REPRESSIVE ADAPTIVE STYLE, DISEASE SEVERITY, AND PSYCHOLOGICAL

FUNCTIONING OF ADOLESCENTS WITH INFLAMMATORY BOWEL DISEASES.

By

ARMANDE GIL

(Under the direction of Jonathan Campbell)

ABSTRACT

The impact of a repressive adaptive style on disease status, self-reports of psychological functioning, self-reports of quality of life, and disease severity indices was examined among adolescents with inflammatory bowel disease ($n = 42$) and healthy peers ($n = 302$). As predicted, a larger proportion of adolescent with a repressive adaptive style (38.1%) was found among patients with IBD than among healthy controls (18.5%). In line with prior studies, lower reports of anger expression and depression were found among teen repressors than among nonrepressors across groups. Teen repressors with IBD reported higher levels of quality of life than high anxious and similar levels to low anxious, suggesting that they experience minimal symptoms of the disease. However, their disease severity indices were higher than low anxious patients and similar to those of high anxious patients, indicating worse health functioning. Across disease status and adaptive style groups, parent-adolescent agreement was high. Finally, High concordance rates were found among adaptive style paradigms when depression or anger expression was substituted for anxiety as the repressed affects. Absolute agreement between paradigms was 92% for depression and 93% for anger expression, respectively, when participants were dichotomized into repressors versus nonrepressors.

INDEX WORDS: Inflammatory Bowel Disease, Adolescent, Repressive Adaptive Style, Quality of Life, Disease Severity.

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CHAPTER I

INTRODUCTION

Inflammatory Bowel Disease (IBD)

Organic and Symptomatic characteristics

Inflammatory bowel diseases include two chronic digestive diseases of the small and large intestines: Crohn's Disease (CD) and Ulcerative Colitis (UC). These two disorders have traditionally been grouped together because they share many similarities in epidemiologic, immunologic, clinical, and therapeutic characteristics (Engstrom & Lindquist, 1998). However, advances in immunologic methodologies have recently unveiled differences between CD and UC. It is now widely recognized that although these diseases present with some similar symptoms, they are distinct entities (Camic & Knight, 1997).

The enteric inflammatory process in CD can affect any part of the gastrointestinal tract from the mouth to the anus. The most frequently involved area is the terminal ileum (i.e., last division of the small intestine), and about two thirds of pediatric patients with CD have some involvement of the colon. CD may occur in two or more sites separated by healthy tissue, and its manifestation is often patchy and segmented (Friedrich & Jaworski, 1995). In UC, on the other hand, the intestinal inflammation is continuous and limited to the colon, also called the large bowel. In at least 50% of the children, the UC is extensive, involving all the large intestine. CD restricted to the large bowel is also encountered in about 10 to 15% of cases, defying precise classification among patients without patchy areas or scaring (Friedrich & Jaworski, 1995).

Chronic inflammation in UC is restricted to the mucosa lining of the large bowel, whereas inflammation in CD involves a progressive process that begins under the mucosa and can spread to all layers of the bowel, causing thickening of the bowel wall, scaring, obstruction, and/or infection of extraintestinal systems (Camic & Knight, 1997).

The initial symptoms and signs of IBD in childhood are often insidious, with non-specific features that may result in delay of diagnosis. Clinical manifestation may be extremely variable, depending on the location of lesions, the extent and acuteness of lesions, and their relationships with contiguous structures (Engstrom & Lindquist, 1998). For instance, small bowel CD or upper gastrointestinal involvement tends to result in obstructive symptoms, with abdominal pain and tenderness on palpation. Diffuse small bowel inflammation is often characterized by diarrhea and anorexia, and colonic involvement may result in symptoms similar to UC, with diarrhea, urgency to defecate, and rectal bleeding. Other common manifestations of CD involve anorexia, anemia, dehydratation, and perianal fistulae, anal fissures, and tags. UC typically presents with diarrhea, rectal bleeding, fecal urgency, and lower abdominal cramping.

Extraintestinal symptoms and complications generally occur more often in children than in adults in both CD and UC. They may include skin lesions, conjunctivitis, liver abscesses, painful joints, and arthritis. Bowel obstructions that occur as a result of inflammation and scarring may entail bowel rupture and possible fatal contamination of the abdominal cavity (Anonymous, 1991). Individuals with CD are at an increased risk for colon cancer, particularly after the disease has been present for more than 20 years (Spray, Debelle, & Murphy, 2001). Although, many of the characteristics of IBD in children and adolescents are similar to those seen in adults, growth retardation and weight loss are frequent and specific complications of

pediatric IBD (Rosen, 1991). Growth failure is often accompanied by retarded bone development and delayed onset of sexual maturation (Rosen, 1991). It is thought to be associated with malnutrition and deficiencies in important vitamins and nutrients, malabsorption, inadequate dietary intake, hormonal imbalances, and treatment with corticosteroids (Engstrom & Lindquist, 1998). Growth arrest is less common in children with UC than in children with CD (Engstrom & Lindquist, 1998).

Because the symptoms of IBD are often predominantly extra-intestinal and unspecific, correct diagnosis may be delayed (for instance, symptomatology may be difficult to distinguish from anorexia nervosa) with a year or more often intervening between the onset of symptoms and correct diagnosis (King, 2003). Delay in diagnosis may be associated with even greater growth failure and malnutrition, and many children with unrecognized inflammatory bowel disease may undergo inappropriate treatments such as growth hormone therapy or psychiatric therapy (Richards, Prendergast, & Booth, 1994; Spray et al., 2001). Early diagnosis is important because it prevents future complications both in the intestinal tract and in the extraintestinal systems (Spray et al, 2001). Extensive medical investigations are routinely performed in childhood IBD because only radiology, histology, sonography and biochemistry can reliably determine a diagnosis of IBD and a differential diagnosis of CD versus UC. Upper and lower endoscopies with biopsies are fundamental to confirm differential diagnosis and radiologic investigations of the small intestine and blood tests are essential in the assessment of disease activity (Buller, 1997). In spite of careful and detailed medical evaluations, a differential diagnosis cannot be made in approximately 15% of pediatric cases (Motil & Grand, 1988).

Typical medical investigations for pediatric IBD are often troublesome and distressful for the children even if very careful preparations are used.

Epidemiological Data

Several studies suggested that the worldwide incidence of UC has been declining. Conversely, the incidence of CD worldwide was reported to increase in frequency. Incidence estimates vary greatly, but the Crohn's and Colitis Foundation of America estimates the incidence of CD to be approximately 15 per 100,000 and the incidence of UC to be 18 per 100,000. Males and females are equally affected by pediatric UC whereas a slightly increased preponderance of male patients is affected by pediatric CD (Mamula, Markowitz, & Baldassano, 2003). Two peak periods of onset are usually recognized (Hanauer et al., 1998). The greatest peak of onset occurs during adolescence and young adulthood. The smaller peak of onset occurs between the ages of 55 and 80 years (Hanauer et al., 1998). About 2% of all patients with IBD present before the age of 10 years, but 30% present between the age of 10 and 19 years (Buller, 1997). A significant proportion of young patients develop the disease just prior to or during puberty (Buller, 1997). IBD tends to be more prevalent in countries with temperate rather than tropical climates, and the incidence of IBD is higher in Canada and in northern United States than in the southern states (Lewis, Aberra, Lichtenstein, Bilker, Brensinger, & Strom, 2004).

Medical Treatment

Whereas UC may be chronic or include intermittent acute episodes, CD follows a course of unpredictable remissions and exacerbations over many years (Baldassano et al., 2001). At least 75% of patients with IBD undergo surgery at least once in the course of their disease (Traue & Kosarz, 2000). Bowel obstruction is the primary indication for surgery. Surgery can involve

radical removal of the inflammed bowel, or local surgery that focuses on the specific complications of the disease (i.e., perianal complications). As opposed to UC, surgery in CD is not curative and the disease tends to recur after surgical intervention (Baldassano et al., 2001). High rates of postoperative recurrence were found to be associated with severe disease at the time of surgery and with colonic transmural (i.e., below the mucosa) inflammation (Baldassano et al., 2001). In the absence of a medical or surgical cure, the goal of pharmacological treatment is to maintain symptomatic control and to minimize the impact of the disease on the patient's quality of life, while, at the same time, managing the side effects of treatment medication (Hanauer et al., 1998). The principles of medical treatment are approximately the same for CD and UC (Walker-Smith, 1997). Current medical therapy is selected on the basis of the severity of the disease and its complications. It emphasizes a program rather than a drug and considers the individuality of the therapeutic response.

Pharmacological therapies for IBD induce remission in mildly, moderately, and severely active IBD. They usually involve anti-inflammatory and immunomodulatory agents, corticosteroids, supportive drugs (e.g., anti-diarrheal agents), antibiotics, and nutritional therapy to counteract malnutrition, anemia, and bone demineralization (Hanauer et al., 1998). Corticosteroids, a typical first line short-term therapeutic intervention for moderately and severely active IBD, induce temporary remission by suppressing the immune system. Unfortunately, steroids have many distressing side-effects such as growth suppression, hirsutism, acne, and sleep and mood disturbances (King, 2003). They are generally not well tolerated over a long time period especially as they induce dependence. The introduction of infliximab (i.e., remicade) for moderately and severely active CD has permitted the induction of longer-term

remission of disease activity than was previously possible among pediatric patients and has reduced steroid usage (Greig & Rampton, 2003). Infliximab is a new and innovative pharmacological agent given in the form of infusions over a period of at least 2 hours. It reduces the infiltration and production of inflammatory cells in the inflamed areas of the intestine with few side effects on the child's overall functioning and appearance. However, in spite of pharmacological research efforts to generate medical treatments that are both efficient and comfortable, none of the currently available pharmacological agents have demonstrated prophylactic effects. That is, none of the currently prescribed medications is able to prevent future disease exacerbations and relapses (Greig & Rampton, 2003). To date, fluctuations between disease recurrences and remissions remain unexplained and mostly unpredictable.

Multifactor Model of Pathogenesis

Despite intensive research efforts, the etiology of IBD remains unknown. No convincing evidence has linked a parasite, fungus, or virus to either CD or UC (Anonymous, 1991). There is strong evidence that genetic factors play a role in the etiology of IBD. Reports of familial aggregation, high concordance rates between monozygotic twins (44.4%) as compared to (3.8%) for dizygotic twins, and associations with other genetically determined diseases converge in support of a genetic predisposition (Mamula et al., 2003; Shearman & Finlayson, 1982). Epidemiological data in 1074 pediatric patients with IBD showed that 31% of the children had a member of the extended family with IBD, 4% and 12% had a sibling or parent with a history of IBD, respectively (Mamula et al., 2003). Genetic vulnerability to IBD is hypothesized to express itself through genetic predisposition to immune-mediated injury of the intestine in the form of gastrointestinal tract hypersensibility to stress such as gut permeability (Levenstein, 2002).

Early internal and external environmental influences were also hypothesized to play a role in promoting individual susceptibility to IBD (Mamula et al., 2003). For instance, lack of domestic hygiene and high incidence of early enteric infections may impair the normal maturation of the mucosal immune system necessary to allow tolerance of oral antigens later in life (Gent, Hellier, Grace, Swarbirck, & Coggon, 1994). Although evidence is lacking for an infectious cause of IBD, infectious processes were found to trigger relapses of the diseases. For example, a respiratory tract infection may commonly precede relapse of CD, whereas acute, infectious gastroenteritis more often precedes relapses in UC (Shearman & Finlayson, 1982). Smoking, diet, and drugs have also been implicated in the pathogenesis of IBD (Greig & Rampton, 2003).

The current dominant view is that the pathogenesis of IBD involves a defective regulation of the mucosal immune response to factors present in the gut flora. That is, the tolerance of ordinary antigens present in the mucosal environment appears to be compromised and the mucosal immune system seems unable to down regulate once a response has been initiated. Currently, a multifactorial theory encompassing genetic, autoimmune, and infectious processes is thought to account best for the etiological factors implicated in the onset of IBD. In addition, psychological factors and stress are regarded as factors that exacerbate patients' symptomatology or induce active phases of the diseases (Ondersma et al., 1997). The current challenge is to determine how the potential etiological factors whether genetic, environmental, dietary or psychological, combine to cause a chronic activation of the mucosal immune system.

A Biopsychosocial Perspective on IBD

Illness is best understood as the interaction of biological, psychological, and sociocultural process (Drossman, 1993). A *systems* or *biopsychosocial* approach (Engel, 1977) to illness provides an overarching theoretical framework to understand and study the complex and multi-directional interactions between genetic diathesis, immune functions, and environmental, psychosocial, and behavioral factors in IBD. A biopsychosocial model presumes that illness is the result of subsystems interacting at multiple levels. It links cognitive and emotional centers of the brain with the neuroendocrine axis, the immune system, and the enteric nervous system by bi-directional pathways (Mayer & Raybould, 1990). Physiologically, the enteric nervous system has spinal and autonomic connections with the central nervous system, and sympathetic innervations involve all portions of the gastrointestinal tract. The enteric nervous system is also endowed with a dense network of nerves ensuring constant intestinal, immune, and endocrine interactions (King, 2003). Neural connections from associative centers permit external and internal information (i.e. emotions, thoughts, memories, etc.) to affect GI sensation, motility, and secretion, and vice-versa (Fullwood & Drossman, 1995). That is, intestinal dysfunction can also affect pain sensations, perceptions, and mood (Drossman, 1993). Finally, neurotransmitters and neuropeptides that play a role in the emotional, perceptual, and pain centers of the brain, have receptors localized along the gastrointestinal tract, thereby facilitating constant brain-gut exchanges (Shabsin & Whitehead, 1991).

In vitro animal experimentations and human observations suggested that environmental changes or stressors, as well as the organism responses to change, influence physiological functions and may produce disease susceptibility through the concurrent effects of

neurotransmitters, endocrine factors, and immune system alterations (Shabsin & Whitehead, 1991). Animal research also demonstrated that environmental stress can produce gastrointestinal damage in the predisposed organism in the form of ulcers or colitis, and clinical studies in human provided data in support of such a relationship (Drossman, 1993). The immune-based pathogenic model of IBD presumes that immune system dysfunctions may mediate the relationship between genetic diathesis, stress/distress, and disease state. It is known that stress or psychological distress leads to alterations in immune system functioning through a cascade of hormonal and cellular changes (Kiecolt-Glaser, 1989). During a stressful episode, corticosteroids first enhance, and then, suppress the immune system back to baseline levels. When stressors are of long duration, suppression of the immune system goes below baseline levels into an immunosuppression phase (Salposky, 1998). However, chronic activation of the immune system may also impair compensatory returns to original baseline levels in some individuals. Immune systems that are more and more active over time become overstimulated and enter phases of overactivation when autoimmune processes, similar to the inflammatory responses observed in IBD, are likely to develop (Salposky, 1998).

The Impact of Stress and Psychological Distress on Disease Activity

The impact of stress on IBD activity was investigated mostly among adult patients (Levenstein, 2002). Two reviews of the literature on stress and disease activity in IBD concluded that no significant causal association between stressful events and exacerbation of the disease was found (North & Alpers, 1994; Levenstein, 2002). According to Levenstein, the reviewed prospective studies probably did not assess the impact of stress long enough to capture a significant accumulation of subtle alterations in disease activity over time. Indeed, Levenstein argued that the influence of stress is likely to take place over time in the form of progressive gut sensitization to stressful events. Research with animals supports the assumption of progressive sensitization of the gastrointestinal tract to stress. Qiu, Vallance, Blennerhassett, and Collins (1999) injected a chemical agent that triggered IBD activity and symptoms in rats. The researchers let the animals recovered and applied experimental stressors such as loud noise and restrain with minimal doses of the triggering agent. Experimental stressors and minimal doses of the disease promoting agent were sufficient to induce exacerbations of IBD. Two recent studies among adult patients with UC also reported an association between stressful events, psychological distress, and subsequent exacerbations of UC over the medium and long-term (Levenstein et al., 2000; Mittermaier, Beier, Tillinger, Gangly, & Moser, 1998). None of these studies demonstrated a causal relationship between distress and onset of IBD, rather they confirmed an association between distress and IBD relapses. Based on currently available data, most researchers consider that stress is more likely to play a role in worsening IBD than causing it.

What is more, research in both functional and organic gastrointestinal disorders indicated that stress or psychological distress enhances perceptions of bowel motility and sensations of pain coming from an oversensitive and/or lesioned enteric system (Burke, Elliott, & Fleissner, 1999; North & Alpers, 1994). Further, concurrent mental health difficulties moderate the illness experience and its response to treatment, and individual differences in temperament, personality, or cognitive ability color the way in which symptoms are perceived, evaluated, and responded to. Like in any other condition, the subjective experience of IBD may worsen in times of stress even though objectives measures of disease activity do not reflect an exacerbation. As a result, increasing complaints of symptoms in times of stress may be mistakenly interpreted as reflecting disease activity.

It is important to distinguish between functional and medical disease severity or activity. Dissociations between functional and organic severity were apparent in clinical investigations. Research reports about measures of disease activity on the one hand, and research findings about measures of health-related quality of life on the other hand, repeatedly yielded discrepancies or weak relationships between objective (i.e., biochemical, radiologic, endoscopic, physicians' ratings) and subjective (i.e., self-reports of symptoms) indices of disease activity (Koot & Bouman, 1999; MacPhee, Hoffenberg, & Feranchak, 1998). Conversely, both in adult and in pediatric patients, subjective indices of disease activity (i.e., symptom reports, quality of life reports) were found to be associated with level of psychological functioning (Loonen, Grootenhuis, Last, de Haan, Bouquet, & Derkx, 2002; Guthrie, Jackson, Shaffer, Thompson, Tomenson, and Creed, 2002; Wood, Watkins, Boyle, Nogueira, Zimand, & Carroll, 1987),

thereby confirming the premises that psychosocial factors play a key role in patients' perceived health status.

Health-related Stress and Adjustment

A multidetermined systems perspective on health assumes that the patient's physical and psychological dispositions interact with affective, cognitive, and organic processes in an ongoing fashion, each one impacting on the other in a reciprocal manner. Thus, the impact of stress or psychological distress on disease activity is considered to be bi-directional. That is, the disease process itself may also affect young patients' moods and overall adjustment. Disease symptoms and its treatment generate stress through pain, unpleasant medical investigations, impairment in normal social functioning, and alterations in body image (Drossman, 1993; King, 2003; Mamula et al., 2003). Health-related stress may further affect the organism functioning, with disease-related stress maintaining or worsening disease activity as in a feedback loop. According to Kinsman, Dirks, and Jones's (1982) theory of the psycho-maintenance of chronic physical illness, how the young patient adjusts to the stresses of his/her disease may participate in the maintenance or remission of the disease process. In other words, how children and adolescents with IBD deal with disease-related stresses may, in part, determine their health outcomes as well as the course of their illness.

Models of risk and protective factors in childhood chronic illnesses account for the complex interactions between disease, environmental, social, and personal factors (Wallander, Varni, Babani, Banis, & Wilcox 1989) within a *biopsychosocial* framework. Wallander et al.'s (1989) risk-resistance model posits a series of variables that moderate the relationships between disease parameters, stressful events, and child outcome. These variables are intrapersonal factors

(i.e., temperament, mental health, competence), social-ecological factors (i.e., family environment, social support, parental adjustment), and stress processing factors (i.e., cognitive appraisal and coping strategies). Maladaptive or adaptive stress responses, in turn, are also moderated by intrapersonal and socio-ecological factors such as child's temperament, learning experiences, sense of self-efficacy, and beliefs about his/her illness. The current immune-related model of etiology of IBD and the possible role of stress and/or psychological distress in its maintenance and course highlight the importance of exploring pediatric patients' style of adapting to health-related stress and its consequences on child's health outcome.

A large part of pediatric research on the psychological factors associated with patients diagnosed with IBD has aimed at detecting psychological diseases rather than at describing psychological functioning and its impact on adjustment to health threats. Most investigations have replicated adult studies by utilizing diagnostic tools designed to differentiate between pathological versus non pathological states, and made comparisons between groups according to the type and proportion of mental disorders present in each of them. Attempts at detecting mental illnesses may be motivated by a desire to better serve and attend to the needs of patients with IBD. They are also encouraged by third party payers for the reimbursement of health psychology services for patients with gastrointestinal diseases (Camic & Knights, 1997).

From a research perspective, the long-standing debate about whether or not mental disorders precede or follow the diagnosis of CD, betrays an attempt at disconfirming or confirming the role of mental health functioning as a contributing etiological agent for the development of gastrointestinal inflammations. In addition, detecting comorbid mental diseases implies the exclusion of patients functioning at a sub-syndromal level, whose psychological

processes may be maladaptive enough to prevent appropriate coping strategies. Moreover, such a disease-based approach does not indicate the role of mental disorders in the recurrence and remissions of the disease, as well as the specific psychological mechanisms interacting with organic activity. Finally, oversimplified assumptions about mental and physiological disease comorbidity put investigators in an either/or position with regard to the level of psychological functioning among patients with CD (Wood et al., 1988).

Conceptual and Empirical Framework

Exploration and description of cognitive and affective processes (i.e., causal attribution, cognitive appraisal, emotional regulation, and personality-based psychological predisposition) lend themselves better to the understanding and study of complex mind-body relationships than the assessment and quantification of mental disorder diagnoses. Psychological research rooted in a biopsychosocial perspective focuses on delineating the psychological functioning and profile of children and adolescents diagnosed with IBD as compared to other chronically ill or healthy children. These psychosocial studies attempt to highlight the multiple relationships between psychological traits, states and disease severity as measured with subjective (i.e., symptom report) and objective (i.e., laboratory analyses) instruments.

The main findings of these investigations reveal (1) that children and adolescents with IBD tend to exhibit more depressive and anxiety symptoms than healthy peers, and more behavioral difficulties than siblings and healthy peers (2) an association between self-reported disease severity and self-reported level of psychological functioning (3) an inverse relationship between disease severity as assessed by subjective measures and medical/biochemical assessment of disease severity and (4) an inverse relationship between disease severity as

assessed by objective measures and level of psychological functioning for a subgroup of children with IBD. That is, depressed children diagnosed with IBD were found to be less severely ill than non-depressed children and conversely, non-depressed were reported to score higher on measures of disease severity than depressed children (Burke, Kocoshis, Cahndra, Whiteway, & Sauer, 1990; Burke, Neigut, Kocoshis, Chandra, & Sauer, 1994). More specifically, disease severity was reported to be associated with style of psychological functioning rather than with level of psychological functioning. Indeed, children who showed a high level of emotional restraint scored high on laboratory measures of disease activity. Paradoxically, they reported low levels of physiological symptoms (Wood et al., 1987).

Several authors suggested that the demonstrated tendency to deny physiological distress among a subgroup of children with IBD also applies to their psychological distress (Schmitt, 1970; McMahon et al., 1973; Drossman et al., 1991; Gold, Issenman, Roberts, & Watt, 2000). Indeed, discrepancies between parents' reports of pediatric patients' psychological wellbeing and patients' own reports of their psychological wellbeing emerged in the IBD psychosocial and quality of life literature (Wood et al., 1987; Engstrom, 1999). Additionally, there is evidence that children with IBD report fewer stressful events than their typical peers, which points to the possibility of inaccurate self-reporting of stress levels as well (Gitlin et al., 1991).

Wood et al. (1987) hypothesized that a possible mechanism underlying both discrepancies between disease activity and subjective reports of distress, and reported associations between psychological style and disease activity, involves a particular style of adaptation to stress. Pediatric models of adjustment among patients with chronic illnesses or disability also posit that stress responses in the form of stress processing, style of responding,

and coping strategies both mediate and moderate the relationship between stressors and child's

adjustment (Wallander et al., 1989; Rudolph, Dennig, & Weisz, 1995). According to these

models, how a young patient adapt to stress affects how and whether a chronic illness such as

IBD impacts his/her overall adjustment outcome (Thompson, Gustafson, & Gil, 1995). Similarly,

Wood et al.'s hypothesis for IBD presumes the possible mediating and/or moderating effect of

pediatric patients' adaptive style on their overall wellbeing, including behavioral functioning,

disease severity, and quality of life. Wood et al. proposed that a repressive style of coping with

stressful events might be associated with more disease activity, more observed behavioral

distress, and with self-reports of good adjustment and well being.

Within the context of a risk and protective factor conceptual framework, an exploration

of Wood et al.'s theoretical postulate may be useful in understanding the adaptive style of

pediatric patients' with IBD and how their style of adaptation influence their overall adjustment.

Because the course of IBD is unpredictable, exploring pediatric patients' adaptive style is critical

to understanding how young patients' style of responding to stress may play a role in the

induction and maintenance of remissions or relapses and in the preservation or promotion of

adequate quality of life and psychosocial adjustment.

Repressive Adaptive Style

Repression comes from the Latin word "reprimere" which roughly translates into "to hold

back"or "to check." (Websters Third New International Dictionary Unabridged, 1971). In the

field of psychology, the meaning of the term "repression" has evolved since it was popularized

by Freud's writings (Singer, 1990). It is important to distinguish repression as a mechanism, and

repression as a defense strategy or adaptive style. All are linked and embedded in each other but imply different outcomes in terms of individual functioning (Singer & Sincoff, 1990).

The <u>mechanism</u> of repression involves forgetting or inhibiting. It is a process that occurs in normal development, and it is necessary for learning and being efficient in one's work and interpersonal relationships. Schwartz and Kline (1995) used the example of infant reflexes that are thought to disappear as part of normal development. These reflexes are actually inhibited by the frontal lobe and do not disappear. They can be disinhibited by damage to the frontal cortex, by hypnosis, or by inhibition of the frontal cortex with drugs. Repression also permits individuals to focus and to forget about irrelevant information. For example, some knowledge can be repressed for some months or years until it is reactivated (Reisberg, 2001). In that case, repression as a psychological or biological mechanism is adaptive and necessary for survival (Schwartz & Kline, 1995).

In the context of psychological defenses, repression takes on the particular meaning of keeping painful ideas and feelings out of conscious awareness. As a <u>psychological defense</u>, repression is also part of normal development and can be adaptive or maladaptive. Anna Freud (1936) and other developmental psychologists (Mahler & McDevitt, 1968) explained that defenses become pathological only when they are used with great intensity, in situations where they are not needed, or if they are age-inappropriate. In the context of psychological defenses, the cognitive mechanism of repression remains the same but it takes on the purpose of protecting the self. That is, it allows individuals to heal from traumatic or painful experiences. It also provides a protection against information that threatens one's sense of self and may generate anxiety (Singer, 1990). As an <u>adaptive style</u>, repression characterizes individuals who tend to

repress psychological, or even somatic, distress consistently across stressful situations and types

of stressful events (Weinberger, 1990). This study focuses on the repressive adaptive style.

