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ANOREXIA NERVOSA: THE TEENAGERS' PERSPECTIVES

By

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A Thesis
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In Partial Fulfilment of the Requirements
for the degree of

MASTER OF NURSING

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LOIS A. STEWART-ARCHER

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial
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ABSTRACT

The study of anorexia nervosa (AN) has been, and continues to be a major effort in psychiatry. Even though researchers and clinicians have studied this disorder, the etiology, as do effective and comprehensive treatment, and a high survival rate remains elusive. It is therefore important to nurses and the nursing profession, as one of the primary care givers, to gain insight into and have a better understanding of the disorder. The literature offers many perspectives which might suggest the need for a multi-causal model, such as a biopsychosocial one, which may be needed for the future understanding of AN.

This phenomenological study was directed towards obtaining interview and questionnaire data from seven teenaged women in hospital, aged 13 to 19 with moderate to severe anorexia nervosa, for a total of 24 interviews. Data obtained by interview were supplemented by use of the Yale-Brown-Cornell Eating Disorders Symptom (YBC-EDS) questionnaire, permitting some quantitative analysis.

Areas like the meaning they gave to AN, peer and family relationships, and leisure activities not only brought to the fore some very important and previously undocumented issues, but also validated previous research and associated theories. Concerns such as their fear of intimacy, quality and quantity of rituals and preoccupations, the relationship between illness level and friendships, and the stages of the perpetuating cycle of AN were developed by the teens and then analyzed. The teens also discussed several recommendations for follow-up. The

study's findings might be helpful in: understanding the teens' experiences as they relate to the disorder, generating further research questions and, aiding clinicians to be more sensitive to the teens' needs.

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CHAPTER ONE

*I do not remember
that I did ever in all my practice see one
that was conversant with the living
so much wasted with the greatest degree
of a consumption like a skeleton
only clad with skin.
(Morton, 1714)*

STATEMENT OF THE PROBLEM

Anorexia Nervosa (AN) is an eating disorder characterized by severe self-induced weight loss, secondary physiologic disturbances, and associated psychiatric disturbances. It is an illness of developed countries as it is unknown in Third World Nations (Bruch, 1973; Szmulker, 1985). It is usually seen in major cities and was at one time thought to afflict only those in the upper socio-economic class. It is now found in upper- and middle-classes, mostly amongst those of Jewish, Italian, and Catholic populations (Rowland, 1970; Stavrakaki & Williams, 1990). AN occurs only under conditions of abundant and/or adequate food supply. The prevalence is on the rise wherein one in every 200 adolescent female is affected (Garner & Garfinkel, 1985; Stavrakaki & Williams, 1990). Ninety to ninety-four percent of anorexics are women. A bimodal distribution for age of onset was found with peaks at 14.5 and 18 years of age (Mickley, 1988; Stavrakaki & Williams, 1990). These ages coincide with the time when the adolescent

female is attempting to become more independent from her family (Fowler, 1989).

This research will: a) review the theoretical perspectives of AN in order to examine the interrelated factors of a psychological, developmental, familial, socio-cultural, physiological, and biological nature that may produce the clinical picture of AN; b) explore ways in which to attempt to fill the gaps in knowledge as regards to the clients' perspectives by answering the question: What are the perceptions and experiences of adolescent girls who are either moderately or severely affected by AN concerning self-image, peer and family relationships, school, leisure activities, life style, and interventions related to their weight?; and c) serve as a basis for increased understanding of the disorder to facilitate more effective treatment modalities. With this knowledge, one would hope that understanding may ultimately lead to prevention, as current prognosis for recovery is poor (mortality rate is as high as 20%, Garfinkel, Garner, & Goldbloom, 1987). Also, prolonged and sustained periods of re-hospitalizations result in over-utilization of scarce health care dollars, over-burdening of the health care system, and the reported resultant burn-out of nursing personnel.

CHAPTER TWO

LITERATURE REVIEW

AN is a syndrome, that is, a collection of symptoms (Andersen, 1977). Describing a disorder as a syndrome indicates that the fundamental cause is unknown. This strategy keeps one from assuming knowledge prematurely. A syndrome however, can be reliably diagnosed and the crucial diagnostic criteria for AN follow.

Diagnosis

Russell's (1979) criteria have been used for some time: 1) self-induced starvation, 2) a morbid fear of fatness, and 3) an abnormality in reproductive hormone functioning, indicated by amenorrhoea in females, or decreased sexual drive and functioning in males. Andersen (1985), after examining Russells's criteria, adds that whenever a profound fear of fatness is present and the patient fears loss of control over eating after going on a diet, despite obvious thinness, no other explanation, medical or psychologic, has later proved to be the hidden cause for the disorder besides AN.

The Feighner et al., (1972) criteria consist of six main categories. All the criteria in categories one to five must be met. These are age, weight-loss, disturbance in self-concept, a distorted attitude towards eating, no other psychiatric disorder, and no known medical reason to

account for the weight loss. In addition to the foregoing, at least two of the six criteria in category six; for example vomiting and amenorrhoea must be met. This criteria provided for the first time, inter-institutional criteria, with specific values for weight change. These numbers have been a help [standardization of criteria]; and a hindrance [necessary but artificial guides, for example: requiring more than 25% weight loss].

The diagnostic criteria from the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) (1994) has also provided criteria for AN. The patient thus diagnosed must: 1) demonstrate a refusal to maintain body weight at or above a minimum normal weight for age and height; 2) experience an intense fear of gaining weight or becoming fat even though underweight; 3) demonstrate a disturbance in the way in which his/her body weight, size or shape is experienced, or denial of the seriousness of current low body weight; and 4) in post menarcheal females, experience amenorrhoea, that is the absence of at least three consecutive menstrual cycles.

For research purposes however, patients have been described according to the DSM-IV criteria, even though clinically, researchers are still dependent upon Russell's (1979) criteria for decisions on the basic nature of the patient's disorder. The diagnosis of AN may be crystallizing as it has remained fairly stable over time.

DETERMINANTS AND RISK FACTORS

There is no single etiology for AN. A theory that could address the diversity and complexity of this disorder would necessarily involve interactions between socio-cultural, psychological, and biological forces which then must be integrated within a developmental framework. Risk factors such as: cultural, familial, psychological, and biological are cogent reminders of the breadth of the problem.

As with other psychiatric disorders, AN may be seen as the product of multiple interacting variables: biological, psychosocial/behavioural, psychological/developmental and familial, although all these factors may not be identified in all diagnosed patients (Cousins, 1983; Garfinkel et al, 1987; Johnson & Connors, 1987; Katz, 1985; Lucas, 1981).

Biological factors that have been implicated are: a genetic predisposition, hypothalamic and neurotransmitter dysfunction, and a high rate of affective illness. The psychosocial/behavioural theory views the symptom as maladaptive learning that is reinforced by events in society, especially the culture's equation of thinness to successful women. Psychological/developmental theory focuses on personality, body image distortion, gender identity and sex role. The familial link underscores the view that the family ignores the AN individual's needs to deflect conflict and maintain the facade of a close, loving family. This

individual who is then unable to develop individually becomes symptomatic (Doyen, 1982). An overview of all these theories will be presented with particular emphasis on developmental and familial theories of disease linkage.

