of those women expressing an interest in the study were forwarded to the researcher. During the initial telephone contact, the researcher provided a more complete explanation of the study and addressed any questions or queries posed by potential participants. All of the eight women contacted agreed to participate in the study, and a mutually convenient time and location was identified for the initial interview.

Study participants determined the location of the initial interviews. Six of the interviews were conducted in participants' homes and two in a private room at the researcher's place of work. Both of these locations provided maximum comfort and ensured confidentiality.

Each interview included an introductory or warm-up period that lasted approximately fifteen minutes. During this time the researcher reviewed the consent form, clarified any concerns, and ensured that all participants understood what was expected of them. When the researcher was confident that participants understood the study and expressed an interest in participating, written consent was obtained (see Appendix B). Subsequently, all of the interviews were audiotaped and lasted a minimum of 60 to a maximum of 90 minutes. Participants were asked to describe their experiences of living with a child with encopresis. Data were collected using a semi-structured interview schedule (see Appendix C).

A second interview was scheduled with all participants within a two month period, following transcription of the data and initial thematic analysis. Six of the follow-up interviews were conducted in participants' homes, one at a participant's work place, and the other in the researcher's office. At this time, each participant was asked to confirm the accuracy of the interpretive summary prepared by the researcher from her interview text. Participants were also asked to identify any gaps in the data. Two of the second interviews elicited new data. Any misconceptions or omissions were clarified and, where necessary, revisions were made to the interpretive summaries. In these instances, a third telephone interview was scheduled to confirm the findings and to more accurately capture their lived experiences. Each of the eight women eventually confirmed that the summary accurately described their experience and received a copy of their interpretive summaries.

Interview Approach

The interview approach was designed to elicit each mother's thoughts and feelings as they related to her experience of living with a child who had encopresis. Initially, participants were given the opportunity to describe their experiences without interruption. When necessary, the researcher used questions from the interview schedule to prompt or clarify statements and/or facilitate participants' articulation of their lived experiences (see Appendix C). Interview questions were based on areas highlighted in the literature, the researcher's clinical experience, and aspects of experiences associated with phenomenological research (van Manen, 1990). During the phenomenological interview, the researcher must remember to remain centred on the data, listen attentively, avoid interrogating the participant, and treat the participant with respect and sincere interest in the shared interaction (Streubert & Carpenter, 1995). A number of interview techniques were used to elicit further commentary on selected aspects of participants' experiences (e.g., probing, reflection, silence, etc.).

Ethical Considerations

Prior to commencing this study, permission was requested and approval received to conduct the study from the Human Investigation Committee (HIC), Memorial University of Newfoundland (see Appendix D). Initial contact with study participants was made by an intermediary (i.e., one of two pediatricians practising in the Corner Brook area). Additional questions or concerns were addressed by the researcher during subsequent telephone contact. During the initial interview, the researcher discussed the purpose, possible risks and benefits of the study, stressed the voluntary nature of participation and the freedom to withdraw at any time, and reviewed study expectations with participants (e.g. approximate time involved, ability to refuse to comment on any questions posed by the researcher, etc.). Written, informed consent, for participation and audiotaping, in the presence of the researcher and a witness was obtained. Participants were also given a copy of the consent which included the researcher's name and phone number.

Appropriate measures were taken to ensure confidentiality of all data. Audiotapes and other records pertaining to study participants were treated as confidential throughout the study and storage periods. During the taping of interviews, participants were identified by first names only. Codes as opposed to names were assigned to each transcript and corresponding audiotapes. Members of the thesis committee were asked to review and discuss the initial three interviews to provide feedback on the researcher's interview technique and to assist with identifying underlying themes. However, only the researcher was aware of the identity of participants. The typists who transcribed the interviews were instructed about the importance of maintaining confidentiality. Tapes, transcriptions, and consent forms were stored in a locked drawer. Following completion of the study, the tapes were erased.

It was anticipated that any risk from participating in this study would be minimal. In order to avoid any potential negative effects, the researcher used a non-leading and non-threatening approach during the interviews. Every effort was made to be sensitive to participants' discomfort while they discussed sensitive material. When participants became upset during the interview, the researcher waited for them to regain their composure, ascertained their willingness to continue, and offered to refer them back to the relevant pediatrician for further counselling. Participants were advised to contact the researcher at any time during the study with any questions or concerns.

A final ethical consideration was the concern that participants might develop a false impression or hope that they might somehow personally benefit from being involved in this type of study. This can sometimes happen when one is asked to speak about frustrations, concerns and worries related to a significant event or experience. This issue was addressed and clarified in the introductory meeting, and reminders given to participants during a follow-up interview. Participants did indicate, however, that they found it helpful having someone interested in listening to how they were experiencing living with a child with encopresis.

Data Analysis

The interview data were transcribed verbatim within 48 hours of the interview. Nonverbal information was documented immediately following each interview. The researcher listened to participants' verbal descriptions, while reading and re-reading the transcriptions, to ensure their accuracy and to make any necessary corrections or additions. This approach also helped the researcher to become immersed in the data.

Using the typed transcriptions, the researcher read and re-read the text searching for themes. A line-by-line approach was followed during thematic analysis of the data (van Manen, 1990, 1997). Each sentence or sentence cluster was examined and re-examined as the researcher tried to develop some insight into the phenomenon and to grasp an understanding of participants' experiences. Every effort was made to bracket any personal thoughts, feelings, preconceptions, or beliefs about what it was like to live with a child with encopresis. This was necessary to ensure that all interpretations were grounded in participants' meanings. The outcome of this initial approach to the data was the identification of statements, phrases, and paragraphs that seemed to reflect something essential about the phenomenon. All the units of general meanings gleaned from the text were noted, even redundant ones.

During the second phase of the analysis, the researcher applied the research question to the general units of meaning to highlight those which seemed to be most relevant for participants' experiences. At this stage, the researcher's thesis supervisor reviewed the proposed themes and highlighted any areas requiring further consideration. Eventually, selected statements, labelled units of relevant meaning, became the basis for constructing interpretive summaries. These summaries represented an attempt to explicate the meaning of the lived experience as described in the text, and were revised repeatedly to ensure that sufficient attention was being given to the essential themes. Collaborative discussions were also held with the thesis supervisor during the initial stage of interpretive summary development.

Once the relevant themes were identified and interpretive summaries confirmed by participants, the researcher began the task of writing a report on the findings. In order to facilitate this process, the researcher reflected upon her personal experience working with parents and children with encopresis in different clinical areas, and reviewed notes taken during data collection and analysis which provided meaningful insight into the lived experiences of study participants. A social worker's published account of clinical encounters with this population was also reviewed (Buchanan, 1990).

Through the process of writing and rewriting, the researcher, with guidance and input from the thesis supervisor, developed a clearer understanding of the emergent themes. As the researcher tried to express in words the essence of what was being conveyed by participants, the themes began to assume a unique, but interrelated, form. Eventually, the written accounts of the themes culminated into a hermeneutical interpretation of the text. van Manen (1990, 1997) provided the following commentary on this phase of the analysis: "The inscribing, the writing of the text *is* the research; it is a relic of embodied reflections" (p. 129).

The final step in the analysis is what van Manen (1990, 1997) refers to as "balancing the research context". That is, the researcher constantly assessed the overall text in terms of the significance of the parts (themes) for the total structure or essence of the lived experience. van Manen cautioned that the researcher must be careful not to get caught up in writing the themes and lose sight of the essence. In fact, at several points throughout the study, the researcher found it necessary to step back, study the parts, and to assess how each part contributed to the total picture.

Credibility of Findings

Qualitative studies should not be evaluated against the same reliability and validity standards as used in quantitative research. The goal of rigor in qualitative research is to accurately represent the experience of study participants (Streubert & Carpenter, 1999). Qualitative research should be evaluated by examination of the credibility, fittingness, auditability and confirmability of findings (Sandelowsky, 1986). Credibility (truth value) was established by having participants review an interpretive summary of their interviews. These summaries were written to reflect the emerging themes. Participants confirmed that these summaries were reflective of their experiences. Gaps in the data were identified and then clarified or substantiated at the second, and when necessary, the third interview.

Another method of credibility and auditability (consistency) is to have an impartial researcher, experienced in qualitative research, read the interview transcripts and independently identify themes. The research committee consisted of two nurse researchers, one proficient in phenomenological research and one with clinical expertise with the phenomenon, as well as a physician from Health and Community Services Western in Corner Brook who provided content and clinical expertise. Once themes were identified, intersubjective agreement between the researcher and the thesis supervisor was achieved at each phase of the data analysis. This discussion facilitated a richer understanding of the phenomenon under study, and assisted with uncovering hidden meanings.

To address fittingness of the findings, the researcher recruited participants who had experienced the phenomenon under study and who were able to articulate their experiences. Fittingness was also enhanced by providing rich thick slices of data, such as numerous direct quotes from participants, in the discussions of the findings.

Confirmability (neutrality) was achieved by ensuring that credibility, auditability, and fittingness were established. As well, the researcher used bracketing to promote objectivity. That is, an attempt was made to decrease researcher bias by holding in abeyance any preconceived beliefs and opinions during the analysis of data (Streubert & Carpenter, 1999). Confirmation of the relevant interpretive summary by each participant indicated to the researcher that bracketing had been used effectively during data analysis.

CHAPTER 4

Findings

What is it like to live with a child who has encopresis? This question was explored from the perspective of eight mothers who have experienced living with a child with encopresis. This chapter is divided into three sections. The first section presents a brief overview of study participants. The second section describes the themes that emerged from the phenomenological analysis of the data. The final section captures the essence of the mothers' lived experience with encopresis.

Introduction to Participants

The eight women who agreed to participate in this study were mothers who had been living with a child with soiling problems for a period of two to eight years. Most of the participants' children were diagnosed with encopresis around the age of four years. All of the participants were part of a nuclear family, with another child present in six of the families. With regard to the children with encopresis, there were two females and six males who ranged in age from 8 to 13 years.

Following extensive contact with health care providers over several years, most of the participants observed some improvement in the frequency of soiling episodes. However, only three participants felt confident that their child's condition was in remission. These women indicated that their child had been symptom free for a period of a year or more, however it continued to have implications for their lives. According to Pyles and Gray (1997), there is no definitive cure for encopresis; successful management means that the patient's symptoms are in remission.

Thematic Analysis

This section presents a detailed discussion on the themes identified from the thematic analysis of the interview transcripts of mothers living with a child who has encopresis. The participants' narratives represented a rich cluster of similar but disparate experiences. The themes that emerged from the descriptive commentary reflected the ongoing frustrations, as well as the challenges, involved in caring for a child with encopresis. Although presented separately to highlight different aspects of the lived experience, each theme flows into and overlaps with the other. The four themes identified were: dealing with uncertainty, becoming frustrated with care giving, struggling to endure, and taking control.

Dealing with Uncertainty

Mishel and Braden (1988) defined uncertainty as the inability to determine the meaning of illness-related events. Mishel (1984) also suggested that uncertainty is generated by events characterized as vague, ambiguous, unpredictable, unfamiliar, or lacking information. The meaning of uncertainty for study participants was shaped by the difficulties encountered while striving to understand the reasons for soiling mishaps. Without the presence of readily identifiable physiological and/or emotional factors, participants began to question how they may have contributed to the problem and whether or not they could cope with the challenges of an uncertain future.

The transcripts of most study participants conveyed the message that the child's elimination patterns did not quite conform with expected norms, and never quite achieved bowel control. The frustrations experienced with toilet training led many mothers to question why this child was having so much difficulty. When soiling mishaps persisted beyond the normal toilet training period, they became apprehensive and concerned about the presence of some underlying problem. The following commentary captures one mother's concerns about her son's tendency to withhold stool and refusal to use the toilet:

> He was close to three and we were making no progress with the bowels. He just wouldn't do anything in his potty. He would hold it and he wouldn't do a thing so we knew then there were problems. It wasn't quite right, but at that time no *one* would help us because he was too young.

A second mother also talked about her early suspicions about the possibility that her daughter may have bowel control problems. She described the toilet training period thus:

> When she was in diapers she was fine, she had regular bowel movements

> and everything looked great. . . .She could not be potty trained. So that was just before she was four, it's been basically since she was getting out of diapers. Maybe it was her whole life and we just didn't know the difference, like she didn't have any control. Now she didn't have any constipation, but the soilings. I can remember my poor babysitter at the time, she was trying to potty train her because I was working full time then. She nearly went out of her mind because she couldn't understand why was this happening - why! She was pretty frustrated at the time.

Although most mothers recognized that toilet training is usually accomplished by four years of age, some of them were not too concerned with their child's slow progress. A couple of mothers with sons de-emphasized the problem at first, attributing the slower pace to male/female differences.

> *[Son]* was a little slower than our daughter in getting toilet trained. . . .I also knew that sometimes boys are a little slower. I remember he was almost four. . .and he still was not having regular bowel movements in the toilet. Between three and four, and I said gee what in the heck is going on here.

> Well, he had trouble potty training but then again everyone tells you that boys are more difficult than girls. So I just thought that that's normal.

These mothers assumed that their child's seemingly lack of interest in bowel control was due to the fact that boys took a little longer than girls. However, when the normal toilet training period was passed, the possibility of an underlying problem became more of a reality. One mother summarized her perspective thus:

> You think for a long time that they are not getting trained. You just think that they are taking a real long time to get trained. You didn't really realize until they were in school that this was a concern. So there is no one point where you suddenly know that something is wrong. . .because some kids are three before they are trained.

With the passage of time and no significant improvements in toileting behaviours, participants engaged in more intensive efforts to identify reasons for their child's continued difficulties.