Throughout this paper, the terms "repressive adaptive style," "repressive coping style" and

"repressive defense style" are used synonymously. An historical overview is offered first to

present the consistencies and alterations in the understanding and investigation of the repressive

defense style over time.

Repression in psychoanalytic theory

Defenses, as defined by Freud, are mechanisms of self-protection designed to anticipate

conditions of threat to the self by preventing unacceptable ideas and feelings from becoming

conscious (Erdleyi, 1990). For mostly 30 years, Freud used "repression" synonymously with

"defense" and other terms such as "suppression," "dissociation," and "inhibition" to represent

warding-off processes (Schwartz & Kline, 1995). Defenses were thought to develop over the

course of psychosexual development in the first five years of life. Defenses or repression were

also thought to be adaptive in the sense that they prevent the ego from being overwhelmed and

help it to adapt to social norms by denying or distorting reality (Singer & Sincoff, 1990).

However, Freud emphasized that when used frequently defenses or repression can become

pathological, inducing individuals to develop a style of avoiding reality. In other words, defenses

and repression could become the source of anxiety and be pathogenic (Cramer, 1998).

In the last part of his career, Freud redefined the concept of repression as a specific

defense mechanism. This reformulation occurred at a time when he was particularly interested in

memory. Freud held that repression is a specific defense mechanism aimed at reducing

psychological distress induced by painful and affectively charged memories.

The important point of Freud's theorization of repression as defense mechanism is that the information is not repressed solely because it is unpleasant; it is repressed because it is incompatible with self-concept or ego. That is, repression involves a process of self-deception. Discrepancies between personal standards for behavior, acceptable emotions and actual affect or past/present behaviors generate discomfort, negative affect, and anxiety. As a result, individuals use a variety of cognitive strategies to avoid awareness of these discrepancies. Repression, through forgetting and inhibition, is one of these strategies.

Erdleyi (1990) reviewed Freud's definition of repression throughout his career and concluded that his position about whether or not repression is a conscious or unconscious phenomenon is not clear. It is Anna Freud's book "The Ego and the Mechanisms of Defense" ([1936] 1946) that established that defense mechanisms are unconscious. However, Anna Freud suggested that defensive cognitive events may reach consciousness fleetingly and may be overtaken by forgetting almost immediately. That is, the affect or idea that is too threatening for the individual reaches consciousness and is warded off immediately before the normal process of emotional-cognitive integration and expression takes place. Nonetheless, the isolated unacceptable emotion or motivation remains and keeps generating anxiety (Safran, 1998).

Freud's understanding of the unconscious and emotional and cognitive processes such as repression was deeply rooted in his metapsychology of biologically inherited instinctual drives. However, we can distinguish between Freud's insights about the relationship between emotions, the unconscious, and cognition, and his theoretical framework to acknowledge his intuitive insight that psychopathology can originate, in part, from a failure to fully process internally generated information consistent with the conscious experience of emotions (Safran, 1998). This

internally generated information can be thought of as action-disposition information, which under normal circumstances constitutes a vital component of emotional experience (Safran & Greenberg, 1998).

The construct of repression in individual difference research

Following Freud's delineation of repression, several experimental psychologists attempted to educe its underlying mechanisms beyond its function as an ego defense. During the 1940s and 1950s, investigators asked participants to make lists of their pleasant and unpleasant experiences (Holmes, 1990). Later, participants were asked to recall the experiences they had recorded. The investigators then compared the two lists to determine whether subjects were less likely to recall pleasant than unpleasant experiences. In most studies, it was found that unpleasant experiences were less likely to be recalled and the findings were taken as evidence for repression (Holmes, 1990). Some investigators reported data demonstrating that the recall of personal experiences was due to the intensity of the experience rather than to their pleasantness or unpleasantness, and these studies were widely rejected as irrelevant. In the 1950s, researchers tried to demonstrate experimental repression. Anxiety, in the form of negative feedback was created in order to produce forgetting. Then, anxiety was removed (i.e., participants were told about the experiment) to prove that the repressed material was still available in long-term memory. This phenomenon was called "the return of the repressed" (Erdleyi, 1990). These experiments were criticized for representing a simplistic and fallacious interpretation of Freud's concept as the forgetting of the disagreeable (Rappaport, 1959). Moreover, some experimentalists argued that other cognitive processes such as attention could account for the findings and should be investigated (Davis, 1990).

Because of problems in operationalizing repression as a cognitive mechanism, researchers in the 1960s began studying repression as a trait, and a number of measures designed to identify individuals who consistently use repressive defenses to cope with stressful situations were constructed (Erdleyi, 1990). The best known and most widely used of these early scales was the Byrne Repression-Sensitization Scale (Byrne, Barry, & Nelson, 1963). This measure evolved from the perceptual defense literature in which repressors were defined as individuals who have heightened recognition thresholds for anxiety-provoking stimuli (Davis, 1990). This scale claimed to distinguish between sensitizers (who approach threatening stimuli) and repressors (who avoid threatening stimuli). However, the Byrne scale turned out to be very highly correlated with measures of trait anxiety, thus leading to a confounding between repression and true low-anxiety (Weinberger, 1990). That is, participants who scored low on the Byrne scale could either be truly low in sensitization to negative emotions or could be using repressive defenses to avoid the experiences of negative affect.

The most influential approach to measuring repression emerged from an empirical study by Weinberger, Schwartz, and Davidson (1979). Weinberger et al. hypothesized that "the widespread disillusionment" among researchers for the lack of correlations between self-reports of anxiety and behavioral and physiological markers of anxiety could be accounted for by the confounding presence of repressors in the sample population. Therefore, they developed a method to distinguish psychometrically between individuals accurately reporting low levels of negative emotions from individuals whose self-reports of low levels of negative emotions are inaccurate (Weinberger, 1990). They used a combination of trait anxiety (i.e., Taylor Manifest Anxiety scale) and defensiveness measures to detect repressive individuals (i.e., Marlowe-

Crowne Social Desirability Scale). The results of the study yielded a 2 × 2 table identifying four

coping styles:

Table 1

	Defensiveness	
	Low	High
Anxiety Low	Low Anxious	Repressors
High	High Anxious	Defensive High Anxious

Weinberger et al. defined repressors as those participants who score low on self-report measures

of anxiety (at or below the 50th percentile) and high on a measure of defensiveness (at or above

the 75th percentile). That is, whereas low anxious individuals are truly carefree, with little

preoccupation for self-image, repressors exhibit low trait anxiety because they use a repressive

coping style. The investigators validated their four-fold group distinction by employing

physiological and behavioral measures of anxiety. They hypothesized that repressors would (1)

report significantly less cognitive than somatic anxiety (2) and display discrepancies between

their self-perceptions and objective recordings of physiological and behavioral indices of

anxiety.

Participants were presented with a phrase association task. The instruction was to

complete phrases as quickly as possible with whatever came to mind. Results show that

repressors had low self-reported anxiety after the stressful task. They reported significantly less

anxiety than even the low anxious participants. However, their physiological and behavioral

measures of anxiety indicated that they were as stressed as the high-anxious participants. On the

other hand, low-anxious participants were low on self-report, physiological, and behavioral measures of anxiety. When the investigators asked participants to describe in a few words the most "outstanding or important characteristics" of their personality, repressors almost always emphasized self-control or some appropriate standard of behavior, and the experience of negative affect was often excluded from their self-concept definition. Weinberger at al. remarked "they clearly value a rational, non-emotional approach to life." In contrast, low-anxious individuals displayed openness to experience and interpersonal relationships.

Repressors' physiological reactivity was found to be equal to or greater than that of the high-anxious subjects. They responded with significantly greater increases in forehead muscle tension than either the high-anxious or the low-anxious groups. Their increases in palmar sweat gland activity and heart rate were equal to those of the high-anxious participants and were significantly greater than those of the low-anxious participants. Furthermore, in responding to the phrase associations, repressors had significantly more verbal interference than the low-anxious group, with the high-anxious group falling in between. They also responded significantly more slowly than the low-anxious participants and were especially slow in responding to sexual and aggressive phrases. High-anxious subjects adjusted to the task and responded more quickly over time. Conversely, repressors did worse over time and showed substantial sensitization.

Schwartz (1990) indicated that had the true low-anxious and repressive subjects been combined into the typical low-anxiety group, the average of the true low-anxious subjects' response times and the repressors' response times would appear artifactually indistinguishable from the high-anxious groups. Additionally, the low-anxious group would appear to show

sensitization over the course of the experiment rather than the relatively quick response latencies they exhibited. For Schwartz, the breakthrough in this study was twofold (1) it distinguished between truly low-anxious and repressors, thereby shedding light on the confounding use of low-anxious control groups in the literature (2) and it confirmed that the Marlowe-Crowne Social Desirability scale taps into self-deception as well as impression management.

Theories of the Repressive Adaptive Style

The repressive adaptive style was explained from three main theoretical perspectives. It was construed from a socio-emotional and psychodynamic perspective that focuses on the motivation for maintaining a repressive style of adaptation and on the cognitive-emotional dissociation involved in the repressive defense style (i.e., Weinberger's theory of repressive coping style). The repressive adaptive style was interpreted in a bio-physiological framework that highlights homeostatic disregulation and heightened physiological arousal (i.e., Schwartz's repression-disregulation-disorder theory). Finally, the repressive coping style was explained from a cognitive perspective emphasizing cognitive biases (i.e., Eysenck's cognitive theory of repression). All three perspectives represent different aspects of the repressive style of adaptation. Consequently, the theories related to each of these perspectives complement each other and converge scientifically to provide an emotional, cognitive, and biological conceptualization of the repressive defense style. A section on emotions and unconscious cognitive processing is inserted as an explanation to the emotional and cognitive processes referred to in Weinberger's theory.

Weinberger's Theory of the Repressive Defense Style

In subsequent writings, Weinberger (1990) defined what he calls a "repressive coping style" and alternatively "repressive defenses." Accordingly, individuals who exhibit a repressive style of coping with stress tend to fail to recognize their own affective responses, consider maintaining low levels of negative affect as central to their self-concept, and consequently engage in a variety of strategies "to avoid conscious knowledge of their genuine reactions." That is, repressors display an observable dissociation between emotions and cognition. Because Weinberger conceptualized repression as a defense mechanism, he also theorized that it takes place out of conscious awareness. For Weinberger, the fact that repressors employ cognitive strategies to convince themselves that they are not prone to negative affect, but that their behaviors and physiology indicate the contrary, is central to claiming the existence of unconscious processes.

Weinberger's conceptualization of the repressive defense style is rooted in Freud's conceptualization of repression. Repressors' motivation to avoid awareness of negative emotions originates in the psychoanalytic tradition where it is assumed that information is repressed because it is not compatible with a conscious belief about self. Likewise, Weinberger (1990) argued that individuals with repressive defense styles avoid awareness of affects and impulses that are incompatible with their self-image. However, it is important to highlight that Weinberger's theoretical concept and empirical findings are set within a larger socio-cognitive framework. That is, Weinberger abstracted the Freudian defense of repression out of its (1) instinctual-drive metatheory and re-situated it in (2) the socio-cognitive metatheory of information processing where it is more amenable to empirical examination and validation.

Emotions and Unconscious Cognitive Processing

The information-processing metatheory of cognition studied the concept of the unconscious within a cognitive framework and through a series of experimental studies. Most cognitive psychologists agree that unconscious information processing is qualitatively different from conscious information processing (Reisberg, 2001). For example, in unconscious processing all possible meanings of an input are activated and processed in parallel and sensory input automatically activates a variety of different pathways in the nervous system (Reisberg, 2001).

Unconscious processing allows for rapid responses to a variety of stimuli that are potentially threatening to the organism (Lang, 1985). It is therefore intrinsically tied to action disposition (i.e., motoric activity and autonomic responses) and to emotions: the subjective experience of emotions has been conceptualized to be the result of the processing of action-disposition information combined with information processed from the environment (Safran & Greenberg, 1998). This synthesis of information is assumed to take place at an unconscious level.

Neuropsychological evidence supported cognitive studies of unconscious processing by showing that sensory messages can be transmitted directly to regions of the limbic systems without being relayed through the neocortex (Smock, 1999), and that emotions emanate, in part, from subcortical centers that are semiautonomous from verbal information processing, which partly account for conflicts between what we feel and what we know (Smock, 1999).

Information-processing theories emphasize meaning as the main function of the unconscious. Meaning is appraised through the action-disposition that environmental information evokes in us and therefore, the unconscious is endowed with a survival value that

guarantees the perception and processing of information that the conscious mind could not focus on due to its restricted processing ability (Neisser, 1967). In cognitive theory, the unconscious is a bridge between the external world and the conscious mind. This conceptualization of the functional role of the unconscious points to the informational value of emotions when fully synthesized into awareness, and explains why psychological problems can result from a failure to process emotional information into awareness (Safran & Greenberg, 1998).

Schwartz and Kline (1995) postulated that, in the repressive adaptive style, the vital and adaptive feedback loop between affect and cognition is interrupted, in such a way that the two processes are no longer mutually regulating and synthesis of emotions at a conscious level is impaired. Disregulation of the organism occurs therefore out of conscious control. Inhibition of the emotional and thus, informational content of stimuli disrupt the interaction between organism and environment as well as between mind and body. A state of disorder may develop, thereby leaving the individual prone to disease development and with a poorer prognosis in already established health conditions.

Schwartz's Repression-Disregulation-Disorder Theory

According to Schwartz (1990), a disregulation of homeostatic mechanisms is at the origin of excessive physiological arousal in the repressive personality style. Disregulation itself is assumed to result from an inhibiting, avoidant cognitive style that produces disconnection between feedback mechanisms. That is, the normal homeostatic process of arousal followed by a return to baseline levels is altered by continued cortical inhibition or inattention to physiological signals that causes lower level physiological systems to enhance signal strength. Hyperarousal of

autonomic responses is accompanied by a failure to return to baseline levels. A state of disorder propitious to disease formation may ensue.

Disregulation can take the form of chemical imbalance, with high levels of endogenous opioids masking physiological signals of distress arising in the body, thereby preventing repressors from attending to physiological information. It can also take the form of a disconnection between cerebral hemispheres, whereby nonverbal, autonomic information emerging from the right hemisphere is not processed verbally by the left hemisphere. It is known that the right hemisphere is the principal receptive organ for sensory impressions that arise from one's body (Joseph, 1982). It also mediates emotional arousal and nonverbal expression whereas the left hemisphere "translates" and organizes nonverbal incoming information from the right hemisphere (Joseph, 1982). When information from the right hemisphere is weakly available for interpretation, speech areas select the most probable interpretations and express those that have the most strength. Incorrectly interpreted endogenous or exogenous information may result, giving credence to the hypothesis of a cognitive interpretative bias in the repressive adaptive style (Eysenck, 2000).

Eysenck's Cognitive Theory of the Repressive Adaptive Style

Eysenck (2000) criticized Weinberger's theory for including little information about the cognitive processes involved in the repressive style of adaptation. Eysenck distinguished between four cognitive biases: (1) selective attentional bias: The tendency to attend selectively to potentially threatening stimuli (2) opposite attentional bias: The tendency to avoid attending to potentially threatening stimuli (3) interpretative bias: The tendency to interpret ambiguous stimuli in a threatening fashion (4) opposite interpretative bias: The tendency to interpret stimuli

in a non-threatening fashion. All the biases in this theory are assumed to involve processes operating below consciousness (Eysenck, 2000).

Repressors are defined as individuals who possess an opposite attentional bias and an opposite interpretative bias. Eysenck hypothesized that repressors avoid attending to their own behavior and physiological activity and interpret their own behavioral information and physiological signals in a non-threatening manner. They also selectively avoid attending to negative information in long-term memory and interpret such information in a non-threatening fashion.

In neuropsychological research, some studies suggested that emotions are differentially processed by the two cerebral hemispheres. The left hemisphere is preferentially activated by stimuli with positive emotional valence and adds a positive cast to stimuli it receives. The right hemisphere is preferentially activated by stimuli with negative emotional value and adds a negative cast to the stimuli it receives (Altemus, Wexler, & Boulis, 1989). These findings seem to confirm Eysenck's but also Weinberger's and Schwartz's hypotheses of a cognitive style oriented toward avoiding distressful stimuli and favoring positive causal interpretations in the face of distressful stimuli.

The Repressive Adaptive Style as a Process of Adaptation

Lazarus and Folkman (1984) defined coping as intentional physical or mental actions that are directed toward external circumstances or internal states and that vary depending on the type of stressor. According to Lazarus and Folkman's model of coping, once a situation has been appraised as stressful, individuals engage in two types of coping responses: they resort to emotion-focused and/or problem-focused strategies to face situational demands. Problem-

focused strategies attempt to modify the demands of the situation or to increase the personal and environmental elements to face it. Emotion-focused strategies attempt to diminish or alleviate the psychological or emotional impact of the stressful situation. Other authors differentiated approach responses from avoidance responses. Approach responses entail actions that seek to transform the stressful situation or to manage stress. Avoidant responses, on the other hand, avoid dealing directly with the source of stress, preferring to engage in denial or distracting activities (Altshuler & Ruble, 1989).

In the last decade, researchers criticized binary definitions of coping as too simplistic and highlighted that , although widely used, Lazarus and Folkman's definition of coping represents only one aspect of coping i.e., conscious and goal-directed processes (Fournet et al.,, 1998). Eisenberg, Fabes, and Guthrie (1997) argued that coping is not always conscious and goal directed, but that it also includes regulatory processes that are automatic and self-regulatory. Eisenberg et al. remarked as well that coping research needs to be integrated with research in the biological bases of reactivity.

Some researchers attempted to elaborate on the definition of coping by incorporating automatic and dispositional-based responses to stress. For example, Skinner and Wellborn's (1994) model of coping differs from Lazarus and Folkman's model in that coping is dichotomized between voluntary and involuntary or automatic responses to manage stress. Similarly, Compas, Connor-Smith, Osowiecki, and Welch (1997) developed a multidimensional model of responses to stress by distinguishing voluntary and involuntary responses to stress as primary dimensions. Connor-Smith, Compas, Wadsworth, Harding, Thomsen, and Saltzman (2000) tested Compas et al.'s model using confirmatory factor analyses in three samples of

adolescents reporting on their responses to stress in different domains. The factor structure

identified did not support Lazarus and Folkman's distinction between problem-focused and

emotional-focused coping. That is, problem-focused and emotional-focused coping did not

emerged as primary dimensions distinguishing among coping strategies. Conversely,

confirmatory analyses yielded a two-factor model differentiating between two primary

dimensions of adaptation: voluntary and involuntary responses to stress further differentiated

into engagement versus disengagement response to stress, thereby confirming Compas et al.'s

theoretical premises.

In their model, Compas et al. postulated that coping processes, such as defined by

Lazarus and Folkman, are only a subset of regulatory responses to stress that involves conscious

and volitional efforts to adapt to stressful situations. They proposed that another subset of

regulatory responses to stress is involuntary stress responses that do not involve conscious effort

and are not readily under the individual's control. Involuntary stress responses are rooted in

individual biological and temperamental differences, and they evolve with the normal processes

of development as the individual learn to interact with his/her environment and develop working

models of self and others. Involuntary stress responses can be conceptualized as constituting

individual styles of adaptation to stress. In turn, from Compas et al.'s theoretical perspective,

adaptive style can be construed as involuntary, unintentional, and automatic trait-like responses

to stress.

Compas et al.'s and Connor-Smith et al.'s distinction between coping responses (i.e.,

voluntary stress responses) and involuntary stress responses broadens the definition of coping

into the construct of "adaptational processes." Adaptational processes represent a more dynamic,

dimensional, and multifactorial approach to stress responses that integrates different aspects of the broad set of processes enacted in response to stress.

Weinberger's trait-oriented repression-based adaptive style concept accommodates the definition of a repressive defense style. Cramer and Block (1998) defined psychological defenses as mechanisms that occur unintentionally, without conscious efforts, and out of conscious awareness. When they are used repeatedly over early development, psychological defenses become integrated in the individual's style of adapting to distressful situations or defense style. The definition of defenses is very similar to the definition of involuntary stress responses and both concepts of adaptive style or defense style are to be understood within the larger framework of processes of adaptation.

Whether conceptualized as a defense style or stress-response style, depending on the researcher's theoretical lens, a repressive adaptive style is to be distinguished from coping strategies. This position was supported by empirical data. Phipps and Srivastava (1999) found that, in a population of older children and adolescents with cancer, the repressive adaptive style was unrelated to the coping process of blunting or denial (i.e., awareness of subjective distress but the individual refuses to acknowledge it). Similar results emerged in an adult study where the repressive defense style was found to be a construct independent from avoidant coping (Fuller & Conner, 1990).

The second dimension of engagement versus disengagement from the stressor, or from one's reaction to the stressor, may help us specify the nature of a repressive defense style. According to Weinberger's theory, a repressive adaptive style involves disengagement from one's responses to the stressful situation. Whether or not emotional and cognitive disengagement

is associated with behavioral avoidance in the context of a repressive defense style is still to be investigated. Lack of association between a repressive adaptive style and measures of avoidant coping might indicate that, in the context of a repressive style of adaptation, cognitive and emotional disengagement might be associated with observed behavioral engagement. That is, repressors might disengage from their own reactions to the stressor in order to facilitate approach to or facing the stressor. If this the case, the repressive defense style might be adaptive in allowing repressors to cope with a stressful situation they cannot avoid or change such as chronic illness and its treatment. This assumption has never been investigated.

The Repressive Adaptive Style and Stress and Coping Models

Delineating the function of a repressive adaptive style within the framework of stress and coping models can help us construe its role as a factor of adaptation and its possible impact on children's coping abilities.

Wallander, Varni, Babani, Banis, and Wilcox (1989) developed a model identifying factors that contribute to differences of adjustment in chronically ill and handicapped children. According to Wallander et al.'s model, stress-processing factors moderate the relationship between disease-related stress and child adjustment. Within this model, adaptive style in general and the repressive defense style in particular may be accounted for by the stress-processing factors which *moderate* adjustment outcomes, along with cognitive appraisal and coping strategies. In Thompson, Gustafson, and Gil's (1995) transactional model of stress and coping, the illness-outcome relationship is a function of the transactions of illness parameters, demographic parameters, and mediational processes. Within this model, the repressive defense style may be accounted for by the mediational processes that *mediate* the illness-adjustment

relationship. Depending on the model of reference, the repressive adaptive style can be conceptualized as a mediator or moderator of adjustment.

A model elaborated by Rudolph, Dennig, and Weisz (1995) may help us conceptualize the role of the repressive defense style in the illness-adjustment relationship. Rudolph et al. remarked that existing stress and coping models do not clearly discriminate among various components of the adaptational process. Their model of stress and coping in the medical setting distinguishes coping processes from mediator variables of adaptation, thereby accommodating a more specific representation of the nature and function of a repressive adaptive style in the illness-adjustment relationship. If we conceptualize a repressive adaptive style as one of the adaptational mediator variables distinct from coping responses, it then appears to *mediate* the illness-related stress and outcome relationship as well as *moderate* the mediating effect of coping strategies (see Figure 1). Such a conceptualization is consistent with Compas, Connor-Smith, Saltzman, Thomsen, and Wadsworth's (2001) assumption that involuntary stress responses influence the nature and efficacy of coping strategies and directly mediate the stress-adjustment relationship. Compas et al. postulated that coping strategies "both draw on and are constrained by" individual dispositional tendencies to respond to stress. This theoretical conceptualization of the role of the repressive defense style also reconciles the theoretically differential function assigned to the repressive defense style when plugged in previously described models of stress and coping.

Developmental Perspectives

As a latent dimension of personality, the repressive defense style is assumed to show temporal and cross-situational stability. Extending the repressive defense style construct from the

adult to the adolescent literature appears to be a logical step toward providing evidence for the stability of the construct from a developmental perspective (Steiner, 1992). Currently, there is no data supporting the hypothesis that the repressive defense style emerges as a response to the diagnosis of a serious or chronic disease. Pediatric studies reported no relationship between time since diagnosis and degree of defensiveness or between time since diagnosis and categorization as repressor versus non-repressor. Overall, pediatric studies evidenced stability of the repressive adaptive style one year following a diagnosis of cancer (Phipps & Srivastava, 1997; Phipps & Srivastava, 1999; Phipps, Steele, Hall, & Leigh, 2001). In Fritz et al.'s study involving two psychometric paradigms, classification remained stable over the course of one year with a temporal stability of 95% using anxiety as repressed affect and 96% using anger as repressed affect. Phipps and Srivastava's adaptive style classification among children with cancer remained stable over one year following diagnosis, and time since diagnosis was not found to be related to adaptive style classification. Lastly, Phipps et al. showed that adaptive style classification among children with cancer and children who are chronically ill remained stable over four weeks, six months, and one year following diagnosis.

The assumption that a repressive defense style represents a stable component of personality is most probable at this point, but it does not imply its role in the etiology of chronic illnesses (Phipps & Srivastava, 1999). Prospective longitudinal studies are needed to empirically investigate the genesis of a repressive adaptive style over time in typical populations and to examine possible changes in response to the illness experience.

Temperament

As a personality style, the repressive adaptive style can be linked to the temperamental constructs of reactivity and self-regulation. The reactivity dimension of temperament helps us understand the possible genetic-constitutional origins of the repressive defense style. Reactivity encompasses individual differences in physiological responses to stress (i.e., high physiological reactivity for repressors) which have been conceptualized along the dimensions of cardiovascular and neuroendocrine responsiveness (Rothbart & Ahadi, 1994). The temperamental construct of self-regulation helps us understand the role of high levels of defensiveness among repressors. From temperament theory, repressors attempt to self-regulate high emotional responses by inhibiting internal signals of distress (Rothbart & Ahadi, 1994).