PSYCHOLOGICAL THEORY

Personality

Personality consists of "an individual's enduring response patterns across a variety of situations" (Harre & Lamb, 1983). Personality is defined therefore, as an individual's relatively distinctive and consistent ways of thinking, feeling, and acting.

The relationship between personality and AN is complex. Cousins (1983) and Strober (1985) believe that no specific AN personality type exists, but rather that social insecurity, limited spontaneity, perfectionism, impaired autonomy, excessive dependency, and compliancy are probably the early premorbid signs of disturbance which predispose to the development of AN.

The chronic malnutrition seen in AN contributes substantially to the obsessional, depressed, and introverted states (Doyen, 1982; Yates, 1989). AN patients are persistently preoccupied with calorie counting and the mental imaging of food (Rothenberg, 1986). These thoughts are experienced as dystonic and out of the individual's control, although

some unconscious gratification is derived from the mental imaging. AN according to Rothenberg (1986) and Fowler (1989) is a translation of the classical obsessive-compulsive neurosis to unrecognized anxiety and anger.

Body Image

Body image perception has been conceptualized as the mental picture of one's body, the product of conscious and unconscious perceptions, feelings, and attitudes (Allon, 1976; Worsley, 1981; Fowler, 1989). Inherent are the values, beliefs, needs, present and past experiences, and expectations of society. The relationship between body image perception/personality characteristics and weight status of the adolescent female has been much researched. It has been reported that the non-obese adolescent female has a more positive body image perception (Glucksman, 1972; Allon, 1976; Worsley, 1981).

Even though researchers such as Cohn et al. (1987), Maloney & Ruedisueli (1993) continue to support the above view, in the past, researchers such as Bruch (1973) viewed distortions in body image as central to the process of AN. These earlier studies however, were unfortunately fraught with methodological problems (Slade, 1985). At present, the significance of body image is questionable (Thompson, 1987). Body size estimation according to Norris (1984) may not be the

most appropriate measurement, but rather the instability of the body image and/or the discrepancy between the ideal and perceived body size (Lindholm & Wilson, 1988), may be the most reliable indicators of pathology. Overestimation of body size in "normal" women is related to decreased self-esteem which according to Rosen et al., (1987), Shaw & Kemen (1989), and Juhasz (1989) is a characteristic of individuals who are attempting to reduce weight. If body image distortion persists in AN, it does seem, according to Freeman et al., (1983) to predict a poor response to treatment.

Cognitive Distortions and Stress

Fenichel (1985) describes cognitive distortion as the process of disguising, hiding, or otherwise modifying unconscious mental elements so that they are allowed to enter consciousness. These distortions may be effected, for example: by dropping out or repressing associative links between conscious content and unconscious impulse.

The cognitive approach to AN emphasizes the faulty assumptions which maintain the particular symptom pattern. Higher levels of restraint are related to more negative and simplistic self schema (Neimeyer & Khouzam, 1985; Stavrakaki & Williams, 1990). As the self deprivation increases, the patient tends to view her body and food as useless and strongly defends this position. This is highly resonant of

medieval women afflicted with this illness (Williams, 1990). The AN patient is consumed by a morbid fear of fatness and spends most waking hours ruminating on intake and output.

AN patients tend to distort and overgeneralize and dichotomous thinking is quite common (Garner & Bemis, 1982; Garner, 1985). Bruch (1978) believes that there is a critical weight for each patient below which malnutrition maintains an abnormal mental state.

Stress can be defined as the process by which environmental occurrences threaten and/or challenge and may be seen as harmful if it is severe or prolonged. For the anorexic, control of excessive eating and the maintenance of a slim figure are considered almost unquestioned goals (Shaw & Kemeny, 1989). Failure to achieve slimness leads to a sense of guilt and shame and a definite source of stress. Yates (1989) however, does not believe that stress in and of itself is sufficient to explain the "genesis or perpetuation" of AN.

Identity and Sex Role

Studies of sex role do not support the view that AN females are more feminine or traditional than other women (Boskind-Lodahl & White, 1978) nor do they support Crisp's (1977) view that anorexic females reject the traditional female role. The importance of appearance however, does seem to be related to both AN and femininity

(Timko et al., 1987). The patient with AN does not appear to have a clear sense of who she is and tends to absorb prevailing standards in an attempt to positively view herself (Scott, 1987). The anorexic female with low self esteem searches for indications of her worth; since thinness is viewed as a valuable asset for women, she chooses to diet in order to feel better about herself (Burns, 1979; Juhasz, 1989; Yates, 1989).

SOCIO-CULTURAL AND BEHAVIOURAL FACTORS

AN is most commonly found in the upper-socio-economic classes (Bruch, 1973; Szmulker et al., 1986) of industrialized countries. The association of AN and class begins at age 15, and the incidence increases with socioeconomic strata (Jones et al., 1980). Thinness, scrupulousness about food, eating, and exercise become the primary focus in the lives of these females. Today's ideal shape is more tubular than it was 20 years ago. Role models are drawn primarily from fields of: ballet (Garner et al., 1987; Hamilton et al., 1985); modelling (Cosins et al., 1986); gymnastics (Calabrese, 1985); and cheerleading (Lundholm & Littrell, 1986). Women who are overweight, on the other hand, are seen as weak, unable to take care of themselves, and indulgent (Wooley & Wooley, 1979).

These anti-fat attitudes and behaviours become the substance of

self-hatred even among those who are not overweight (Wooley & Wooley, 1979). Johnson & Connors (1987) in reviewing research, discovered that children devalue obesity and that it connotes social isolation for girls. Almost 7 percent of children aged 8 to 13 score in the anorexic range on the new child version of the Eating Attitudes Test (EAT) which reflects children's attitudes towards eating (Maloney et al., 1988). This trend continues into adolescence and adult life. A woman's success on the job may depend upon her appearance. Women in pictures that are manipulated to increase the bust size are rated as less intelligent and less competent than when they were shown having smaller busts (Kleinke & Staneski, 1980). Thinness in women is equated with higher educational and vocational status.

BIOLOGICAL FACTORS

There are a host of hypothalamic and neurotransmitter dysfunctions as well as a genetic predisposition in families with a positive history of alcohol abuse in anorexic patients who have self-starved (Halmi, 1983). Researchers and clinicians have also noted a high preponderance of affective illness which is known to have biological correlates in AN patients and their families (Gershon et al., 1984; Hendren, 1983; Pope & Hudson, 1985; Stavrakaki & Williams, 1990; Walsh, 1982; Walsh et al., 1985; Yager & Strober, 1984).

Anorexic individuals demonstrate increased plasma cortisol levels and decreased rates of cortisol metabolism (Casper, 1993; Halmi, 1987; Walsh et al., 1981). Not all neuroendocrine abnormalities in AN can be attributed to weight loss as 1/3 to 1/2 of the females who develop AN cease to menstruate prior to the occurrence of significant weight loss (Dally, 1969; Halmi, 1974; Morgan & Russell, 1975).