While reflecting on the past to identify acceptable explanations for the child's long-term problems, all of the mothers focussed on early warning signs. A few mothers could identify problems with constipation, stemming from infancy. The following excerpts provide insight into how study participants viewed the early months after the birth of their child:

> Actually, he had a problem right from the start, even when he was a baby. I had to use a thermometer when he was ready to have a bowel movement. I would have to do that and press his legs up. He used to strain and nothing would come out so I would have to help him.
>
> When he was an infant, *[child]* had hard bowel movements. He was never normal, ever. . . .it was hard from day one.
>
> When he was still on the bottle he used to force it *[strain to have a bowel movement]* so much you'd see milk coming out of his nose. Sometimes he used to push so hard. This is when I used to give him suppositories and then he'd be okay.

Because problems with constipation persisted over time, some mothers questioned whether or not hereditary factors were the main culprits.

> I used to get constipated a bit like back when I was younger, but I mean everything is normal now. I don't know, it could be hereditary. Like mom's never seen nothing like this before, even though my sister had problems when she was younger and had her bowels stretched. . .she's been fine ever since.
>
> I grew out of it *[constipation]* you know as a teen. I don't think I had a soiling problem. I just didn't go very often, and I would have painful bowel movements but I don't think I soiled the way *[my child]* has soiled. I don't

> remember that part of it.
>
> [C*hild's father]* used to apparently do that when he was young. But I don't know if he actually had what *[son]* had or if he truly was just lazy. . . .and actually it was [*child's]* uncle who was worse. *[He]* had a lot of it. So I wonder if it is hereditary.

There were a number of mothers who felt that their child's problems began when (s)he started to use the toilet. Some of the mothers described a circular process of withholding that resulted in constipation, painful defecation, and subsequent refusal to use the toilet.

> Well, I guess that's why he wouldn't sit on the toilet. Because he experienced some pain when he did have a bowel movement, where he held it in, I guess. This is why he wouldn't sit down.
>
> I think he was scared to do it, to have a bowel movement. He kind of held it back, I think, but I really don't know.

Although some mothers were able to find concrete evidence for a physiological basis, it was often difficult to separate the physical from other factors. As one mother articulated, her son's problems with bowel functioning had negative repercussions for his emotional well-being:

> Sometimes he says, "You know when I poops mommy it hurts; it hurts my bum". So this is why I keep giving him the mineral oil and it doesn't hurt you know. But I think it might scare him, when he sees a bowel movement so big it's scary.

Other participants began to look for the possible influence of psychological, behavioural or emotional factors. A couple of mothers believed that their child had become fearful of using the toilet: "It was like he was afraid to sit on the toilet. As he got older we would have to say now you have to sit down on the toilet because he wouldn't wait to finish his bowel movement"; "He was afraid to have a bowel movement *[by sitting on the toilet]* so he wouldn't have them enough". Another mother wondered if the fears exhibited by her child around certain events were somehow linked to encopresis:

> I found here lately for the past couple of years like he is very fearful. I don't know if that is associated with it? Even in the daytime you would have to go in and turn the light on in the bathroom. Like he is afraid of everything.

In other instances, mothers searched for possible inherent personality traits that could explain their child's behaviour. Some mothers used terms, such as lazy, intense, unhappy, and inattentive, to describe their child. One mother defined what she meant by her child being lazy as follows:

> We thought he was just too lazy. You know, the first thing that comes to your mind, he's too lazy and he just doesn't want to take the time. He wants to go back playing and doesn't want to take the time to sit down and finish it.

She further elaborated on how this trait was an inherent component of her son's demeanor: "I just thought it was him, he was just being lazy because he is a lazy child in every other aspect of his life"; "In everything he needs to do you have to prod him along and get him to do it. . . .So I just thought this is just one more thing you know." Another participant attributed toileting difficulties to her son's normally intense behaviour. She reasoned that because he was so intense he sometimes forgot to tend to his basic needs, like going to the bathroom. The following excerpt captures how intensity was seen as a form of distraction:

> He was very intense in terms of staying to finish games. . . .we didn't see that might be a sign of being very uptight, well we did but we didn't! When you're so busy doing everything else you just say okay, that's who he is.

She elaborated further on how she was defining the significance of her son's behaviour: "He was so intent on playing whatever he was playing, he would often have pee accidents as well".

Other mothers commented on the negative impact of unhappy or inattentive behaviours. One woman described her child thus: "He is not a happy child. I mean he has things he likes to do and stuff, but to say he is a happy child, he's not like that". Another woman spoke of her child's apparent disinterest in focussing on school activities: "In grade three or four they *[teachers]* mentioned to me about him being a day dreamer, and that he wasn't connected to the rest of the class, like he is off on his own".

When children continued to experience soiling problems beyond the normal toilet training period, study participants became frustrated with the slow progress and began to question their capabilities as a parent. A couple of mothers described their misgivings about whether or not they somehow contributed to the problem: "Had no clue what was going on, had no clue, *[pause]* couldn't figure it out. Started to think what am I not doing here?"; "I thought it was something that I was doing wrong. Like how come no other kid has this. . . .I didn't know really what I should do. Like what was my next step? Where should I go now?"

Several mothers described experiencing feelings of self-blame and guilt as they reflected upon what they might have done wrong or could have done better. The uncertainty surrounding potential ineffectiveness is captured in the following comments:

> I know that this is a medical problem and all that, but you can't help think, in the back of your mind, was it something I did. What's wrong with me and why does my child have it you know. . . .And you feel guilt. It is very upsetting.
>
> Not enough people are aware of it. I'm sure if other people say that their child was four or five years old and they are not potty trained, the looks that they might get, right? And they must think bad mother, right? Well, if it wasn't me going through this and somebody else said to me. . . not knowing what it is, I would probably think, "Gee what is wrong with you, you can't potty train your child".
>
> What have I done to cause this? You know it's there. What have I done? What haven't I given him? Is it food? What's going on in my family life that's making him constipated?. . . How come he's so sick? Why won't he go to the bathroom? Not understanding.
>
> I used to think, you know, what did I do to make him like this. Is he under stress? Is there anything I could have done that would have changed that? Did I not react quick enough when he first got constipated and little things like that?

As the above excerpts illustrate, several of these women questioned their role in the development and continuation of encopresis.

Besides feelings of self-blame and guilt, some participants described feeling powerless to help their child deal with his or her soiling problems because of apparent difficulties with self-esteem and self-confidence. One mother talked about her son's self-esteem problems thus: "Just recently he said, 'What's wrong with me? I'm the only one with this and I'm stupid'. . . .It would break your heart I'm telling you". This mother further described how she struggled to use a consistent approach with both of her children:

> I know he can't feel very good when I'm always at him. . . .When you are harping on him all the time. . .he takes that to mean. . . .we love his sister more than we love him. You try to overcompensate but you don't want to do too much with him because you don't want her feeling that way. . . .So it is a constant struggle. It's like a juggling act. I mean it is terrible.

From a slightly different perspective, one participant described the stress associated with having to deal with the negative effects that soiling had on her son's self-esteem. This mother voiced feeling guilty as she reflected upon the steps taken by her son to try and please her:

> Here I was on to him all the time *[about going to the bathroom]*. . . .So there's one more thing in his life, and I'm looking back now, that he couldn't please me. I'm on to him about that. . .you know self-esteem issues. Very low self-esteem.

When the child seemed to have self-esteem or self-confidence problems, this compounded the uncertainty experienced by study participants concerning what parenting tactics or approaches would bring the most success.

Feelings of inadequacy as a parent were sometimes exacerbated following visits with health care providers, especially physicians. Instead of developing greater insight into their child's problems and how to best deal with them, several participants left physicians' offices feeling more responsible for what was happening to their child. One mother described how her feelings of guilt were compounded when she took her child to a pediatrician who was negative and accusatory: "He's constipated!. . . .How could he get so constipated?" This interaction with the pediatrician reinforced the notion that she was to blame for her child's health problem. Another mother reported that the physician attributed slow progress with the treatment to her lack of discipline:

> I actually went to a doctor here who blamed me. He did! He said, *[pause]* because she was older now, if I had been stricter, if I had been keeping to the regime, if I had been more forceful. . . . she would be taking this lactulose. This is after months and months of taking it, and he basically blamed me.

It was apparent that some participants sometimes experienced increased uncertainty about their ability to adequately manage encopresis after seeking guidance and support from health care providers.

The uncertainty surrounding the adequacy of parenting skills was further intensified in the presence of inconsistent progress with toileting practices following implementation of various treatment approaches. Many participants were very discouraged when their child experienced relapses in bowel control after having been free of soiling for a period of time. As one mother indicated, improvement in the rate of soiling mishaps did not mean that the problem was resolved: "I can't say there was no improvement because there was improvement. But it's just that she can be improving one week and she can be worse the next." The following comments capture the peaks and valleys of living with encopresis:

> So he started to have a bowel movement every time he was going to the toilet for awhile and I was getting so proud of him. Everything was going

> so well, I said, "My God, he is getting better". . . *[Then]* I would find a pair of underwear with 'skid marks'. . .but it wouldn't be just a little bit it would be a lot. Sometimes he would do the whole works in his pants.
>
> My husband [*would say]* I can't understand this. . .and he would shake his head more than once at her. . . .We thought we had her bowels under control there about six months ago. . . she went about two months without soiling and from then on right up until now she's been soiling all the time.
>
> When she was four, she went into the hospital for. . .bowel retraining. We were hoping then that this would be the end of it. . . .Unfortunately it *[success]* didn't last long, and since then I can't even count how many times she's been in the hospital.

The inconsistencies experienced with soiling problems following interventions only served to increase participants' frustrations. One mother described feeling up-tight and experiencing on-going tension: "There were bouts when he would have nothing, and there'd be no soiling. We'd still be uptight. I'm still up-tight around it. Well you know there's worries about what happens in the future with him". Another mother also talked about the emotional turmoil of small successes: "Oh yes, you could almost see the change in him overnight and he was really good about it. But here lately he is slipping a little bit again and I have to stop myself because I'll get angry".

For many mothers, numerous visits and consultations to different physicians and pediatricians was a quest for answers to their child's problems. These encounters did not always resolve their questions or concerns and often increased, rather than reduced, stress and anxiety. One participant had taken her daughter to many physicians, even outside the province, in search of explanations and treatment. Although she now has a very supportive pediatrician (i.e., someone willing to spend the time to listen to her concerns and frustrations), she described the anguish and pain of not being able to find more help for her child: "My daughter has been like this now, to me, since she's been eight months old and I'm not getting *any* help. It *doesn't* seem like I'm getting *anything*".

The experience with inconsistent responses to different treatment plans also raised fears about future relapses even when the child had been symptom-free for a couple of years. The following excerpts capture the ongoing concerns of some mothers:

> I didn't know at first if this would happen again, and they told me that down the road it could happen again. That's a concern. Wondering how he'll deal with it, now that he is older. Will he be worse this time? Like that's scary.
>
> I just worried about when and if he was ever going to get over it. I mean you are hearing about children eight and nine years old and they are still battling this. . . .I was scared to death because in the literature you read it is a tough thing to deal with. It is a tough problem to solve. . . . it just seemed like the road was so long, right, and I just couldn't imagine going through all that frustration for another two or three years.

Summary. As the preceding discussion illustrates, the meaning of uncertainty for study participants was shaped by the challenges experienced while trying to understand why their child developed encopresis. Eventually, these mothers started to blame themselves for their child's problems and questioned their capabilities as parents. Guilt, self-blame, and feelings of inadequacy were intensified when the child continued to experience difficulties despite concerted efforts to follow recommended treatment plans. The information and guidance received from health care providers, especially physicians, did little to increase their understanding or relieve feelings of being inept.

Becoming Frustrated with Care giving

The Oxford Dictionary (1995) defines the term "frustrate" as preventing achievement of a purpose. Participants described clearly the factors which contributed to their frustration: a) discrepancy between the child's cognitive ability and behavioural habits, b) physical/emotional stressors of care giving, c) embarrassment/shame and overprotectiveness, and d) health care providers' limited support.

Participants indicated that sometimes they were puzzled by the discrepancy between the child's behaviour and his or her level of cognitive functioning. Several mothers described feeling really frustrated by having a child who was very bright and yet, for some unknown reason, refused to use the toilet. The depth of frustrations experienced by these mothers was enhanced considerably when they were convinced that their children were aware of what they were doing. One mother described her feelings thus:

> Here he was four years old, knew better, could understand everything, was a very bright child but still just for some reason he refused to go to

> that potty. No matter how many bribes we used and believe me there were many. . . .He just wouldn't do it *[have bowel movement in the toilet]* and that was so frustrating and aggravating you just couldn't imagine.

Another mother commented on the amount of time that she spent with her daughter trying to reason with her about the importance of using the toilet and changing her clothing following soiling mishaps. As her daughter approached puberty, she was becoming more and more desperate to find a way to convince her daughter of the need to modify her behaviour.

> She's been doing it for years and I mean I'll sit her down and hold her hand and try and talk about the situation. And she understands it completely. Totally understands it. But still for all it won't stop her from soiling and not changing. . .and now she's almost to puberty. You know she's starting to show signs of getting older. . .

It was apparent that many of these mothers, from time to time, believed that their child's soiling mishaps were not always accidental in nature. In fact, some mothers were convinced that their children not only were aware of the soiling problems but refused to expend much effort into trying to modify their behaviours. One mother's comments reflected how difficult it was for her not to believe that her son was exercising control by refusing to use the toilet.

> I remember standing in his bedroom door and trying to reason with him. And you know you don't reason with a six year old. But. . .he's bright. Maybe he can understand and do the logical stuff because he was logical in game playing and all sorts of other things. But he wasn't logical around this. Because it's power and control.