Attachment and social learning theories

According to Bowlby, on the basis of early experiences with caregivers, children construct cognitive-affective schemas of self and others which guide affect regulation, form self-image and shape habitual patterns of response to distressing situations (Bowlby, 1979). During child-caregiver interactions, the child learns parents' expectations regarding the experience of negative emotions (Rothbart & Ahadi, 1994). Some types of parental responses to children's emotional expression are linked to emotional suppression in children (Jamison, Lewis, & Burish, 1986). Some parents may disapprove, invalidate, or minimize their children's natural emotional responses to distressing situations (Jamison, Lewis & Burish, 1986). They may also disconfirm their children's observations and appraisal of events (Valiente, Fabes, Eisenberg, & Spinrad, 2004). When children are negatively sanctioned for their expressions of negative emotions, they may feel overwhelmed by their own emotions and may not learn to cope with them constructively (Valiente, Fabes, Eisenberg, &

Spinrad, 2004). Moreover, parents who do not express negative emotions in front of their children may not give them an opportunity to learn how to cope with them and may also teach these children that negative emotions are not acceptable (Valiente, Fabes, Eisenberg, & Spinrad, 2004).

Freud observed that repressive defenses are associated with families that de-emphasize conflict and emotion (Steiner, 1992). Some empirical evidence among adolescents suggests that repressors' families present features similar to the "psychosomatic family" described in family systems research. Steiner investigated repressors' family environment in a group of adolescent psychiatric patients diagnosed with eating disorders, mood disorders, somatization disorders, identity disorders, and anxiety disorders. Adolescent repressors described their families as high in cohesion and togetherness and low in conflicts. Repressors also indicated that their families place low emphasis on achievement, that they are less affected by external influence, and that they tend to reward conformity and ignorance of conflicts when contrasted with other groups. Altogether, enmeshment, conformity, and conflict avoidance stood out as salient features of repressors' family functioning. This type of family functioning was found to avoid the expression of distress as well as the resolution of conflicts (Minuchin, 1974; Steiner, 1992). Interestingly, Steiner observed that family members corroborated patients' self-reports and reported lower child-parent discrepancies than published norms, thereby substantiating the importance of conformity in these families.

Parental invalidation of emotional expression is associated with an avoidant-insecure attachment style (Jamison, Lewis, & Burish, 1986). Mikunlincer, Florian, and Weller found that people with an avoidant attachment style express anxiety through increased somatization, maintain emotional distance, deny their insecurity, and devaluate the importance of events that

may cause painful feelings (Mikulincer, Florian, & Weller, 1993). Mikulincer and Orback (1995) examined differences in attachment styles with respect to differences in emotional regulation and found that people with an avoidant style of attachment inhibit accessibility to unpleasant emotional memories and use high levels of defensiveness to protect against the experience of negative affect. Mikulincer (1995) reported that teenagers with an avoidant attachment style differ from securely attached teens in that they showed low accessibility to negative self-aspects. Cooper, Shaver, and Collins (1998) reported that adolescents with an avoidant attachment style are less depressed, less hostile, more academically able, less socially competent that securely attached children. Adolescents with secure and avoidant attachment styles did not differ on the majority of risk or problem behaviors. However, whereas low level of involvement in risk behaviors appeared to reflect securely attached adolescents' psychological health, among teenagers with an avoidant attachment style, it appeared to stem from anxiety and social deficits. Cooper et al. interpreted their findings in terms of differences in styles of experiencing, expressing, and regulating negative emotions between both groups.

Converging evidence from the attachment literature seems to link repressive adaptive style and avoidant attachment style. In the context of pediatric populations, drawing a parallel between repressive adaptive style and attachment style is all the more relevant as illness was reported to activate the attachment system (Feeney, 2000). In the context of illness, a repressive adaptive style may be adaptive so as not to risk distancing or alienating significant others or peers (Feeney, 2000). It may also be maladaptive because it may prevent the child from relying on familial or peer support systems to cope with the stresses of the illness.

Empirical Studies the Repressive adaptive Style in Adults Populations

According to Weinberger, a repressive defense style involves cognitive inhibition of distressing internal cues outside of the individual's conscious awareness. Repression of distress signals is motivated by the individual's fear of social rejection and the need to protect his/her self-image from emotions deemed socially inappropriate. When repression becomes a pattern of adapting to life stress, it is conceptualized as a repressive defense style.

As explained previously, Weinberger, Schwartz, and Davidson identified four groups based on their scores on measures of trait anxiety and defensiveness. One of these groups was called repressors. Weinberger et al. found that, in a laboratory-induced stressful situation, repressors' physiological and behavioral responses were higher than those of low-anxious participants and similar to those of high-anxious participants. However, after the stressful task, repressors reported less anxiety than low-anxious participants.

Subsequent research with adults confirmed and extended these findings, providing support for the main tenets of Weinberger's theory. Adult investigators followed Weinberger et al.'s psychometric paradigm to detect a repressive style of adaptation. That is, individuals scoring at or below the 50th percentile on an anxiety scale and at or above the 75th percentile on a defensiveness measure were typically defined as "repressors." The Marlowe-Crowne Social Desirability scale (MCSDS) was the defensiveness measure of choice in most studies. Explorations of the constructs measured by the MCSDS in adults revealed that self-deception rather than impression management account for the most part of the variability in scores (Barger, 2002; Ellingson & Sackett, 1999; Pauls & Stemmler, 2003).

Self-deception was reported in many investigations as one of the main features of a repressive adaptive style. Adult studies showed that repressors (a) present themselves in a more positive way than non-repressors on self-report questionnaires, (b) believe that negative events are less likely to happen to them, and (c) are genuine about their own self-perceptions when they report experiencing little negative affectivity or arousal (Eysenck & Derakshan, 1999; Eysenck & Derakshan, 1997; Myers & Reynolds, 2000).

Adult experimental data also evidenced the existence of inhibiting cognitive processes and biased information processing of unpleasant emotions and sensations among repressors (Calvo & Eysenck, 2000; Newman & McKinney, 2002). Moreover, adult repressors were found to be less sensitive to pain than non-repressors, suggesting that inhibition of internal signs of distress encompasses both psychological and physical pain (Jammer & Leigh, 1999).

Many researchers explored the impact of the repressive adaptive style on health among adult populations. Adult empirical studies demonstrated that repressors' experience intense physiological and behavioral reactivity during stress-inducing experimental situations (Boden & Dale, 2001; Newton & Contrada, 1996) and that their autonomic arousal is similar to that of high-anxious participants (Derakshan & Eysenck, 1997). From a mind-body perspective, adult researchers showed that self-reports of low distress, intense physiological and behavioral reactivity, and biased information processing form a maladaptive combination that places adult repressors at risk for health problems (Barger, Marsland, Bachen, & Manuck, 2000). That is, (1) adult repressors' health indices revealed a biochemical makeup associated with the development of chronic and serious health conditions (i.e., high blood pressure, impaired immune functions, high levels of glucocorticoids, and high levels of blood lipids) (Barger, Marsland, Bachen, &

Manuck, 2000; Brown, Tomarken, Orth, Loosen, Kalin, & Davidson, 1996; Esterling, Antoni ,

Fletcher, Margulies, & Schneiderman, 1994; Jammer & Leigh, 1999) and (2) empirical studies

among patients already diagnosed with cancer, HIV, multiple sclerosis or other serious

conditions indicated that repressors exhibit a worse progression of disease, more recurrences,

and more elevated mortality than non- repressors (Flowers, Armentrout, Booraem, Kraft, Maddi,

& Wadhwa, 1995; McKenna, Zevon, Corn, & Rounds, 1999; Vindel, Sirgo, & Manga, 1994).

The Repressive Adaptive Style in Childhood

Applying an adult construct to childhood raises the issue of its generalizability. Possible

developmental variations in the clinical and construct validity of defensiveness over time deserve

more investigations. In childhood, there is a risk of confounding self-deception with the capacity

to have insight into one's internal states and, therefore, to recognize and label feelings. Existing

studies of a repressive adaptive style in childhood (see chapter 2) considerably reduced the risk

of a confound with introspective ability because most studies comprise samples in the adolescent

age range. A few studies included children aged 7, but it is the minimum age limit that was

found. For the most part, the repressive adaptive style was investigated among children who had

reached the formal operations stage of cognitive development (11 years old and older). The

emergence of formal operational thinking allows the adolescent to realize the significance of

chronic and serious illnesses and to carry out internal introspections into their feelings and

motivations (Harbeck-Weber & Peterson, 1993).

In children, the repressive adaptive style was mostly investigated among pediatric

populations. Pediatric studies adhered to Weinberger et al.'s (1979) paradigm consisting of the

interaction between a measure of distress and a measure of defensiveness to categorize

repressors. Adolescent repressors were found to exhibit characteristics similar to those identified among adult samples (i.e., self-deception, biased self-reports, and inhibition of signals of distress). However, only one study focused on young repressors' autonomic reactivity and no study investigated the impact of a repressive adaptive style on patients' health.

Conclusion

The presence of a subgroup of children using a repressive style of adaptation among pediatric patients with IBD was hypothesized by Wood et al. (1987). More recently, Loonen, Derkx, Koopman, and Heymans (2002) also argued that discrepancies between parents' reports and patients' reports of adjustment may be explained by a repressive style of adaptation. In this study, I investigate the presence and features of a repressive style of adaptation among adolescents diagnosed with IBD.

The developmental stage of middle and late adolescence was chosen as a basis for selecting study participants because (1) the incidence of IBD was reported to peak in adolescence (2) adolescents' cognitive maturity allow them to have insight into their own feelings and behaviors and to understand the multifactorial nature of their illness (3) adolescents are in the process of forming both an identity and their own intrinsic way of facing life challenges and (4) chronic illness, especially IBD, presents many challenges to the developmental tasks of adolescence, including identity formation, social and emotional independence, body image formation and acceptance, and reliance on peer relationships.

This investigation is concerned with the proportion of adolescents with a repressive adaptive style among pediatric patients with IBD, the impact of a repressive coping style on

patients' physical and psychological well being, and the possible concurrent operationalization

of a repressive adaptive style using depressive feelings and anger as repressed affects.
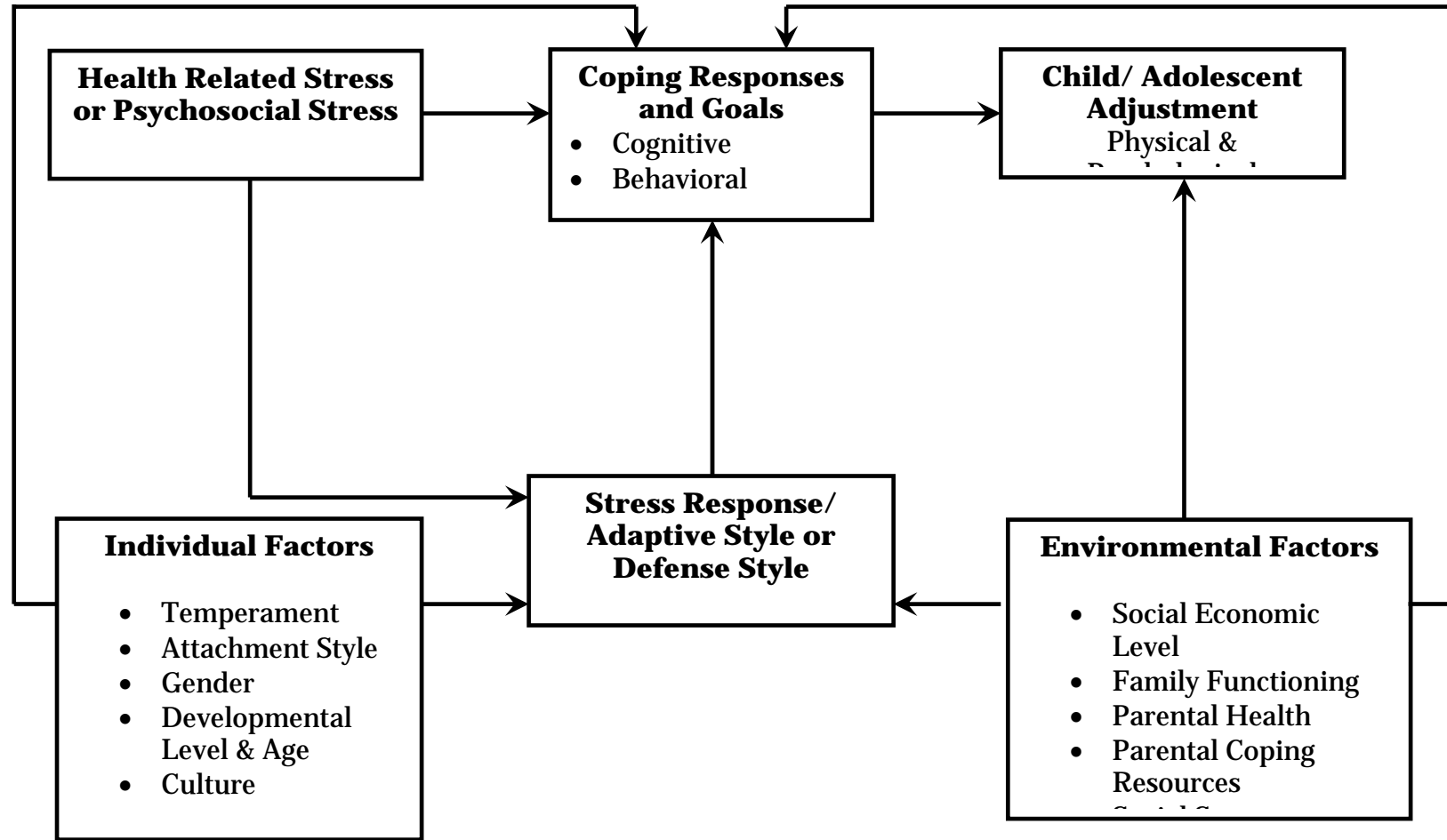
Figure 1. The repressive adaptive style as mediator of the stress-adjustment relationship and moderator of coping responses

CHAPTER II

A REVIEW OF THE LITERATURE

The purpose of this chapter is to review empirical findings related to (1) the psychological adjustment of children and adolescents with IBD (2) the quality of life of pediatric patients with IBD and (3) the repressive adaptive style in pediatric populations. The literature summary related to the psychological functioning of pediatric patients with IBD encompasses various psychosocial constructs studied in relationship to pediatric IBD i.e., depression, anxiety disorders, behavioral functioning, life stresses, locus of control and coping. The literature review focused on health-related quality of life is intended to provide information about the impact of IBD on patients′ daily functioning and their subjective experience of the illness. The section dedicated to empirical findings on the repressive adaptive style in childhood and adolescence reviews exclusively studies that used Weinberger et al.′s paradigm in the assessment of adaptive style. Finally, a final section of this chapter presents the purposes of my project and the hypotheses that motivate it.

Psychological Adjustment of children and adolescents with IBD

Inflammatory bowel disease (IBD) has historically been categorized as "psychosomatic in origin" (Hogan, 1989). This assumption led to a body of literature attempting to demonstrate that psychological dysfunction plays a main role in the etiology of IBD (Rustgi, Wise, & Boyle, 1985). Studies focused on the psychogenesis of IBD were motivated by a search for a primary etiological agent. They were framed within a bio-medical model, relying on unilinear and

unidirectional cause-effect interactions between mind and body (Schwarz & Blanchard, 1990).

From the beginning of the seventies on, the underlying unilinear and causal perspective gave

way to studies developed within a biopsychosocial model (Camic & Knights, 1997) especially in

the pediatric literature on IBD (Wood et al., 1987). The biopsychosocial model assumes

multifactorial, bi-directional, and indirect as well as direct causal mechanisms (Camic &

Knights, 1997). In this model, biological-physiological, psychological-behavioral, and socio-

environmental factors are conceptualized to interact in a complex and intrinsic fashion,

depending on the physiological condition under study (Camic & Knights, 1997).

To date, hypotheses regarding the etiological role of psychological factors in IBD have

not yet been established, mainly because they are difficult to test (North & Alpers, 1994). For

this same reason, it is unlikely that psychosomatic etiological hypotheses will ever be disproven.

Nevertheless, the fact that none of the currently available medications is able to prevent

recurrences of the disease indicates that factors other than medical ones may influence the course

of the illness (Greig & Rampton, 2003). Additionally, many studies agree with the fact that

greater functional impairment occurs in the psychological and social dimensions than in the

physical dimension in IBD (Drossman et al., 1991). This suggests that to fully understand the

impact of IBD on the patient, the clinician must elicit the degree of psychological as well as

physical impairment. It goes without saying that, for the reasons just mentioned, considerable

discussion continues regarding the role of psychological variables in the ongoing disease process

(North & Alpers, 1994).

The following literature review encompasses the major research contributions to the

understanding of mind-body relationships in pediatric IBD. Reviewed investigations were

located through PSYCHINFO or MEDLINE and include studies published from the 1980′s up to

now. Earlier investigations are mentioned briefly to situate previous knowledge and

understanding on the mind-body dynamics in pediatric IBD. The existing literature about the

psychological adjustment of children and adolescents with IBD consists of an array of studies

covering a broad range of psychological concepts such as affective disorders, behavioral

functioning, self-esteem, locus of control, coping, and life stresses. These studies are not easily

grouped or described within a broader theoretical framework but rather represent a collection of

individual findings that accumulate over time.

Early Investigations of Psychosocial Variables

Early studies strove to understand the mechanisms by which the mind could induce the

body into exhibiting organic dysfunction. Framed within a psychoanalytic perspective, these

studies were based on the hypothesis that abnormal colonic structure and function was caused by

an ambivalent attachment bond with the mother, resulting in hostile reactions from the child as

well as a fixation at an anal stage of development. Intense negative emotions turned inward on a

vulnerable intestinal system were thought to induce IBD symptoms.

Sperling (1946) identified IBD as an outlet for anger and psychological pain. Based on

her experience in working with children suffering from IBD, she noted that the condition

resembles depression in behavior and in personality structure and dynamic. However, Sperling

differentiated both conditions on the ground that in depression, internalized aggression is

manifested by an attack of the superego on the ego, whereas in IBD the attack is aimed at the

organism. In other words, Sperling perceived IBD as the somatic expression of conflict and

frustration and as an attempt by the body to free itself from the accumulated anger. Prugh's

(1950, 1951) laboratory experiments confirmed Sperling's analysis. Prugh showed that by

experimentally inducing angry emotions in pediatric patients with IBD, he obtained an activation of the colonic response.

Early pediatric studies of psychosocial variables in IBD were criticized because they relied on selected samples, included unreliable diagnosis, and did not utilize control groups. Some studies even included patients with Irritable Bowel Syndrome rather than IBD in their samples (North, Clouse, Spitznagel, & Alpers, 1990). Nonetheless, these researchers opened the door to a description and understanding of possible mind-body mechanisms at the origin of IBD (Levenstein, 2002; Steinhausen & Kies, 1982).

Depression

In a group of 17 pediatric patients with IBD, 60% of the patients fit the criteria for major emotional disturbance according to ICD-9 (no specific definition of emotional disturbance is provided by the authors). Among clinical variables, radiological and histological data and frequency of relapses were not associated with psychopathology. Only growth retardation correlated positively with psychopathology. Because growth retardation is a secondary effect of the disease, the results suggest that psychopathology may be secondary to symptomatology. Importantly, all the children in the IBD group were medicated with corticosteroids, therefore indicating that affective difficulties might also have been secondary to medication (Hanauer et al., 1998). These results were replicated in a study investigating the psychological adjustment of pediatric patients with IBD with the addition of a teacher questionnaire (Steinhausen, 1988). Teachers′ ratings supported the above findings of high rates of emotional disturbances among children and adolescents with IBD.

In a group of 20 children and adolescents with IBD, the above findings were once again replicated. That is, 60% of the patients were diagnosed with a psychiatric disorder according to

the DSM-III-R criteria as compared to 15% of the typically developing children in the control group (Engstrom & Lindquist, 1998). Depression and anxiety were the most frequent disorders. There was a trend for more frequent psychiatric disturbances in patients with UC than in patients with CD. No statistically significant association was found between psychiatric disorders and disease severity or disease duration. However, earlier onset of IBD was associated with more psychological difficulties than later onset.

Engstrom (1999) also found that a majority of children with IBD (i.e., 60%) met criteria for a psychiatric disorder according to DSM-IV, which was significantly more than in the two other groups of children with chronic illnesses (i.e., diabetes and tension headache) and a group of healthy controls. Psychiatric disorders clustered around depression and anxiety. Moreover, the IBD group self-reported higher rates of depressive symptomatology than the healthy group and the group of children with diabetes but their scores were comparable to pediatric patients with headache.

The psychological functioning of 24 children diagnosed with CD and 20 children diagnosed with UC was compared to the psychological functioning of a group of children with non-organic abdominal pain and a group of healthy controls (Raymer, Hamilton, & Weininger, 1984). Depression scores were higher in both patients with CD and patients with UC than in healthy controls. There was no significant difference between children with recurrent abdominal pain and children with IBD on depression scores, suggesting that depressive symptoms do not discriminate between organic and non-organic abdominal pain. It is noteworthy that all the children in the IBD group were receiving treatment medication with steroids whereas non-organic sick children were not.

Burke et al. (1989) suggested that depression and anxiety may reflect the psychological impact of the change in lifestyle as well as of the physical changes induced by the disease and treatment. They listed three other possible causes of depression inherent in the physiological changes brought about by IBD. They are (1) foliate deficiency, which has been implicated in the pathogenesis of depression. (2) malabsorption of tryptophan and tyrosine, precursors to serotonin and dopamine (3) and treatment with corticosteroids. Burke et al. investigated the prevalence of depression in a group of children and adolescents with IBD as compared to a group of children and adolescents with cystic fibrosis (CF). Children with CD were found to have a higher accumulated prevalence of major depression than did children with CF and no patients were found to have a history of depression predating their illness. Conversely, children with UC demonstrated an accumulated greater prevalence of dysthymia when compared to the groups with CD and CF. At the time of assessment, similar results emerged with higher rates of depression among patients with CD than among patients with UC or CF, and higher rates of dysthymia among patients with UC than in the other groups.

Preliminary findings on depression among 13 children newly diagnosed with IBD revealed that 3 were diagnosed with major depression shortly after diagnosis (Burke, Kocoshis, Chandra, Whiteway, & Sauer, 1990). Children with depression were among the least severely ill individuals, indicating that disease severity and severity of depression were inversely related. Results also suggested that steroid use and severity of illness were not related to the development of depression, at least at the onset of IBD: none of the three depressed children was treated with steroids whereas 7 of the 10 children who were not depressed were receiving 25 to 60 mg of corticosteroids per day. Depression, on the other hand, was found to be significantly associated with life events and maternal depression.

In a follow up study, Burke, Neigut, Kocoshis, Chandra, and Sauer (1994) found that out of the 36 children with IBD assessed shortly after diagnosis, 5 were given a diagnosis of major depression and 10 were given a diagnosis of atypical depression. Only one patient had exhibited depressive symptoms before the onset of IBD. Depression was diagnosed only if sufficient symptoms were present to allow diagnosis without reliance on symptoms that could be symptoms of the illness. None of the children were treated with steroids at the time of the study and depressed children were found to be among the less severely ill children.

 Szajnberg, Krall, Davis, Treem, and Hyans (1993) also assessed for psychiatric disorder in a group of 15 children with IBD (11 with CD and 4 with UC). Eleven children were found to have DSM-III diagnoses and 6 had more than one diagnosis. Diagnoses included separation anxiety (n=6), major depression (n=3), phobias (n=4), obsessive-compulsive disorder (n=3), overanxious disorder (n=2), and panic disorder (n=1). The Rorschach measures indicated a high level of constriction, anxiety, and depression and revealed an increased use of intellectualizing defenses as well as a large amount of repression and denial.

In a group of 102 adolescents with IBD, 25 self-reported a score superior to 12 on the Children Depression Inventory (CDI) and 31 reported a score superior to 9 (Szigethy et al., 2004). Further evaluation revealed that 16 met criteria for a diagnosis of affective disorder with comorbid diagnoses including anxiety disorders and one diagnosis of eating disorder. Scores on the CDI were associated with age at diagnosis, with later onset IBD being associated with greater depressive symptomatology. Conversely, there was no statistically significant association between disease severity and depressive symptoms, and there was no difference in mean scores on the CDI between acute disease, chronic intermittent disease, or chronic disease course. However, male adolescents with moderate or severe disease reported more depressive symptoms

than male teen patients with inactive disease. These results were not true for female patients or for patients with mild disease. An analysis of male patients′ reports showed that differences of depressive symptoms between moderate/severe and inactive disease were due to scores on three items: anhedonia, fatigue, and decreased appetite, which are directly related to the physiological impact of disease activity.

Overall, an increased prevalence of depression was reported among children and adolescents with IBD as compared to typically developing children and adolescents and to pediatric patients with other chronic illnesses. In all reviewed studies, level of psychopathology was found to be unrelated to disease severity or activity as measured by medical indices, and in three studies the most depressed patients were the least severely ill. Contrary findings related to the association between age at diagnosis of IBD and psychopathology appeared: Engstrom and Lindquist (1991) found that earlier age at onset was associated with more psychological problems whereas Szigethy et al. (2004) reported that later onset of IBD was associated with greater depressive symptomatology. Finally, a trend for patients with CD to exhibit more depressive symptoms than patients with UC was found. There is no agreement about whether or not depressive symptoms and disorders preceded a diagnosis of IBD.

Anxiety

Burke et al. (1989) found no difference in the prevalence of anxiety disorders between children and adolescents with IBD and children and adolescents with Cystic Fibrosis. A trend for phobic disorders to be more frequent in patients with UC than in patients with CD was found but the lifetime prevalence of other anxiety disorders was similar between both groups. In most cases, the anxiety disorder predated the onset of IBD whereas no patients had been depressed before the onset of their illness. At the time of assessment, there were higher rates of phobic and

separation anxiety disorders in the group of children with UC than in the group of children with CD or Cystic Fibrosis but these differences did not reach statistical significance. In a follow up study, Burke et al. (1994) found that out of 36 children and adolescents with IBD, 10 were given a diagnosis of anxiety disorder shortly after diagnosis of their illness. With the exception of two cases, anxiety disorders preceded the diagnosis of IBD. Finally, as described before, Szajnberg et al. (1993) found that among 15 pediatric patients with IBD, 8 patients met criteria for an anxiety disorder diagnosis.

Children and adolescents with UC self-reported more obsessive compulsive symptoms than children and adolescents with CD, but both patients with UC and CD self-reported similar rates of obsessive compulsive symptoms than a group of patient with Cystic Fibrosis. None of the patients met criteria for a diagnosis of obsessive compulsive disorder (Burke, Meyer, Kocoshis, Orenstein, Chandra, & Sauer, 1989).