The hypothalamus secretes more corticotrophin-releasing factor which stimulates the adrenal cortex during periods of starvation. The degree of elevation of corticotrophin-releasing hormone in the cerebrospinal fluid of AN patients correlates with the severity of their depression (Gold & Rubinow, 1987). As a result of this depression, several reports have noted the high incidence of death wishes, suicidal ideation, and suicide attempts in AN populations (Cantwell et al., 1977, Dally & Gomez, 1979). Suicide is the first or second most frequent cause of death in AN patients (Crawshaw, 1985; Hoffman & Halmi, 1993; Kaplan & Sadock, 1985). A majority of these findings revert to normal once the depression associated with starvation has been relieved and the patient has gained weight (Hotta et al., 1986; Yates, 1989).

In AN, the neurohormonal changes of cortisol production and metabolism, and serotonin production appear to be secondary to inadequate nutrition. The basis for the menstrual dysregulation has not

been explained, nor has the significance of decreased levels of norepinephrine at long-term follow-up. Increased levels of the endogenous opioids and decreases in serotonin and norepinephrine may be of importance in perpetuating the disorder.

PHYSIOLOGICAL THEORY

Hunger and Activity

AN is often thought of as a state of reduced appetite. It could more accurately be described as a refusal to eat in the face of substantial appetite. A striking early pre-starvation finding is the patient's constant awareness of hunger (Rothenberg, 1986). In the acute phase of the illness, AN patients may deny that they are hungry, but a controlled study shows that they have a stronger urge to eat, are more preoccupied with food, and are more anxious when hungry (Garfinkel, 1974). One means of decreasing hunger is to increase activity (Epling & Pierce, 1988).

Epling & Pierce (1988) postulate that AN can arise as biobehavioural factors which are triggered by the combination of a strict diet and exercise. This theory is based upon Routtenberg's (1968) study in which rats were fed a single daily meal and given the opportunity to run on an activity wheel. The rats predictably increased their wheel running time and diminished their food intake. Body weight not only

declined, but the animals ran until they died of self-starvation if the process was allowed to continue.

Epling & Pierce (1988) suggest that cultural pressure to diet and exercise set the stage for individuals who seek greater self-control to develop eating disorders. Excessive activity is reported in 38% to 75% of anorexics and most of these females were already usually quite active prior to any weight or diet changes (Ching, 1963; Kron et al., 1978; Crisp et al., 1980).

Vigorous exercise causes an increase in endogenous opiates, and the increase in opiates could diminish hunger when the person also is restricting food. For AN patients, vigorous exercise could be an important means of diminishing hunger. In addition, vigorous exercise would enable her to metabolize calories and it would enhance her resolve by taking her away from the source of food.

AN patients are thought to have had early problems in separation from the primary caregiver. Later in life, they appear to reenact early conflicts through their relationship to food. AN patients may then be self-medicating their great hunger, and desperately yearning to be cared for.

FAMILIAL THEORY

The governing framework of this theory is the systems model. This

postulates that certain types of family organizations foster the development of disorders and that the child's symptoms play an important role in maintaining family stability. Much of this thinking is influenced by the work of Minuchin et al., (1978). Minuchin's assumptions however, were based on family studies that lacked controls and did not take into account changes within the family that the illness may have produced (Yager, 1982). A pattern of pathology similar to the one Minuchin (1978) proposed above has since been found in families of children with other psychosomatic conditions and in the families of offsprings that are borderline but not anorexic (Katz, 1985). Although the family pathology in AN is not unique, most clinicians do recognize that certain family dynamics serve to initiate and prolong the illness. As in other disorders, the sickest patients usually come from the most troubled families (Morgan et al., 1983).

A central theme of family development during the period when children are adolescents is the tension between individuation and cohesiveness. From an individual developmental perspective, adolescence has been viewed as a period of individuation (Blos, 1960, 1979). Adolescents are expected to reassess the investments they have made in significant others from their childhood, especially their parents and decrease the intensity of these childhood ties. The energy released

in this process is presumably directed towards the elaboration of new associations and the emergence of new interests, values, and goals. The achievement of a new level of individuation within the family is evidenced by the adolescent's ability to have a view point that differs from that of her parents and to experience a sense of distinctiveness (Cooper et al., 1983). Nevertheless, the adolescent is still a part of the family where emotional commitment is expected from both parents and children.

From a family system perspective, the presence of adolescent children introduces a process of redefinition in the expectations of reciprocal role relationships, the exchange of resources and the expression of affection (Newman & Newman, 1986). Adolescent children are at once more competent, and therefore more capable of providing resources to the family. From the parental perspective, the emphasis changes from actually providing safety, protection, and comfort for a child to worrying more about the child's safety, protection, and comfort (Rossi, 1980). A new balance must be struck between individuation and cohesiveness in order for the adolescent to mature in ego strength and social competence, and for the family group to preserve an optimal sense of harmony. Ego strength encompasses the many integrative processes that permit an individual to take a subjective point of view.

Loevinger et al., (1970) believe that the extent to which individuation is nurtured depends upon the ego level of the parents and the ability to modify their parenting style to promote new levels of autonomy in their adolescent children. These findings also indicate that the sense of connectedness to the parents through explanation and flow of ideas and information seem to contribute to the adolescents' ability to clarify his own perceptions and points of view.

Odor (1986) in his analysis of a model of family socialization, proposes that parent ego stage is related to specific parenting styles, and that parenting styles are related to adolescent ego development. Odor (1986) further proposed that if parents allowed their adolescents a high amount of involvement in the family decision-making process (permissiveness) and frequently gave their adolescents explanations for rules, expectations, and limits (induction) then this would give the adolescent optimal opportunity to maximize his ego development.

Minuchin's (1978) findings clearly describe significant changes in symptoms when family interactional patterns are changed in a certain manner. He describes five characteristics of families containing an anorexic child. These characteristics are: a) enmeshment; b) over-protectiveness; c) rigidity; d) low threshold for conflict; and e) instability.

Enmeshment

Enmeshment is viewed by Minuchin as extreme closeness of family members to the extent that it is difficult for individuals to have an autonomous identity. This therefore results in diffuse interpersonal and subsystem boundaries which leads to an intrusion upon each family member's thoughts and feelings as well as results in confusion of roles.

Infants in enmeshed families may receive superb care, yet the parents, too tired from caring for the children, do not have much time for each other or for outside interests. However, if these parents do not teach their children to obey rules and respect adult authority, the children may be unprepared to successfully negotiate their entrance into school. Since they have not learned to accommodate to others they may be rejected by their school mates. These children, as is the case in AN, often present as depressed and withdrawn.

Members of enmeshed family systems may feel that a sense of belonging requires yielding of autonomy. This lack of "subsystem differentiation" discourages mastery of problems and autonomous exploration which particularly in children inhibits cognitive/affective skills (Minuchin, 1974).