Other participants spoke about how disturbed and irritated they were with their child's apparent indifference toward soiling episodes. One mother described her son's nonchalant attitude towards underwear soiling: "He shows no shame for it, he just laughs and goes on his merry own way. . . .he *doesn't* seem to care." A second mother expressed a similar sentiment:

> She's not embarrassed. She's really not, I wish she was. She really couldn't care less, that's the attitude that she has. Now whether or not that's true, I don't know. . . .I'll say to her, "I can't imagine that you're not embarrassed by this". She'll just shrug her shoulders, you know.

Still another mother commented on how her child would soil underwear and not seem to notice or be bothered by it.

> It was like he was oblivious to it all. We couldn't believe. . .that he couldn't smell what was going on, when he would have an accident. He would just sit there. Wouldn't have a clue.

Participants realized that their child's soiling problems were becoming very physically and emotionally taxing for them. With time, the entire family began to feel the repercussions of the ongoing stress and burden of care.

With increased frustrations over the disparities observed between cognitive abilities and behaviours, a number of mothers acknowledged that it was sometimes difficult to control their emotional responses. One mother talked about her efforts to reach her daughter while trying to maintain a positive approach: "She's not listening. She totally tunes it all out. No matter how hard I try and put it in really happy terms, or stay away from the mad, angry or whatever. Still she blocks it out." This participant elaborated further on how frustrated she becomes with her daughter's attitude and behaviour:

> I feel so bad that sometimes I'll get mad, not mad at the situation, not mad

> that she poops her pants, just mad that she won't tell me. . . .I'll say, "Go to the bathroom, you have to go to the bathroom." Then I'll realize, okay she didn't go and look what happened. She pooped in her pants, and I'll get mad. She blanks it all out, and then I'll feel bad.

A second mother found it extremely puzzling that her son had so much difficulty mastering the simple task of having a bowel movement in the toilet when he was so successful with challenging games. She described how difficult it was trying to control her feelings when she believed that he was very aware of his actions.

> I remember him very clearly, and I think these are the times when I would lose it more. He'd be out in the living room with us or downstairs or whatever, and he'd just go off by himself and the next thing you'd know he would be smelling. So I knew that he knew.

As primary caregivers, the mothers experienced many physical and emotional stressors while caring for a child with encopresis. Participants spoke about the burden of care placed on the family unit. Frequent reference was made to the time consuming and unrelenting regime of enforcing dietary and toileting recommendations, monitoring soiling episodes, changing and washing clothes, and ensuring that the home was odour free.

Acquiescence to the child's desires was sometimes easier than struggling with him or her to eat important, but not necessarily desirable, foods (i.e., fruits, vegetables and fibre). One mother commented on the frustrations experienced while trying to foster good nutritional habits: "Things that I cook, that I know he likes, he'll take 3 to 4 teaspoonfuls. . .and he'll say I'm full, I can't eat *any* more. When he says he's full, he's full". Other mothers echoed similar sentiments:

> I tried to change it *[diet]* but there was really nothing I could do because *[pause]*, it didn't matter how much fruit. I tried and I tried to encourage him and we were always talking about it, but it was a physical thing and it wasn't working.
>
> We had to cut out fat in his diet and *[give him]* a high fibre diet. But it is hard you know. Because I find it very hard to put a ten year old on a high fibre diet, especially you know with Halloween and the foods they don't like.
>
> Always analyzing, always looking at what he is eating. The biggest problem. . .has been, "No you can't have that bag of chips; no you can't have those chocolate bars". A lot of his friends. ...have a lot of pop and a lot of chocolate bars, kids stuff. We've always had to say, "No you can't". Not always, sometimes.
>
> He didn't like the bran, didn't want it, wouldn't eat it. Meal time in the hospital was torture, torture. It is also at home actually. I've tried to get him to eat. He says he doesn't want to eat. He's always full.

Besides the difficulties experienced with modifying eating habits, there was the challenge of identifying appropriate food substitutes when recommended products were not available locally. One woman described her difficulties thus: "Like he loves pasta, whole wheat pasta, but it is very hard to find that stuff around here. . . .He is the type who won't eat fruit. . .but it is very hard knowing what to get".

Reinforcing good toileting habits was an equally frustrating task. Recommended toileting regimes required that the child sit on the toilet after each meal. Most children were reluctant to do so and a great deal of perseverance was required. One mother commented on the toileting regime thus:

> That is a lot for him to do, to go sit on the toilet for ten minutes after every meal. He doesn't want to do that. After he eats he wants to go play.

> That was a lot of fuss. That alone was a lot of problems.

A second mother also voiced her frustrations not only with trying to get her child to use the toilet after a meal but also having to deal with his resistance to taking mineral oil.

> It was a fight to get him to go to the toilet because he didn't want to go. Taking the Mineral Oil was a big fight. I was giving it to him in a syringe and I had to put it in the back of his throat because he would never take it . . . .All of this was frustrating and very hard on me. . . .One of his grandparents is a nursing assistant and she would say you have to hold him down and force it into him. I said well I don't like to do that, I'd like it to be voluntary. But it was the only way we could get it into him.

The time consuming nature and constant frustrations of the dietary and toileting protocols only represented one aspect of the daily hassles experienced by these mothers. Participants commented on the constant vigilance required to detect soiling mishaps and then to institute timely interventions to keep the child physically clean. One mother described how time consuming and difficult it was dealing with her son's soiling problems:

> So I was giving him that *[mineral oil]*. Then when the mineral oil started to come out of his bum it would be like an orange liquid, bright, bright orange. He was ruining furniture, he was ruining his clothes, he was ruining his bed, he had it over everything.

The constant physical and emotional demands placed on participants is also captured in the following comments:

> I didn't know what else to do. You just went through the motions every day. You cleaned him up, you dressed him and sent him on his way, and a half-hour later he'd come back and do the same thing again. I mean there was days, I'm telling you, eight and nine pairs of underwear. . . .It was terrible. More pairs went in the garbage. You could imagine, I mean

> some of it was such a mess I couldn't even face it. . . .I didn't like to have to put him in pull-ups. I worried what that was going to do to him. . .but there came a point when we had no choice.
>
> More work. Oh yes! Yes! Instead of having one baby and a big boy that could come in and use the bathroom, we'd have him come in all the time, from the outside, and he would say, "I smeared." And you would get mad at him and he'd come in again an hour later. . .it was just non-stop. I mean there was a lot of frustration. I mean. . .the worry about it and how we were going to help him.

Participants also discussed their ongoing efforts to maintain a home free from fecal odours. This was necessary because it was not unusual for the child to hide soiled underwear to avoid being scolded. A couple of mothers commented thus:

> I'd go in to clean up his room and I'd say where is all his underwear. I couldn't find any underwear in there. . .I found it in the closet, up on the shelf, underneath the bed, behind the dresser. This is before we found out it was encopresis. I hate to admit it but I would scream at him and shout and he didn't want to hear that any more so he hid it. He thought, I suppose, I'll hide it away.
>
> I open up the hamper upstairs and you can just smell it. He'll just take it *[dirty underwear]* and stuff it under the clothes in the hamper. . .and he won't tell me that it is there because usually I make him clean it himself. I say *[child]* if you want to poop in your clothes that is fine but I am not cleaning it any more. He has to clean it and scrub it and put it in the hamper and I will wash it when I wash the clothes.

The unpredictable nature of soiling episodes, as well as the child's tendency to hide soiled garments, certainly added to these mothers' frustrations with care giving demands.

In addition to the physical and emotional demands, there was the personal side of living with a child with encopresis. Several mothers described feeling embarrassed or humiliated by having a child who had failed to master bowel control at an appropriate age. Feelings of shame/embarrassment, when confronted with either the norms of toilet training or having to share information about their child's problem with others, exacerbated the emotional stress and strain associated with care giving. A couple of mothers described feeling embarrassed about the toilet training successes enjoyed by others.

> When it first started it was kind of embarrassing. You know, you've got your friends with their young children, "Oh, my little kid was potty trained when he was a year old, or a year and a half". And here was *[son]* two and three years old and getting stains in his underwear. So it was kind of embarrassing.
>
> And a lot of people kept saying "Oh, he's not toilet trained yet." I kind of felt like he should be with everybody saying, "Oh my goodness, he's almost two and he's not toilet trained."

Still other mothers talked about the embarrassment they experienced when others had to be informed about their child's soiling problem. One woman talked about her discomfort when she had to tell the parents of her child's friends about her son's problem:

> And I'd be embarrassed. You know, this is my child. If he has accidents when he's going out when he's seven or eight years old, what's going on here?. . . .We told the mothers of his very close friends. And we'd always bring an extra set of clothes, and say, "If he has an accident, give me a call". . . .But it was awful.

This participant went on to describe further her feelings of shame or embarrassment: "Shame is not understanding what's wrong with your child. What else can we do? What else are we not noticing? What is he reacting to?

Why is he playing these games with us?"

Feelings of shame/embarrassment were also fostered by not having a good understanding or insight into the child's soiling problems prior to the encopresis diagnosis. One woman spoke about feeling embarrassed about her child's soiling problems after consulting with a physician. Because the physician failed to diagnose her son's condition, she concluded that she was responsible for his problem. She commented thus: "I did go to the doctor and I never got any satisfaction. I was thinking it can't be anything medical or he would know about it. You think it's your child [*only]*, and a bit of shame creeps in there".

As the children grew older, participants became more and more preoccupied with fears and worries about soiling mishaps outside of the home. Bowel incontinence was an area of great concern because of its social ramifications (i.e., peer ridicule because of odour). They were especially concerned that other children would subject the child to humiliation and shame. Many participants believed that concealing the problem from others was necessary to avoid stigmatization. The emotional stress associated with attempts at concealment is captured in the following commentary: "He is almost seven years old and he is still soiling in his pants. The kids at school, once they get a hold of this he is going to get a name put on him for life". Mothers worries and fears about their child having soiling mishaps at school is also captured in the following excerpts:

> I've been terrified. I'm just waiting for the other shoe to fall. You know, just waiting for the teasing to start. I can't believe she's going to grade five and hasn't had them. Now there have been some comments made but they've never been directed at her, because. . .I don't think anybody would really think of her in that way.

> Will other children want to play with him. . . .worried whether *[son]* would soil himself and turn his friends away. That was one of my biggest worries, that one of the kids at school would make fun of him.

> You're always worried that when you go somewhere there will be an accident. And as a mother you are terrified that he is going to get a name at school and once the kids label him, like I was so afraid, like what kind of a name would they give him, like stinky or something like that. And you know that kids can be so cruel and then if they give him that name then he would be stuck with that name. . . .I was more concerned, not for me but for him you know. Like I didn't want his feelings hurt.

Because accidents at school or in the presence of others were likely to result in extreme social distress for children, mothers were constantly driven to implement measures to help protect their child from peer humiliation.

Participants felt compelled to protect their child from psychological trauma. One mother described how she tried to conceal her son's problem from others: "It's hard because if you go to a movie or something you have to check his underwear". Despite these efforts, accidents did happen.

> They had sort of a flee market or fair type thing at the school and I was over working at the tables and he came out with his class. . .and as soon as he came close to me I could smell him. I said, "Oh, my goodness". Now here I had to try to get away from the table. . .and it was like your sneaking around. It is terrible. I took him in the washroom and I cleaned him up and I had to take his underwear and put it in a bag and throw it away.

This excerpt illustrates some of the extreme measures that mothers had to take in order to protect the child from his or her peers.

Protecting the child from potential harm was a common theme that emerged from the transcripts of study participants. One mother talked about her attempts to alleviate embarrassing moments for her eleven year old daughter by having her wear sanitary napkins. Although this approach proved to be helpful, an additional worry was the potential for placing too many demands on her daughter:

> When *[she]* is going out I will say to her there's no soiling is there and she would say, "No mom, I got none". . . .I know I'm getting on her nerves, I don't want her out soiling. . . .and she would say, "No mom there's no soiling, I promise you". And I said, "Make sure you're not out around other kids like that". I said "*[Child]*, please." It's embarrassing for her. I know it is.

One participant described the degree of planning required for any normal family event: "I mean even if we were going out for a drive on a Sunday, if we were planning on going outside the city limits, we had to pack a bag as we didn't know where it would fall upon us". Another participant also commented on the importance of always being prepared for soiling accidents: "I would be very cautious and would make sure that before he went out he would sit on the toilet." Upon reflection, she recognized her overprotective behaviours: "We'd always be dragging this bag around, of extra clothes. . . .and a lot of attention, as I look back, gets paid to his going to the bathroom all the time".

The need to protect the child from embarrassment and humiliation was so great that several mothers were forced, at times, to refrain from following physicians' advice and try to manage the encopresis themselves. One mother specifically decreased the recommended dosage of mineral oil prescribed by the pediatrician: "When he takes a lot of mineral oil, it comes through his pants. It's bright orange. It's really smelly. . . .Plus he's in school and I don't want his friends seeing that." Another participant took control of her daughter's dietary management and discontinued recommended treatment, in part, because it did not seem to be making any difference. This is captured in the following excerpt: "After trying almost all her entire life *[eleven years]*, it's not working. So we say shag it, we're going to give it a try, and she's certainly no worse for wear. . .she's a bit better actually". It was especially difficult for mothers to enforce recommendations when they could not see the usefulness of the interventions. It was even more difficult when negative consequences of treatment were observed: "It got to the point where she would look at it *[mineral oil]* on a spoon and literally throw up. . . .I had to take her off that even though the doctor would say, 'No, don't take her off, keep her on it'".

A second participant described her frustrations with not knowing the cause of and treatment for soiling problems despite having taken her son to several physicians over the years: "He did complain about some pains in his abdomen, a lot. I had him to the doctor I don't know how many times. . . .They did blood work and stuff like that and couldn't find anything". Another mother indicated that initial visits to the family doctor was more disconcerting than helpful. The physician surmised that her child had psychological problems which did not help matters. "When he was four I had taken him to see the family doctor who told me it was in his mind. He is holding it back. . . .But I knew it was not in his mind. It had to be physical." Still another mother spoke about physician disinterest and lack of support.