Results related to the prevalence of anxiety disorders and symptoms suggest that IBD pediatric patients exhibit more anxiety difficulties than healthy children but no more than pediatric patients with Cystic Fibrosis. Contradictory results appear about whether or not anxiety preceded a diagnosis of IBD. A trend for patients with UC to present more anxiety difficulties than patients with CD was found.

Behavioral Functioning

Parents of pediatric patients with IBD reported higher total scores on the Children′s Behavior Checklist (CBCL; Achenbach, 1983) than parents of healthy controls and than parents of children with diabetes (Engstrom & Lindquist, 1991; Engstrom, 1999). Higher parent ratings for children with IBD were statistically different from healthy children and patients with diabetes on both the internalizing and externalizing scales, with no differences in scores for patients with

CD and UC (Engstrom & Lindquist, 1991; Engstrom, 1999). However, scores of the IBD groups were comparable to the headache group. Engstrom found both externalizing and internalizing psychological subscales of the CBCL-Parent to be elevated among children with IBD and he did not report a significant difference between UC and CD functioning. The fact that the scores of the tension headache group and the IBD group were similar on most instruments points to the unpredictability of both diseases, characterized by sudden recurrences and remissions varying in length and intensity, as major factors in the etiology of psychological distress.

Other findings from Engstrom's study indicate striking discrepancies between child and mother reports. Children with IBD reported an almost normal well-being whereas their mothers reported the lowest wellbeing for their children. These discrepancies were not found in the healthy group or among children with diabetes. Another interesting finding was provided by the Lie scale in the Reynold Children Manifest Anxiety Scale, where children with IBD scored significantly higher than the three other groups. These results may indicate that these children have a greater tendency to deny their problems, a finding that has been reported by several authors (Schmitt, 1970; McMahon et al., 1973; Wood et al., 1987; Drossman et al., 1991). Engstrom reported that many of the children with IBD were difficult to interview and that their answers were short, concrete, and "relatively unemotional." According to Engstrom, many of the children denied that IBD had any impact in their lives. He concluded his observations by writing: "However, it is worth noting than in the medical files, where psychological comments are rare, about half of the children with IBD were described as "dissimulating."

In another study, children and adolescents with IBD self-reported more behavioral difficulties on the CBCL than their siblings and normative means (Wood et al., 1987). Parents of patients with IBD completed the parent form of the CBCL and discrepancies emerged between

patients' with CD self-ratings and their parents' ratings especially on the social competency subscale. These discrepancies did not hold true for the group of patient with UC. On a measure of perceived competence, parent-child discrepancies were also evident for the group of patients with CD especially regarding social and emotional aspects of functioning. Children and adolescents with CD attributed personal strengths and weaknesses primarily to the cognitive domain while parents emphasized difficulties with social competence and emotional expression.

In Wood et al.'s investigation, the pattern of results on the CBCL also revealed that patients with IBD displayed an internalizing, over-controlled psychological style. When behavioral ratings were compared to level of disease activity, it was found that level of disease activity and level of behavioral dysfunction do not predict each other. On the other hand, level of disease activity was positively associated with psychological style (i.e., internalizing versus externalizing). That is, the higher the score on the internalizing subscale, the sicker the child was according to medical data (i.e., laboratory indexes). Finally, in the group of patients with CD objective indices of disease severity were not associated with subjective reports of disease severity. However, subjective reports of symptoms were associated with an internalizing psychological style. These findings were not true for patients with UC. Wood et al. hypothesized two possible mechanisms linking psychological style with disease activity. The first involves a negative explanatory style associated with learned helplessness. The other relies on a repressive coping style mediating environmental or health-related stress and organic and mental dysfunction.

Gold, Issenman, Roberts, and Watt (2000) investigated the mental health profile of children with IBD in comparison to children with functional gastrointestinal complaints (FGI). Patients with IBD were found to be well adjusted, not depressed, and with higher than average

self-concept. None of the results on the CBCL feel in the clinical range. All the children in the IBD group were treated with corticosteroid medication and most were in remission at the time of evaluation, which suggests that patients with IBD in remission may compare to normal children regarding psychological wellbeing. However, Gold et al. postulated the possible role of denial in answering self-report scales.

Ondersma, Lumley, Corlis, Tojek, and Tolia (1997) used measures of anxiety, depression, hostility, and positive affectivity (PA), in a sample of 56 adolescents diagnosed with IBD. Expressed hostility resulted to be inversely related to objective measures of disease activity, with expressed hostility being associated with less disease activity and less expressed hostility being associated with more disease activity. In addition, it was found that higher self-reported hostility was associated with worse subjective health. Higher negative affectivity was also related to worse subjective health but it was unrelated to medical indices of disease activity. Finally, positive affectivity was inversely related to subjective health. Overall, negative affectivity was found to be associated to self-report of disease activity whereas the degree of expressed hostility resulted to be unrelated to subjective reports of disease activity but inversely related to objective measures of disease activity.

Altogether, parents′ and self-report ratings on behavioral scales revealed that pediatric patients with IBD exhibit more behavioral problems when compared to normative means, healthy controls, and siblings. Only one group of researchers found pediatric patients with IBD to be well-adjusted in a sample of patients in remission. Engstrom and Lindquist (1991) and Engstrom (1999) found both the externalizing and externalizing scales to be elevated in patients with IBD. Conversely, Wood et al. (1987) reported the internalizing subscale to be the most elevated. In terms of mind-body processes, Wood et al. found that psychological style on the

externalizing-internalizing continuum was associated with disease severity as assessed by medical indexes, with more internalizing style being associated with more disease severity. On the other hand, across studies, level of behavioral difficulties was not found to be associated with disease severity as measured by medical indices but was reported to be related to self-reports of disease severity. Finally, one group of researcher reported expressed hostility to be associated to disease severity as measured by medical indices.

Stressful Life Events

Across 4 studies, it was found that pediatric patients with IBD who were given a diagnosis of affective disorder reported higher levels of stressful life events and intrafamilial conflicts than patients who did not meet criteria for a psychiatric diagnosis (Burke et al., 1989; Burke et al., 1990; Burke et al., 1994; Szajnberg et al., 1993). In another study, pediatric patients with IBD self-reported higher rates of stressful life events than children with non-organic gastrointestinal pain, with children with CD reporting higher numbers of stressful events than children with UC (Raymer et al., 1984). On the other hand, Steinhausen did not found any differences in the number of reported stressful life events between patients with UC, CD, or healthy controls, and Gitlin, Markowitz, Pelcovitz, Stohmayer, Dorstein, and Klein (1991) found that IBD reported significantly fewer stressful events than control participants did.

Three studies found that higher rates of life events were positively associated with a diagnosis of depression (Burke et al., 1989; Burke et al., 1990; Burke et al., 1994). Conversely, Steinhausen (1983) found that in a group of pediatric patients with IBD, the rate of stressful life events in the past six months was not associated with severity of psychopathology. With regards to the relationship between life events and disease severity, Ondersma et al. (1997) reported that the frequency of self-reported stressful events over 12 months was unrelated to any disease

severity parameters but was positively associated with levels of negative affectivity. Steinhausen (1983) reported an inverse relationship between number of stressful life events and number of relapses both in patients with CD and UC, suggesting that low amount of stressful events was associated with more disease recurrences.

Locus of Control and Coping

Locus of control refers to the degree to which individuals perceives what happens to them as being within their control. It is though that the extremes of the locus of control continuum (i.e., external or internal locus of control) contribute to difficulties in overall adjustment and to adjustment to illness (Steinhausen & Kies, 1982). Steinhausen (1982) compared children and adolescents with IBD to a group of patients with asthma and a group of patients with Cystic Fibrosis. Pediatric patients with CD and UC self-reported more internal locus of control than healthy controls, with a tendency for children with psychiatric disturbance to show more external locus of control than well-adjusted children across groups. Conversely, Engstrom (1999) found that children and adolescent with IBD reported more external locus of control than patients with headache, patients with diabetes or than healthy children. In this study, the correlation between locus and control and psychopathology was very low but extremes of the locus of control continuum correlated with severe psychiatric disturbances.

Children and adolescents with IBD resort to avoidance as a style of coping with stressful situations (Gitlin et al., 1991). Gitlin et al. found a trend for pediatric patients with IBD to minimize anticipated stressors prior to their occurrence and for not initiating action when faced with a stressor. Various investigations also reported the presence of emotional avoidance and reduced expression of distress among pediatric patients with IBD (Engstrom, 1999; Gold et al, 2000; Szajnberg et al., 1993; Wood et al., 1987). Loonen, Grootenhuis, and Derkx (2004)

reported that adolescents with IBD exhibit more avoidant behaviors than their healthy peers. Finally, children and adolescents with IBD also self-reported more rigidity in their coping style than healthy children, meaning that children suffering from IBD tend to use the same coping strategies whatever the situation-specific parameters (Gitlin et al., 1991).

Conclusion

Because of the chronic and debilitating nature of IBD, its embarrassing symptoms, and its impact on patients' quality of life, an understanding and evaluation of pediatric patients' socio-emotional and behavioral adjustment represent the foundation of efficacious and efficient medical and psychological interventions to facilitate young patients' adaptation to their disease. With one exception, investigations related to the psychological functioning of pediatric patients with IBD revealed an increased prevalence of affective disorders and behavioral problems among this population.

Across investigations, level of psychopathology resulted to be unrelated to disease severity as assessed by medical indexes, which implies that severity of socio-emotional and behavioral disturbances may not be the best route to investigate the impact of psychological variables on the organic course of inflammatory bowel diseases. On the other hand, some findings indicate that level of negative affectivity is associated with subjective reports of disease severity, suggesting that psychological difficulties may be associated with how the disease is experienced by the patient.

There appears to be no agreements among researchers as to what psychological style on the externalizing-internalizing continuum characterize best pediatric patients with IBD. However, data on adaptation point to the presence of emotional, behavioral, and cognitive avoidance as well as to a tendency toward not expressing emotional distress among pediatric patients with

IBD. Moreover, both an internalizing psychological profile and unexpressed hostility (Ondersma et al., 1997; Wood et al., 1987) were found to be associated with increased disease activity, suggesting that the way these patients communicate their feelings and needs may be related to the course of their disease.

Inconsistent findings among studies may reflect methodological weaknesses in the literature on the psychological functioning of children and adolescents with IBD. Most studies include small samples with wide age range covering different developmental phases of childhood and adolescence. In addition, there is no consistency across studies regarding measurement of disease severity and psychopathology. The use of non-standardized instruments and variations in the measurement of depression (i.e., exclusion or no exclusion of somatic symptoms) make it difficult to compare and interpret published results in order to delineate a theoretical biopsychosocial model of pediatric IBD.

Table 2

Studies of the Psychological Adjustment of Children and Adolescents with IBD

Reference	N	Age Means (Range)	Question under Study	Outcome
Steinhausen & Kies (1982)	7 patients with UC 10 patients with CD 17 healthy peers	13.33 13.32 13.45 (7-17)	Psychopathology	60% of patients fit criteria for a diagnosis of emotional disturbance. Growth retardation is associated with psychopathology.
Steinhausen (1982)	7 patients with UC 10 patients with CD 17 healthy peers	4-14 no means	Locus of control	Children with IBD exhibited more locus of control than healthy peers.
Steinhausen (1983)	7 patients with UC 10 patients with CD 17 healthy peers	5-18 no means	stressful life events	No differences in the number of reported stressful life events between patients with UC, CD, and healthy peers.
Raymer, et al. (1984)	44 patients with RAP 24 patients with CD 20 patients with UC 30 healthy peers	8-16 no means	Emotional adjustment	More depressive symptoms in the IBD and RAP groups than in the control group. No significant difference between IBD & RAP groups.

Table 2 (Con't)
Studies of the Psychological Adjustment of Children and Adolescents with IBD

Reference	N	Age Means (Range)	Question under Study	Outcome
Steinhausen (1988)	7 patients with UC 10 patients with CD 17 healthy peers 36 patients with CF 36 patients with BA	5-18 no means	Emotional adjustment	Teachers′ ratings confirmed Steinhausen & Kies′ results IBD groups were similar to CF group for emotional problems.
Wood et al. (1987)	51 patients with CD 41 siblings 37 patients with UC 24 siblings	6-17 no means	Psychological functioning and disease severity	Patients with IBD reported more behavioral problems than siblings and normative means. Among patients with CD, parent ratings on adaptive scales were Internalizing style was associated with disease severity. Level of behavioral difficulties was not associated with disease severity. Subjective reports of disease severity were unrelated to medical indices.

Table 2 (Con't)
Studies of the Psychological Adjustment of Children and Adolescents with IBD

Reference	N	Age Means (Range)	Question under Study	Outcome
Burke et al. (1989)	41 patients with CD 14 patients with UC 52 patients with CF	13.19 11.07 12.19	Emotional functioning	Patients with CD had higher prevalence of depression than patients with CF. Patients with UC had greater prevalence of dysthymia than patients with CD or CF. At the time of assessment, same results emerged. No difference between groups in prevalence of anxiety disorder. A trend for children with UC to show more phobia and separation anxiety than children with CD and CF.
Burke et al. (1989)	33 patients with CD 11 patients with UC 46 patients with CF	13.62 11.18 12.6	Obsessive-compulsive Symptoms	A trend for patients with UC to report more OCD symptoms than patients with CD but levels of self-reported OCD symptoms among children with IBD and CF are similar.
Burke et al. (1990)	8 patients with CD 5 patients with UC	12.28	Depression	Patients with depression were the least severely ill. None of the depressed children were treated with steroids.

Table 2 (Con't)
Studies of the Psychological Adjustment of Children and Adolescents with IBD

Reference	N	Age Means (Range)	Question under Study	Outcome
Gitlin et al. (1991)	36 patients with IBD 38 healthy peers	6-19	Stress mediators	Patients with IBD minimize stressors prior to their occurrence. Passivity when confronted with stressor. Rigidity in coping style.
Engstrom & Lindquist (1991)	11 patients with UC 9 patients with CD 20 healthy peers	16.5 16.5 16.4 (9-18)	Psychological adjustment	More behavioral difficulties in patients with IBD than healthy peers. Both externalizing and internalizing scales were elevated. 60% of patients with IBD met criteria for a psychiatric disorder. Psychiatric problems and disease severity were unrelated. Earlier onset IBD associated with more emotional and behavioral problems than later onset IBD.
Szajnberg et al. (1992)	15 patients with IBD	11.6	Psychopathology	11 children were diagnosed. Repression, denial, contrition were found Among diagnosed chil children higher levels of intrafamilial conflicts.

Table 2 (Con't)
Studies of the Psychological Adjustment of Children and Adolescents with IBD

Reference	N	Age Means (Range)	Question under Study	Outcome
Burke et al. (1994)	21 patients with CD 15 patients with UC	11.98	Correlates of depression in new onset IBD.	5 children were diagnosed with major depression and 10 with atypical depression. Depressed children were the less severely ill. Patients not on steroids. Only 1 patients had depressive symptoms before onset of IBD. 10 were given a diagnosis of anxiety disorder. Anxiety symptoms preceded IBD diagnosis.
Ondersma et al. (1997)	34 patients with CD 22 patients with UC	15.1 (11-17)	Examined negative affect, hostility, positive affect	Expressed hostility associated with less disease activity. Higher levels of hostility associated with worse subjective health. Higher negative affect associated with worse subjective health but unrelated to medical indices of disease activity Positive affect associated with subjective health.

Table 2 (Con't)
Studies of the Psychological Adjustment of Children and Adolescents with IBD

Reference	N	Age Means (Range)	Question under Study	Outcome
Engstrom (1999)	20 patients with IBD 20 patients with headache 20 patients with diabetes 20 healthy peers	16.5	Mental health	60% of patients with IBD met criteria for a psychiatric disorder, mostly depression and anxiety. More depressive symptoms than children with diabetes and healthy peers. Both externalizing and internalizing scales were elevated. Discrepancies between child and mother reports. Lie scale ratings were the highest among patients with IBD. Denial was clinically observed.
Gold et al. (2002)	36 patients with IBD 26 RAP	12 26	Psychological Adjustment	Children with IBD were found well-adjusted, not depressed, and with higher than average self concept. All the children were treated with steroids and were in remission.

Table 2 (Con't)
Studies of the Psychological Adjustment of Children and Adolescents with IBD

Reference	N	Age Means (Range)	Question under Study	Outcome
Szigethy et al. (2004)	74 patients with CD 28 patients with UC	12.6 11.9 (4-19)	Depressive symptoms	16 met criteria for a diagnosis of affective disorder. 25 had a score in the clinical range on the CDI and 12 had elevated scores. Disease severity and depressive symptoms are unrelated. Differences in depressive Symptoms between severe/ Moderate disease and inactive Disease were explained by 3 items: anhedonia, fatigue, decreased appetite.

Note. UC=ulcerative colitis; CD=Crohn′s disease; CF=cystic fibrosis; RAP=recurrent abdominal pain; BA=bronchial asthma; IBD=inflammatory bowel disease; CDI=Children′s Depression Inventory.

Quality of Life of Children and Adolescents with IBD

There is growing recognition among physicians that in order to fully understand chronic diseases, there should be a convergent assessment, not only of symptoms and biological factors, but also of psychosocial ones such as the impact of illness on patients' overall psychosocial adjustment and patients' attitudes, beliefs, and behaviors in relation to their illness (Garrett & Drossman, 1990). The terms quality of life is a novel concept designed to capture the essential aspects of psychosocial outcome in chronic illness and its treatment. The concept of quality of life was born out of an interest in patients' adaptational processes and their outcomes. The concept of quality of life is concerned with how well a particular patient adapts to his/her illness and its treatment. To say it differently, quality of life refers to the impact of a chronic illness on a patient's daily functioning. The concept of quality of life assessment represents a more holistic view of illness that fits well with the components of the bio-psycho-social model. An emphasis on adaptation outcomes is especially relevant in the case of unpredictable and disabling diseases such as IBD (Kunsebeck, Korber, & Freyberger, 1990).

Health-related quality of life measures are global measures of patients' perception of illness experience and functional status that incorporate social, cultural, psychological, and disease-related factors. Quality of life measures provide subjective information that complements well the objective measures of disease activity. Quality of life scales measure domains that are independent of organic disease processes but that are affected by it. In association with disease parameters, they provide a clearer picture of health and allow for an evaluation of the efficacy of medical treatments on patients' functioning in daily life (Ferry, 1999).

There are two main types of quality of life instruments: generic instruments and disease-specific instruments. Generic measures are sometimes too imprecise to reflect impairment of

function in patients because each chronic illness impacts patients' functioning differently and each chronic illness requires different kinds of adjustments (Koot & Bouman, 1999). Disease-specific quality of life measures are often preferred to assess desirable and undesirable effects of pharmacological, surgical, and psychosocial treatment because of their sensitivity a particular illness characteristics.

In this section, I review investigations related to the quality of life of pediatric patients with IBD. Studies were located in PSYCINFO and MEDLINE by entering the key words "quality-of-life," "pediatric," "IBD," and "children." Studies of quality of life in children and adolescents with IBD employed both generic and disease-specific assessment tools for measuring quality of life. Investigations of the quality of life of pediatric patients with IBD are mainly descriptive and consist of listing and ranking areas of concerns. A subgroup of these research reports is dedicated to the development, validation, and cross-cultural validation of a disease-specific questionnaire for older children and adolescents with IBD (see table 3).

Four investigations carried out in England used patients' focused groups and a non-standardized research questionnaire to assess the impact of IBD on children and adolescents' psychological wellbeing, schooling, friendships, and social/sport activities. No validity or reliability data was reported about the questionnaire utilized in these studies. Pediatric patients reported difficulties with taking holidays and long distance traveling, participating in school trips, and engaging in sport activities. Socially, pediatric patients reported that IBD did not prevent them from making friends but made it difficult for them to stay at friends' houses. Children and adolescents with IBD expressed worries about the future, body image, side-effects of medication, and unpleasant medical investigations. They also complained about the lack of understanding of teachers and health professionals. Finally, a large proportion of children and

adolescents with IBD thought they were achieving below their potential in school because of hospitalizations, school day missed, and inability to concentrate on schoolwork due to pain or other symptoms (Akobeng, Miller, Firth, Suresh-Babu, Mir, & Thomas, 1999; Akobeng, Miller, Firth, Suresh-Babu, Mir, & Thomas, 1999; Moody, Eaden, & Mayberry, 1999; Rabbett, Thwaites, Dady, Firth, Hillier, Miller & Thomas, 1996). In terms of focus group process, the investigators remarked that during the first few sessions, young patients with IBD denied that IBD had any impact on their lives. However, during the last few sessions, they expressed frustration about physical symptoms such as pain, diarrhea, and tiredness. They also revealed anxiety about their physical appearance and unpleasant medical investigations.

Two of these British studies measured parents' and siblings reports' of quality of life in relation to their child's disease. Parents reported concerns about the future, their child's education, their child's being teased at school, and the psychological effects of IBD on their child's socio-emotional development. In addition, parents indicated that IBD affected progress in their career because they had to take extensive time off. They pointed out that their ability to choose jobs and job location was limited because of the need to live close to a treatment center. Parents also expressed that their child's IBD placed a strain on their marital life and evoked tendencies to blame each other for their child's disease. Finally, parents reported concerns related to the financial burden of treatment.

Siblings of children and adolescents with IBD reported jealousy toward their ill sibling because of special treatment and attention from parents, less time with parents, and more chores at homes (Akobeng et al., 1999; Rabbett et al., 1996). Overall, pediatric patients' reports of quality of life tended to be more optimistic than parents' reports were. Interpretation of these differences is difficult due to the wide age range of participants included in these studies. Small

sample sizes and a bias in participants' selection may have influenced the reported results. Indeed, three studies noted that four patients declined to participated because they were "too sensitive" about their illness and one of them was hospitalized in a psychiatric unit. One study mentioned that all the participants were in a remission phase.

Mackner and Crandall (2004) reported on the school functioning of adolescents with IBD. Their results revealed that teenagers with IBD had more school absences during the past school year than their healthy counterparts. However, adolescents with IBD had similar GPA, rates of special education services, and rates of grade retention than their typically developing peers.

A Dutch study reported on parent-child concordance regarding patient's health-related quality of life. Children and adolescents with IBD reported higher levels of quality of life than their parents. Discrepancies were larger in subjective domains such as negative emotions and social functioning. Parent-child agreement was higher regarding disease symptoms. The authors proposed three possible explanations for parent-child differences in ratings (1) differences of perspective, (2) a repressive style of adaptation, and (3) response shift (i.e., constantly changing internal standards as a result of adapting to the situation).

The role of social support and coping in relation to health-related quality of life were assessed with a general quality of life scale among 30 adolescents with IBD (MacPhee, Hoffenberg, & Feranchak, 1998). Greater intimacy and satisfaction with social support networks were significantly associated with better quality of life. No association was found between adolescents' coping strategies and their quality of life. Conversely, parents' coping strategies were found to be inversely correlated with adolescents' quality-of-life. That is, the more parents implemented coping strategies related to maintaining or strengthening family ties, increasing social support for the family, and information-seeking behaviors, the worse their adolescent

child's quality of life was. No specific interpretation of these findings was provided by the researchers.

Loonen, Grotenhuis, Last, and Derkx (2004) also assessed the influence of coping on the quality of life of adolescents with IBD. They found that optimistic thinking was positively associated with quality of life scores whereas depressive symptoms were negatively associated with quality of life scores. The greater use of avoidance behaviors among teenagers with IBD as compared to healthy peers was not found to be associated with quality of life ratings, possibly suggesting that avoidant behaviors do not contribute to changes, in either a positive or negative direction, to adolescents' with IBD wellbeing.

Three studies assessed quality of life scores in relation to disease severity. In MacPhee et al.'s investigation, quality of life score were not correlated with disease activity scores as rated by two gastroenterologists blind to the questionnaire results. On the other hand, in a Dutch study, self-reported disease activity was found to be associated with quality-of-life scores (Loonen, Grootenhuis, Last, de Haan, Bouquet, & Derkx, 2002) . In Loonen et al.'s (2004) investigation, disease activity was found to be associated to the symptoms subscales, the emotional functioning subscale, and the social functioning subscale of a quality of life questionnaire.

A disease-specific quality of life questionnaire for IBD was developed by a research group in Canada and is currently being standardized across the US. Potentially relevant issues and concerns to older children and adolescents with IBD were gathered through interviews with patients and caregivers, experts, and literature. Children and adolescents with CD shared many concerns with children and adolescents with IBD but other issues were more troubling to one patient group than the other. For instance, children with CD expressed greater concerns about height, appearance, fatigue, and low energy. Patients with UC were more concerned about bowel

symptoms, especially gas, diarrhea, urgency and bleeding. Concerns about having flares up, the lifelong nature of IBD, treatments and investigations, the effects of IBD on family, and worries about future health problems were shared. However, CD appeared to interfere with activities in more ways affecting school attendance and performance in sports. Analyses of patients' responses resulted in a final questionnaire of quality of life called the IMPACT that is organized around six domains: IBD related symptoms, emotional functioning, social functioning, systemic symptoms, concerns related to treatment, and body image (Griffiths, Nicholas, Smith, Munk, Stephens, Durno, & Sherman, 1999). Excellent reliability ($\alpha = 0.96$) and validity studies were reported by the same team (Otley, Smith, Nicholas, Munk, Avolio, Sherman, & Griffiths, 2002). Scores on the IMPACT differentiated patients with quiescent, mild, and moderate/severe disease as assessed by disease activity measures.

A cross-cultural comparison of the IMPACT indicated that British children and adolescents with IBD, who completed the item-reduction questionnaire used in the IMPACT development, ranked issues similarly to the young Canadian patients (Richardson, Griffiths, Miller, & Thomas, 2001). Cross-cultural translation and validation of the IMPACT questionnaire for a Dutch sample of pediatric patients with IBD showed that the Dutch patients with IBD also reported impairment in social functioning, emotional functioning, body image, and impairment related to IBD symptoms (Loonen, Grootenhuis, Last, Koopman, & Derkx, 2002).

Conclusion

The fact that some researchers did not provide information about the psychometric properties of their research instruments raise some questions about the validity of reported data and renders difficult comparisons of results across investigations. In addition, published research on quality of life for pediatric IBD remains descriptive without sufficient attempt to assess

quality of life in relationship to disease activity and to differentiate self-reported disease activity from medical assessment of disease activity. Future studies should investigate the variables that contribute to quality of life in children and adolescents with IBD in order to single out targets of intervention to improve pediatric patients' adaptation to their illness.