Overprotectiveness

Minuchin proposes that overprotectiveness of all family members,

especially the child, may retard the AN child's development as she feels responsible for protecting the family by involving the entire family as a smokescreen to submerge systemic conflicts.

Rigidity

During adolescence, the family is required to change its ground rules to allow teenagers to develop independence. Minuchin believes that much importance is placed (in families with anorexic individuals) upon maintaining the status quo. The rigidity of these families does not allow this and preferred transactional patterns are fixed.

Minuchin suggests that members of disengaged (inappropriately rigid boundaries) family systems may function autonomously, may lack feelings of belonging and loyalty, as well as the capacity for interdependence, and for requesting needed support. A disengaged system, therefore, tolerates a wide range of individual variation. Stress in one family member is not likely to cross over its rigid boundaries to activate familial support systems unless it is of a high level.

Conversely, high level stress in enmeshed subsystems may result in immediate action across the boundaries as members immediately affect each other. The enmeshed family may respond to any variation from the norm with excessive alacrity, while the disengaged family tends not to respond even when a response is necessary (Minuchin, 1974).

Low Threshold for Conflict

In families with anorexic members, difficulties tend not to be confronted directly, negotiated nor resolved. The resultant effect is that of a family which is unable to work through disagreement.

Instability

A fifth characteristic proposed by Minuchin is that of the role of the symptom bearer as the maintainer of family stability. Parents who are unable to confront each other directly, may unite in protective concern for their sick child, or a parental conflict is transformed into conflict over the child and her management as the ill child presents a focus of concern thereby allowing the family to avoid conflicts. This forms a rigid triad which strengthens the rigid family structure. In Minuchin's view, the family system then reinforces this action in order to preserve its ineffective coping method of conflict avoidance.

Overprotective, ineffective parental behaviour has been proposed as increasing the AN patient's difficulties with autonomy and impulse control (Bruch, 1973, 1977; Garner et al., 1976; Minuchin et al. 1978). This in turn increases her anorexic behaviour, which may increase parental protectiveness and ineffectiveness. Anorexic behaviour frequently increases family tension, placing further strain upon their already poor methods of conflict resolution (Martin, 1983; Minuchin,

1978; Minuchin et al., 1985). This increases parents sense of ineffectiveness. In other words, the more family enmeshment, the more unresolved conflict; the less individual autonomy, the more anorectic behaviour; the more conflict, the more pressure on family loyalty which completes the cycle by increasing enmeshment. Each cycle of interaction between the AN patient and her family therefore, has the effect of reinforcing the preceding disturbed behaviour.

In spite of the profusion of papers on family dynamics, the contribution of the family to the eating disorder is not fully clear since some families can function extremely well (Yager & Strober, 1985) and yet present a severely ill child. Family functioning therefore, appears to explain some, but not all of the factors in the genesis of AN.

DEVELOPMENTAL THEORY

Eating may be used to express the earliest conflicts over loving and being loved, loving and hating, attacking and being attacked, punishing and being punished (Ritvo, 1984). The AN patient's passions revolve around the body (self) and food (mother).

Crisp (1980) underscores the patient's intense fear of becoming physically and emotionally mature. Although patients remain emotionally dependent on their families, their sexual adjustment can be reasonably good (Morgan & Russell, 1975; Raboch, 1986).

Bruch (1973), Doyen (1982), and Halmi (1983) identified interpersonal factors in infancy which set the stage for later development of AN. The developmental crisis of infancy is trust/mistrust (Erikson, 1963). Basic trust involves confidence, optimism, and a reliance upon self and others. A sense of trust forms the basis for later identity formation, and social responsiveness to others. Mistrust, on the other hand, is the sense of not feeling satisfied emotionally or physically. Later predominant feelings and behaviours are pessimism, lack of self-confidence, antagonism, and bitterness towards others. Security and trust are fostered by prompt, loving, consistent responses to the infant's distress needs as well as by positive responses to happy, contented behaviour. If the caregiver, usually the mother, fails to meet the infant's primary needs then fear, anger, insecurity, and mistrust result. If the most important people fail her, then there is little foundation on which to build faith in others (Murray & Zentner, 1985).

For normal development to occur, the primary caregiver who is usually the mother (and therefore will be used here, for the sake of argument) must confirm the child's existence and internal states by responding to her bodily needs. When the mother superimposes her own distorted or inaccurate perceptions on the child, the child is then

unable to learn who she is, how she feels, or what it is to be satiated. This results in an arrest of cognitive development at the preconceptual stage of concrete operations (Piaget, 1952). The child feels confused and helpless and eventually adapts by attending to the needs of others in an overly compliant manner.

Since the infant builds a sense of wellbeing through the relationship with a mother who is soothing and predictable, "good enough parenting" according to Winnicott (1965) will enable the child to internalize this self-regulatory function and then become able to modulate internal tensions and self-esteem. The child who has been inconsistently or poorly nurtured may develop a defect in self cohesion. When stressed, the AN patient is placed out of touch with inner experience leaving her with the inability to self-soothe, and feelings of incompetence, ineffectuality, and "out of controlness" abound. Internalized, this results in hunger, emptiness, and a restless boredom relating to others as extensions of herself (Goodsitt, 1983, 1985; Swift & Letven, 1984; Yates, 1989).

Selvini-Palazzoli (1978) believes that the infant splits off the internal representation of the mother and that the image remains unintegrated throughout childhood. At puberty she experiences the changing contours of her body as the archaic mother. She attempts to

control the mother by mastering her body. Therefore the adolescent who is predisposed to AN is poorly equipped to meet the challenges of establishing autonomy and independence. She achieves instead, some sense of mastery by controlling her body through diet (Bruch, 1973, 1977; Garner et al., 1976; Minuchin et al., 1978).

Masterson (1977) of the object relations school of thought, views AN as existing in a spectrum of personality structures ranging from the psychotic to borderline-neurotic. The level of organization achieved depends upon whether the arrest was at the separation-individuation or approaching object constancy phase of development (Mahler et al., 1975). If the parent rewards dependent, clinging behaviour, and rejects age-appropriate behaviour, then borderline organization occurs. The child then feels that being assertive or taking the initiative will result in abandonment and is therefore left with feelings of emptiness and struggles to establish autonomy. This pattern of development is also characteristic of borderline personality disorders, but Masterson does not explain the reason why some develop AN while others do not.

AN is found predominantly in females. Beattie (1988) relates this to a girl's more difficult individuation-separation from the preoedipal mother. Even in healthy girls, the ambivalent struggle persists long past the oedipal phase and is revived intensely at puberty. When the

mother/daughter relationship is overly close and hostile-dependent, a variety of psychopathologies such as AN and depression may occur. The AN then becomes a continuing, locked-in conflict which maintains the original, hostile-dependent bond to an internalized or actual mother.