> The least helpful was when doctors would look up and tell you that it's nothing, it's just a simple little 'he wants attention'. . . .I thought I knew him better than that. I really knew that it wasn't just attention that he needed.

Summary. The frustrations experienced, as a result of the many demands associated with care giving, were clearly articulated by study participants. Mothers described many situations and events that enhanced their feelings of frustration (i.e., discrepancy between cognition and behaviour; physical/emotional stressors; and embarrassment, shame and overprotectiveness). Although some participants felt that their child's cognitive abilities conflicted with toileting behaviours, others were not convinced that the child understood the full implications of soiling mishaps. No single factor appeared to trigger or heighten frustrations more so than others. Rather, it seemed that when all these factors were combined the frustrations mounted and participants struggled to endure the hardship.

Struggling to Endure

The third theme identified was struggling to endure. Collin's (1995) dictionary defines struggle as proceeding with difficulty or great effort, or making strenuous efforts against opposition forces. Synonyms for struggle include: contend, fight, battle, strive, and toil. Enduring is defined as that which is long lasting or chronic (Collins, 1995). The word endure means to carry on despite hardships; to bear with tolerance. Synonyms for endure include: survive, persevere, abide, and suffer. Study participants' descriptions of the process of fighting to deal with the constant demands imposed upon them by their child's condition reflected a struggle to endure. Two factors defined this struggle: a) feeling alone and isolated and, b) feeling consumed.

Prior to and following the diagnosis of encopresis, several participants described feeling alone and isolated. A couple of mothers attributed these feelings to not knowing anyone who had a child with similar problems: "I didn't think anyone else had this problem"; "I didn't know any of them who was going through it". A third mother expressed similar feelings: "I still don't know of anyone else who has it, and I've mentioned it to a hundred people".

The limited availability of helpful supports, within family/social networks or on a professional level, exacerbated participants' feelings of being alone to deal with their child's problems. One participant expressed her frustration with having to cope on her own in the following manner: "Nothing helps you cope; nothing, just life. There's nothing. There's no support groups or anything like that. I don't know anybody who has this". This woman also indicated that the presence of significant others, while helpful to a degree, could not really provide her with the support needed to help her cope: "Basically we're lucky we [*have*] a great family. Anytime I want to talk to my sisters about it, they just sit and listen, but they don't have any words of wisdom or whatever".

A number of participants commented on the kind of supports needed to help them cope with the day-to-day demands of caring for a child with encopresis. It was obvious that the mere presence of supportive others to confide in from time to time was not enough to enhance their coping abilities. What was also needed was someone who understood the emotional demands of the situation. One mother's comments captured this discrepancy between "being there for support" and "truly understanding":

> They're *[family]* all very supportive. But you know supportive but not necessarily understanding. I've come to realize, not that anybody has ever said anything, but like I had one friend in particular, I know she doesn't understand, and she just can't. But she's never ever said anything to down the situation. . . .I just never would feel very comfortable talking to her about it. . . .No matter how good they are they don't understand.

A second participant felt that friends who were more understanding had careers in the health care field. Despite their greater understanding, she still doubted whether they completely understood and, thus, felt some discomfort when talking about her experiences with them: "Very understanding *[friends]*. Most of our friends are people in the health care field, or health care professionals. . .but it is still awkward. I think there's still a few who don't fully understand, or appreciate it, what it is".

Other participants expressed their displeasure and frustration with physicians who displayed inadequate knowledge about and understanding of encopresis. One mother recognized that her son had a problem with bowel elimination during his third year. Because a diagnosis of encopresis is not made until after the fourth year, this woman felt that treatment was unnecessarily delayed: "At that time nobody would help us because he was too young". Another participant described feeling left alone to manage her son's condition because physicians failed to recognize the symptoms of encopresis: "Most of these four years I had no one; there was no doctor who accepted it. So it was me trying to fix it on my own by whatever prize I could give him if he had a bowel movement and put stickers on his calendar".

Other participants expressed frustration with physicians' limited knowledge and guidance. When one mother suspected that her son might have encopresis and approached her family doctor, she was surprised that he had little knowledge about the condition.

> I had heard about encopresis before I took him because [*my sister - a nursing student*] had mentioned it to me. . .She got me some papers and then I went down to the library and went into the Internet and got what I could on it. I said, "This has to be what he has." I went over to my doctor here and I told him I wanted to see the specialist because I thought he had encopresis. He said, "I never heard encopresis was soiling." He said, "It's when you wet the bed.". . . .I said, "No, I have papers. It is more than that." So anyway he gave me the letter to go see [*the pediatrician*].

A second participant also talked about her dissatisfaction with medical care:

"Never investigated the family history. Never did any tests. Never did anything". This woman felt that if a more thorough investigation had been completed, she would have looked to the family history to help her understand the reasons for her son's problems: "It didn't click in that I had had terrible problems; forgot that [*husband's*] mother has had terrible problems all of her life and needs tons of bran every day".

Even when physicians were perceived to have some insight into the problems posed by encopresis, participants often felt that their concerns were not taken seriously. One participant described her perceptions thus: "Some doctors do take it seriously, to a certain extent, but they don't live through it. They just see the child, and when the child leaves they forget about it". Following a prolonged period of dissatisfaction with physicians and unsuccessful results with prescribed regimens, she turned to home remedies and over-the-counter medications hoping that she would find a cure: "I did start a new laxative on my own, and actually it's pretty good. It's a herbal laxative. . . .I always keep trying different things, hoping I'll find a miracle".

For some participants, the problems with inadequate information and practical advice continued after their child was referred to a specialist. After two years of dealing with her son on her own, one mother described her frustration with a pediatrician in the following manner: "The pediatrician gave us nothing. Didn't give us any kind of pamphlet which would have been really helpful". A second mother also expressed dissatisfaction with the advice provided by a pediatrician: "I did go to the doctor and I never got any satisfaction. . . .I go in that office for two minutes and I'm out and nothing's learned". Still another mother indicated that she had limited information on encopresis after making numerous visits to different health care providers for eleven years: "I don't even know. . .what it is. I know it is a bowel problem, that's all I know. As for what type of bowel problem it is I can't tell you".

Feelings of not being supported by physicians was further reinforced during the child's hospitalizations. A couple of mothers spoke about their dissatisfaction with the limited interest demonstrated by the pediatrician.

> When son was in the hospital for five days, I think I actually saw *[the doctor]* twice. *[Doctor]* was there the first day I came in. . . .*never came* back no more until the last day when he was released. . . .didn't come over to see how [*my child]* was doing or nothing like that.
>
> We saw [*pediatrician*] once or twice in there, no other comment to us. *[Doctor]* came, "How are you doing *[child]*?" *[Child]* said, "I'm doing fine." And that was it.

The perceived lack of understanding by health care professionals enhanced participants' worry and concern for their child's well-being. One mother described her fears thus: "I'm wondering. . . will this keep going the rest of his life, or will he eventually end up with bowel cancer. . .sometimes you just think the worst". Another mother was also worried about the future physiological effects of this condition: "We don't know how long it's going to go on. And we're worried. The doctors have told us that if her bowels stay large by the time she's an adult she'll have problems for the rest of her life". Still another mother was concerned that her child's current soiling problems might pose psychological problems for him in the future: "I worry too, what is it doing to him. Is it going to affect him when he grows up. . .affect the type of person he is going to be"?

Seeking answers to the complex nature of encopresis involved considerable time and effort. Frustrated with the limited support received from health care providers, especially physicians, some participants sought information from other sources. However, for the most part, such efforts did little to provide them with helpful information. One mother commented on the usefulness of different sources:

> I haven't been given a lot. The only. . . written information that I have on it is the stuff that I was given when I was in the hospital. . . .I found a Parenting magazine and there was an article in it about children soiling in their pants. . .but the ages were only about two to four, something like that. I didn't read hardly anything on six to seven year olds doing this kind of thing. Maybe I'm just not looking in the right places.

A second mother spoke about her limited success in finding information on the Internet and in the library: "I looked it up on the Internet. I looked it up in the library, and I asked questions. There really isn't a whole lot out there. . . .Maybe I haven't looked through enough, but I certainly haven't come across anything".

The ongoing problems with encopresis and the constant treatment demands left many participants feeling totally consumed with care giving activities. As participants struggled to endure, it became more and more difficult for them to feel in control of their lives. One mother described the consuming feelings thus:

> Oh, it was horrible. It was absolutely horrible. Because you lose control. You lose control of everything else going on in your life, because you're so focussed. You come home, "Oh, I wonder if he was okay today." The whole thing centres around his problems.

Another mother expressed a similar sentiment: "It is consuming. It is all-consuming. . .it is continual. I mean you are living with it every hour in the day".

Several participants compared the care giving demands of a child with encopresis to that of an infant. The following excerpts capture how mothers were making such a comparison:

> Well you know having a child with encopresis is almost like having a newborn baby. . . up all hours of the night with her, that's what's she's like. And half of the whining is caused from having cramps in her stomach. She just can't sleep comfortable.

> With this type of thing you had to be taking all kinds of underwear, pull-ups everywhere you went, and wipes. It was just like having a little baby to change.

> But for us it was really, really frustrating because changing a baby's diaper can be bad enough but when they go through this for five years in their clothes. I didn't realize this would be an ongoing thing, but it never ended.

Other participants spoke about the difficulties experienced when they were forced to deal with soiling episodes, in inconvenient places. The following comments highlights some of the frustrations experienced by participants:

> Especially if you go somewhere and you didn't have extra clothes. He'd say, "Mom I think I had an accident". . . . One time I had to go in a store and buy him a pair of underpants and a pair of pants to wear home. That was frustrating!

> I remember a horrific time *[when]* we were traveling. . .and *[child]* had an

> accident. . . .And he doesn't tell us. And I was livid. My thinking was okay you know when it happens, if you can't realize it when you have to go. . . .but once you've gone you got to tell us so we can get you to the gas station or whatever." And we drove for a long time and it was horrible, but what can you do. Nothing you can do.

The constant struggle with trying to cope with the burden of caring for a child with encopresis sometimes led to feeling out-of-control. One participant described the family dynamics thus: "We would be into battles with him, discussion matches. Because here we are trying to. . .reason with a six-seven year old who is very bright. But reality is, he can't reason". She elaborated further on the impact of her son's attempts at control: "But at six it was manipulation. But it was him trying to take control, because we were into yelling matches".

Other participants described somewhat similar situations. The following excerpts capture their struggles as they tried to come to grips with the problems posed by their child's condition:

> After awhile I think he just got scared to go to the toilet because I was getting frustrated. I'd get mad and I'd say *[child]* go sit on the toilet you got to go. Of course it seemed like a chore to him and he didn't want to go. He'd just sit on the floor and do it in his pants.
>
> It's just one task after another, it's a battle, it's a fight. He gets frustrated, I get frustrated. He gets mad, I get mad and it is just horrible. It's horrible! I've been at this now for four years.
>
> We got to the point where we used to fight with him and argue with him and shout at him.
>
> You tend to get mad at him because when they are three and four and they are still doing it *[soiling]*. You find that for the first couple of times

> throughout the day you'd be more patient. Then after four or five times of coming in the house with him having soiled his underwear, you sort of start to get mad and say, "*[Child]* you must feel it you know".
>
> I remember many a time just going nuts with *[child]*, and say, "What is going on? It's not that hard to walk from here to the washroom. Your bedroom is here. . .can you just not move. Go right across the hall".

The tasks associated with caring for a child with a chronic condition was not only time consuming but also had a negative impact on participants' physical and emotional energy reserves. As one participant indicated, care giving demands were so emotionally taxing that she could understand the potential for abuse in certain situations: "But I can see it leading to more than that because it is very bad. . . .I can see if you have a tendency for child abuse to occur because that's how bad it is". Even when the children entered school, many participants not only worried about the child being stigmatized but also had to ensure that measures were in place to deal with soiling mishaps. One mother talked about how she needed to have someone as a backup when she was at work.

> It's a constant. Sometimes when I'm away for business or meetings or whatever, I have to make sure I have everything laid out exactly. . . who's going to be around, and who she can call so she'll always know. . . .So there has to be basically someone on duty to help her and this has been going on since kindergarten.

In retrospect, participants wondered how they managed to cope with the many care giving demands: "Nobody knows how hard it's been *[crying]*"; "I don't know how I got through it I really don't know. . . It was hard, it was really hard".

Participants were confronted with many challenges as they struggled to cope with their child's condition. The long and arduous journey experienced left them feeling totally consumed by daily care giving tasks and alone to cope with the seemingly never ending demands. Available informal and formal supports did little to increase their understanding of encopresis or how to manage a child with this condition. After struggling to endure the experiences defining this uphill battle, participants eventually reached a level of understanding that enabled them to achieve some degree of acceptance.

Taking Control

A fourth theme which emerged from the data was "taking control". Having lived many years with a child with encopresis, participants slowly but surely gained valuable experiential knowledge which enabled them to see beyond the problem and develop a clearer picture of the total situation. As mothers developed greater insight into the child's condition and focussed less on causal factors, they became cognizant of what produced positive results, experienced less stress, and felt more in control of the situation. Although worries about the future continued, they were happier with themselves and their child, better able to accept the situation, and more confident about sharing experiences with others.

Following years of reflecting on the causative nature of encopresis, some participants began to forge a link between stress and the frequency of soiling mishaps. Of significance was the perception that soiling problems could possibly be due to the child's inability to handle stress in a meaningful way.