One of the major drawbacks of these investigations is the lack of developmental sensitivity applied to result reports and interpretations. Most samples included children over a large age range (i.e., 6 to 17 or 8 to 17) and therefore encompassed participants at different stages of cognitive and emotional development. In most reviewed studies, the methods utilized and the analyses performed did not reflect differences in developmental progression as related to quality of life and illness. Future research projects need to take a more developmental approach by exploring differences and changes in the functional impact of IBD over time. The IMPACT questionnaire is designed for young patients aged 8 to 17. Results from the ongoing standardization study should be informative as to the developmental differences in perceived quality of life among pediatric patients.

Although disease activity indices measure changes in organic disease processes, they do not tell us how pediatric patients are functioning on a day to day basis and how they feel about their illness. Assessment of health-related quality of life is important to monitor the emotional and social development of pediatric patients with IBD, their limitations in functioning, and the side-effects of treatment.

The Repressive Adaptive Style in Pediatric Populations

Explorations of the existence and features of the repressive adaptive style (RAS) in childhood and adolescence are fairly recent. The first child studies employing Weinberger's paradigm appeared at the beginning of the 1990's. The purpose of this review is two-fold: (1) to

summarize and critique empirical investigations of the repressive defense style in youth and (2) to highlight salient methodological issues in existing studies. The reviewed studies were selected on the basis of their adherence to Weinberger et al.'s methodological paradigm, consisting of the interaction between a measure of distress and a measure of defensiveness to categorize repressors (Weinberger, Schwartz, & Davidson, 1979). The reviewed studies were identified following a literature search conducted using PSYCINFO and MEDLINE, crossing the words "repressive coping," "repression," "repressive style," "adaptive style," "repressive defense," "repressive defensiveness," "children" and "adolescent." One study was presented at a conference and was obtained directly from the author. A total of 11 empirical investigations were found, including samples of chronically ill and healthy children aged 7 to 18 years old (see Table 2).

Findings of the reviewed investigations will be discussed within broad conceptual frameworks aimed at (1) understanding the RAS in a health-related context, (2) addressing methodological issues in the existing empirical childhood investigations and (3) reviewing possible moderator variables of the RAS. In this paper, I will use the phrases "repressive adaptive style" and "repressive defense style" (RDS) interchangeably in reference to Weinberger's construct.

Table 3

Studies of Quality of Life among Children and Adolescents with IBD

Reference	*N*	Age Range	Question	Outcome
Rabbett et al. (1996)	16 patients With CD	8-17yrs	QoL of children with CD (self-reports & parent reports)	Child concerns: absenteeism, distraction from schoolwork, Problems engaging in sport activities Problems to go on school trips. Parental concerns: marital strains, Job prospects, schooling, future.
Akobeng et al. (1999)	24 patients with CD	8-17yrs	Pilot study to assess QoL of children with CD	Concerns: absenteeism, inability to engage in school sports, problems to stay at friend's house, anger, depressive symptoms among children on steroids. Elemental diet is preferred treatment. Do not achieve to potential, worries about future, lack of energy, body image.
Akobeng et al. (1999)	20 parents 7 siblings of patients with IBD	7-17yrs	QoL of parents & siblings of children with IBD	Parental concerns: marriage, career, financial burden, guilt, restricted life style, side effects of medication. Siblings' concerns: parents keeping information about illness from them, fear about the disease and treatment, others bullying ill sibling, jealousy.

Table 3 (continued)

Studies of Quality of Life among Children and Adolescents with IBD

Reference	*N*	Age Range	Question	Outcome
Moody, Eaden, & Mayberry (1999)	99 patients with CD	6-17yrs	QoL of children with CD	Concerns: absenteeism, lack of understanding of teachers, do not achieve to potential, problems to participate in sports concerns about going on holidays or stay overnight outside their homes. Worries about the future.
MacPhee, Hoffenberg, & Feranchak (1998)	30 patients with IBD	11-16yrs	Adolescents' with IBD QoL and coping strategies Parents' coping, social support.	Patients' degree of satisfaction with social networks is positively correlated with their QoL scores. Patients' coping strategies did not correlate with their QoL, parents' coping scores were inversely related to their children's QoL. No correlation between patients' illness severity and their QoL scores.
Mackner et al. (2004)	36 patients with IBD 28 healthy peers	11-18yrs	School functioning of adolescents with IBD.	More school absences than healthy peers but similar rates of special education services and GPA levels.
Griffiths et al. (1999)	117 patients with IBD	12-17yrs	Item-reduction phase of development of a specific measure to assess QoL of of children with IBD: IMPACT questionnaire.	Concerns: height and appearance, fatigue, low energy, lifelong nature of IBD, surgery, frustration, anger pain, diarrhea, miss out on activities, school attendance and performance.

Table 3 (continued)
Studies of Quality of Life among Children and Adolescents with IBD

Reference	*N*	Age Range	Question	Outcome
Otley et al. (2002)	147 patients with IBD	9-18yrs	Reliability and validity of the IMPACT.	Readability level: grade 4. Excellent internal reliability. Differentiates patients with different levels of disease severity.
Richardson et al. (2001)	53 patients with IBD	12-17yrs	British patients scored item-reduction questionnaire used with Canadian patients in Griffiths' et al. study.	Concerns reported by British children correlated strongly with concerns reported by Canadian children.
Loonen et al. (2002)	83 patients with IBD	8-18yrs	Develop a Dutch version Of the IMPACT Dutch sample.	Concerns reported were similar to those of Canadian children. Good psychometric properties.
Loonen et al. (2002)	83 patients with IBD	8-18yrs	QoL of children and adolescents with IBD using both a generic and specific measure Dutch sample.	Impairment in motor functioning and autonomy, negative emotions: anxiety, jealousy, anger.

Note. QoL = Quality of Life; IBD = inflammatory bowel disease; CD = Crohn's disease; UC = ulcerative colitis

Validation of the RDS in children with chronic illnesses

Autonomic Reactivity

Physiological validation of the repressive defense style among children who are chronically ill is of great importance to assess its possible health consequences and influence on treatment outcomes. As mentioned above, adult empirical studies reported that a repressive adaptive style has serious implications in terms of health risks and outcomes. Heightened physiological arousal was shown to result in hormonal and immunological changes that may exacerbate medical illness and induce variations in disease activity (Brown, Tomarken, Orth , Loosen , Kalin, & Davidson, 1996; De La Torre, 1994; Sapolsky, 1998). Nassau, Fritz, and McQuaid (2000) examined physiological reactivity among adolescents diagnosed with asthma. The researchers found a trend for children categorized as repressors to show heightened skin conductance from baseline to stress as compared to low-anxious children. Although their results did not reach significance, Nassau et al.'s trend produced a medium effect. Low power might have limited researchers' abilities to detect significant differences on physiological indices of reactivity (i.e., only 18 out of 95 adolescents were classified as repressors in this sample), and further data are needed to know whether the repressive defense style is associated with physiological reactivity in youth (Nassau, Fritz, & McQuaid, 2000). Elucidation of the presence or absence of physiological reactivity in young repressors is all the more important as heightened autonomic arousal may, in part, explain individual variations in response to treatment among chronically ill children (Fritz, Spirito, & Yeung, 1994; Phipps & Steele, 2002).

Inhibition of Signals of Distress and Self-Report Bias

Youth with chronic illnesses were found to be at risk for psychosocial difficulties, and impaired affective-cognitive integration and synthesis was associated with psychopathology (Blatt, 1990; Boice, 1998; Bowlby, 1979; Safran & Greenberg, 1998; Traue & Pennebaker, 1993).

Therefore, child repressors who are ill may be at risk for psychological distress (Smith & Steiner, 1992). However, failure to acknowledge distress is one of the main outcomes of utilizing a repressive style of adaptation (Myers, 1998).

Empirical studies using self-report questionnaires reported that adult repressors score high on adaptability, successful coping, and health, and low on fear, anxiety, sadness and hostility (Myers, 1998). Pediatric investigations confirmed adult findings that repressors report low levels of emotional distress and present themselves as well-adjusted individuals. Canning, Canning, and Boyce (1992) investigated the presence of a repressive defense style among children diagnosed with cancer. They hypothesized that the counterintuitive reports of low levels of psychological distress among children with cancer could be accounted for, in part, by the confounding presence of patients with a repressive style of adaptation. Canning et al. identified a larger proportion of repressors in the group of adolescents with cancer than in the control group, and patients with cancer reported less depressive symptomatology than healthy peers and normative populations. When these results were entered in regression analyses, repressor status was found to account for a significant portion of the variance in depression scores across both groups.

Phipps and Srivastava (1997, 1999) replicated Canning et al.'s results. In their study, repressors obtained the lowest depression scores across both groups of adolescents with cancer and healthy peers. In Nassau et al.'s experiment, teen repressors with asthma reported less state anxiety than non-repressors during and following an embarrassing experimental task, whereas a trend for higher autonomic reactivity among repressors seemed to indicate the contrary. Lastly, Phipps and Steele (2002) found that across three groups of children with cancer, chronic illnesses, and healthy peers, participants identified as repressors self-reported less anger expression than non-repressors. Across studies, chronically ill and typically developing adolescents with a repressive adaptive style

reported less anxiety, less depression, and less anger than adolescents who are non-repressors, and less anxiety, less depression, and less anger expression than normative populations (Canning, Canning, & Boyce, 1992; Fritz, Spirito, & Yeung, 1994; Phipps & Srivastava, 1999; Phipps, Steele, Hall, & Leigh , 2001; Steele, Elliot, & Phipps, 2003).

Adult empirical studies provided substantial support to Weinberger's suggestion that repressors are as likely to experience distress as non-repressors. Adult studies also evidenced that repressors' psychological functioning incorporates a self-regulatory and inhibiting mechanism that protects them from overwhelming and ego-threatening emotional arousal (Myers & Reynolds, 2000). The proposed mechanism underlies repressors' difficulties with processing and expressing negative states (Myers, 1998). What differentiates well-adjusted children (low-anxious, low-depressed, low-angry) from children with a repressive defense style is that they do not exhibit a high level of defensiveness. Therefore, self-reports of children with a repressive defense style may be more the product of their psychological defense than the product of psychological health (Smith & Steiner, 1992). Young repressors' self-reports may very well mirror what Shedler, Mayman, and Manis (1993) called "the illusion of mental health." Identifying repressors among well-adjusted pediatric patients may help prevent the emergence of psychological and social difficulties as well as interruptions in the socio-emotional development of these children.

High levels of defensiveness were also found to interfere with repressors' awareness of their somatic reactions, and biases in adult repressors' self-reports of physical wellbeing were reported (Jammer & Leigh, 1999; Myers & Vetere, 1997). Adult investigations revealed that repressors fail to pay attention to physical signals of distress and tend to underreport physical discomfort (Jammer & Leigh, 1999; Myers & Vetere, 1997). Smith and Steiner (1992) reported three cases of adolescent repressors with respiratory stridor who presented a repressive style of adaptation. The adolescents

denied emotional distress as well as the bodily cues of distress associated with emotional biofeedback. According to Schwartz's "Repression-Disattention-Disregulation" theory (1983, 1990) the inhibiting processing style characteristic of a repressive style of adaptation may produce a disregulation of feedback mechanisms in such a way that physical signals of distress are not acknowledged. Currently, there is no data measuring the degree to which young patients with a repressive defense style are attentive to bodily signs that indicate fluctuations in their disease activity. There is also no data assessing possible biases in young repressors' reports of physical wellbeing.

Repressors' inhibition of somatic signals of distress may have consequences in terms of health behaviors and treatment compliance such that appropriate medical care may be postponed and daily self-care may be impaired. Clinical observations advanced by pediatric researchers seem to support this point. Phipps and Steele (2002) suggested that, in children with diabetes, a repressive style of adaptation to illness may result in poor metabolic control and noncompliance to medical regimen. Similarly, Fritz, Spirito, and Yeung (1994) remarked that teen repressors with asthma seemed to have difficulty recognizing sensations of dyspnea early enough to implement self-management strategies. One of the main characteristics of adolescence is the propensity to engage in risk-taking behaviors, especially health-endangering behaviors (Williams, Holmbeck, & Greenley, 2002). A repressive defense style may impair young people's ability to assess the risks associated with medical noncompliance, and adolescents with a repressive defense style may be even more likely to exhibit behaviors that may aggravate their health status and lead to disease relapses. The inhibiting, avoidant information-processing style that characterizes repressors may make it difficult for young repressors to adjust to the reality of their disease and to implement the necessary lifestyle changes recommended by their physicians. To this day, the impact of a repressive adaptive style on a

young patient's attention to physiological changes, self-report of wellbeing, and treatment compliance remains an area of investigation for pediatric researchers. Some investigators hypothesized that impaired treatment compliance may mediate the influence of a repressive style of adaptation on health outcomes, thereby providing a conceptual base for further exploration (Fritz, Spirito, & Yeung, 1994; Myers & Reynolds, 2000; Schwartz, 1990).

Self-Deception

Extending our understanding of children's adaptational processes in an illness-related context may help improve the accuracy, and therefore the validity, of the assessment of their physical and psychological wellbeing (Smith & Steiner, 1992). The use of repressive defenses by some well-functioning children highlights the need to interpret self-reports of wellbeing with caution. Paulhus' research into the construct of social desirability showed that socially desirable responding incorporates two factors: self-deception and impression management (Paulhus, 1991). Self-deception is at the core of Weinberger's theory of the repressive defense style. Self-deception reflects response distortion resulting from an unconscious tendency to provide inflated, positive self-reports, whereas self-management reflects response distortion that is due to intentional faking (i.e., lying) (Paulhus, 1991).

Phipps and Srivastava (1999) explored the idea of circumventing repressive defenses among pediatric oncology patients. They hypothesized that a pleasure scale would be less subject to the influence of defensiveness than a depression or anxiety scale because it includes items about pleasurable events that assess lack of euphoria rather than dysphoria. Repressors in both groups reported less depressive symtomatology but also less anhedonia than non-repressors. Young repressors' self-reports suggested a bias towards minimization of affective distress, which emerged

independently of the transparency or lack of transparency of the self-report scale for socially desirable answers.

The Repressive Adaptive Style and Coping

Most child and adult investigators hypothesized that the repressive defense style may foster maladaptive coping processes (Canning, Canning, & Boyce, 1992; Nassau, Fritz, & McQuaid, 2000; Fritz, Spirito, & Yeung, 1994; Phipps & Srivastava, 1997, 1999). Indeed, disregulation of appraisal mechanisms may promote poor coping responses by preventing the individual from coping with stressful situations realistically. Richards, Benson, Cushing, and Steele (2004) investigated whether adaptive style was predictive of coping method among a group of typically developing teenagers. More specifically, the researchers investigated the influence of a repressive adaptive style on adolescents' choices of coping strategies. In this study, only behavioral avoidance coping predicted a child's adaptive style, and teen repressors reported less behavioral avoidance and fewer avoidant coping strategies than non-repressors. Due to the self-report nature of collected data, biases in teen repressors' reports might have affected the study outcomes. The addition of significant others' reports and health-professional observations would be helpful to bypass repressors' defenses and enhance the validity of obtained results. More research is necessary to assess the impact of a repressive adaptive style on children's choices of coping processes and on their efficacy, especially in a health-related context. Conceptually, delineating the function of a repressive adaptive style within the framework of stress and coping models can help us understand its possible impact on children's coping abilities.

Methodological issues

Measurement Weaknesses of Existing Studies

No consistency has been found among pediatric investigations with regard to the methodology employed to classify repressors. On measures of distress and defensiveness, some investigators used the cut-off points originally proposed by Weinberger et al. and widely applied in adult empirical studies that is, below the 50th percentile on a measure of distress and at or above the 75th percentile on a measure of defensiveness, whereas other investigators used cut-off points below the 50th percentile on distress and above the 50th percentile on defensiveness (Weinberger, Schwartz, & Davidson, 1979). These inconsistencies make comparisons with adult studies difficult. In addition, some elements of self- and other-deception may be present as part of typical human functioning, and the use of more stringent cut-off scores on defensiveness ensures the clinical, ecological, and construct validity of the repressor category (Baumeister & Cairns, 1992; Freud, 1915). If, in some studies, more stringent cut-off scores were adopted, a proportion of children categorized as repressors would migrate to the low-anxious cell, with important consequences regarding findings associated with the characteristics and impact of the repressive defense style in youth.

 If developmental factors account for the use of more lenient cut-off scores on defensiveness in childhood and adolescence, such factors should be clearly delineated and explained.

Concurrent Psychometric Operationalization of the Repressive Adaptive Style Construct

In line with Freudian theory, Weinberger's theory postulates that a repressive defense style involves the repression of affects that threaten an individual self-concept (Weinberger, 1990). That is, negative emotions, other than anxiety, are also repressed. Pediatric studies involved the measurement of negative emotions (e.g., depression or anger) as a possible

alternative to an anxiety scale in the assessment of the repressive defense style (Phipps & Srivastava, 1997, 1999). For example, Fritz et al. used anxiety and anger as repressed affects to detect repressors. Concordance rates between the anxiety/defensiveness and the anger/defensiveness paradigms were found to be as high as 85% in girls and 74% in boys. Phipps and Steele (2002) reported that absolute agreement for repressor classification between anger and anxiety paradigms was 90.5%. When anxiety and anger were entered simultaneously in the adaptive style paradigm as two repressed affects, the total number of repressors was reduced, but the pattern of results remained the same.

Results of child studies indicate that the repressive adaptive style in youth also involves the repression of depression and anger. High concordance rates between different psychometric paradigms (low depression, high defensiveness; low anger expression, high defensiveness; low anxiety, high defensiveness) contribute to establishing the construct validity of the repressive defense style among children and adolescents (Phipps & Srivastava, 1997, 1999). Some overlap in the different models of categorization suggests that some children repress more than one emotion (Fritz, Spirito, & Yeung, 1994). The concurrent validity of using a depression or anger scale to detect repressors among children could be enhanced if future investigations could determine whether child repressors tend to repress a specific emotion on a regular basis or if they tend to repress more than one emotion.

Moderating variables of the repressive adaptive style

Health status emerged as a variable influencing the proportion of children categorized as repressors (Steele, Elliot, & Phipps, 2003). All reviewed studies with pediatric samples reported a higher proportion of repressors among children who are ill than among healthy controls, providing support for an association between disease state and repressive adaptive style in youth.

In addition, comparisons across studies reveal lower proportions of repressors among children diagnosed with asthma than among children diagnosed with cancer. Conversely, studies comparing children with cancer to children with other chronic and serious diseases (e.g., diabetes mellitus, cystic fibrosis, and rheumatic disorders) yielded no differences between groups regarding the proportion of repressors (Phipps & Steele, 2002; Phipps, Steele, Hall, & Leigh, 2001). A larger number of repressors might be present among children with seriously disabling or deadly diseases than among children with chronic but less consequential diseases, although this assumption calls for more systematic examination. We know that a repressive style of adaptation was associated with increased disease severity and morbidity among adult patients (McKenna, Zevon, Corn, & Rounds, 1999). Such data are nonexistent in children. The direction of the relationship between increased disease severity and repressive style of adaptation has not been empirically established in children or adult samples, and it can be hypothesized to be bi-directional. That is, a repressive defense style may promote greater disease activity, and greater disease activity may elicit greater reliance on a repressive adaptive style.

Race also moderated the categorization of children as repressors in Steele, Elliot, and Phipps' study (2003). A higher proportion of repressors was reported among African-American children and adolescents across both groups and across repressed affects (i.e., anxiety and anger). However, review of the study demographic data indicated that 62% of Caucasian children, as compared to 31% of African-American children, were from families in the two highest socio-economic categories, and 34% of the African-American sample was included in the lowest two socio-economic categories. It might be that socio-economic situation (SES), better than race, explained the relationship between greater repressive defenses and African-American children in Steele et al.'s study. Children from low-income families are more affected

by undesirable life events than children from high-income families, and strong associations between negative emotions and SES have been reported (Chen, Matthews, & Boyce, 2002; Gallo & Matthews, 2003). Children from low social classes may develop a repressive style of adaptation as a way to protect themselves from the overwhelming presence of negative emotions and the adverse impact of difficult social and familial life conditions.

Steele et al. detected an additive effect of race and illness on the proportion of children categorized as repressors. Demographic characteristics of the sample indicate that more African American than Caucasian children were identified as seriously ill, raising again the issue of the mediating effect of SES. Associations between low SES and increased disease morbidity and mortality were widely reported, and several studies that compared the effects of race and SES found that SES remains significantly associated with child health, even after controlling for race(Chen, Matthews, & Boyce, 2002; Gallo & Matthews, 2003). The accumulated effect of adverse social conditions and poor health might explain the increased presence of repressors among African-American children who are ill as compared to Caucasian children who are ill.

Conclusion

The presence of a repressive style of adaptation was identified in adolescence, especially among pediatric populations. Adolescent repressors were found to exhibit characteristics similar to those identified among adult samples (i.e., self-deception, biased self-reports, and inhibition of signals of distress). Across studies, chronically ill and typically developing children and adolescents with a repressive adaptive style reported less anxiety, less depression, and less anger than children who are non-repressors, and less anxiety, less depression, and less anger expression than normative populations (Canning, Canning, & Boyce, 1992; Fritz, Spirito, &

Yeung, 1994; Phipps & Srivastava, 1997, 1999; Phipps, Steele, Hall, & Leigh, 2001; Steele,

Elliot, & Phipps, 2003).

Methodological inconsistencies between studies were found for the cut-off points used to

assess the presence or absence of a repressive adaptive style. Some investigators chose a cut-off

point at the 50th percentile on defensiveness whereas others utilized the 75th percentile cut-off

point proposed by Weinberger et al. Taking into account developmental considerations, future

research should explore whether or not the 75th percentile cut-off point used in adulthood is

appropriate for young samples. In addition, weaknesses in the psychometric properties of

defensiveness measures in childhood highlight the need for further research regarding the

manifestation and assessment of defensiveness in youth and regarding whether or not children

and adolescents can be reliably classified as repressors.

Many pathways remain open for investigators interested in exploring the repressive

adaptive style in youth, especially in the context of mind-body interactions. To date, only one

study focused on young repressors' autonomic reactivity, which is another main characteristic of

a repressive adaptive style in adulthood. Further research into young repressors' physiological

changes is needed. Elucidation of the presence or absence of physiological reactivity in young

repressors is all the more important as adaptive style may, in part, explain the impact of a

repressive adaptive style on health outcomes and responses to treatment (Fritz, Spirito, &Yeung,

1994; Phipps & Steele, 2002).

Future investigations should also examine the impact of a repressive adaptive style on

health outcomes and behaviors to see if adult health data associated with a repressive style of

adaptation are replicable in childhood. More specifically, the reported associations between a

repressive defense style and physical health call for pediatric investigations examining the

interaction of a repressive adaptive style with disease course and severity, treatment compliance, young repressors' self-reports of pain and physiological symptoms, and patient-physician relationship. My project builds on the findings reported by both pediatric and adult studies. In the next section, I present the purposes of my investigation and the hypotheses to be tested.

Table 4

The Repressive Adaptive Style in Childhood and Adolescence

Reference	N	Age Range & Mean	Measures of the Repressive Adaptive Style
Steiner (1992)	221 psychiatric patients 52% outpatients 48% inpatients	15.5 boys 16.3 girls (no range)	State-Trait Anxiety Inventory Below 50th percentile Marlowe Crowne Social Desirability Scale Above 50th percentile
Smith & Steiner (1992)	3 adolescents with respiratory stridor	13.3 (12-15)	State-Trait Anxiety Inventory Below 50th percentile Marlowe Crowne Social Desirability Scale Above 50th percentile
Canning, Canning & Boyce (1992)	31 children with cancer 83 healthy controls	14.7 15.8 (12-18)	State-Trait Anxiety Inventory Below 50th percentile Children Social Desirability Questionnaire Above 50th percentile
Fritz, Spirito, & Yeung (1994)	83 children with asthma	11.4 (10-15)	Children Manifest Anxiety Scale-Revised At or Below 50th percentile Marlowe Crowne Social Desirability Scale At or Above 50th percentile Anger Expression Scale At or Below 50th percentile

Table 4 (continued)
The Repressive Adaptive Style in Childhood and Adolescence

Reference	N	Age Range & Mean	Measures of the Repressive Adaptive Style
Phipps & Srivastava (1997)	107 children with cancer 442 healthy controls	12 11.4 (7-16)	State-Trait Anxiety Inventory Below 50th percentile Children Social Desirability Questionnaire At or above 75th percentile
Phipps & Srivastava (1999)	107 children with cancer 442 healthy controls	12 11.4 (7-16)	State-Trait Anxiety Inventory Below 50th percentile Children Social Desirability Questionnaire At or above 75th percentile
Nassau, Fritz, & McQuaid (2000)	95 children with asthma	11.5 (9-14)	Children Manifest Manifest Anxiety Scale Below 50th percentile Children Social Desirability Scale At or above 75th percentile Weinberger Adjustment Inventory
Phipps, Steele, Hall, & Leigh (2001)	130 children with cancer 368 healthy controls 121 chronically ill children (Diabetes, cystic fibrosis, juvenile rheumatoid disorders)	13.08 12.75 12.22 (7-18)	State-Trait Anxiety Inventory Below 50th percentile Children Social Desirability Scale At or above 75th percentile

Table 4 (continued)
The Repressive Adaptive Style in Childhood and Adolescence

Reference	N	Age Range & Mean	Measures of the Repressive Adaptive Style
Phipps & Steele (2002)	130 children with cancer 368 healthy controls 121 chronically ill children (diabetes, cystic fibrosis, juvenile rheumatoid disorders)	13.08 12.75 12.22 (7-18)	State-Trait Anxiety Inventory Below 50th percentile Children Social Desirability Scale At or above 75th percentile Anger Expression Scale for children Below 50th percentile
Steele, Elliot, & Phipps (2003)	251 chronically ill children (Cancer, diabetes, cystic fibrosis, juvenile rheumatoid disorders) 368 healthy children	12.71 (7-18)	State-Trait Anxiety Inventory Below 50th percentile Children Social Desirability Scale At or above 75th percentile Anger Expression Scale for Children Below 50th percentile
Richards, Benson, Cushing & Steele (2004)	123 typically developing children	12 (11-13)	State-Trait Anxiety Inventory Below 50th percentile Children's Social DesirabilityScale At or Above 75th percentile

<u>Purpose of the Study</u>

The purpose of this study is five-fold: (a) to investigate the incidence of the repressive adaptive style among adolescents diagnosed with IBD as opposed to typically developing peers; (b) to study the impact of a repressive defense style on disease severity as assessed by both subjective and objective measures; (c) to investigate the impact of the repressive defense style on adolescents' behavioral adjustment; (d) to explore the multiple emotional aspects associated with the use of a repressive defense style within groups of adolescents with IBD and their typical peers; and (e) to examine the concurrent validity of multiple methods in assessing the repressive adaptive style among adolescents.