As discussed above, a model explaining the pathogenesis of AN has to be multi-faceted to allow for prediction of the individual at high risk for developing the illness and the necessary and appropriate individualized treatment plan. Risk factors, which will vary for each individual, may interact to produce dieting which may result in the pressured, socio-culturally idealized slim female form. The family then magnifies these cultural attitudes; but in such a family system that discourages autonomy in adolescence, the individual may become developmentally stunted.

Based on the literature reviewed, it would appear that the family may also have a history of affective disorder, alcoholism, or even a history of an eating disorder which are biological risk factors. With progressive weight loss, physiological factors such as increased endogenous opiates, and psychological factors such as altered thought processing, feeling, and behaviour supervene and a self-perpetuating cycle may develop. It is hoped that this study will assist in formulating a model to address the complexity.

This paper thus far, has presented material from psychological, biological, physiological, and socio-cultural view points in an attempt to explore the various theories, factors, and predisposing elements that could result in AN. Important findings that emerge are that: food restriction may affect the neurochemical environment of the brain; early experiences in the process of separation may have a role in AN; certain types of family organizations foster the development and continued existence of AN; there exists a relationship among personality, body image, cognitive distortions, gender identity and AN; and that food restriction and activity may interrelate with sociocultural, psychological, and biological factors to pave the way for the development of AN.

Gaps in knowledge persist however, and the researcher in this study enhanced an understanding of the perceptions and experiences of adolescent girls with AN concerning: self-image, peer and family relations, school and leisure activities, life style, and personal interventions related to their weight. Presently, much of the knowledge regarding the concerns of individuals with AN is medically identified and defined by professionals, including to a lesser extent, nursing. This researcher views this position as one that presents a barrier to effective and appropriate nursing care of these patients as these individuals' perspective, a most important and critical dimension, is missing. This

study also reveals differences that exist in terms of concerns based on disease stage and age; and factors which may influence the quality, type, and level of care that is necessary for these patients.

Chapter 3 will not only describe the research design, sample, and data collection tools, but a plan for protection of the subjects as well.

CHAPTER THREE

RESEARCH DESIGN

The techniques by which data are collected is not a neutral enterprise, and how data is gathered can significantly shape the pertinent aspects of the study (Habermas, 1979). With this in mind, the research focus is to explore, describe, and interpret the perceptions and experiences of adolescent girls with AN concerning: self-image, peer and family relations, school, leisure activities, life style and interventions related to their weight. The relationships of perceptions and experiences to the disease stage will also be examined.

Sample

A maximum of ten teen-aged girls medically diagnosed with anorexia nervosa, in one of the two stages: moderate and severe were recruited for this study. A sample size of ten is deemed adequate since major recurring patterns and saturation of categories, may be reached after about seven interviews. Seven individuals were recruited from the Child and Adolescent In-patient and Eating Disorders units, PsycHealth Centre; and from the Paediatric Medical/Surgical unit, Children's Hospital, all at the Health Sciences Centre.

The girls ranged from being: attractive to beautiful, underweight to grossly underweight, and thin to emaciated, but none agreed with the

assessments. When they were described as being attractive or beautiful, they each felt "here we go again, being seen as just a body instead of a person". However, when asked to describe themselves, they all felt that "something was wrong" with their appearance that is, cheeks too puffy, hair too brown, chin too rounded, hips too wide, forehead too flat, and so forth, focusing on the body. It appeared as if they too have been influenced, and focused on appearance or the body, as opposed to the person. One individual, however, also included "sensitive, loving, and kind" as descriptions of herself.

The choice to study two groups, moderate and severe, was made because members of the mild group are generally not seen in an institutionalized setting. They have either not been diagnosed and are still living in the community, or have been diagnosed but deemed safe to remain at home. For those, the disorder is considered manageable and/or non-threatening, and best followed or treated in an outpatient setting. In either case, this group was not assessed.

Group assignment was based on: length of illness; onset of illness; number of hospitalizations and duration of each; co-morbidity factors; treatment required; Yale-Brown-Cornell Eating Disorders scores; and content analysis of interviews, hence a comprehensive clinical assessment and evaluation. Based on the foregoing, four of the teens

were assigned to the severe group and three to the moderate group.

After approval for access to the Health Sciences Centre was granted, contact with potential participants was made via the managers of these units. These managers screened the individuals for their ability to meet study criteria prior to approaching them as potential participants. If they fulfilled the criteria of the study, the parents and these patients were asked if they agreed to speak with the researcher. An explanation of the researcher's interest in examining the perceptions and experiences of patients with AN was provided at that time.

The researcher explained the reason for the study, its criteria, and explored whether or not they were interested in participating. If both parties were agreeable to the teenager's participation in the study, a written copy of the consent detailing role, expectations of participant and researcher, and the process was given to the interested participants and their legal guardian(s) for their perusal. Four participants were minors and therefore also required the consent of their parent/guardian. The three adults were quite pleased that they were able to make the decision on their own.

After they accepted, completed the questionnaires (YBC-EDS and demographic) and were interviewed; these individuals were 'staged' or categorized into one of the two groups, moderate or severe, by the

researcher in consultation with Dr. Eric Vickar who agreed to this task. Dr. Vickar is the Clinical Director of the Child and Adolescent Psychiatric Inpatient Services at the Health Sciences Centre. To be considered for this study, participants had to be: medically diagnosed, staged, and treated for anorexia nervosa; medically stable and physically fit to be interviewed; thirteen to nineteen years of age; able to read, write, and speak English; living within the city of Winnipeg (decrease urban/rural confounding variables); and able to give written, informed parental and patient consent.

Data Collection

Where and from whom data is obtained determines the meaning derived through interpretation. Extreme care was taken in recording and observing the data. Diverse data sources and gathering techniques enrich the data and allow for the identification of potential errors. Denizen (1978) has named it "triangulation". This research utilized intensive three-time interviews, which were audio-taped; field notes; and questionnaires. The participants therefore, were the primary sources of data for this study, and the researcher, the primary instrument.

Interviews. Once the participants agreed to take part in the study, a mutually agreeable place and time to collect data was determined. The

young women were interviewed in a place of their choice. Five chose their private hospital bedrooms with the doors closed, and two chose their living-rooms at home with no other family member present in the house. There was nothing to distract the teens except for the insertion of new tapes for interviewing and the infrequent crackle of the overhead paging system. Interview times varied, but most of the interviews occurred on weekdays between 1600 and 1930 hours.

Each of the three interviews were to be about 45 minutes in length, totalling 135 minutes per participant. The interviews however, ran for an average of one 60-minute and two 80-minute interviews totalling 220 minutes per participant. Some even requested a fourth interview because they felt they had more to say. The twenty-four interviews yielded copious amounts of valuable and informative data. The interviews were spaced approximately, three weeks apart to allow for transcription of the interviews and primary interpretation.

The researcher introduced a general theme for each of the three interviews with an open-ended question intended to focus the participants' thoughts, but allowed for freedom of expression. The content and direction varied according to the responses. The general theme for the first interview was the participant's response to being diagnosed with AN and the resultant self-concept/self-image issues. The

themes for subsequent interviews were: a) the adjustment to the diagnosis; b) life style changes, and peer and family relationship; and c) leisure activity and interventions related to their weight. The opening or comparable question for the first interview was: What is it like being diagnosed with AN? In succeeding interviews, an opening question such as: What has happened to you since we last talked?; followed by an introduction of the theme of the current interview were employed.