Several participants commented on how stress present in the child's life had a negative impact on the incidence of soiling mishaps. One mother felt that the stress resulting from family's frequent relocations may have been the main culprit in the onset of her child's soiling problems: "He has friends here, but the first year we moved he didn't want to be here and he cried and wanted to go back and be with his best friend." A second mother also noted that soiling problems increased when her child had to adjust to a lot of changes at school: "You know, it was a lot of switching around, a lot of new teachers. A lot of changes, and he doesn't like changes. I think it is a stressor". A third mother recalled that her son's soiling episodes increased when he was being teased by another child:

> At this time there was a little boy across the road and he seemed to be bullying *[son]*. . . .You know like telling him his bike was a baby bike, and different little things like that really bothered *[son]*. And it seemed like at that time he was worse than before.

Another mother noticed that her son seemed to have more control over bowel movements when he was happy: "When he is in a really good mood this is when I find he goes to the bathroom more".

With the development of greater insight into encopresis, participants became aware of the limitations of certain approaches used with their child. Some participants, who believed that soiling problems were intentional, resorted to shame tactics or punishment as a way to promote appropriate toileting behaviours. One mother commented on her use of shame tactics thus:

> We tried to shame him, but probably we shouldn't have. . . .But there was a point we did. We were so desperate. Well, we wouldn't want his friends smelling the pooh in his pants. I mean four years old but he didn't care. . . .It never came up that one of his friends said that they smelled something. If something like that had happened, I don't know, it might have made a difference then.

A second participant had considered punishing her child but upon reflection abandoned the idea because of her concerns that this approach would be more detrimental than beneficial: "Throughout the day he came back and forth four and five times and we would get angry. But I think it would have been a lot worse on him if we had punished him". Another mother described her efforts in the following manner: "You knew you had to try not to blame him. You know what it is like sometimes, and I'm not a patient person. I have a very short fuse, but I was pretty good with him".

A number of participants commented on the futility of directing anger toward the child following soiling mishaps, and how this approach could actually compound the problem. One mother summarized her perspective thus: "Well definitely not shouting at him because it makes it worse. I find too that his self esteem is very low, which is to be expected. So the shouting didn't help and that's for sure". She elaborated further on how she adjusted her approach:

> We got to the point where we used to fight with him and argue with him and shout at him. Then I thought well maybe that is the wrong thing. I'll just ignore it. So I said, "I don't care if you do it in your pants. I'm not

> going to fight with you. . . I'm just going to ignore it all." It seemed like it worked. . .for about a year and a half it seemed like it wasn't too bad.

Other mothers also discovered that exhibiting anger toward the child seemed to make things worse rather than better. A couple of mothers made the following observations:

> Well, I know getting angry with him doesn't do anything. That just frustrates him and he kinda just tightens up. . . .I don't get angry with him any more. I'm trying to just let it ride right, let him do it on his own. Then he might feel better about it.

> After awhile I stopped getting angry at him because I kind of clued in that this was a physical thing. But I don't think he suffered the self-esteem problem which he would have had if he had continued on with it.

As participants developed greater insight into their child's condition, they focussed less on problems and redirected their energies toward identifying and implementing effective measures. After living with encopresis for eight years, one mother described feeling more in control of her feelings and less preoccupied with finding a cause for her daughter's condition:

> I'm starting to deal with it more in the last two or three years than I was first, because at first, I was always down and wondering why, why, why! Why is this happening to [*child*], why is it my youngster? But now, after dealing with it for ten years, it gets like you're living with it. . . .you try your best to be calm, be patient.

A second mother reported feeling a sense of relief when she realized that her child probably had no control over the soilings: "I think understanding that it was something he was not in control of. . . .was a big break through for me to relieve some of my guilt as well as to relieve him. And it changed our relationship around this". Another mother found that by being more patient and placing less emphasis on soiling mishaps, there was less stress and more positive results: "I think some of his change had to do with us backing off. . . .And it became not a match, not a tug of war, because that just added stress to everybody".

Having a child with a chronic condition, like encopresis, seemed to place a great deal of stress on the family unit. One participant found that when she reappraised the meaning of soiling mishaps she was able to more successfully manage his behaviour and facilitate better family functioning:

> I've had to bite my tongue several times. . . .But reality is, approaching it that way gives him the dignity that it's just something like a scrape on the knee. . . .It has helped. . .us because it's not a big issue. So the family functions better.

A second participant reported that learning to deal with soiling episodes required a great deal of patience. The importance of being patient enough to talk with the child about the problem is captured in the following commentary:

> I think you really got to have patience. That's number one. . . .Before any medications or before anything. And you kind of got to sit down and let him tell you. . . .I know there was times when I'd get really frustrated, and I'd say, "Oh [*child*]." And he'd say, "But mom I can't help it".

A third mother also recognized the benefits of engaging in open discussions with the child about his soiling problems:

> We talk about it openly now, at home too, that took a while. Every once in a while I'll say, "Have you been going to the washroom lately?" And he'll say, "Yea, I went yesterday." And the other day he was doing something and I said, "Do you need a pill?" And he said, "Yea, I might". And then after a while he said, "No you don't have to give me one, I just went".

Several participants spoke about the importance of using the right management approach with the child. One participant recognized the benefits of trying to motivate her child to assume more self-care responsibilities:

> I find I do get angry first and then I sort of got to talk to myself and say just wait a second now. Don't say anything and explain to him that you have to try harder. Just because you have encopresis doesn't mean you don't try. You have to try to get over this.

Another participant discovered through trial-and-error that a non-threatening and positive approach worked best.

> So when he was eleven or twelve he was more able to say, "Mom, I need some help". We also put it that okay, if you have an accident. . . .Let's just deal with it. You're getting big enough now that you can go in and change yourself. Put the underwear in the toilet afterwards. If they're too dirty, here's a bag. No hassles, no guilt, no what did you do.

Still another participant also recognized the importance of helping her child assume control of bowel elimination and mishaps: "I said, '*[Child]* if you need to use the bathroom go and sit on the potty. . . and do what you got to do and then come in and get cleaned up and you can go again'". When informed by a physician that her son's soiling problems were being aggravated by the bullying behaviours of another child, one mother began to approach the situation differently:

> Once I realized what he had, I think I had to be little bit more strict. . . . in telling him you have to go out. . .fight back. . . .We didn't go out and fight his battles. He had to learn to look after himself outside. . . .They *[other children]* kept telling him that he was nothing. . . .He went out and he started to fight back, and he was fine after.

Some participants also realized that their child needed guidance to develop insight into their problems and recognize what worked best for them. One participant described how she worked with her son to develop a toileting regime that was acceptable to both of them: " I think he was going *[to the toilet]*, not because he had the feeling to go. Basically, he was timed to use the bathroom and he would make a commitment to go". Another participant also recognized the significance of encouraging her son to follow a toileting routine and not to ignore the urge to defecate: "Since the beginning, once [child] has an urge for a bowel movement, if he delays it, that feeling could be gone for a day before it comes back. . . . You have to be so careful with him all the time".

In some instances, participants reported that having a physician who was supportive, insightful and understanding of the child's condition helped make encopresis more manageable. One participant described how she felt differently about things when she found a physician who helped her understand her child's problem:

> [*The physician*] was excellent, was absolutely excellent. . .told us exactly what we were looking at. [*The doctor*] opened the doors, and asked some questions which we had never even thought of. We found out in an interview that [*our child*] got frightened at school, either in kindergarten or grade one, when somebody looked under the stall, when he was sitting trying to have a bowel movement. That was it! He never was going to have a bowel movement anywhere else except at home.

Another participant shared a similar experience about how she developed better insight into her child's condition upon receiving support from an understanding physician:

> So we went to [physician] who told us she had to retrain his bowel because the bowel couldn't feel anything that's why the leakage would be there. *[Son]* couldn't feel the bowel movement there. So if you don't feel anything your not going to use the bathroom. It was so filled up it used to leak around it and end up in his pants. It then made perfect sense to me.

Of equal importance to participants was the presence of strong family supports. Several mothers acknowledged the assistance of supportive husbands who helped with caregiver demands: "He *[husband]* was just as much a part of it as me. He went through it as much as me". Other participants expressed similar feelings.

> Taking turns looking after it, my husband and I. One day it would be his turn and the next day it would be mine.

> He's *[husband]* starting to find it a little bit embarrassing, when he has to clean her up. Not because of the situation or anything like that, but she's ten years old now, and he'll say, "*[Wife]* I can't, can you go?". . . .But when I'm not around he'll still do it, you know, when he has to. And he'll get her to get into the tub, and get her to wash herself. . . .But he's wonderful. Really, really supportive.

With stress singled out as a key contributing factor to encopresis and it's many relapses, many of the narratives conveyed the message that meaningful understanding coupled with a good dose of tolerance and patience seemed to work the best for these mothers. Equally important for participants was the presence of supportive others.

As participants adjusted and readjusted the approaches taken to manage soiling incidents, eventually positive outcomes were realized. Children demonstrated pride in their accomplishments and felt more in control of their bodily functions.

With time, mother and child became happier with themselves and each other. One participant described her son's positive self-appraisal thus: "When he has a bowel movement he gets really excited, 'Come here mom!. . . .Look, I did a poop!'. . . .It is a real treat for him. . . he knows that it makes me happy and plus I think he feels good". A second mother also commented on the changes observed in her child: "He was finally happy. He wasn't happy if this was happening to him all the time and us getting angry. He knew that he had a problem, and when [*the doctor*] cured him he sent a card".

After spending considerable time and effort on bowel retraining, one mother described the pleasures derived from knowing that her son is now able to recognize the urge to defecate and to respond appropriately to this stimulus:

> I wanted him to feel like he has to use the bathroom and now he uses the bathroom every second night, always at the same time. . . .And if he skips that second night I'm really happy to see him go up in the middle of the next day because it shows that he does have the urge. If he goes past the two nights then by the next day he will have the urge. . . .So that urge will come to him now, where it never did before.

Another mother also indicated that she derived satisfaction from knowing that their child was happier with himself: "He's really happy. He's got a buddy in his class. This is the age where things are awkward too for a thirteen year old boy, but he seems very comfortable". This participant also described feeling more contented as her son began to assume more self-responsibility for managing his encopresis: "Every night before he goes to bed he changes his underwear. I suppose he's just gotten used to it. If there's anything (soiling). . . .He just don't like it. He's forever changing his underwear".

Participants reported that their care giving experience made them more alert to children with similar problems, as well as more willing to share their experiences with other mothers. One mother described how she tried to help another mother:

> It must be fairly common because in the same kindergarten class there was another little girl with it. I knew the little girl's aunt and I mentioned that to her and she said that *[her niece]* was the same. So we told *the child's* mom and she took her to *[our doctor]* and she was also cured.

After several years of dealing with encopresis mothers found it beneficial to discuss their child's condition with teachers prior to the beginning of a new school year. One participant commented thus:

> I went to his teacher. . .and explained that he has a little condition with his bowels and when he needs to go, no matter what they are doing, not to say, 'No, wait a minute or anything like that'. So they know. And he knows I told the teachers that so he knows they understand.

A second mother commented on the importance of informing teachers about her child's soiling problems:

> When I found out what it was I went over to the school and took the papers I had and let the teacher read it. You know he hadn't heard of it. He was going to photocopy the papers and pass it around to all the teachers so they could be aware of it.

Summary. Participants gained greater insight into their child's problem through their lived experiences. After years of struggling with the unknown and feeling alone in their struggle, most participants were able to rise above the challenges posed and take charge of the situation. That is, by developing more confidence in their abilities to deal with the challenges of encopresis, participants were better able to accept their children's condition and use more effective approaches to help them develop a greater sense of personal control.

The Essence

Through formal, unstructured interviews, participants were encouraged to reflect upon and then describe their experience of caring for a child with encopresis. The themes identified from the participants' narratives were dealing with uncertainty, heightened frustration with care giving, struggling to endure, and taking control. Following the identification of themes, the researcher read and re-read the interpreted text to grasp an understanding of the unifying thread connecting the particulars of this experience. The researcher concluded that *rising to the challenge* reflected the true meaning or essence of the experience.

Initially, each mother felt profound feelings of uncertainty as they struggled to comprehend why their child failed to master toilet training. For most of the mothers this uncertainty increased when their search for possible underlying causes failed to generate any readily identifiable physiological or emotional factors. As soiling problems persisted well beyond the normal toilet training period, participants questioned their parenting skills and became fearful of their ability to cope with an uncertain future. Feelings of guilt and self-blame were enhanced following interactions with physicians and inconsistent progress with recommended treatment protocols. Despite these feelings, or perhaps because of them, mothers did not abandon their pursuit for answers but rather were motivated to increase their efforts. As well, there was a beginning recognition that major adjustments might be needed to help the child, themselves, and the entire family unit. By continually searching for acceptable ways to restore a sense of order and balance to their family lives, these mothers rose to the challenge of addressing, rather than avoiding, the uncertainty in their lives.

As these mothers struggled to contend with the unpredictable nature of soiling mishaps and feelings of humiliation and shame, they became extremely frustrated with not being able to gain more control over the situation despite expending a tremendous amount of physical and emotional energy. They also intensified their efforts to protect their children from ridicule, while trying to avoid the shame and embarrassment of having others discover their ineptness at toilet training. The mothers' stories clearly portrayed their frustrations and exhaustion in dealing with routine household responsibilities while struggling to meet the constant physical and emotional demands of caring for a child with encopresis (i.e., keeping the child and home physically clean, and ensuring that the child ate the proper food, maintained a scheduled toilet routine, and took prescribed medications). Despite feeling frustrated and unsupported, they were somehow able to rise above the many challenges confronting them on a daily basis and carry on with normal family activities.