The first purpose of this project is based on research about adaptive style in pediatric populations and on data about the psychosocial adjustment of pediatric patients with IBD. On the one hand, pediatric studies of the repressive adaptive style revealed a larger presence of repressors among pediatric populations than among healthy peers. On the other hand, data on the psychological functioning of pediatric patients with IBD suggested the presence of patients with a repressive style of adaptation. Psychosocial studies among pediatric patients with IBD showed that some patients self-report low physical and psychological distress when disease activity measures and observers' ratings imply the contrary. One study found a large proportion of pediatric patient with an over-controlled psychological style as compared to healthy siblings and another study revealed that pediatric patients with IBD tend not to express angry feelings. Projective test data pointing in the direction of repressive defenses and researchers' clinical impressions of a repressive style among patients further imply the possible presence of a significant number of pediatric patients with IBD resorting to a repressive style of adaptation.

Therefore, it is assumed that a larger proportion of adolescent repressors is present among pediatric patients with IBD than among healthy peers.

The second purpose of this study is to explore the impact of a repressive adaptive style on disease severity, as measured by objective laboratory values and self-reports of quality of life. Explorations of the repressive adaptive style in pediatric populations replicated adult data that repressors inhibit signals of distress and produce optimistically biased self-reports of well-being even though behavioral and autonomic indexes point to the contrary. However, no pediatric investigation to date has specifically researched the impact of the repressive defense style on illness severity among pediatric patients in general or among patients with IBD in particular. A series of adult studies reported that the repressive defense style has important health-related implications in terms of disease progression and health outcomes (Dirks, et al., 1979; Jammer & Leigh, 1999; Jammer & Schwartz, 1996; McCormick, Taylor, Rivolier, & Cazes, 1985). Further, studies related to the psychological functioning of children and adolescents with IBD reported that patients rating themselves as well-adjusted tend to have more active and severe disease than pediatric patients rating themselves as depressed, anxious, or angry. Pediatric investigations also found that unexpressed hostility or an over-controlled psychological style of functioning may be associated with disease severity as assessed by objective medical measures (Ondersma et al., 1996; Wood et al., 1987). More specifically, it was found that style of psychological functioning rather than level of psychological functioning was associated with disease severity. Finally, a study of the quality of life of adolescents with IBD reported that disease activity as assessed by medical markers was not related to subjective scores on a quality of life scale (MacPhee et al., 1998). Wood et al. postulated that a repressive style of adaptation may mediate and moderate the relationship between health-related stress and health outcome for a subgroup of pediatric

patients with IBD. Based on theoretical tenets and empirical data among adults, a repressive

adaptive style should be associated with disease severity as assessed by medical indices but with

mild disease as assessed by self-reports of functional impairments. In this study, it is

hypothesized that greater disease severity as assessed by medical markers, and mild disease

severity as evaluated by self-reports of quality of life, will be associated with a repressive style

of adaptation.

The third purpose of this study is to investigate the impact of a repressive adaptive style on

the behavioral adjustment of adolescents with IBD and their healthy peers. One of the main

characteristics of a repressive style of adaptation is low reports of distress. However, adult

cognitive and social empirical studies as well as pediatric study showed that repressors' low

reports of distress are more a reflection of self-deceptiveness than actual adjustment. In addition,

some researchers highlighted than the presence of repressors among individuals at the low end of

the distress continuum confounds research results and may underlie discrepancies between report

of distress and physiological measures of distress as well as between self-rated adjustment and

significant other's ratings. Wood et al. hypothesized that a repressive adaptive style among a

subgroup of pediatric patients with IBD may underlie parent-child ratings discrepancies.

Recently, Loonen, Derkx, Koopman, and Heymans (2002) reiterated the hypothesis that a

repressive style of adaptation might undergird discrepancies between pediatric patients' with

IBD and their parents' reports of patient's health-related quality of life. In this study, it is

hypothesized that adolescents with IBD and typical peers, using a repressive adaptive style, will

self-report low behavioral dysfunction whereas their parents will report behavioral difficulties.

The fourth and fifth purposes are based on Phipps and Srivastava's (1999), Canning et al.'s

(1992), and Phipps and Steele's (2002) investigations that suggested that a depression scale and

an anger scale could be appropriate substitutes for an anxiety scale for the assessment of a

repressive defense style according to Weinberger's paradigm. A possible way of testing the

construct validity of the repressive defense style is by introducing two other dimensions of affect

that may be repressed. Indeed, although Weinberger et al.'s methodology focuses on anxiety as

the main object of repression, Weinberger's theory posits that the repressive defense style

involves the repression of any emotions threatening the individual's theory of self (i.e., an ideal

of psychological and physical health). In this study, I propose to use an anger scale and a

depression scale as possible alternative instruments to the measurement of repression.

Hypotheses of the Study

Hypothesis 1: The proportion of adolescents with a repressive adaptive style in the IBD

sample will be greater than the proportion of adolescents with a repressive adaptive style in

the healthy sample.

Hypothesis 2 (a): Adolescents diagnosed with IBD exhibiting a repressive style of

adaptation will report better quality of life than adolescent patients without a repressive

adaptive style (i.e., high anxious and defensive high anxious). Quality of life for repressors

and low anxious is expected to be similar.

Hypothesis 2 (b): Adolescent diagnosed with IBD exhibiting a repressive adaptive style will

show greater disease severity than adolescent patients without a repressive style of

adaptation, particularly low anxious (i.e., the disease severity index is expected to

differentiate low anxious from repressors).

Hypothesis 3: Adolescents with a repressive adaptive style will show significantly poorer behavioral adjustment than non-repressors as assessed by parents' ratings (i.e., lower agreement parents and teen repressors than between parents and teen non-repressors).

Hypothesis 4 (a): Adolescents with a repressive style of adaptation will show lower anger expression scores than adolescents without a repressive style of adaptation (i.e., high angry and defensive high angry). Anger expression scores are expected to be similar for repressors and low anxious.

Hypothesis 4 (b): Adolescents with a repressive style of adaptation will show lower depressive symptomatology than adolescents without a repressive style of adaptation (i.e., high depressed and defensive high depressed). Depression scores are expected to be similar for repressors and low anxious participants.

Hypothesis 5 (a): The use of anger expression, instead of anxiety, as the index of distress in the adaptive style paradigm will identify a similar proportion of children across adaptive styles to the anxiety-based paradigm.

Hypothesis 5 (b): The use of depression, instead of anxiety, as the index of distress in the adaptive style paradigm will identify a similar proportion of children across adaptive style to the anxiety-based paradigm.

CHAPTER 3

METHOD

<u>Participants</u>

IBD group

Participants diagnosed with IBD were recruited from two different sites: the Children′s Center for Digestive Healthcare in Atlanta, GA and the Center for Pediatric Inflammatory Bowel Disease in Philadelphia. The Children′s Center for Digestive Healthcare is located in the Children′s at Scottish Rite hospital in Atlanta and it is one of the biggest centers for gastrointestinal diseases in the Southeast. The Center for Pediatric Inflammatory Bowel Disease is located in the Children′s Hospital of Philadelphia. It is one of the largest centers for IBD treatment in the United States and it provides care for patients all over the world.

At the Children′s Center for Digestive Healthcare, letters of invitation to participate in the study as well as parental and minor consent forms were sent to 45 families whose children were diagnosed with IBD and were aged 14 to 18 years old. Exclusion criteria were: (a) being older than 18 years old and 11 months and younger than 14 years old (b) unable to read English and (c) not returning signed consent forms. Out of 45 invited families, 36 agreed to participate and 33 returned completed questionnaires. Three sets of questionnaires were discarded because of missing data and a total of 30 adolescents and parents from the Children′s Center for Digestive Healthcare provided complete data that were included in statistical analyses. All 30 participating adolescents were attending the Children′s Center for Digestive Healthcare for outpatient treatment only.

At the Center for Pediatric Inflammatory Bowel Disease in Philadelphia, 12 families were approached at the time of their physician appointment and all consented to participate. Exclusion criteria were similar to those mentioned previously. All 12 families returned complete protocols and their reports were included in data analyses. Overall, across both medical sites, a total sample of 42 adolescent patients with IBD was recruited for the study.

Control group

A control group of typically developing peers in grades 9 to 12 was recruited at Madison County High School in Danielsville, Georgia. Madison County is a rural county located in Northeast Georgia. Teachers who volunteered to take part in the study distributed letters of invitation and consent forms to their students. Students aged 14 to 18 years old who returned signed consent forms were eligible to participate in the study. Exclusion criteria were: (a) being older than 18 years old and 11 months and younger than 14 years old (b) being known by the school to suffer from a chronic or serious disease (c) unable to read English and (d) not returning signed consent forms. Data were collected on 302 students, which represented about 50% of the 600 letters of request that were distributed. The rate of participation is approximate because, due to students′ absences and to the duplication of requests for participation to students present in more than one volunteering classes, an exact percentage of refusals could not be calculated. The school counselor checked the health status of participating students and none of them was found to have a school record of serious or chronic health problems. Out of the 302 students who took part in the study, 207 returned a completed BASC parent form (i.e., 68.54 %). All data provided was complete. Participants′ demographic information is presented in Table 5.

Table 5
Demographic and Medical Information of Participants

	Controls (*n* = 302)	IBD (*n* = 42)
Age [*M (SD)*]	16 yrs, 4 months (1 yr, 2 months)	16 yrs, 5 months (1 yr, 2 months)
Age range	14-18 yrs, 11 months	14-18yrs, 11 months
Age groups %		
14-15yrs 11 months	42.1%	30.9%
16-17yrs 11 months	40%	50%
18-18yrs 11 months	17.9%	19%
Gender %		
Male	36.8%	59.5%
Female	63.2%	40.5%
Grade %		
9th grade	32.8%	11.9%
10th grade	21.9%	31%
11th grade	17.2%	33.3%
12th grade	28.1%	23.8%
Diagnosis %		
CD		61.9%
UC		26.2%
Undecided		11.9%
Time since diagnosis *M* (*SD*)		3 yrs, 7 months (2 yrs, 3months)
Age at diagnosis *M* (*SD*)		12 yrs, 8 months (2 yrs, 1 month)

Table 6

Demographic Information of Parents

	Controls (n = 207)	IBD (n = 42)
Parental education level		
Mother [*M (SD)*]	12 yrs, 6 months (2 yrs, 3 months)	15 yrs, 2 months (2 yrs, 7 months)
Father [*M (SD)*]	12 yrs, 4 months (2 yrs, 11 months)	16 yrs (3 yrs, 5 months)
Completed high school		
Mother	31.8%	31%
Father	34.8%	24.4%
Completed college		
Mother	5.6%	28.6%
Father	5.0%	22.0%
Graduate school		
Mother	7.3%	33.3%
Father	6.0%	41.5%
Rater %		
Mother	87%	81%
Father	12%	19%
Other	1.0%	0%

Procedure

        This study was approved by the Institutional Review Board of The University of Georgia

and the Institutional Review Board of The Children's Hospital of Philadelphia. Prior to data

collection and for both groups, the researcher explained to participants and their families that the

study deals with the coping style of chronically ill and healthy adolescents. Participants were

asked to provide informed consent (both parental consent and child assent) and to complete a

battery of self-report scales assessing their emotional and behavioral functioning as well as

quality of life for patients with IBD. Self-report measures were administered in a random order

throughout data collection to counterbalance possible biases in the collected data as a result of

systematic completion order. At medical sites, diagnosis of IBD was established based on

conventional clinical, endoscopic, radiological, and histological criteria. Diagnoses were

recorded by the researchers from the medical files. Finally, the questionnaires were administered

to outpatients to avoid possible confounding effects related to hospitalization.

        At the Children′s Center for Digestive Healthcare, families were sent letters of invitation

explaining the nature and purpose of the study with contact information for more information.

Families who returned completed and signed parent and minor consent forms were sent

questionnaires by mail to complete at home with a stamped return envelope. Laboratory values

and medication regimens were recorded from the patients′ files at the center by the researcher.

The most recent laboratory values (i.e., 1 month old at a maximum) were entered in the data set

and used for statistical analyses.

        At the Children's Hospital of Philadelphia, data collection took place at the time of

participants' scheduled appointments with their physicians. Families whose children were

eligible to participate were approached at random by the researcher and explained the nature of the study. Families who signed parent and minor consent forms were administered the questionnaires under supervision in the outpatient waiting area. No time limit was placed on completion. Laboratory testing was performed at the time of the appointment as part of routine laboratory testing. Laboratory indices were subsequently recorded by the researchers when testing results became available in the medical charts.

For control peers, questionnaires were administered by the researcher to the participating students during class periods. Participants were informed about confidentiality rules and were explained the nature of the project. Before the beginning of test administration, participants were distributed the parent report form of the BASC with a short demographic questionnaire to take home. Participants were asked to return the completed parent forms to their teachers on an agreed date. At the end of data collection, 20 student names were drawn at random among the pool of participating students. The 20 students whose names were drawn were offered a free movie ticket for taking part in the study.

<u>Measures</u>

The Behavior Assessment System for Children- Self-Report of Personality- Adolescent (BASC-SRP-A; Reynolds & Kamphaus, 1992)

The BASC-SRP-A is a personality inventory that assesses adolescents' self-perceptions of emotional and behavioral functioning. It was designed for use among teenagers aged 12 to 18 years old and includes 186 items that are responded to as *True* or *False*. The BASC-SRP-A takes about 30 minutes to complete. The BASC-SRP-A has 14 scales measuring adaptive and maladaptive constructs, and it yields the following composites: School Maladjustment, Clinical

Maladjustment, Personal Adjustment, and an overall composite score, the Emotional

Symptoms Index. The Anxiety scale of the SRP-A contributes to the Clinical Maladjustment

composite and the Depression scale of the SRP-A contributes to the Emotional Symptoms Index.

Special indexes were incorporated to assess the validity of adolescents' responses: the *F*

index, the *L* index and the *V* Index. The *F* index is a measure of an adolescent's tendency to

present himself or herself in an excessively negative way. The *L* index is a measure of an

adolescent's tendency to present himself or herself in an extremely positive way, and the *V* index

was designed to detect invalid responses due to poor reading comprehension, failure to follow

directions, or poor contact with reality.

The BASC manual (Reynolds & Kamphaus, 1992) provides three types of reliability

evidence: internal consistency, test-retest reliability and interrater reliability. Internal consistency

reliabilities of the SRP-A scales are high, averaging about .80 for each gender. The Anxiety and

Depression scales are among the scales with the highest reliabilities. Coefficients alpha for the

Anxiety scale are .88 for females, .86 for males, with a total of .87 between the ages of 12 to 14

years old, and .87 for females, .84 for males, with a total of .87 between the ages of 15 to 18

years old. Coefficients alpha for the Depression scale are .90 for females, .88 for males, with a

total of .89 between the ages of 12 to 14 years old, and .87 for females, .85 for males, with a total

of .86 between the ages of 15 to 18 years old. Test-retest reliability coefficients are .80 for the

Anxiety scale and .77 for the Depression scale (see Reynolds & Kamphaus, 1992).

The validity of the BASC-SRP-A was assessed with four different methods: factor analysis,

experts' judgments, correlations with other personality measures, and analysis of score profiles

of group of children with particular clinical diagnoses. These four methods demonstrated good

content, concurrent, construct, and criterion validity of the SRP-A (see Reynolds &

Kamphaus, 1992). Factor analyses of scale inter-correlations indicated that the Anxiety and

Depression scales correlate at .53. The Anxiety scale correlates .53 with the Somatization scale,

and the Depression scale correlates .49 with the Somatization scale.

The BASC-SRP-A exhibits a number of high correlations with analogous scales from other

self-report instruments (Reynolds & Kamphaus, 1992) including the Minnesota Multiphasic

Personality Inventory-Adolescent Version (MMPI-A; Butcher & Williams, 1992) and the

Achenbach's Youth Self-Report (YSR; Achenback, 1991), providing support for the concurrent

validity of the SRP-A. For example, the Anxiety scale correlates .76 with the Anxiety scale of

the MMPI-A and the Depression scale correlates .43 with the Depression scale of the MMPI-A.

Overall, the BASC-SRP-A is a reliable and valid measure of adolescent's personality, including

emotions and self-perceptions.

Children's Social Desirability Questionnaire (CDS; Crandall, 1975)

The CSD was used to measure the construct of defensiveness (Crandall, 1975; Crandall,

Crandall, & Katvosky, 1965). The CSD is a modified version of the Marlowe-Crowne Social

Desirability Scale for adults. The CSD was normed on a total sample of 956 grade school and

high school students. It consists of items representing behaviors and attitudes that are socially

desirable but improbable. Crandall et al. (1965) reported corrected split-half reliabilities ranging

from .82 to .95 and test-retest reliabilities ranging from .85 to .90 after 1-month interval.

Two versions of the CSD are available. One version was designed for younger children and

uses a yes/no question format. This version is usually presented via recording and contains 25

items. The other version was designed for adolescents and presents 48 statements with true/false

responses (Robinson, Shaver, & Wrightsman, 1991). Phipps and Srivastava (1999) used a

25- item version in a yes/no question format that was made up of items from both previously

described questionnaires. The selected items agreed in content and presented the highest item-

total correlations. Phipps and Srivastava reported a Cronbach's alpha of .88 for their version of

the CSD among a sample of 110 children. In this study, Phipps and Srivastava′s modified

questionnaire was used.

Anger Expression Scale for Children (AESC; Phipps & Steele, Unpublished)

The AESC is a non-standardized research scale of trait anger expression. The components of

anger expression included in the scale (i.e., anger-in, anger-out, anger-control, and anger

expression) have exhibited relatively stable internal reliabilities estimates across studies with

adult participants (Forgays et al., 1997; Spielberger, 1988) as well as good predictive and

concurrent validity (Deffenbacher et al., 1996; Jacobs et al., 1989). The AESC was developed in

the context of an investigation of adaptive style in both healthy and ill children. Children with

serious chronic illnesses (cancer, cystic fibrosis, juvenile rheumatoid disorders, and diabetes ($n =$

251) and a group of healthy controls ($n = 368$) completed the AESC. Factor analyses produced a

two-factor structure: items from Anger Expression and Anger-out scales co-varied as a single

factor which the authors labeled "anger expression" and items from Anger-control and Anger-in

subscales could be reduced to a single factor labeled "anger control." The two-factor structure

emerged both in the healthy control sample and the chronically ill sample. The anger expression

subscale is a 12-item subscale with an internal reliability estimate of .83. The anger control

subscale is 9-item subscale with an internal reliability estimate of .82.

Internal reliabilities were nearly identical within the healthy control sample and the chronically ill sample. The Anger Expression subscale was significantly and negatively correlated with the Anger Control subscale. The Anger Expression subscale was also negatively correlated with defensiveness on the Children's Social Desirability Questionnaire (CSD) and positively correlated with trait anxiety on the State-Trait Anxiety Inventory for Children (STAIC). The Anger Control subscale was significantly positively correlated with the CSD but not with the STAIC.

Seriously and chronically ill children reported less anger expression than healthy children and the AESC was sensitive to children's adaptive styles, with repressors reporting significantly lower levels of anger expression and high anxious children reporting the highest levels of anger expression. Children identified as repressors or as defensive high anxious also exhibited significantly higher scores on the anger control subscale.

Stability of both the Anger Expression and the Anger Control subscales was demonstrated at 6- and 12- month intervals. Test-retest coefficients ranged between .47 and .57 for the Anger Expression subscale and between .38 and .54 for the Anger Control subscale.

The Behavior Assessment System for Children-Parent Rating Scales (BASC; Reynolds & Kamphaus, 1992)

The BASC-PRS-A is a comprehensive measure of a child's adaptive and problem behaviors in community and home settings. It uses a four-choice response format, and it takes 10 to 20 minutes for parents to complete. The BASC-PRS has three forms at three age levels: preschool, child, and adolescent. In this study, the BASC-PRS for adolescents was used. The BASC-PRS consists of 126 items and it includes five composites: Externalizing Problems, Internalizing

Problems, Other Problems, Adaptive Skills, and a Behavioral Symptoms Index. It also

includes an *F* index as a check on the validity of the parent ratings as well as critical items that

may be interpreted individually.

Internal consistency reliabilities of the composite scores are in the middle .80s to low .90s

between the ages of 12 to 18 years old for both genders, and test-retest correlations for the

composites vary between .70s to .90s. Finally factor analytic studies provided support for the

validity of the BASC-PRS, and the scale was shown to correlate highly with other measures of

child's behavior and personality including the Child Behavior Checklist (CBCL; Achenbach,

1991).

IMPACT: Quality of Life Index for Pediatric Inflammatory Bowel Disease (Griffiths et al., 1999;

Otley et al., 2002)

Assessment of health-related quality of life is important for measuring the impact of chronic

disease on the patient's overall daily functioning. The IMPACT questionnaire is a disease-

specific quality-of-life questionnaire developed for use in pediatric IBD. It is intended to reflect

patients' perception of their health status and to serve as both a descriptive and evaluative. The

IMPACT is a self-report questionnaire. It takes about 15 minutes to complete and contains 33

questions encompassing six domains: bowel, body image, functional/social impairment,

emotional impairment, tests/treatment, and systematic impairment. Each question uses a 10 cm

visual analogue scale with two anchors at either end expressing extreme answers (i.e., 0 cm

represents the worst concern and 10 cm an absence of concern). The measured length is

multiplied by 0.7 giving a maximal score on each item of 7. Individual items are equally

weighted and scores range from a maximum of 231 to a minimum of 0, with higher scores

representing a better quality of life. The IMPACT was normed on 147 patients aged 10 and older. The IMPACT has a Cronbach's alpha score of 0.96 and a test-retest coefficient for the total score of 0.90 over two weeks (i.e., two weeks is a commonly chosen interval for reliability assessment of quality of life to decrease chance of a change in disease activity occurring). The results of construct validity testing indicate that patients who perceived themselves as having a poor quality of life had lower IMPACT scores and patients with quiescent disease had significantly greater IMPACT scores compared with patient groups having intermittently or chronically active disease.

<u>Laboratory Markers</u>

Assessment of disease activity in IBD is done using clinical parameters and various biological disease markers (Seibold, 2003). However, definition of disease activity in IBD is a major problem (Nielsen, Vainer, Madsen, Seidelin, & Heegaard, 2000). Ideally, a disease marker must be able to identify individuals at risk for a given disorder, be specific, and mirror the disease activity (Nielsen et al., 2000). No such marker has yet been identified for IBD (Garrett & Drossman, 1990; Nielsen et al., 2000). In this project, laboratory markers were used in the assessment of disease severity in conjunction with prescribed medication, alternative treatment, and number of hospitalizations. Three biological markers were selected based on their extended and typical use in clinical tests i.e., Erythrocyte sedimentation rate (ESR), serum albumin levels, and hematocrit levels (Seibold, 2003). Hematocrit levels, serum albumin levels, and ESR are the three laboratory indexes included in the Pediatric Crohn′s Disease Activity Index (PCDAI; Hyams et al., 1992). Although routinely used in IBD, these laboratory markers assess the degree of active inflammation in the whole body and they are not specific with respect to inflammation

in the gut (Nielsen et al., 2000). In addition, none of these biological markers are specific or sensitive enough in isolation (Seibold, 2003) and no single lab test is adequate to reflect disease activity in all patients (Hyams et al., 1992).

Erythrocyte Sedimentation Rate (ESR)

The erythrocyte sedimentation rate (ESR) is a classical marker of acute phase response. It is based on the density of red blood cells. In IBD, the ESR provides a rapid assessment of plasma protein alterations during inflammation. Higher ESR values indicate greater disease activity, infection, tissue damage or inflammation. In IBD, ESR values increase. ESR is commonly performed for screening symptomatic children with IBD (Khan, Schwarzenberg, Sharp, Greenwood, & Weisdorf-Schindele, 2002). It is almost always abnormal in children with IBD (Buller, 1997). In UC, the correlation between ESR and disease severity is good. In CD, correlations between ESR and disease activity depends on disease location (Hyams et al., 1992; Nielsen et al., 2000).

Albumin

Albumin is an abundant protein in the blood which serves to maintain the somatic pressure of the blood. Serum albumin levels decline in active disease. They reflect acute phase protein response during inflammation (Nielsen et al., 2000). Cabral, de Carvlho, and Miszputen (2001) reported that serum albumin levels correlate inversely with disease activity, and Viscido, Corrao, Taddei, and Caprilli (1999) found that serum albumin levels in combination with ESR were able to discriminate patients with and without recurrence in 88% of the cases. Low levels of serum albumin occur in people with inflammation, malnutrition, and serious liver or kidney disease.

Serum albumin concentration is considered a sensitive marker of inflammatory disease

activity in IBD (Cabral, deCarvalho, & Mizputen, 2001).

Hematocrit Levels

The hematocrit level measures how much space in the blood is occupied by blood cells. It

usually decreases in IBD and indicates anemia, active bleeding, and hemorrhages in the

gastrointestinal tract.

Altogether, laboratory values have the following meaning:

(a) Increased ESR **(↑)** values = Increased disease activity **(↑)**;

(b) Decreased Albumin values **(↓)** = Increased disease activity **(↑)**; and

(c) Decreased Hematocrit values **(↓)** = Increased disease activity **(↑)**.

Index of Disease Severity

A total score assessing the degree of disease severity was calculated by adding scores on the

following variables:

1. The number of medications currently taken by patients for the treatment of IBD.

   Medications were classified in seven categories i.e., corticosteroids, immunomodulatory

   drugs, anti-inflammatory drugs, infliximab, antibiotics, support drugs (e.g., anti-reflux

   drug, anti-diarrheal drugs), and nutritional supplements (e.g., fish oil, probiotic or any

   other supplement modifying the gut luminal flora, herbal suppository, vitamins,

   minerals, homeopathy, juice). For each category, the number of medication reported was

   counted in the total score for disease severity. Medication categories were given

   different weights in the total score according to their function and the degree of severity

   they indicate. Corticosteroids and infliximab, which are prescribed in cases of severe

disease activity or relapses over the short-term, were given a weight of 2, immunomodulatory drugs, anti-inflammatory drugs, and antibiotics, which are prescribed in cases of moderate to mild diseases or to maintain remission, were given a weight of 1.5. Support drugs (which are prescribed on a per needed basis or for symptom relief) and nutritional supplements were given a weight of 1.