The semi-structured interview guide was developed from the literature and clinical experience. The guide addressed concerns and experiences of individuals suffering from varying illness levels of AN. Opening (grand tour) questions, were descriptive and broad (general) serving to encourage the participant to discuss concerns about perceptions, preferences, problems, feelings, and attitudes and whatever other phenomenon was relevant to the study (Spradley, 1979). Both the interviewer and the subject were free to deviate from the prepared agenda and introduce thoughts or observations that were particularly relevant to their own emerging perspectives as the conversation unfolded (Wilson, 1983). Areas of potential stress and concerns of specific interest to the researcher as identified from clinical experience and the literature, were probed to elicit additional information (Swanson, 1986; Wilson, 1983).

Silence was used to allow the participants to fully express themselves prior to the introduction of probes which were used to extract information about details, feelings surrounding events, and for further clarification and explanation in an attempt to direct the interviews. This ensured that the respondents' responses moved the data from general to the specific to produce a more comprehensive overview of the respondents' experiences (Fetterman, 1989).

Explanation probes detailing rationales for the existence of the respondents' specific concerns, and detail probes for general data gathering regarding concerns, were used. Partially structured interviews allowed the interviewer latitude to move from content area to content area, to follow up on cues suggested by the respondent, and to spend various amounts of time interviewing subjects. Predetermined questions were covered in some sequence, by the end of the interview. Clarification and validation from the respondents will be utilized throughout the interview to enhance understanding and comprehension of their lived reality.

Questionnaire. The demographic data were to describe the sample. Previous research has demonstrated the relevance of physical, psychological, and social variables in influencing concern, and this was helpful in interpreting the data.

Field notes were kept on observations made during the interviews to facilitate the analysis and interpretation of the data. Schatzman and Strauss (1982) have offered the following model which was utilized. The model consists of: a) observational notes, describing events experienced through watching and listening (contains the what, who, where, and how of a situation with as little interpretation as possible); b) theoretical notes used to purposely attempt to derive meaning from the observational notes (interpret, infer, conjecture, and hypothesize to build an analytic scheme); c) methodological notes (instructional notes to oneself critiquing one's tactics and reminders of methodological approaches which might be fruitful) and; d) personal notes of one's own reactions, experiences, and reflections. As field work relies on the investigator's ability to "take the role of the other" and be introspective, the above approaches were useful. Observational notes were the most useful as the teens' verbalizations often times were incongruent with their body language. Smiles, grimaces, raised eyebrows, winks, fiddling with the microphone and bed linen, and strategic coughs were actions that placed their words into context and allowed for clarification on points and accuracy of researcher's perceptions.

The research focus was studied using a qualitative phenomenological interpretive approach to understand the meanings and practices of teens

diagnosed with AN as cognitive, behavioural, emotional human beings. Assumptions of phenomenological-interpretive analysis reflect the following ideas: situations are grasped as meaningful wholes by individuals who share common background meanings and languages; understanding one's world need not be conscious and fully cognitive; particular concerns shape human involvement in the world; concerns set up what is salient about situations and how people will act; language is the communication of one individual's mental representation of reality to another; the task of a researcher is to uncover and understand meanings embedded in the practices and expressions of those under investigation and; to access "lived meanings" the researcher must study the pragmatic activity of daily life (Skodol-Wilson, 1989).

Demographic features were summarized using descriptive statistics including: frequency distributions, measures of central tendency, and variability to describe the overall sample characteristics in terms of demographic, illness level, and concerns. Qualitative content analysis revealed similarities, differences, trends and patterns across groups which were used to analyze and verify explanations of the data. Analyses emphasized the description of processes occurring within each participant and comparison between and within the two illness level groups, and of the theoretically derived groups which provided summary

profiles of the participants. The data collection instruments: Yale-Brown-Cornell Eating Disorder Symptom (YBC-EDS) Checklist (Sunday, 1994) and the interview guide are semi-structured [Refer to Appendix G]. Permission was granted by Dr. Suzanne Sunday, author of the YBC-EDS checklist, for its utilization in this research. The interview guide was developed from clinical experience augmented by current research findings. Data was amassed through utilization of intensive interviews, demographic information, and field notes.

The data amassed from the interviews were analyzed using elements of the constant comparative method. Analysis entailed examination of the smallest unit of information that contributed to understanding and could stand alone, that is, an analysis consisting of words, phrases, sentences, and or paragraphs (Lincoln & Guba, 1989). The first interview was coded into categories of concern, perception, and experience as they related to the data (Glaser & Strauss, 1967). Each category that emerged from the data, during encoding, was then compared to previously coded categories for similarities, differences, trends, and patterns resulting in emergent properties and dimensions (Grove, 1988). Although subsequent interviews were coded into categories derived from the initial interview, new categories emerged in subsequent interviews.

A comparison of similarities and differences in perceptions and experiences among participants' interviews was also conducted as recommended by Fetterman (1989), Glaser & Strauss (1967), and Spradley (1979). Differences in concerns, perceptions, and experiences according to illness level emerged as similarities and differences in the identified or designated categories. Similar categories emerged among the participants of the same age and disease level while differences emerged among participants of differing ages and illness levels.

Categories were then integrated producing a full description of concerns, perceptions, and experiences in light of their properties, dimensions, and differences among the groups. The researcher anticipated discovery of aspects previously not elucidated in the literature or as tacit knowledge which then was brought into public space.

The procedure therefore, was this:

1. Approach for contact
2. Sign consents
3. Complete YBC-EDS questionnaire - 20 minutes
Discuss concerns - 40 minutes
4. Discuss concerns - (2 or 3) 80 minute sessions
5. Staging by Dr. Vickar
6. Complete data analysis
7. Results to participants, if so desire

Measures to ensure rigor have been integrated into the design of the study and include: a) prolonged contact of about nine weeks with

participants actively ensuring continuous validation of data; b) independent audit of researcher's data collection, techniques of analysis, and data-supported findings by thesis committee members experienced in grounded theory/phenomenological research method; and c) triangulation across data sources, that is, i) focal and comparison groups (age, disease level), ii) multiple collection techniques: interviews, fieldnotes, iii) differing types of information (for example: perceptions, thoughts and feelings), and iv) quantitative and qualitative methods of analysis.

Protection of Subjects

Informed consents were obtained from both the legal guardians and the participants. Consents were written and explained in lay terms and were also explained in such terms. It was reinforced that participation was voluntary and that they were able to withdraw at any time during the study if they so desired. The interview format, and demographic data collection tool were explained in terms that the participants and their parents/legal guardians were able to understand. The researcher, thesis chair, and internal and external members only had access to the transcriptions of the tape-recorded interviews, demographic data, questionnaires, and field notes. The above data was coded to correspond with the participants' names, addresses, and telephone numbers with

the coded data and actual data in separate locked cabinets. The thesis committee members had access only to the coded data. There was no information or data linking the participants of the study to the transcripts or the results of the study. Anonymity was thereby maintained.