As the participants struggled to endure, they became fearful that they would wear out from the emotional and physical demands placed upon them. The mothers admitted that, from time to time, they entertained the notion that their child was intentionally soiling and exhibiting annoying behavioral patterns. These thoughts sometimes led to angry outbursts, and reduced feelings of being in control of their lives, especially when they reflected upon the growing upheaval in family life. While significant others were somewhat helpful, comfort measures or words of advice were not always meaningful for reducing feelings of uncertainty, frustration, and anxiety. The prolonged dissatisfaction experienced by mothers with unsuccessful management of their child's encopresis, motivated several of them to go beyond normal supports (i.e., family/friends and health care providers) to other sources (e.g., library, Internet, etc.) to help unravel the mystery. It was apparent from the narratives that these mothers persisted in their pursuit to identify more efficient and effective management approaches to help them cope with the multiple challenges confronting them in their lived worlds.

Finally, either through trial and error or by sheer persistence in finding supportive health care providers, some participants reached a level of understanding that helped them accept and cope with the problem. Insightful refocusing of energies ensued when these mothers understood the problem more clearly and were able to differentiate between least (i.e., punishment, directing anger at the child, and focussing on the soiling mishaps) and most (i.e., placing less emphasis on soiling, being more patient, using a non-threatening and positive approach, reappraising the meaning of soiling episodes, open discussions with the child and trying to motivate self-care responsibilities in the child) helpful approaches. All of the mothers spoke about how they cultivated a support network to help them accept the challenges posed by the uncertainties, frustrations, and struggles. Physician contacts which offered support, insight and understanding were viewed as being most beneficial.

In reflecting on their lived world, the participants identified how the experience of having lived through this ordeal resulted in a new, positive orientation toward family life. For some, there was an awareness that the challenges presented an opportunity for learning and growth. Having lived through this experience, several mothers indicated they were now able to prevent similar bowel problems from occurring in their other children, as well as directing other parents to useful supports. These comments were outward signs that parents were learning to accept and integrate the challenges life had bestowed upon them in a meaningful way.

Chapter 5

Discussion

This chapter discusses study findings in relation to relevant literature. The first section presents a discussion on individual themes and the essence of the experience. The second section offers new insights into the experience of living with a child with encopresis and significance this may have for improving the quality of care provided by health care providers.

Living with a Child with Encopresis

Study participants were confronted with many challenges while trying to come to terms with this troublesome and disturbing condition. Participants described a long and difficult experience which is best captured in the phrase *rising to the challenge*. Although study findings provide new insights into the experience of living with a child with encopresis, there are aspects of individual themes that provide additional support for clinical and research findings presented in the literature.

Dealing with Uncertainty

This theme captures the uncertainty experienced by mothers in their search for answers as to why their child continued to have soiling mishaps beyond the normal toilet training period. The pattern that emerged in their quest for a cause was a circular one that shifted from physiological, psychological, behavioural and emotional factors to possible interactive combinations. Ultimately, the level of frustration with not being able to isolate an underlying cause resulted in self-blame, feelings of guilt, and concerns about the adequacy of their parenting skills to deal with the problem.

In the current study, many participants reported experiencing difficulties during the toilet training period, and commented that this child was slower to train than their other children. Buchanan (1990) and Bernard-Bonnin et al. (1993) report similar findings, with 55% and 53.5% of parents experiencing child resistance to toilet training, respectively. Fireman and Koplewick's (1992) findings also support parental difficulties around toilet training. In contrast, Borowitz et al. (1999) did not find that the toileting habits of children with encopresis differed from those of asymptomatic siblings and nonsiblings.

With the continuation of toileting difficulties into the preschool period, study participants intensified their efforts to identify a causal basis for the soiling problems. Although there is very little reference to this in the literature on children with encopresis, there is some support in the literature on parents of children with chronic illness. Horner (1997) reports that mothers who cared for a young child with asthma were confronted with an unending illness of unknown origin and were driven to search for answers as they started to "wear out" from watching their child struggle with illness symptoms.

Several mothers believed that physiological factors (i.e., constipation, painful defecation, and/or bowel dysfunction due to hereditary factors) were responsible for their child's soiling problems. During the initial assessment of children with encopresis, Buchanan found that 64% of parents identified a current or past history of constipation and 25% a positive family history of constipation. Bernard-Bonnen et al. (1993) report that approximately 50% of parents surveyed believed that physical factors, especially intestinal dysfunction and painful defecation, were responsible for encopresis. A history of painful defecation is also supported by Borowitz et al. (1999), Levine (1982), and Partin, Hamill, Fischel, and Partin (1992).

Without an actual or potential physiological basis for soiling problems, study participants wondered whether psychosocial, behavioural, or emotional factors (i.e., fearful of the toilet; lazy, unhappy, intense, or inattentive behaviours; low self esteem and self-confidence) were somehow responsible for their child's soiling problems. As Buchanan (1990) reports, parents mentioned neurotic type behaviours (i.e., shy, withdrawn, miserable, or tearful) most frequently, aggressive and antisocial behaviours, school problems (i.e., fear of toilets, teasing from peers, low self-confidence, and lowering of academic performance), and social isolation. Loening-Baucke et al. (1987) report comparable findings. Other researchers have also noted that parents of children with encopresis report the presence of attentional dysfunction or hyperactivity (Bernard-Bonnin et al., 1993; Gabel et al., 1986; Johnston & Wright, 1993; Levine, 1982). In contrast, Borowitz et al. found that the number of parents reporting learning disabilities, academic failures, attention-deficit hyperactivity disorder, or behaviour problems in school were comparable among children with encopresis, asymptomatic siblings, and asymptomatic nonsibling controls.

As mothers' concerns increased with the slow progress being made with toilet training efforts, they began to question how they may have contributed, or may be contributing, to the problem. Believing that they were somehow responsible, the ensuing feelings of guilt and self-blame heightened their uncertainty. Buchanan (1990) also notes that mothers tend to report feelings of self-blame, guilt and shame about their child's soiling. Similar feelings of shame, guilt and blame are reported by other authors (Buchanan & Clayden, 1992; Castiglia, 1987; Levine, 1982). In a study of families of children with a chronic illness, like encopresis, Anderson and Elfert (1989) also report that mothers' continuously question how they might be responsible for their children's illness.

Becoming Frustrated with Care giving

This theme captured how the-never-ending care giving demands associated with soiling mishaps heightened mothers' frustrations and decreased their ability to cope with the daily challenges. The transcripts of these mothers clearly portray the mounting frustrations experienced in response to the separate and interactive interplay among several factors - discrepancies between the child's cognitive and behavioural abilities, the physical and emotional stressors of care giving, feelings of embarrassment/shame and overprotectiveness, and the limited support received from health care providers.

In certain instances, mothers talked about being extremely frustrated by a "bright child" who seemed to be indifferent to the problem, denied having soiled, and hid dirty underwear. Although no comparable discussions were found in the literature on parents' frustrations with observed differences between cognitive and behavioural functioning, there is reference to parental reports about denial and concealment of, and/or indifference to, soiling behaviours (Fireman and Koplewicz, 1992; Sprague-McRae et al., 1993). Other authors also make reference to parents' frustration with the nonchalant attitudes toward soiling, and the hiding of soiled underwear (Buchanan, 1990; Buchanan & Clayden, 1992; Fireman and Koplewick, 1992; Johns, 1985; Levine, 1992).

Physical and emotional stressors also contributed significantly to the frustrations encountered with care giving. Many references were made to the time consuming and unrelenting regime of enforcing dietary and toileting regulations, monitoring of soiling incidents, changing and washing of clothes, and ensuring the home is free of fecal odour. Other researchers report that parents are frustrated by the frequent cleaning of soiled clothing (Bernard-Bonnin et al., 1993; Castiglia, 1987; Fireman & Koplewick, 1992). Stewart et al. (1995) note that many mothers of chronically ill children also describe the rigorous, time consuming, and unrelenting daily regime of treatment and management of symptoms.

Within the current study, mothers acknowledged that heightened frustrations with care giving activities sometimes made it difficult for them to follow recommended treatment regimes when confronted with strong resistance from their children. In fact, it was often the child's opposition to treatment measures that made it difficult for mothers to maintain a positive attitude and control emotional outbursts. Researchers and clinicians suggest that sometimes children with encopresis are not treated successfully because parents fail to comply with recommended regimes (Buchanan, 1990; Chaney, 1995; Rappaport et al., 1986), or lack the requisite skills to effectively manage a demanding regimen (Loening-Baucke, 1996; Stark et al., 1990). However, as the current study's findings suggest, participants questioned the usefulness of recommended treatment protocols, especially when certain measures increased care giving demands due to negative consequences (e.g., throwing up mineral oil, increased frequency of fecal staining, etc.).

Several study participants described feeling embarrassed or humiliated by having a child who had not successfully mastered bowel control after the age of 4 years. Other clinicians and researchers report that encopresis is often a source of embarrassment for parents (Buchanan, 1990; Dwivedi & Bell, 1993;

Ellett, 1990) and family members (Castiglia, 1987). In the current study, several mothers reported feeling bad that their child had not been toilet trained, and humiliated or embarrassed when they had to share information with others about their child's problem. Other researchers have also found that parents are reluctant to admit their child has a difficulty with elimination because it implies failed parenting (Buchanan, 1990; Buchanan & Clayden, 1992). Chaney (1995) also notes that parents who view their child's soiling as deliberate behaviour, instead of a health problem, fail to seek medical care.

Participants also became preoccupied with fears and worries that their child would be ostracized by other children. Surprisingly, mothers in this study made few references to actual peer teasing about soiling mishaps. In contrast, several authors report that children are often teased by peers for their soiling behaviour (Buchanan, 1990; Chaney, 1995; Griffin, Roberts, & Graham, 1999; Lowery et al., 1985; Sprague-McRae et al., 1993). Within the current study, the constant vigilance maintained by the mothers around soiling mishaps, as well as some of the extreme measures taken to protect the child from ridicule, could account for the limited reference to embarrassing moments due to teasing from peers.

The limited support provided by some health care providers did little to alleviate the frustration experienced by mothers. In many cases, physicians were unable to answer questions or reduce uncertainties, and often added to mothers' frustrations. Other authors report on the potential for increased parental stress following inappropriate physician response to concerns (Levine, 1982, 1992). Stewart et al. (1995) also note that mothers of chronically ill children often are stressed when interactions with health professionals fail to provide them with sufficient and/or appropriate information. Similar to the current study's findings, Anderson and Elfert (1989) found that mothers feelings of being somehow at fault for their child's illness was reinforced following contact with health care providers. What was especially disturbing about some of the mothers comments in the current study was that physicians not only failed to listen to their concerns but also questioned the adequacy of their parenting skills.

Struggling to Endure

This theme captures the onerous experience of struggling with the difficult task of caring for a child with encopresis. Embedded within the stories related by study participants was a deep sense of aloneness and isolation - alone to deal with a problem that others knew very little about. Feeling isolated within immediate and extended families, as well as the network of friends and peers, many of these mothers became totally consumed by the continuous care giving demands.

In the current study, most of the mothers felt alone and isolated because they were unaware of other children with similar problems. Buchanan and

Clayden (1992) note that parents' feelings of isolation may be attributed to their reluctance to admit that their child has a soiling problem, and having strong inhibitions about sharing their experiences with others. Levine (1982) also suggests that the isolating facet of encopresis occurs, in part, because there is a lesser tendency to acknowledge and publicize this condition as compared to other childhood dysfunctions. In a study of mothers of chronically ill children, Florian and Krulik (1991) report that situational loneliness is possibly due to disruptions experienced in previously satisfying social relationships.

The limited availability of helpful supports either within family or social networks reinforced participants' feelings of being alone to cope with the encopresis. The mere presence of supportive persons to share experiences was not enough, but rather someone was needed who understood the emotional and physical demands of the situation. Stewart et al. (1995) report that mothers' descriptions of their care giving experiences portray a persistent sense of isolation while managing their child's chronic illness. These mothers also felt that significant others, in general, provided limited emotional support, and spouses, in particular, provided very little practical support. Likewise, Haverman and Eiser (1991) report that mothers receive little helpful support from husbands and family members.

Several study participants displayed frustration and displeasure with physicians who failed to conduct a thorough investigation of their child's problems or take their concerns seriously. Similarly, Florian and Krulik (1991) note that mothers of chronically ill children do not perceive formal caregivers as sources of emotional or tangible support. The perceived lack of understanding by health professionals enhanced participants' worry and concern for their child's future well-being, and pushed them to pursue alternatives (e.g., other physicians, magazines, the Internet, etc.). The literature dealing with this aspect of mothers' experiences is rather limited. Buchanan and Clayden (1992) suggest that parents dissatisfaction with health care providers is reflected in their movement from agency to agency to find the inevitable cure.

The continual challenge of dealing with the daily demands of encopresis totally consumed study participants. When physical and emotional reserves became overtaxed, participants felt less in control of their feelings and more prone to angry outbursts. In an earlier study of parents of children with encopresis, Baird (1974) observed that anger was a predominant emotion which was often severely repressed, denied or ignored. Baglow (1987) also recognized the presence of anger in the parents of children with encopresis. Fireman and Koplewick (1992) report that parents could identify at least one episode in which they lost control, used corporal punishment, or yelled in response to a soiling incident. Buchanan and Clayden (1992) suggest that the high levels of stress common in mothers of 'soiling children' can increase the child's risk for physical abuse. Within the current study, participants' stories indicated that they reached a critical juncture when they became fearful of losing control. It was at this point of experiencing intense frustration that these mothers wondered whether or not they were capable of finding the necessary energy and motivation to continue dealing with care giving demands.

Taking Control

This theme captured the experiential process that led study participants to develop greater insight into possible reasons for encopresis and a better understanding of the most helpful strategies to use with the child. By developing a clearer perspective on the total situation, mothers felt more in control of the situation, experienced less stress, and were generally happier with themselves and their child.