2. Number of times corticosteroid medication was used in the past 12 months. The exact number of times corticosteroid medication was used was counted toward the total score assessing disease severity.

3. Number of hospitalizations due to IBD in the past 12 months. The exact number of hospitalizations was used for the total score assessing disease severity.

4. Results of hematology tests for the erythrocyte sedimentation rate, the albumin and hematocrit levels. For albumin, ESR, and hematocrit hematology tests, raw test results were coded following the range of values used in the Pediatric Crohn's Disease Activity Index (PCDAI) for both males and females.

CHAPTER IV

RESULTS

The group of healthy adolescents ($n = 302$) and the group of adolescents diagnosed with

IBD ($n = 42$) were compared on demographic characteristics. Statistical analyses showed that

both groups did not differ in mean age at testing, $F (1, 342) = 0.23$, *ns*. However, differences

between groups for gender and parent educational levels were found. The group of patients with

IBD included more male participants than the control group of healthy teenagers; $^2 (1, 136) =$

$8.09, p < .01$, and parents' levels of reported educational attainment are higher among

adolescents with IBD than among healthy adolescents; $t (246) = -5.67, p < .001$ for mothers'

educational levels and $t (238) = -6.23, p < .001$ for fathers' educational levels.

Within the group of patients with IBD, 61.9% of patients were diagnosed with CD as

compared to 26.2% of patients diagnosed with UC. When diagnosis was impossible to make due

to difficulties in clinically differentiating CD from UC, a diagnosis label of "undecided" was

recorded in patients' medical charts. In the study sample, "undecided" diagnoses were given to

11.9% of patients. The chi square test of independence was used to test the relationships between

diagnosis types and gender as well as between diagnosis types and age groups. Diagnostic

categories were found unrelated to patients' gender; $^2 (2, N = 42) = 0.95$, *ns.*, with both

gender groups exhibiting similar distribution of IBD diagnoses. Diagnostic labels were also

found to be unrelated to a particular age group; $^2 (4, N = 42) = 2.66$, *ns.*, with the three age

groups showing similar proportions of IBD diagnoses.

<u>Is there a relationship between a repressive adaptive style and IBD?</u>

It was hypothesized that a greater proportion of adolescents exhibiting a repressive style of adaptation would be identified in the group of patients with IBD than in the group of healthy controls. In order to categorize study participants into the four adaptive styles delineated by Weinberger et al. (1979), the distributional shape of self-report data for the control group on the Children's Social Desirability scale (CSD) was examined. The resulting distribution of scores in the data set indicated an almost normal distribution, with most of the scores being clustered near the middle of the continuum of observed scores and with a decrease in score frequency in both directions away from the center. Kurtosis and skewness were, respectively, .187 and -.635, suggesting a relatively normal distribution. Correlations between defensiveness, anxiety, depression, and anger expression are presented in Table 7 for the total sample. Correlations between the CSD and the other scales revealed that the measure of defensiveness was negatively correlated to the Anxiety, Depression, and Anger Expression scales, respectively. In addition, the Anxiety scale was positively correlated to the Depression and Anger Expression scales, respectively (the correlation with the depression scale being the strongest).

Table 7

Correlations between variables for the Combined Sample

	CSD	Anxiety	Depression	Anger Expression
CSD	----			
Anxiety	-.369**	----		
Depression	-.301**	.571**	----	
Anger Expression	-.466**	.381**	.460**	----

Note. N= 344; CSD = Children's Social Desirability Scale; ** *p* < .01.

Before proceeding to the effects of adaptive style, differences between groups of healthy

and chronically ill adolescents on self-report measures were examined (see Table 8).

Adolescents with IBD and healthy controls did not differ in their reports of defensiveness; *F* (1,

342) = 0.22, *ns*, in their reports of anxiety; *F* (1, 342) = 1.72, *ns*, and in their reports of

depressive symptomatology; *F* (1, 342) = 3.06, *ns*. A relationship was found between disease

status and reports of anger expression, with the group of adolescents diagnosed with IBD

reporting less anger expression than the group of healthy controls; *F* (1, 342) = 6.44, *p* = .01.

Table 8

Differences between Adolescents with IBD and Healthy Controls on Self-Report Measures.

	IBD Group		Control Group			
	M	SD	M	SD	F	p
Defensiveness (CSD)	9.21	5.73	8.86	4.40	.223	ns.
Subjective Distress (BASC Anxiety scale)	46.43	10.15	48.66	10.32	1.72	ns.
Depression (BASC Depression scale)	48.02	7.71	50.99	10.60	3.06	ns.
Anger Expression (AESC)	27.00	6.77	30.21	7.79	6.44	.01

Note. CSD = Children's Social Desirability Questionnaire; AESC = Anger Expression Scale for Children; IBD = Inflammatory bowel disease; BASC = Behavior Assessment System for Children.

Participants were classified into one of the four categories of adaptive style, i.e., truly low anxious, repressors, high anxious and defensive high anxious, following Weinberger et al.'s (1979) paradigm consisting of the interaction between a measure of distress and a measure of defensiveness. In the present study, the measure of anxiety is the BASC-SRP-A Anxiety scale and the measure of defensiveness is the CSD. On both scales, cut-off points originally proposed by Weinberger et al., and widely applied in both adults and child empirical studies, were used. Altogether, high defensiveness was assessed at or above the 75th percentile on the CSD and low anxiety was assessed below the sample mean on the BASC Anxiety scale. For the combined sample, cut-off scores for levels of defensiveness and anxiety were determined based on the control group score distribution for the respective scales. On the CSD, self-reports of defensiveness yielded a cut-off score of 12 at the 75th percentile of the CSD score distribution. On the BASC Anxiety scale, self-reports yielded a mean score of 48. Table 9 present the

distribution of teen participants into the four adaptive style categories for the control group

and the group of patients with IBD.

Table 9
Adaptive Style Distribution

	Healthy (n = 302) % (n)	IBD (n = 42) % (n)	Total (N = 344) % (n)
Low Anxious	29.5% (89)	21.4% (9)	28.5% (98)
Repressors	18.5% (56)	38.1% (16)	20.9% (72)
High Anxious	42.1% (127)	38.1% (16)	41.6% (143)
Defensive High Anxious	9.9% (30)	2.4% (1)	9.0% (31)

Note. A score of 12 or above on the CSD = high defensiveness; a score below 48 on the BASC-SRP-A anxiety scale = low anxiety; low anxious = low defensiveness and low anxiety; repressors = high defensiveness and low anxiety; high anxious = low defensiveness and high anxiety; defensive high anxious = high defensiveness and high anxiety.

Before analyzing differences in adaptive styles between groups, the effect of time since

diagnosis or age at diagnosis on style of adaptation among patients with IBD was tested. Two,

one-way ANOVAs were performed with adaptive style as the independent variable and time

since diagnosis or age at diagnosis as the dependent variable. No relationship was found between

style of adaptation and time elapsed since diagnosis; $F (2, 37) = 0.03$, *ns.* and between style of

adaptation and age at diagnosis; $F (2, 37) = 0.00$, *ns.*

The independent samples chi square test indicated that adolescents with IBD and healthy

adolescents differed significantly in adaptive styles; $\chi^2 (3, N = 344) = 10.04, p < .05$. Adaptive

style categories were dichotomized between repressors and non-repressors for both groups of

healthy and chronically ill adolescents, producing a two-by-two table with four possible

contrasts. One directional contrast was carried out for the repressor category (i.e., the proportion

of teenagers in the group of patients with IBD is larger than the proportion of teenagers in the

healthy group), following the procedure presented by Marascuilo and Serlin (1988) for post hoc

multiple comparisons with an overall $\alpha = .05$.

Marascuilo and Serlin's procedure is based on Dunn's (1961) suggestion that, because post

hoc comparisons are not mutually exclusive, the risk of committing at least one type I error is

increased. Therefore, to make a decision regarding the null hypothesis, Marascuilo and Serlin

use Z critical values that are provided by Dunn's table for multiple comparison tests and that are

based on the number of contrasts. Results confirmed our hypothesis that, proportionally, there

are more adolescents with a repressive adaptive style in the groups of adolescents with IBD than

in the group of healthy controls; $\chi^2 (1, N = 344) = 8.52, p = .001$. Because contrasts are not

independent from each other, and from the whole sample, these results also imply that the group

of healthy adolescents includes more non-repressors than the group of patients with IBD (See

Figure 2).
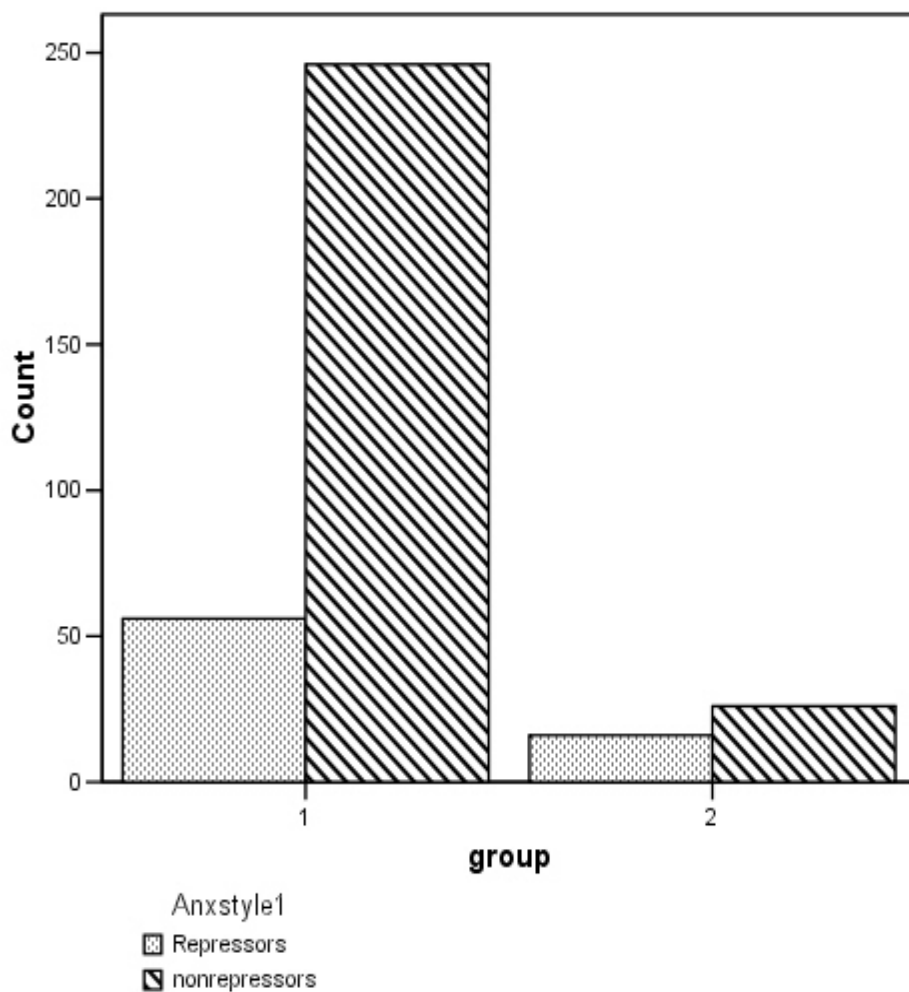
Figure 2. The repressive adaptive style among adolescents with IBD and healthy controls
    1 = Healthy Controls; 2 = Group with IBD

The distribution of age groups and gender across adaptive styles for both groups of healthy and chronically ill adolescents is presented in Table 9. We examined a possible effect of age and gender on adaptive style for both groups. No differences were found in the proportion of adolescents in each of the three age groups across adaptive styles for either the group of healthy adolescents; ^{2} (6, $N = 302$) = 5.76, $p > .05$, or for the group of adolescents with IBD; ^{2}

(6, $N = 42$) = 4.89, $p > .05$, suggesting that there is no relationship between adaptive style and adolescents' ages at testing.

For the whole sample, there were differences in gender distribution across styles of adaptation; ^{2} (3, $N = 344$) = 39.42, $p < .01$, indicating a relationship between adaptive style and gender. Adaptive style categories were dichotomized between repressors and non-repressors, and a non-directional post hoc comparison was carried out for repressors between males and females. Results indicated there was a larger proportion of males in the repressor category than female; ^{2} (1, $N = 344$) = 14.06, $p < .001$. Given that these contrasts are not independent from each other, and from the whole sample, these results also imply that less male than female adolescents are present in the non-repressor category.

Due to the over-representation of males in the group of adolescents with a repressive adaptive style, the effect of gender on the outcome variables was examined using one-way ANOVAs. Significant differences between males and females participants were found in self-reports of depressive symptomatology; F (1, 342) = 17.21, $p < .01$ and in self-reports of anger expression; F (1, 342) = 10.19, $p < .01$, with female reporting more depressive symptoms and more anger expression. Females and males participants also differed in their quality of life reports; F (1, 40) = 6.11, $p < .05$, with females reporting better quality of life than males. Finally, male and female participants did not exhibit different levels of disease severity; F (1, 40) = 1.72, $p > .05$.

Table 10

Demographic Variables and Adaptive Styles

| | | Gender | | | | | Age | | | | | |
| | | IBD | | Healthy | | IBD | | | Healthy | | | |
n	Male	Female	Male	Female	14-15	16-17	18	14-15	16-17	18	Total
Low Anxious	7	2	47	42	3	5	1	37	36	16	98
Repressor	12	4	29	27	3	10	3	29	15	12	72
High Anxious	6	10	31	96	6	6	4	50	57	20	143
Defensive High Anxious	0	1	4	26	1	0	0	11	13	6	31
TOTAL	25	17	111	191	13	21	8	127	121	54	344

Note. $N = 344$

<u>Is there a relationship between a repressive adaptive style and quality of life?</u>

It was hypothesized that adolescents categorized as repressors would report better quality of life than adolescents who are non-repressors (i.e., high anxious and defensive high anxious) but similar quality of life to low anxious. Considering gender differences in self-reports of quality of life, the relationship between a repressive adaptive style and levels of quality of life was analyzed using a one-way analysis of covariance, with gender as the covariate. The defensive high anxious group was not included in the analysis of variance due to its small frequency (n =1). There were significant differences across adaptive styles in the levels of reported quality of life among teen patients with IBD; $F (2, 38) = 5.18$, $p = .01$. Partial eta squared was .219, suggesting that 21.9% of the variability in quality of life scores was accounted by adaptive styles. Post hoc pairwise comparisons were carried out by the Dunnett-T3 test because the Levene test of homogeneity of variances was rejected $p < .05$. Contrast results revealed that significant differences in total quality of life scores were present between repressors ($M = 193.8$, $SD = 25.9$) and high anxious participants ($M = 143.1$, $SD = 29.3$), with means differences indicating that adolescents with a repressive style of adaptation reported higher levels of quality of life than high anxious adolescents. However, as expected, no differences were found between repressors and low anxious participants ($M = 176.2$, $SD = 57.9$).

<u>Is there a relationship between a repressive adaptive style and disease severity?</u>

It was hypothesized that, among patients with IBD, adolescents exhibiting a repressive adaptive style would show greater disease severity than non-repressors, especially low anxious. A disease severity index consisting of (a) laboratory indices (b) medication prescribed for IBD (c) number of times corticosteroid medication was prescribed in the last 12 months and (d) number of hospitalizations due to IBD in the last 12 months was computed. The number of

medication prescribed at the time of testing was weighted according to the type of medication

(i.e., the degree of disease severity it implies). Corticosteroids and infliximab, which are

prescribed in cases of severe, active, or refractive IBD over a short-term period of time (Greig &

Rampton, 2003), were given a weight of two, anti-inflammatory and immunomodulatory drugs,

and antibiotics, which are prescribed for moderate or mild IBD or for maintenance of disease

remission (Greig & Rampton, 2003), were given a weight of 1.5, support drugs (e.g., anti-

diarrheal agent, prescribed on a per needed basis for symptom relief) and nutritional/herbal

supplements were given a weight of 1. Mean severity indices were compared for the groups of

low anxious adolescents ($M = 6.11$, $SD = 3.3$), repressors ($M = 10.56$, $SD = 4.9$), and high

anxious patients ($M = 7.43$, $SD = 3.0$) using a one-way ANOVA, given that there are no gender

differences in disease severity. The defensive high anxious group was not included in the

analysis due to its small size. Results reached significance levels; $F (2, 38) = 4.2$, $p < .05$. Based

on partial eta squared, 18 % of the variance in disease severity was accounted by adaptive styles.

Further follow-up analyses were carried out by the Dunnett T3 test. Results indicated that

repressors' disease severity indexes differed significantly from low anxious patients'; $p < .05$,

with low anxious patients showing lower disease severity than repressors. There was no

significant difference between high anxious and repressors in disease severity.

Table 11

Correlations between disease severity, anxiety, and defensiveness

	Disease Severity	Anxiety	Defensiveness
Disease Severity	------		
Anxiety	-.171	------	
Defensiveness	.412**	-.652***	------

Note. $n = 42$; ** = $p < .01$; *** = $p < .001$.

Do parents observe more behavioral and emotional difficulties among repressors?

It was hypothesized that chronically ill and healthy adolescents exhibiting a repressive adaptive style would show poorer behavioral adjustment than non-repressors, especially low anxious, according to parent reports. Analysis of parents' reports ($n = 249$) were performed with a multiple analysis of variance (MANOVA), using externalizing and internalizing problems as the dependent variables and disease status (IBD or healthy) and adaptive styles (low anxious, repressors, high anxious, defensive high anxious) as the independent variables. Table 12 presents mean scores for chronically ill and healthy adolescents across adaptive styles on parent self-reports.

Results revealed that the interaction between disease status and adaptive style was not significant for both externalizing; $F (2, 243) = 0.70$, *ns*, and internalizing problems; $F (2, 243) = 0.79$, *ns*., suggesting that disease status and adaptive style, taken jointly, had no significant effect on parents' reports. In terms of main effects, parents reported similar levels of behavioral functioning for healthy adolescents and adolescents with IBD; Wilks' $\Lambda = 0.99$, $F (1, 243) = 0.85$, *ns*.

In addition, there were no significant differences in the levels of parent reported externalizing problems; F (3, 245) = 1.58, *ns*, but significant differences were found in the levels of parent reported internalizing problems; F (3, 245) = 12.65, p = .00, between adaptive style groups. Follow up pairwise comparisons revealed that, contrary to expectations, parents' of adolescents with a repressive style of adaptation reported less internalizing problems; $p < .001$ than parents of adolescents who are high anxious and less internalizing problems than parents of adolescents categorized as defensive high anxious; $p = .001$. However, parents of adolescents with a repressive style of adaptation reported similar levels of internalizing problems to parents of adolescents who are low anxious; $p = .99$.

Table 12
Parent Reports of Adolescents Behavioral Functioning for Adaptive Style Categories

	Externalizing Problems			Internalizing Problems		
M	IBD	Healthy	Total	IBD	Healthy	Total
Low Anxious	43.78	51.00	50.08	49.67	46.10	46.55
Repressors	44.56	45.34	45.12	47.56	45.12	45.81
High Anxious	48.44	51.72	51.20	61.00	53.88	55.01
Defensive High Anxious	------	46.79	46.79	------	56.26	56.26

Note. $n = 249$; ----- indicates that the means for the defensive high anxious in the IBD group were not calculated due to its sample size ($n = 1$).

Correlations between parents' reports of anxiety and adolescents' reports of anxiety, and between parents' reports of depression and adolescents reports of depression were .41 and .46 respectively for $n = 249$.

Is there a relationship between a repressive adaptive style and self-reports of anger expression?

It was hypothesized that adolescents with a repressive adaptive style would exhibit lower levels of anger expression than high anxious and defensive high anxious participants but similar

levels of anger expression to low anxious participants. Considering gender differences in self-reports of anger expression, we examined differences in levels of self-reported anger expression across adaptive styles and across groups of patients with IBD and healthy controls using a 2 (disease status) × 4 (adaptive style) factorial analysis of covariance with gender as the covariate, and anger expression as the dependent variable.

No significant interaction was found between disease status and adaptive style regarding levels of anger expression; $F (3, 335) = 1.05$, $p > .05$. That is, no particular pattern in mean differences of levels of anger expression was found depending on both disease status and adaptive style. Using gender as the covariate, significant differences between groups of patients with IBD and healthy controls in self-reports of anger expression disappeared; $F (1, 335) = 1.24$, $p > .05$, indicating that differences between groups previously reported were due, in part, to the confounding effect of gender differences.

Conversely, significant differences in self-reports of anger expression across styles of adaptation were found; $F (3, 335) = 12.43$, $p < .001$. Follow up analyses by the Dunnett T3 test showed that repressors (M = 23.4, SD = 5.2) differed from low anxious ($M = 29.7$, $SD = 7.2$); $p < .001$, high anxious ($M = 33.4$, $SD = 7.3$); $p < .001$, and defensive high anxious ($M = 27.9$, $SD = 4.9$); $p = .001$ in their reports of anger expression, with less anger expression being reported by adolescents with a repressive adaptive style than by adolescents who do not have a repressive style of adaptation.

Is there a relationship between a repressive adaptive style and self-reports of depressive symptoms?

It was hypothesized that adolescents with a repressive adaptive style would exhibit lower levels of depressive symptoms than high anxious and defensive high anxious participants but

similar levels of depressive symptoms to low anxious participants. Considering gender differences in self-reports of depressive symptoms, we examined differences in levels of self-reported depressive symptoms across adaptive styles and across groups of patients with IBD and healthy controls using a 2 (disease status) × 4 (adaptive style) factorial analysis of covariance with gender as the control variable and depression as the dependent variable.

No significant interaction was found between disease status and adaptive style regarding levels of anger expression; F (3, 335) = 0.66, p > .05. That is, no particular pattern in mean differences of levels of depressive symptoms was found depending on both disease status and adaptive style. Using gender as the control variable, differences between groups in levels of depressive symptoms remained nonsignificant; F (1, 335) = 1.33, ns.

Conversely, there were significant differences in reports of depressive symptomatology between adaptive style groups; F (3, 335) = 10.27, p < .001. Post hoc pairwise comparisons by the Dunnett T3 test showed that, as expected, repressors' reports of depressive symptoms (M = 45.0, SD = 4.5) differed from high anxious (M = 56.3, SD = 11.7); p < .01 and defensive high anxious participants' (M = 50.1, SD = 9.7); p < .05, with repressors reporting less depressive symptoms than either of them. Adolescents with a repressive adaptive style and low anxious adolescents reported similar levels of depressive symptoms; p = .422.

Consistency and agreement between adaptive style paradigms

It was hypothesized that high levels of agreement would exist between adaptive style paradigms using anger expression or depression, instead of anxiety as an index of distress. For the combined sample, adolescent were classified into adaptive style categories using the Anger Expression scale and the Depression scale, respectively, as measures of distress. Table 13 and 14 present adaptive style categories based on these indices of distress.

Table 13
Adaptive Style Distribution with the Anger Expression Scale

	Healthy $n = 302$ % (n)	IBD $n = 42$ % (n)	Total $N = 344$ % (n)
Low Angry	28.5% (86)	33.3% (14)	29.1% (100)
Repressors	23.8% (72)	35.7% (15)	25.3% (87)
High Angry	43.0% (130)	26.2% (11)	41.0% (141)
Defensive High Angry	4.6% (14)	4.8% (2)	4.7% (16)

Note. A score of 12 or above on the CSD = high defensiveness; a score below 29 on the anger expression scale = low anger; low angry = low defensiveness and low anger; repressors = high defensiveness and low anger; high angry = low defensiveness and high anger; defensive high angry = high defensiveness and high anger.

The consistency of adaptive style categorizations using anxiety or anger was assessed using cross-tabulation. First, a chi square statistic was used to test the relationship between paradigms. A significant relationship between the anxiety-based and the anger expression based paradigms was found; $\chi^2 (9, 344) = 422.61$, $p < .001$.

Table 14
Adaptive Style Distribution with the Depression Scale

	Healthy $n = 302$ % (n)	IBD $n = 42$ % (n)	Total $N = 344$ % (n)
Low Depressed	41.1% (124)	40.5% (17)	41.0% (141)
Repressors	24.2% (73)	38.1% (16)	25.9% (89)
High Depressed	30.5% (92)	19.0% (8)	29.1% (100)
Defensive High Depressed	4.3% (13)	2.4% (1)	4.1% (14)

Note. A score of 12 or above on the CSD = high defensiveness; a score below 50 on the depression scale = low depression; low depressed = low defensiveness and low depression; repressors = high defensiveness and low depression; high depressed = low defensiveness and high depression; defensive high depressed = high defensiveness and high depression.

Further, concordance of classifications, also called the level of absolute agreement, was computed by adding up the numbers of participants classified by both scales as either repressor or nonrepressor and then dividing the sum by the total number of participants in the study. The level of absolute agreement for anger and anxiety categorizations was 67% and the coefficient of agreement (k) was 0.52 ($p < .0001$) (Table 15). When categorization was dichotomized into repressor versus nonrepressor, the absolute agreement was 93%, with $k = 0.81$.

Table 15

Comparison between Adaptive Style Paradigms Using Anger Expression or Anxiety

	Anxiety Style			
Anger Style	Low Anxious	Repressors	High Anxious	Defensive High Anxious
Low Angry	54	0	46	0
Repressor	0	68	0	19
High Angry	44	0	97	12
Defensive High Angry	0	4	0	12

Note. N = 344; k = .52

A significant relationship between the anxiety-based and the depression-based paradigms was found; $\chi^2 (9, 344) = 435.57$, $p < .001$. The level of absolute agreement for the depression and anxiety categories was 70% and the coefficient of agreement (k) was 0.57 ($p < .0001$) (Table 16). When categorization was dichotomized into repressor versus nonrepressor, the absolute agreement was 92%, with $k = 0.78$.