The data is stored for ten years as recommended by the Medical Research Council. The findings of the study will be presented to interested health professionals, and a summary of the findings was given to the participants and their legal guardians, if they so indicated on the consent forms. The researcher also plans to publish the findings.

There were no potential benefits to the participants. However, in discussing their thoughts, feelings, perceptions, and experiences with a professional trained in the area of adolescent psychiatry with particular interest in and experience of the eating disordered patient, may be of therapeutic benefit. Participants incurred no financial costs and no monetary compensation was offered. No risk was encountered by the participants as they were medically and physically stable. A factor stressed on the consent form was that information of a confidential nature was to be kept as such except in the event that participants and/or others might be harmed (suicide, homicide; physical/sexual abuse) if the information was not revealed. However such harm, or

potential harm was not encountered.

The upcoming chapter will present an analysis of the data collated from the YBC-EDS and demographic questionnaires as well as the interviews.

CHAPTER FOUR

DATA ANALYSIS

All seven participants met the criteria for inclusion and participated in a total of 24 indepth interviews.

Sample Demographics

Participants ranged in age from 13 to 19 years with a mean age of 16 years. All subjects were caucasian, of European ethnic backgrounds [German (4), Scottish (2)]; except for one who was French-Canadian. Parents of all participants were married; except for one whose parents were divorced. All participants lived at home with their parent(s), with four living with parents and sister, two living with parents only, and one living with father. All the fathers worked outside of the home in various management/supervisory positions, with 5 of all mothers being housewives. All participants included pets, which ranged from dogs (4) to fish (1), as members of the family.

Annual family income ranged from \$25,000 to in excess of \$75,000, with a mean income of \$50,000. Age of onset of AN ranged from 9 years to 15 years, with a mode of 14 years, as compared to 14.5 years in previous research. Concurrent chronic illnesses or new health problems arising since diagnosis of AN included: anxiety (7); terminal insomnia

(7); depression (5); obsessive compulsive disorder (4); paranoia (2); and substance usage (2). Table 1 provides additional information pertaining to the demographics of the sample as indicated by the participants.

TABLE 1. Sample Demographics

AGE	LENGTH OF ILLNESS	#HOSPITALIZATIONS	HT(cm)/ WT (kg)	CURRENT TREATMENT	
				Meds.	Therapies
13	4 Years	3X * 8 Mo†	140 27	Prozac CPZ Cisapride	OT Indiv Fam
14	3 Months	2X 1.5 Mo	167.5 51.4	Zoloft	OT Indiv Milieu
15	2 Years	2X 3 Wks	175 59.1	None	Indiv Fam Milieu
17	3 Years	2X 2 Wks	172.5 65	Prozac	Indiv
17	3 Years	9X 3.5 Mo	152.5 40.1	Zoloft CPZ Ativan	Indiv Group Fam
19	5 Years	3X 2 Mo	167.5 56.8	Mellaril Impril Metamucil	Indiv Group Bowel
19	5 Years	11X 3 Mo	152.1 42.3	Zoloft	OT Milieu Fam

* Refers to number of hospitalizations; † longest length of stay

To give a clearer picture of the teens in general, one teen that typified the sample will now be described. Jane (pseudonym) was a

160 cm, 16-year old who having reached 54.5 kg decided that she needed to lose weight in order to enhance her attractiveness. After gradually reducing her diet to 2 carrots, 1 apple, and 50 ml of apple juice each day, and then adding a vigorous exercise program, she dropped to 41 kg. She however, remained discontented about her weight. She had difficulty sleeping, had at times been depressed, and no longer had regular menstrual periods. She was socially inactive and had never dated. She was successful academically, as she was a very conscientious student who studied hard and obtained high grades.

She was a quiet unassuming girl, who described herself as being fat-cheeked, long-faced, fat, and not at all sexy. Actually, her face was usually devoid of make-up, which enhanced her pale, wan, papery skin; and her sunken cheeks. Her attire was usually black or brown, oversized leggings and sweat-tops, and black socks. This emphasized her gaunt, skeletal, and weary-looking frame. The impression of weariness probably came from being akathisia with actions which ranged from pacing to strumming fingers on her bedside table. Her hair was thin and dull, and was either left hanging limply to the sides from an off-centre crooked part, or was pony-tailed loosely and carelessly to the back of the head with a rubber-band. She smiled infrequently and this, added to her sunken, dull eyes made her appear quite sad.

Her room in hospital, was extremely neat and tidy, and in direct contrast to the other teens on the unit. She had tapes and a portable cassette player, but never used them. Cuddly animals were used as decoration for the room and were never handled. Curtains were frequently drawn, creating a darkened, lifeless, gloomy environment.

She did not regard herself as being ill or in need of treatment, and was therefore incensed that her parents had brought her forcibly to hospital. To this end, she vowed to "pay them back" by refusing to eat and not complying with treatment. She hoped that they would finally realize that she was truly not ill, as she had been saying for the past several years. This was said with exasperation and underlined her perception that no one ever listened. Having created a picture of the typical participant, responses to the YBC-EDS questionnaire will now be analyzed.

Questionnaires

All participants completed the YBC-EDS questionnaire. According to them, the questions were easily understood, and they were able to select from the choices presented in the questionnaire. The results in conjunction with clinical assessment and data from the interviews, form the basis for division into groups of moderate and severe illness levels.

The eight-item YBC-EDS was designed as a clinician-rated

assessment of symptom severity with diagnosed eating disorders. The format and process-oriented approach of the YBC-EDS were adapted from the Yale-Brown Obsessive Compulsive Scale (YBOCS) (Goodman et al., 1989). Individual target symptoms, that is preoccupations and rituals, were determined and then assessed in terms of time occupied by symptoms, interference with functioning due to symptom, distress caused by symptoms, and degree of control over symptoms.

Preoccupations can include any food, eating, weight, appearance or exercise-related "thoughts, images, or impulses" that repeatedly occur to the participant. Rituals can include any "behaviours or acts" related to food, eating, weight, appearance or exercise that the participant feels driven to perform.

This technique was developed to remedy the difficulty commonly found in rating eating disorder symptomatology, that is, assessing the potentially limitless number of idiosyncratic eating-disordered thoughts and behaviours. By determining those symptoms particular to a given participant, and then assessing severity of symptoms along the dimensions noted above, the YBC-EDS was used to assess severity of illness across participants with a range of symptomatology. Also included in the YBC-EDS is a set of six provisional items for assessing motivation for change, a potentially important predictor of treatment

outcome. These items assess resistance, insight, and desire for change in reference to rituals. The teens described their experiences with symptoms associated with their illness. This description follows.

Impairment Status/Symptom Experience

Self-reported impairment status varied considerably in most areas as shown in Table 2. Commonalities were pronounced especially in the areas of preoccupation with weight, shape, and appearance (somatic), and exercise across the two groups.