In the current study, some mothers were able to forge a link between more frequent soilings and situations that were problematic and/or stressful for the child (e.g., frequent relocations, teasing by peers, school changes, etc.). Similarly, other researchers have also found that the presence of psychosocial stressors in the child's environment may be predisposing factors for encopresis (Buchanan, 1990; Buluit & Tekant, 1991; Levine, 1982, 1992).

With greater insight into the child's problems, study participants began to see the limitations of using shame tactics or punishment. As well, all of the mothers eventually came to realize that directing anger at the child following a soiling mishap only compounded the problem. Several authors discourage parents from using a punitive approach with soiling accidents, and encourage them to practice patience while dealing with the ups-and-downs of treatment (Abi-Hanna & Lake, 1998; Loening-Baucke, 1996; Stroh, Stern, & McCarthy, 1989). Schmitt and Mauro (1992) encourage parents to respond gently to soiling accidents, to give frequent reminders, and to schedule time for the child to sit on the potty. These authors also strongly advise parents to refrain from threatening/lecturing or punishing/scolding after an accident. Similarly, Younger and Hughes (1983) also caution against the use of anger and other emotional responses.

Without exception, mothers found that they were more successful with outcomes by focussing less on the soiling problem and using a non-threatening, calm and patient approach. Buchanan (1990) captures a similar sentiment in her illustrative summary of mothers' comments on how things improved when they modified their approach to soiling mishaps. That is, some of the mothers articulated quite clearly how tension and scolding tended to increase the frequency of soilings. Within the current study, mothers acknowledged the difficulties of controlling the natural urge to institute punitive measures, especially when they believed that their children were capable of exercising more control over bowel elimination. As several mothers indicated, learning how to instil confidence in their children and helping them gain more personal control was quite a challenge.

Motivating the child to develop strategies that would facilitate greater personal control was identified by study participants as essential to the successful management of encopresis. Buchanan's (1990) study offers some support for mothers reporting greater success when they helped the child understand and build the necessary skills that would enable him or her to take control of bowel routines. This approach has also been recommended by clinicians and researchers. Schmitt and Mauro (1992) strongly recommend that parents help the child become more accountable for bowel movements. Nolan and Oberklaid (1993) comment on using motivational talk sessions with the child. Within the current study, both mother and child experienced less stress and greater feelings of self-confidence as they learned how to take control of the situation.

Participants were rewarded by continually readjusting the approach taken to manage soiling episodes. Mothers indicated they were happier with their children and themselves, and their children seemed to take pride in the small successes from developing more control over bowel elimination. Similar findings were reported by Buchanan (1990). Gutsche and Walker (1989) also note that parents reported positive behavioural changes in the child (i.e., felt better about self) and improved relationships among all family members (i.e., pulling together, less fighting, and happier). Within the current study, the presence of supportive family members, especially husbands, was very important to participants. In a study of mothers of children with chronic illness, Florian and Krulik (1991) report that participants viewed husbands as providing valuable support. Stewart et al. (1995) also acknowledge that the emotional support received from spouses, friends, and family helped mothers cope with the burden of care giving.

Having a physician who was supportive, insightful and understanding was extremely helpful for study participants. Only a couple of studies were identified from the literature that addressed parents' perceptions of the supportive role played by health professionals. Buchanan (1990) reports that some parents made positive comments on the helpfulness of physicians in lending a listening ear, providing guidance and practical advice, and facilitating contact with other parents who were dealing with similar problems. Several clinicians and researchers also acknowledge the importance of having a supportive physician available to help parents cope with the long-term management of encopresis (Crowley, 1984; Hein & Beerends, 1978; Nolan & Oberklaid, 1993; Seth & Heyman, 1994). While the current study provides some insight into what mothers expect from physicians (e.g., listening to their concerns, capable of providing them with helpful information on encopresis and different treatment protocols, etc.), it is puzzling that there is limited research focussing on how physicians can best support parents. This is especially surprising when the evidence suggests that as parents become frustrated with recommended protocols they tend to discontinue treatment.

Having endured many years with a child suffering from encopresis, participants reported that their experiences made them more aware of other children with similar problems, and more willing to share their experiences with others. Mothers also found it beneficial to inform their child's teacher before commencing a new school year. Several clinicians note the benefits derived from enlisting cooperation from the schools to assist with toileting privileges, and management of soiling accidents (Levine, 1982; Papenfus, 1998). As indicated by the descriptive commentary provided by participants in the current study, the confidence in sharing such sensitive information with others came only after years of trying to protect their children from ridicule and humiliation. By moving beyond preoccupation with soiling problems and focussing on meaningful solutions, participants found it easier to implement strategies that facilitated greater control for both themselves and their children.

The Essence

The true meaning or essence of living with a child with encopresis was identified as *rising to the challenge*. The narratives of the mothers portrayed a profound sense of being overwhelmed with the multiple challenges faced while trying to manage the child's illness. This theme of feeling overwhelmed with multiple challenges is also documented in studies of parents with chronically ill children (Anderson & Elfert, 1989; Horner, 1997; Jerret, 1994; Knafl et al., 1996).

It was also apparent that at each stage of lived experience, even as the mothers in this study struggled to endure, they persevered by learning how to cope with and manage events and situations that threatened to overtax their physical and emotional reserves. Eventually, experiential learning coupled with a diagnostic label and professional support helped these mothers take control of the situation and successfully manage their children's illness. Horner (1997) describes mothers' movements from the prediagnosis to diagnosis phase as consisting of redirecting energies from "groping in the dark", searching for answers to an unending illness, to learning everything about the child's chronic illness and how to successfully manage it. Jerret's (1994) study of parents of chronically ill children also captures a movement from recognizing and dealing with emotional responses, to struggling to know, and finally coming to terms with the illness and learning how to manage in a more understanding and competent manner. Similarly, Knafl et al. (1996) describe how the interactions between defining, managing and consequence themes constitute the core component of how families respond to and manage the challenges posed by childhood chronic illness.

New Insights into Mothers' Lived Experiences

From the review of the literature and from the insights gleaned from study participants, it is apparent that the complex interactions between physiologic and psychologic factors make it particularly difficult to manage encopresis (Pyles & Gray, 1997; Levine, 1982). Although the multidimensional nature of encopresis has been accepted by most clinicians and researchers, there is no consensus on an acceptable treatment plan. The use of a multimodal approach is gaining favour among those who recommend that health care providers work collaboratively and use an integrated approach to treatment (Boon & Singh, 1991; Levine, 1982; Pyles & Gray, 1997). Clayden (1991) notes that while pediatricians are in the best position to maintain the coordinating role with other professional groups (i.e, nursing, psychology, psychiatry), they are often too busy to support the family through this distressing, lengthy, and technically bewildering time. The current study findings seem to concur with those of Clayden, particularly in view of the comments on the limited support received from physicians during clinic visits and hospitalizations.

Mothers in the current study related their frustrations with the perceived lack of understanding and indifference of family physicians to soiling problems that continued far beyond the normal toilet training period. The descriptive narratives convey the message that family physicians are ill-prepared to diagnose encopresis, or provide parents with the support and guidance needed to help them manage a child with soiling problems. On an even more dismal note, many of these mothers experienced heightened feelings of helplessness, guilt, and self-blame following interactions with family physicians. It is essential that physicians be perceived as supportive, nonjudgmental and non-accusatory, and insightful so that parents will avail of their services. Based on study finding, it is essential that physicians not only become more knowledgable about the signs and symptoms of encopresis but also how to individualize intervention strategies to address the needs of parents and children.

This study's findings support the importance of health care workers looking beyond traditional curative roles and focussing attention on prevention, and early detection and management of encopresis. An extensive review of the literature revealed that only a few studies focussed on health promotion initiatives for the prevention of encopresis (Papenfus, 1998; Rappaport & Levine, 1986; Taubman, 1997). Because many of the children with encopresis are not seen for treatment until the problem is well established, there is a need for greater publicity about the fact that soiling is a common childhood problem (Buchanan, 1990). The secrecy surrounding the illness and resulting overprotective behaviours places considerable stress on both the child and family. Greater awareness of soiling problems by physicians, as well as other health care providers, will facilitate early detection and, hopefully, avoid long-term problems. Equally important is the fact that parents become aware of these problems much earlier, and not have to suffer through feeling isolated from others in their struggle. Once study participants realized that others were experiencing similar problems to themselves, attitudes changed: "There is comfort in numbers"; "It's such a relief knowing you're not the only one. It's a medical term for what he has. So I thought this is great because there's got to be some type of treatment".

A prevalent theme throughout the narratives was mothers' feelings of helplessness and powerlessness to resolve the child's soiling problems. One mother's comments poignantly portrayed how helpless and hurt mothers felt when unable to alleviate a child's suffering or institute comfort measures: "It hurts because you are trying to help her and you can't. . . .It's just like my heart is tore right out of me because I can't do nothing for her, just sit there and watch her cry". Miller (1992) indicates that helplessness may be induced by the uncertainty of health-illness and treatment situations, and the unpredictability of therapy outcomes. What is conspicuously absent from the literature is documentation on the tremendous burden placed on parents while trying to manage the long-term care requirements of an unpredictable illness. Many references were made to the time consuming and unrelenting regime of enforcing dietary and toileting regulations, monitoring of soiling incidents, changing and washing of clothes, and ensuring the home free of fecal odour. Relapses occurred even after lengthy periods of no soiling accidents. Because of the strong possibility of the relapses, treatment focussed on the management of the problem should be as important as measures taken to reduce or eliminate the soiling.

The case for promoting and protecting health and preventing disease has been established by many accomplishments throughout the twentieth century (Edelman & Mandle, 1998). Encouraging positive health practices has become a major focus of individuals, the government, health professionals, and society as a whole. Prevention of colon dysfunctions has received little attention in the pediatric literature (Hatch, 1988). As considerable investment in time, energy, and financial resources go toward the treatment of constipation and encopresis in childhood and adolescence, further research into preventive efforts is required (Rappaport & Levine, 1986).

CHAPTER 6

Limitations, Nursing Implications, and Conclusions

In this chapter, the limitations of the study will be discussed. Implications for nursing practice, nursing education, and nursing research, and more broadly, for health care in general will be addressed.

Limitations

The researcher utilized a phenomenological method of inquiry to rely upon the participants' ability to reflect upon and describe their experiences to obtain rich data for analysis. In this type of research, the notion of credibility of the findings is enhanced by the selection of participants. As a consequence of this, the participants tend to be "the most articulate, accessible, or high-status members of their groups" (Sandelowski, 1986, p. 32.). Qualitative research findings should never be generalized. All participants in this study were Caucasian and some held careers in fields which would indicate possession of post-secondary degrees or diplomas. It is possible that participants from other cultures and from other socioeconomic backgrounds would express their lived experience differently. Since the objective of this study was to gain a greater understanding of mothers' experiences of living with a child with encopresis, a further limitation is that study findings do not necessarily reflect the viewpoint of the whole family. A final limitation is that all participants had been living with encopresis for a number of years and some had experienced some years of remission, thus their experiences may be different.

Implications

The findings of this study have provided insight into the experience of living with a child with encopresis and highlighted the role of care providers in supporting parents with their care giving role. An important implication for health care professionals is the need to be aware that the context of the "lived world" is significant for the understanding of another's experience.

Nursing Education

Nurse educators are challenged to develop and implement a curriculum to prepare students to meet diverse population needs in an ever changing health care delivery system. Nurse educators have a dual responsibility. Not only must new research findings be continuously incorporated into practice, but nursing students must be educated about the meaning of chronic illnesses and its impact on families. As well, educators can impart on students the beneficial effect that utilization of social support, as a health promotion mechanism, can have on families with chronic illnesses such as encopresis.

Several models have been developed by researchers and clinicians to assist with the management and to a lesser extent, prevention, of encopresis.

Rappaport and Levine (1986) presents an approach to the prevention of constipation and encopresis using a cost-effective developmental model and approach to management. This model, although devised for pediatricians, could be adapted for use by nurses to deliver anticipatory guidance to parents in the prevention of encopresis. Chaney (1995), a pediatric nurse practitioner, proposed a collaborative management protocol for children with encopresis. This model includes input from medical clinicians (physician or nurse practitioners), school nurses, teachers, the children and their families.

While most of the study participants' comments were aimed at physicians, nurses can play a larger role in the management of encopresis. This phenomenological text provided a medium in which mothers' voices were heard. These voices in turn should teach nurses about the lived experiences of mothers whose children have encopresis.

Nursing Practice

While much of the literature focussed on medical management of encopresis, several clinicians have addressed the role of nursing (primary, secondary, and tertiary) in the provision and management of health care for clients (Buchanan, 1990; Chaney, 1995; Dallard, 1998; Ford, 1998; Frost, Ellett, & Winchester, 1994; Lewis, & Muir, 1996; Papenfus, 1998; Sprague-McRae, 1990; Stadtler, 1989; Stadtler & Burke, 1998; Waszak, 1992). Several of these writings depict nurses as working in traditional roles and primarily in hospital settings where the major emphasis is on assessing, planning, implementing and evaluating nursing care. It also appears that the major role centred around implementing strategies to promote adaptive behaviours for overcoming fecal incontinence. From the limited works written from nursing viewpoints, it is apparent that these nurses have expanded their roles to Nurse Practitioners and Clinical Nurse Specialists and are working in diverse settings.

Based on the literature and this study's findings, there are specific roles and skills which clinicians must master if they are to be active forces in promoting the health status of parents of children with encopresis. First, nurses must become knowledgeable about encopresis and how it impacts the family. Second, they must become aware of the significance of support mechanisms needed to sustain parents and their children over this long term problem. Third, they must take the time to understand the lived experience of mothers who have a child with encopresis (i.e., listening to their stories). Fourth, they must recognize the need for informational support and find ways to enable parents to seek informational support. Finally, they must increase public awareness of this often unspoken problem.