Table 16

Comparison between Adaptive Style Paradigms Using Depression and Anxiety

	Anxiety Style			
Depression Style	Low Anxious	Repressors	High Anxious	Defensive High Anxious
Low Depressed	82	0	59	0
Repressor	0	67	0	22
High Depressed	16	0	84	0
Defensive High Depressed	0	5	0	9

Note. N = 344; k = .57

CHAPTER V

DISCUSSION

Adolescence is an important transitional period during which many physical, cognitive, emotional, and psychological changes take place. These changes are considered normative stressors (Seiffge-Krenke, 1998). However, the presence of chronic disease amplifies the normal developmental stresses of adolescence. For instance, adolescence is associated with significant physiological and morphological changes, and one of the tasks of teenagers is to learn to accept their own body in spite of their acute sensitivity to physical deviation. Among patients with IBD, this task can be compromised because the onset of puberty is often delayed and is associated with short stature and excessive thinness (King, 2003; Rosen, 1991). Treatment with corticosteroids may further alter adolescent patient physical appearance with side effects such as weight gain, facial changes, acne, hirsutism, thereby aggravating feelings of unattractiveness and of being flawed. Moreover, the symptoms of IBD are socially embarrassing for all patients but even more for adolescents for whom social acceptance and attractiveness have a huge importance. IBD symptoms have also been reported to trigger feelings of defectiveness and self-disgust (King, 2003), which, in turn raises anxiety about dating and intimacy with peers. Finally, chronic inflammation in IBD is debilitating and leaves the adolescent feeling down and without energy, especially when anemia and pain are present (Mamula, Markowitz, & Baldassano, 2003).

Literature on the psychosocial adjustment of children and adolescents with IBD reflects, with a few exceptions, the above mentioned disease-related stressors and their impact on young patients' functioning. Pediatric patients with IBD were shown to be at greater risk for behavioral, social, and

emotional difficulties than healthy children, with the exception of a few studies reporting good adjustment. The adjustment difficulties of pediatric patients with IBD were reported to be similar to those of children and adolescents with other chronic illnesses (Mackner, Sisson, & Crandall, 2004).

As opposed to the majority of socio-emotional and behavioral studies carried out among pediatric patients with IBD, results of the present investigation indicate that adolescents with IBD report being well-adjusted teenagers with similar levels of anxiety and depression to healthy peers. In fact, they report levels of adjustment which are even better than normative means. These findings of good functioning among adolescents with IBD replicate those reported by Gold, Issenman, Roberts and Watt (2000) and echo those published by previous researchers for children with cancer and asthma (Canning, Canning, & Boyce, 1992, Fritz, Spirito, & Yeung, 1994; Phipps & Srivastava, 1997). These findings could be accepted at face value as "good news," indicating an exceptionally healthy response to stress in this population. However, another plausible interpretation suggested by Wood et al. (1988) for children with IBD is that these self-reports of good adjustment could be biased toward minimization of distress.

Wood et al. (1988) hypothesized that a repressive style of adaptation, defined by high defensiveness, may explain why adolescents with IBD report low levels of subjective distress. That is, adolescent with IBD may adjust to their illness and stress in general, by ignoring and failing to process subjectively negative affect. Weinberger et al. (1979), and Freud before them, suggested that this avoidant cognitive style is an effective strategy to downplay and minimize distress. According to Weinberger, a repressive adaptive style involves cognitive inhibition of distressing internal cues outside of the individual's conscious awareness, with cognitive inhibition leading to self-deception regarding the presence of negative affects and difficulties in the subjective processing of those affects.

In this study, Woods et al.'s (1988) hypothesis was tested with Weinberger et al.'s (1979) paradigm. Weinberger et al.'s paradigm consists of the interaction between a measure of distress and a measure of defensiveness to identify individuals with a repressive adaptive style. The main purpose of this investigation was to examine whether patients' reports may be influenced by their style of adaptation, and more specifically, whether self-reports of patients with IBD are biased towards minimization of distress and a propensity to present themselves in a favorable light.

As predicted, there was a larger proportion of adolescents exhibiting a repressive adaptive style in the group of patients with IBD than in the control group of typically developing teenagers. In this sample, 38.1% of chronically ill adolescents were identified as repressors against 18.5% in the group of healthy control. These results are similar to those reported previously for children and adolescents with asthma and cancer. Fritz et al. (1994) identified 33% of a group of adolescents with asthma as repressors, and Phipps and Srivastava (1997) identified 36% of their group of adolescents with cancer as repressors. These figures represented almost a doubling of the proportions found in the healthy control groups of the respective studies. Results of the present study confirm Wood et al.'s (1988) suggestion that a repressive style of adaptation may mediate the relationship between patients' adjustment and their self-report of adjustment. That is, for some individuals diagnosed with IBD, repressive defenses may decrease self-reports of negative outcomes.

The presence of a repressive style of adaptation was identified by previous child, and especially pediatric, studies in adolescence. Adolescent repressors were found to exhibit characteristics similar to those identified among adult samples i.e., self-deception, biased self-reports, and inhibition of signals of distress. Across studies, chronically ill and typically developing children and adolescents with a repressive adaptive style reported less anxiety, less depression, and less anger than children who are non repressors, and at times, less anxiety, less depression and less

anger expression than normative populations (Canning et al., 1992; Fritz et al., 1994; Phipps & Srivastava, 1999; Phipps & Steele, 2002; Richards, Benson, Cushing, & Steele, 2004; Steele, Elliot & Phipps, 2003).

This investigation replicated previous findings of high levels of psychological adjustment among young repressors according to self-reports. Adolescents with a repressive adaptive style reported less anger expression and less depressive symptoms than nonrepressors although their levels of depressive symptomatology were similar to those of low anxious participants. In other words, the depression scale did not differentiate repressors from truly low anxious, and the anger expression scale revealed even less anger expression in repressors than in low anxious adolescents, suggesting high levels of defensiveness.

Young repressors' reports raise the issue of what Joiner, Schmidt, and Metalsky (1994) called "the low end specificity" problem. That is, the ability of current self-report measures to differentiate individuals who are well-adjusted from those who are highly defensive and who are unlikely to look distressed on self-report instruments. Empirical investigations of the repressive defense style in youth demonstrated a larger percentage of repressors among pediatric patients than among healthy peers. In this study, a repressive adaptive style may have decreased self-reports of negative psychological outcomes for the population of adolescents diagnosed with IBD. That is, at the well-adjusted end of the spectrum, the absence of distress may, for some patients, be primarily as a function of defensive processes.

Detecting young repressors at the low end of the psychological distress continuum may increase the clinical validity of evaluations aimed at assessing the psychosocial functioning of children who are chronically ill. More specifically, the presence of a repressive defense style among children who are chronically ill may, in part, explain conflicting evidence in the literature regarding

the degree to which children who are chronically ill may be at risk for emotional distress and adjustment outcomes (Rudolph, Dennig, & Weisz, 1995). Some authors described a "developmental breakdown," whereas others demonstrated that the general adaptation of children with a chronic illness is good or even better than their typically developing counterparts (Jamison, Lewis, & Burish, 1986; Gortmaker, Perrin, Weitzman, Homer, & Sobol, 1993). For instance, Elkin, Phipps, Mulhern, and Fairclough (1997) found low levels of psychological distress among adolescents and young adult survivors of pediatric malignancy. Cancer survivors' scores on a measure of psychiatric symptoms were even lower than published norms. Seiffge-Krenke (1998) found that adolescents with diabetes reported less everyday stress and less emotional distress than healthy counterparts and published norms. The possible presence of an elevated percentage of repressors in some studies may confound the results and give the impression of good psychological adjustment.

The low depression and anger expression scores reported by adolescents with a repressive style of adaptation across groups of healthy and chronically ill teenagers can also be considered as representing another aspect of the repressor construct i.e., as an adaptive style associated with the cognitive repression of a wide range of negative affect as suggested by theory (Weinberger, 1990). Therefore, the validity and relevance of the construct could be enhanced if it were shown to apply to a variety of negative affects across pediatric samples.

Following Phipps et al. (1999) idea of detecting a repressive style of adaptation using measures of distress other than anxiety, anger expression and depression were used to create categories of adaptive style based on these socio-emotional constructs. Using anger expression as the repressed affect, 35.7% of adolescents were identified as repressors. Using depression as the repressed affect, 38.1% of adolescents were identified as repressors. As predicted, the substitution of anger or depression for anxiety in the adaptive style paradigm produced similar results. These

findings replicate results previously reported in populations of children with asthma and cancer (Fritz, Spirito, & Yeung, 1994; Phipps & Srivastava, 1999; Phipps & Steele, 2002).

The high concordance rate found in this investigation between classification paradigms suggest that adolescents with IBD who repress one negative affect are likely to repress other negative affects to the same degree. These high levels of agreement also provide empirical support to the theoretical tenets of repressive adaptation as involving the repression of distress signals indiscriminately out of fear of social rejection and out of the need to protect one's self-image from emotions deemed inappropriate.

Caution, however, is to be exercised when interpreting these results because correlations between anxiety and depression are high and indicate that these two scales may not be measuring two completely distinct concepts but rather a broader construct of distress. If this is the case, then high rates of concordance between the anxiety and depression paradigms could be due to the fact that these two scales measure the same affect rather than because the construct of a repressive adaptive style extends across negative affects. Similarly, the low depression scores reported by teen repressors are similar to those of low anxious participants and could be interpreted as reflecting the strong correlation between anxiety and depression rather than a manifestation of a repressive adaptive style. However, results related to anger expression indicated that repressors reported even lower levels of anger expression than low anxious even though both adaptive style categories were created with the same cut-off score on the Anxiety scale of the BASC. Therefore, classification agreement with anger as a repressed affect was interpreted as a reflection of repressed anger rather than as a measurement confound.

Although the impact of psychological factors on physical health has been the focus of numerous investigations in children and adolescents (Seiffge-Krenke, 1998), no investigation, to

date, has examined the impact of a repressive adaptive style on patients' quality of life and on patients' disease severity. In this study, repressors' quality of life (as assessed by self-reports) and repressors' their disease severity (as assessed by medical indices) were investigated among the group of adolescents with IBD.

Not surprisingly, adolescents with a repressive adaptive style reported higher levels of quality of life than high anxious and defensive high anxious adolescents and similar levels of quality of life to low anxious adolescents. That is, teen repressors with IBD do not perceive their disease as impairing their daily functioning or as creating additional stress in their lives and, importantly, they reported experiencing minimal amounts of disease symptoms.

Some researchers argued that a repressive defense style may be adaptive when children are faced with intensely stressful situations because it may allow them to function on a day-to-day basis and to adjust to a reality that they cannot control (Phipps & Srivastava, 1997, 1999; Phipps & Steele, 2002; Schwarzwald, Weisenberg, Waysman, Solomon, & Klingman, 1993). For instance, a repressive adaptive style may help patients undergo invasive and painful medical procedures. A repressive style of adaptation may also allow a child to remain active in school and with peers while living with a potentially lethal illness (Phipps & Srivastava, 1999). In the case of adolescents with IBD, a repressive adaptive style may facilitate good quality of life rather than the perception of illness as a stressor. Some researchers argued that accurate reality testing may, in certain situations, be associated with poor psychological adjustment, whereas the adoption of certain illusions may enhance mental health (Taylor & Brown, 1988; Weisenberg, Schwarzwald, Waysman, Solomon, & Klingman, 1993). In fact, self-deception and high defensiveness were suggested to protect against psychiatric disorder (Lane et al., 1990). From that perspective, a repressive defense style represents a protecting factor that may buffer the child against the overwhelming emotions elicited by threatening

and stressful situations, and low scores on depression and anxiety scales or high levels of quality of life for adolescents with IBD are indicative of the reality of the child's psychological functioning rather than a distortion (Phipps & Srivastava, 1997).

The relationship between disease severity and a repressive adaptive style was examined for adolescents with IBD. A disease severity score was created including three laboratory indexes, prescribed medications, the number of times corticosteroid medications were prescribed in the past twelve months, and the number of hospitalizations due to IBD in the past twelve months. Teen patients with a repressive adaptive style were found to present levels of disease severity that were higher than those of low anxious patients but similar to those of high anxious patients. In other words, medical indices distinguished repressors from low anxious and contradicted repressors subjective reports of low disease severity. These results seem to confirm previous studies showing that the repressive adaptive style moderates the perception of symptoms and somatic cues (Steiner, et al., 1987; Fritz et al., 1996). Numerous investigations have demonstrated that, although repressors report low subjective distress, physiological and behavioral evidence reveal that they are upset and that their distress indices are similar to those of high anxious participants (Boden & Dale, 2001; Newton & Contrada, 1996). Minimization and inhibition of psychological pain was suggested to also extend to minimization and inhibition of distressing or threatening physical signals among adult repressors (Schwartz, 1990).

Results of this investigation also confirm adult findings related to the impact of a repressive adaptive style on health outcomes. In adulthood, a repressive adaptive style was found to be associated with a poorer health prognosis and with biochemical markers of health difficulties (Barger, Marsland, Bachen, & Manuck, 2000; Brown, Tomarken, Orth, Loosen, Kalin, & Davidson, 1996; Esterling, Antoni , Fletcher, Margulies, & Schneiderman, 1994; Flowers, Armentrout,

Booraem, Kraft, Maddi , & Wadhwa, 1995; McKenna, Zevon, Corn, & Rounds, 1999; Vindel, Sirgo, & Manga,1994). Inhibition of physiological and physical threatening cues is a hallmark of a repressive style of adaptation that was linked to the adverse health consequences associated with a repressive adaptive style. Schwartz's "Repression-Disattention-Disregulation" theory postulates that the normal homeostatic process of arousal followed by a return to baseline levels is altered by continued cortical inhibition of physiological signals of distress, causing lower-level physiological systems to enhance signal strength (Schwartz, 1983). "Dis-attention" or inhibition produces a disregulation of feedback mechanisms, and a state of disorder propitious to disease formation may ensue. According to Schwartz, the combination of heightened physiological arousal and inhibiting processing style accounts for the maladaptive quality of a repressive adaptive style in terms of health risks and outcomes. Therefore, ignoring, minimizing and poorly monitoring physical cues may delay or interfere with medical treatment in many ways i.e., through physiological reactivity but also through poor compliance with medical regimen or low physician monitoring, for instance.

Altogether, differences in the effectiveness of a repressive style of adaptation may have to do with the period of use that is, with the rigidity of the strategy. The benefits of repression may be positive in the short-term with acute stressors but may become deleterious in patients with chronic disease, leading to slower healing or worsening condition.

Studies of post-traumatic syndromes also indicated that the protective role of repression in the short term may engender psychosocial adjustment problems in the long-term (Brewin & Dalgleish, 1996; Krause, Mendelson, & Lynch, 2003; Phipps, Steele, Hall, & Leigh, 2001). Repressors' information-processing biases are similar to the attentional biases that monitor attention away from trauma-related stimuli in Post-Traumatic Stress Disorder (PTSD), and inhibition of the subjective experience of distress is comparable to inhibition of emotional processing in PTSD

(Brewin & Dalgleish, 1996). Erickson and Steiner (2000) investigated the psychological functioning and personality traits of adolescents and young adult survivors of cancer. Using the Weinberger Adjustment Inventory, they found high levels of restraint and low levels of reported distress among cancer survivors, indicating the presence of a large number of repressors. They also found that the majority of participants met partial current PTSD criteria, including high levels of somatic symptoms. Similarly, although Smith and Steiner's teen patients with respiratory stridor and a repressive adaptive style denied emotional distress and the somatic cues associated with it, they exhibited multiple physical complaints and some PTSD symptoms (Smith & Steiner, 1992). In fact, their levels of physical impairment met formal criteria for diagnoses of somatoform disorders (Smith & Steiner, 1992).

Discrepancies between parents and child reports of socio-emotional adjustment were reported among pediatric patients suffering from IBD, with parents reporting more behavioral problems than pediatric patients themselves (Szajnberg, Krall, Davis, Treem, & Hyams, 1993; Wood et al., 1988). Moreover, discrepancies between self-reports and observers' reports among chronically ill children were suggested to be due, in part, to the effects of high levels of defensiveness (Canning et al., 1992; Fritz et al., 1994; Phipps & Srivastava, 1999). In this study, adolescents with a repressive adaptive style were rated as well-adjusted by their parents. Contrary to expectation, parents' ratings of their children's socio-emotional and behavioral adjustment were even better than those of low anxious adolescents. In other words, teen repressors and their parents showed high agreement regarding patients' psychological functioning. Parent reports of good behavioral adjustment did not affect only repressors but the whole sample of participants. In terms of parent-child agreement across all participants, levels of parent-adolescent agreement for the anxiety and depression scales, were higher than the BASC published correlations for the normative sample.

According to parents, adolescents with a repressive adaptive scale exhibit less externalizing and less internalizing problems than non repressors. These results replicate Fritz et al.'s findings. Fritz et al. assessed parental perceptions of the behavioral functioning of teenagers with asthma. Parents of adolescent repressors with asthma reported lower levels of externalizing and internalizing problems in their children than parents of adolescents who do not have a repressive adaptive style. These findings suggest that, according to parent ratings, a repressive adaptive style may be protective against behavioral difficulties (Fritz, Spirito, & Yeung, 1994). Alternatively, good behavioral adjustment among adolescents with a repressive adaptive style gives credence to personality theory describing repressors as individuals who are conformist, well-behaved, high in self-restraint and impulse control and therefore, unlikely to exhibit observable behavior problems or to express internal distress (Farrell & Sullivan, 2000). Behaviorally, the repressive adaptive style seems to entails behaviors and attitudes that are socially agreeable and generate social approbation (Weinberger, 1997). In adolescence, a repressive adaptive style was shown to protect adolescents from engaging in risk behaviors or illegal activities (Farrell & Sullivan, 2000; Weinberger, 1997). The price of maintaining such a style of adaptation may be internal and physiological whereas its benefits may be social and self-esteem related.

Interestingly, parents of adolescents with IBD rated their children as well-adjusted and problem-free. That is, parents of chronically ill adolescents did not observe worse functioning in their children as a result of their illnesses, and parent-child agreement was high among patients with IBD. These results contrast with most previous research. Wood et al. (1988) found that, according to parents, children with IBD displayed more behavioral problems than normative populations. Likewise, Szajnberg et al. (1992) reported that parents rated children and adolescents with IBD as exhibiting higher levels of internalizing problems than controls. Finally, Engstrom (1999) reported

more behavior problems among adolescents with IBD than among adolescents with diabetes or controls according to parents. Our results replicate Gold et al.'s investigation, the only study to date, that reported good behavioral adjustment among patients with IBD according to parents' ratings. Overall, it is difficult to draw conclusions regarding the psychological functioning of adolescents with IBD ratings because the present state of research reveals contradictory findings and more investigations are necessary to determine whether IBD impairs pediatric patients' functioning at home and in the community.

Although not directly related to any particular hypotheses in this investigation, we examined the relationship between a repressive adaptive style and time since diagnosis and age at diagnosis respectively. No relationship was found between categorization as repressor and time elapsed since diagnosis or age at diagnosis. Such findings are similar to those published by Phipps and Srivastava (1997, 1999) and Phipps and Steele (2002) for children and adolescents with cancer. These results are to be set within the framework of the sensitive debate related to the stability of a repressive style of adaptation. The repressive adaptive style is typically conceptualized as a stable trait which seems to be triggered in period of stress. From that perspective, the repressive adaptive style reflects more a premorbid personality style rather than a response to diagnosis. On the other hand, a repressive adaptive style may also be conceptualized as a response to trauma reflecting the avoidance and numbing characteristic of Post-Traumatic Stress Disorder (Brewin & Dalgleish, 1996) that becomes integrated into personality over time. Such a conceptualization would also defy theories of personality development and trait stability over time. However, both perspectives are not mutually exclusive if a repressive style is conceptualized as being relied on only in periods of stress and if chronic illness is conceptualized as the stressor triggering a repressive style of adaptation. The absence of a relationship between adaptive style and disease chronicity in this, and prior studies, is

suggestive of some stability within chronically ill populations. If adaptive style was related to diagnosis, it would change as time elapses. What is more, Phipps et al. (2001) reported that categorization as repressor remained stable up to one year following diagnosis confirming the stability of this style of adaptation. Therefore, currently available findings seem to indicate that a repressive adaptive style is not a reactive phenomenon or a contingent response to stresses of illness but rather a typical response to stress in general. Current research does not allow us to provide a definite answer to the issue of trait versus reactivity nature of a repressive style of adaptation. Longitudinal studies of repressors are necessary to answer such a question both among individuals who are ill and healthy participants. Importantly, however, it is necessary to highlight that suggesting the stability of a repressive adaptive style does not imply an etiologic contribution of this style of adaptation to disease development. Rather, it provides information about how health-related stresses will be handled and how dispositional adaptive tendencies may influence the choice of coping strategies.

<u>Limitations of the Study</u>

This study has several limitations and raises some methodological issues already present in the existing literature on the repressive adaptive style among children. A major issue in this study involves the reliance on self-report measures whose psychometric features are not fully established although they were developed from highly regarded works. More specifically, this study relied on the Children's Social Desirability questionnaire (CSD) to measure defensiveness (Crandall, Crandall, & Katvosky, 1965). The CSD was modeled after the Marlowe-Crowne Social Desirability Scale (MCSDS) and adapted for use with children. The MCSDS has been demonstrated to be more a measure of self-deception than a measure of impression management, although Paulhus argued that the MCSDS measures a mixture of both (Barger, 2002; Crowne & Marlowe, 1960; Ellingson &

Sackett, 1999; Paulhus, 1991; Pauls & Stemmler, 2003). In fact, self-deception does not rule out that repressors can also exaggerate in order to avoid social disapproval (Pauls & Stemmler, 2003). As far as the CSD is concerned, no data support a distinction between self-deception and impression management in children and adolescents. If such a distinction exists, no data is currently available to tell us what part of the social desirability construct the CSD is most likely to measure in children.

Moreover, psychometric data on the CSD do not offer evidence regarding the reliability and validity of the scale at different stages of development, thereby possibly masking a trend in the characteristics and degree of defensiveness over time. Phipps and Srivastava detected an effect of age on CSD scores, with an excess of younger children and few older children scoring high on the CSD (Phipps & Srivastava, 1997; 1999). Similarly, Crandall and Crandall reported monotonically decreasing means from grade 3 to grade 12 on the CDS (Crandall, Crandall, & Katvosky, 1965). It is possible that defensiveness in adolescence may manifest itself in a way similar to what is found in adult samples and that more developmentally differentiated forms of the CSD are necessary. Crandall and Crandall created two forms, one for children in grades 6 to 12 and one for younger children (Crandall, Crandall, & Katvosky, 1965).Unfortunately, the grades 6 to 12 form encompasses children at different levels of cognitive emotional development, possibly rendering it insensitive to developmental differences in defensiveness within this grade range.

Another limitation of this study is the small number of participants in the IBD group, resulting in a small number of adolescents per adaptive style categories. The expected power of .80 was not achieved for most analyses related to the repressive adaptive style in the IBD group and future studies should try to investigate larger samples of patients with IBD in order to generate more information about differences across adaptive styles and between diagnoses (i.e.,

CD versus UC). In the group of adolescents with IBD, adolescents who were eligible but did not participate in this study may have been more symptomatic and socio-emotionally impaired than the actual participants. Some parents told the researcher that their child refused to complete the scales because they did not want to hear about their disease or because they are too depressed or too anxious to complete the questionnaires. Although research on selective attrition has not been conducted with this population, other studies documented and confirmed that more distressed individuals are less likely to participate in research (Weinberger, Tublin, & Ford, 1990). The inclusion of the abstaining patients would probably change the proportion of repressors in the IBD group.

The group of participants with IBD was recruited in two different sites and in two different ways. At one site, and for the majority of participants, data was collected by mail with pre and follow-up contacts with the researcher over the phone and laboratory indices were collected within one months of questionnaire completion. At another site, data was collected face to face and laboratory indices were collected the same day. Differences in data collection and in the time consistency of the different measures collected may have affected the results in some way and more homogeneity in data collection in future studies may increase the validity of findings.

Finally, the lack of a well-established severity index is also a weakness of this investigation. Although laboratory indexes are the same as those included in the Pediatric Crohn's Disease Activity Index, the overall severity index was conceived for the purpose of this investigation and its accuracy, reliability, and validity are not empirically founded in past research. However, it is believed that the separate components of the disease severity index are reliable and valid enough in reflecting disease activity and medical judgment of severity.

Conclusion

The developmental period of adolescence is characterized by a shift in preference of self-disclosure partners from parents to peers making assessment of diagnostic information difficult at times for health professionals (Seiffge-Krenke, 1998; Williams, Holmbeck, & Greenley, 2002). Very personal thoughts and feelings become increasingly reserved for peers and teenagers are guarded in their styles of presentation to adults. Moreover, adolescents are more likely to respond primarily to social cues and pressure to present themselves in the most favorable light (Williams et al., 2002). Consequently, it is hard to determine how much of a repressive adaptive style reflects normal developmental processes or an extreme of these processes and how much reflects deviant levels of defensiveness as compared to the norm. Both developmental and ego-related perspectives are confounded.

From a socio-emotional and behavioral health perspective, a repressive style of adaptation appears to be associated with good psychological adjustment from the viewpoints of both self and parents. In that context, the study of a repressive adaptive style may fall under the umbrella of the positive psychology movement initiated by Seligman (2000). To some degrees, even some therapeutic treatment techniques such as distraction, focusing on the positive, or "acting as if" promote defensiveness to alleviate psychological symptoms. However, from a mind-body perspective, alleviation of psychological symptoms may translate into worse physical health or somatic symptoms (Smith & Steiner, 1992).

Findings of the psychological adjustment of teenagers with IBD are encouraging. However, considering the larger proportion of repressors found among patients with IBD as compared to healthy peers, it is important to be sure that the positive outcomes revealed here are not partly

reflective of "illusory mental health" (Shedler, Maymen, & Manis, 1993) resulting from psychological defenses.

Altogether, the meaning of a repressive defense style in individual difference research can be approached from two different perspectives that is, a repressive adaptive style can be regarded as introducing error variance in the assessment of children's wellbeing or it can be considered as representing true, meaningful, trait-like variance that provides information about the intrinsic adaptive functioning of some children. The usefulness of considering a repressive defense style as a distinct category of psychological adaptation is supported by empirical physiological, behavioral, and health-related data in the present study and in adult investigations.

Future investigations should further investigate the impact of a repressive adaptive style on health outcomes to see if adult health data are replicable. More specifically, the reported association between a repressive style of adaptation and physical health calls for pediatric investigations examining the interaction of a repressive style with treatment compliance, young repressors' self-reports of pain and physiological symptoms, coping strategies and patient-physician relationships. Finally, longitudinal studies would be useful in understanding the consistency of a repressors categorization over time.

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