Study participants viewed health professionals as having limited knowledge about encopresis and many felt their concerns for the child were not taken seriously. Clients have a right to quality care and professionals have a moral and ethical obligation to be competent practitioners. Nurses can develop expertise in conducting thorough physical and psychological assessments of children and their families. Once assessed, an individualized plan can then be developed in consultation with the child and family. Current study findings support the viewpoint that ongoing assessment and re-evaluation of client and family needs must occur throughout the course of treatment for successful outcomes to be achieved.

Current health reform initiatives focus on shifting the context of care provision from hospital to ambulatory and community settings. The goal is to increase self-care and to foster approaches to care that embody the principles of mutual aid and community support. In the context of this study, it would appear that the informal support system, through families, assumed the greatest role in providing care and support to mothers. While families comprise the largest part of this informal support, some families in the current study were unable to provide this support as they did not know how to access available resources. Nurses, particularly at the community level, can assist family members with these endeavours.

Several study participants suggested that a support group for adults and for children, would assist them in coping with encopresis. Development of support groups is within the mandate of the nurse's role. Support groups are unique in that they place great value on experiential knowledge of its members

(Gottlieb, 1987). Parents may derive comfort from the realization that they are not alone and that others have been there too and learned to cope (Stewart, 1995).

Thus, social support is considered a resource in assisting families to cope with chronic illnesses and this was quite evident from the study participants' narratives. The informal support derived from families and friends far outshone the support expected and rendered from formal caregivers. In fact, some professionals failed to provide the essential support which was so avidly sought. Professionals, as advocates for the ill, need to be reminded of the significance of the losses people experience through dis-empowerment. Once families are enabled to cope with a condition like encopresis, providing them with direction, support and follow-up should assist them to feel in control of the situation and enhance self-esteem.

Displays of inappropriate communication skills were depicted and study participants felt unsupported in their endeavours to comply with management interventions. Clinicians must become aware of the significant role that social support, from a caring and understanding practitioner, fosters in health promotion. Study participants expressed the need for health care providers to impart information, encouragement and hope into the long and arduous treatment plan. This is especially so because of the high relapse rate. In the current study, when participants were cared for by efficient, caring and supportive health care providers, positive results were gleaned (felt happier and more in control of the situation).

Public awareness is needed to inform parents about the common childhood problem of encopresis. Initially, all study participants felt that their children's soiling problems were isolated cases and efforts were made to prevent others from noticing the child's problem. Consequently, many children do not come forward for treatment until the problem is well established. The secrecy also places extra stress on the child and family because of the isolation it engenders. Several mothers indicated that there is a need for accessible, relevant, information on encopresis. This information could be made available to physicians' offices, wellness clinics, and other areas where parents frequent.

Participants in this current study reported that bowel elimination problems were detected as early as infancy and around the toilet training period. Because encopresis is an emotionally painful experience for children over which they have little control, nurses can take a proactive approach and provide anticipatory guidance and education to parents during well child-health checks. By taking time to discuss the importance of proper diet and elimination and the effect of emotional situations on children, the nurse can assist the family in promoting healthy elimination patterns.

It is reasonable to speculate that if the population of children at-risk for encopresis were given appropriate attention and resources, bowel problems in children could be identified earlier and appropriate interventions initiated. Loveys (1990) indicate that those resources include social support, financial resources, access to information and available health promotion facilities. Because parents may not be familiar with encopresis and may not identify it as a health care issue, nurses should inquire about toileting behaviours during well-child checks. Nurses need to pay close attention to stool patterns, toileting behaviours, developmental progress and family psychosocial wellness as a normal part of well child care. Rappaport and Levine (1986) suggest that bowel problems could be decreased by instituting a long-term plan of diet counselling, education to crucial developmental transitions, and specific therapy to treat primary causes of minor or transient bowel problems when they arise and seem significant. As well, nurses need to become more comfortable and adept in using risk assessment tools to aid in health promotion activities. Finally, nurses can play an important role in coordinating and referring to appropriate disciplines with a view to providing comprehensive family care.

Nursing Research

From the findings of this investigation, a number of suggestions can be made for future research in the area of encopresis management. Additional qualitative research into mothers' lived experience with encopresis, using participants from other cultural and socio-economic groups, are needed to determine if the type of care and support as identified in this study would be important to them as caregivers. Although the women in the study were able to speculate on the impact that encopresis had on them, the true experience of fathers, siblings, and families was not explored. Research exploring fathers' and siblings' perspectives would also be valuable. In particular, gaining the perspective of the child living with this disorder, at various developmental stages, would contribute greatly to our understanding of this disorder.

Additional qualitative and quantitative research is necessary to provide useful information to help design appropriate and comprehensive health promotion initiatives. Little nursing research exists on encopresis in children. The majority of studies were conducted in the field of medicine and psychology with a focus on medical and behavioural management. One wonders if these methods alone are sufficient to treat and correct this complex elimination problem. The nursing literature stresses the impact of parental attitudes and the family's understanding of the goals of treatment (Waszak, 1992). Many questions about the types of patient education programs and counselling strategies that are the most beneficial to both child and family are yet to be identified (Waszak).

More research needs to be conducted on prevention of encopresis as current research into the prevention of bowel problems is insufficient to give clear direction in this area (Rappaport & Levine, 1986). These authors note that because considerable investment in time and energy, and financial resources go into treating these bowel problems in childhood and later into adulthood, further research is warranted. Sprague-McRae (1993) acknowledges that continued research to identify risk factors for encopresis and more effective treatment modalities is needed.

Finally, future research could endeavour to investigate the concept of social support and its impact on the family when a child has encopresis. That is, future studies into social support could examine the importance of support in reinforcing adaptive responses for coping with the long term management of encopresis. Does the presence of supports decrease the incidence of relapses? Ultimately, research findings that help to improve and refine existing treatment approaches, making them more effective for children with encopresis is needed.

Study Summary

This phenomenological study on how mothers experienced living with a child with encopresis used van Manan's method (1990,1997). Two unstructured interviews were held with all participants and two of the women were interviewed a third time to validate data. From the interview scripts four themes were identified: dealing with uncertainty, becoming frustrated with care giving, struggling to endure, and taking control.

From the themes, the essence of the lived world of mothers with a child with encopresis was identified as *rising to the challenge.* A discussion of the findings in light of previous literature was presented. Implications for nursing practice, education, and research were presented as well as limitations of the study.

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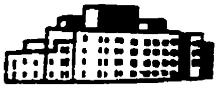
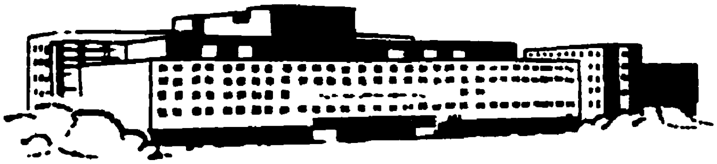
APPENDIX A

Letters of Support

WESTERN MEMORIAL HOSPITAL CORPORATION

OPERATING
WESTERN MEMORIAL REGIONAL
HOSPITAL
J.I. O'CONNELL CENTRE
BONNE BAY HOSPITAL
CALDER HEALTH CARE CENTRE
WHITE BAY CLINICS





P.O. BOX 2005
CORNER BROOK
NEWFOUNDLAND
A2H 6J7

TEL.: (709) 637-5000
FAX: (709) 634-2649

May 27, 1998

Sheila Parsons B.N., R.N.
112 Windsor Street
Corner Brook, NF.
A2H 6S4

Dear Ms. Parsons:

This letter is confirmation that I will be pleased to assist you in your research study on children with a diagnosis of encopresis and their families provided the parents are interested in participating.

Sincerely,

Dr. J. R. van Gelder
Pediatrician

JRV/tk
c.c. office

JARMILA CHRAPPA, MD FRCPC
Clinical Assistant Professor of Pediatrics MUN
SUITE 326, MILLBROOK MALL
CORNER BROOK, NEWFOUNDLAND A2H 4B5
TELEPHONE (709) 634-7741

April 18, 1998

To Whom It May Concern:

RE: PHENOMENOLOGICAL STUDY
HOW MOTHER'S EXPERIENCE LIVING WITH A CHILD WHO HAS ENCOPRESIS

I feel that the proposal for the above study is well prepared reasonable, and likely to allow us to gather very valuable information.

Encopresis is a common pediatric problem. It affects whole family, not just the child. It may be so difficult to manage that hospital admission is necessary. Frustration from the mother's side is very often present.

I will be happy to assist Ms. Parsons with this study.

Yours sincerely,

Dr. J.R. Chrappa, MD., F.R.C.P.C.
Pediatrician

JRC:ps

Dictated & Typed: April 18, 1998

APPENDIX B

Informed Consent

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF NEWFOUNDLAND AND
HEALTH CARE CORPORATION OF ST. JOHN'S

Consent To Participate In Health Care Research

TITLE:	How Mothers Experience Living with a Child with Encopresis: A Phenomenological Study
PROTOCOL TITLE:	N/A
INVESTIGATOR(S):	Sheila Parsons
SPONSOR:	N/A

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time.

Information obtained from you or about you during this study, which could identify you, will be kept confidential by the investigator(s). The investigator will be available during the study at all times should you have any problems or questions about the study.

1. Purpose of study:

   The purpose of this study is to develop a greater understanding of what it means for a mother to live with a child who has encopresis, that is, involuntary bowel movements or soiling on a regular basis after four years of age. A related purpose is to increase nurses and other health care providers understanding of how encopresis impacts the family unit. The information derived from this study may help health care providers identify and implement more appropriate care to address the needs of mothers of children with encopresis.

2. Description of procedures and tests:

   You are being asked to participate in two interviews which will be conducted at a place and time that is convenient for you. Interviews will be audiotaped (with your permission). The tapes will be transcribed word for word, and will be used to help the interviewer remember the details of the conversation and construct summaries for you to reflect upon at a later date. During the second interview, you will be asked to read a summary of the initial interview and confirm whether or not it accurately reflects your experiences. You will also be given an opportunity to provide any additional information at this time. All identifying data will be destroyed following completion of the study.

3. Duration of participant's involvement:

   The first interview will take approximately 60 to 90 minutes to complete. The second interview will be scheduled within two months and will last about 30 minutes.

4. Possible risks, discomforts, or inconveniences:

   There are no expected risks from participating in this study. You may refuse to answer any questions that make you feel uncomfortable, and terminate the interview at any time. All information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the principal investigator. If you become emotionally upset during the interview, support will be offered and the investigator may refer you back to your pediatrician for additional counselling.

5. Benefits which the participant may receive:

   You will not benefit directly from participating in this study. However, the information that you provide may help nurses and physicians to develop a better understanding of the needs of mothers who have a child with encopresis.

6. Alternative procedures or treatment for those not entering the study:

   N/A.

7. Liability statement:

   Your signature indicates your consent and that you have understood the information regarding the research study. In no way does this waive your legal rights nor release the investigators or involved agencies from their legal and professional responsibilities.

8. Any other relevant information:

   Findings of this study will be available to you and health care professionals upon request. Findings may be published, but you will not be identified. The investigator will be available throughout the study to address any questions or concerns.

Signature Page

Title of Project: How Mothers Experience Living with a Child with Encopresis: A Phenomenological Study

Name of Principal Investigator: Sheila Parsons

To be signed by participant

I, , the undersigned, agree to my participation or to the participation of (my child, ward, relative) in the research study described above.

Any questions have been answered and I understand what is involved in the study. I realise that participation is voluntary and that there is no guarantee that I will benefit from my involvement.

I acknowledge that a copy of this form has been given to me.

(Signature of Participant) (Date)

(Signature of Witness) (Date)

To be signed by investigator

To the best of my ability I have fully explained the nature of this research study. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

(Signature of Investigator) (Date)

Phone Number

Consent for audiotaping during interviews

APPENDIX C
Interview Schedule

Interview Schedule

Thank you for agreeing to participate in this study. I understand that you have a child with encopresis. I am interested in knowing what it has been like for you living with a child with this condition. You can share any thoughts, feelings, and ideas about experiences that you feel comfortable talking about. Feel free to talk about whatever comes to mind.

Examples of probes/questions to guide the interview

1. When did you realize that there was a problem with your child's bowel habits? What were your feelings at the time?

2. What do you find most aggravating about the situation? What are some of your biggest concerns/worries?

3. How has your child's condition affected you and your family (i.e., husband, other children)? How has it affected your relationships with others (e.g., friends, extended family, etc)?

4. Could you reflect upon a recent mishap (i.e., soiling accident) and describe your feelings and actions at the time? (**Probes:** Do you see any changes in how you deal with things now as opposed to before your child was diagnosed with encopresis?)

5. What do you find **most helpful** in coping with your child's condition? (**Probes:** Could you reflect upon experiences with your child and talk about things/events that left you feeling good? Can you recall a significant event that helped you cope better with the situation?)

6. Could you identify what is **least helpful** in coping with your child's condition?

7. How would you describe your encounters with health care providers concerning your child's condition? What would make the care better? Can you think of any particular experiences that you found really supportive/helpful?

8. Are there any other comments or thoughts that you would like to share with me about your experiences with your child?

APPENDIX D
Human Investigative Committee Approval

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

1998 07 20

TO: Ms. Sheila Parsons

FROM: Dr. Verna M. Skanes, Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: **Application to the Human Investigation Committee - #98.113**

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled "**How Mothers Experience Living with a Child with Encopresis: A Phenomenological Study**".

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

for Verna M. Skanes, PhD
Assistant Dean

cc: Dr. K.M.W. Keough, Vice-President (Research)
Dr. R. Williams, Vice-President, Medical Services, HCC

SUPPORT
THE OPPORTUNITY FUND

St. John's, NF, Canada A1B 3V6 • Tel.: (709) 737-6762 • Fax: (709) 737-5033 • email: rgs@morgan.ucs.mun.ca