Table 2: Scores from the YBC-EDS Questionnaire

PT	PREOCCUPATION					RITUALS					PREOC & RIT- UALS (60)	GLOBAL SEVE- RITY (6)
#	Food & Eating (12)*	Weight (2)	Somatic (2)	Clothing (3)	Other (3)	Food & Eating (19)	Binge & Purge (8)	Somatic & Hoarding (8)	Weight & Exercise (7)	Lists & Other (3)		
1	4	2	2	3	0	6	0	4	3	0	27	3
2	10	2	1	2	0	12	0	8	5	1	51	4
3	7	2	2	1	1	4	0	4	4	3	53	5
4	4	2	2	0	2	7	1	2	2	2	34	3
5	7	2	2	1	1	4	0	4	4	3	54	6
6	5	2	2	3	2	5	0	4	1	2	39	3
7	5	0	0	0	2	7	0	2	1	0	47	5

* denotes maximum score for each sub-category (multiple choice, Likert scales)

The preoccupation with weight rested solely on the fear of being fat or overweight and hence unattractive, or average in the eyes of peers.

The fear of weighing outside of a narrow range, or preoccupation with a specific weight was apparent. All participants had a specific weight in mind, with four wishing to weigh between the 49.0 kg and 51.4 kg range and three, 40.5 kg and 45 kg.

The participants reported excessive concern about specific body parts namely: prominent clavicle, wrists, hips and ankles - 6, "skinny", spindly arms and thighs - 6; sunken abdomen and cheeks - 7. Exercise preoccupation centred around what activities would result in the greatest caloric loss in the shortest time - jogging was the choice.

The data revealed that all participants were absorbed with preoccupations between three and eight hours per day, but 4 experienced one to three hours of preoccupation-free time in a 24 hour period.

Three teens from the severe group, reported that preoccupations interfered with social and school functioning in an extremely, incapacitating manner [Table 3]. They however, did not wish the preoccupations to cease as they were reassuring. The three members of the moderate group were desirous of change as preoccupations were disruptive. Even though all participants were not affected as severely, they all had to cease attending school for varying periods of time.

Considerable variability was reported with regards to rituals.

Commonalities were reported in the areas of eating and food, somatic, and exercise ritualistic behaviour patterns.

Table 3: Preoccupation/Rituals by Group

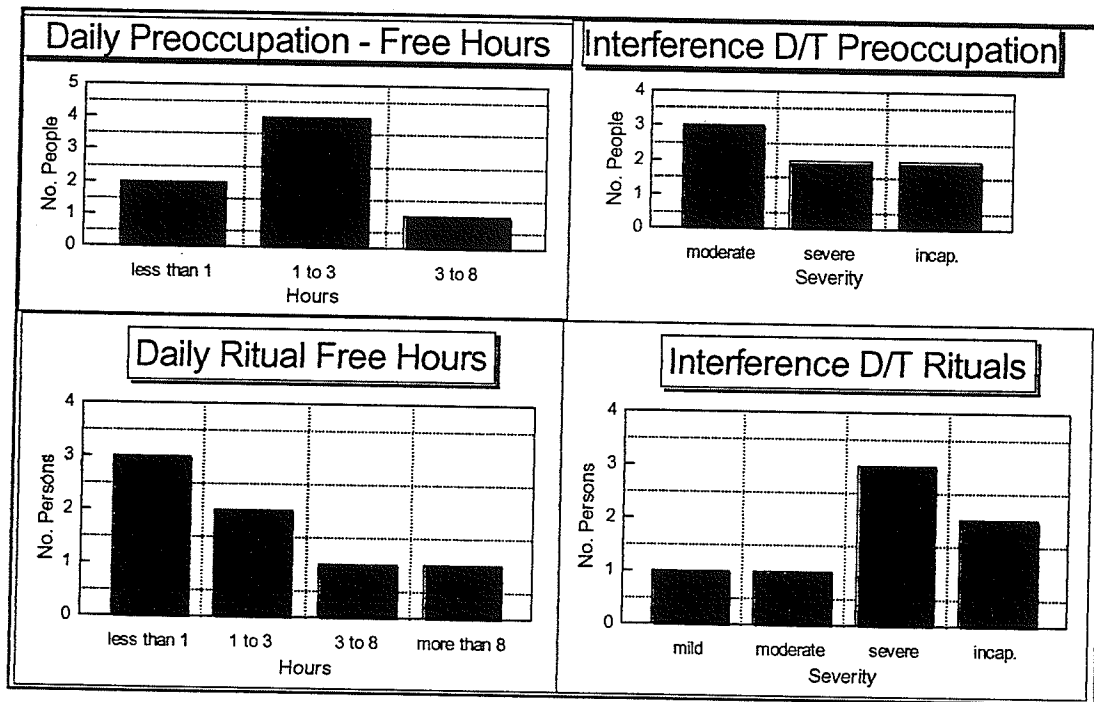
CATEGORY	PREOCCUPATION	MOD- ERATE (3 Teens)	SEVERE (4 Teens)
WEIGHT	a) Specific Ranges 30 kg 40.5 to 45.0 kg 49.0 to 51.4 kg	0 0 3	1 3 0
SHAPE/ APPEARANCE	a) Body Parts Prominent clavicle, wrists, ankles, bony hips Skinny arms, thighs Sunken abdomen, cheeks	3 3 3	3 3 4
EXERCISE (in hospital)	a) Pacing b) Sit-ups c) Other	2 0 1	0 3 1
RITUALS			
EATING & FOOD	a) Avoid Fats b) Manipulate/Stir Food c) Cook for Others d) Constancy of Food Expected e) Collecting/Saving Recipes	2 2 3 3 3 3	3 2 3 4 3
SOMATIC	a) Spanning Wrists	1	3
EXERCISE	a) Constant Motion	1	3
WEIGHT	a) Weigh in Ritualized Way (Eg. 8 a.m. daily)	3	3

Three of the four teens from the severe group, and two from the moderate group expressed the need to avoid fatty foods, like beef; three from the severe group and one from the moderate group needed to manipulate or stir food; six needed to cook for others; and all seven had the need for absolute constancy of the food expected with no substitutions. The almost continuous spanning of the wrists with fingers (must be able to) was performed by four of the participants and was the most frequent somatic ritual. The need to weigh oneself only in ritualized ways, that is, after meals, and after defecating was performed by six of the participants. The four teens from the severe group, and one from the moderate group expressed a need to move at all times, that is, fidgeting or pacing, and reported an inability to sit still. Six of the participants collected and saved recipes [Table 3].

Time spent performing rituals for the majority of participants (3) in the severe group was in excess of 8 hours in a 24 hour period. They also spent less than one hour free of rituals per day [Figure 1]. Interference varied with four girls (3 severe, 1 moderate) reporting severe to extreme, and at times incapacitating impairment. All the members of the severe group were severely anxious from any intervention aimed at modifying the activity, or during the performance of the activity. Three of the women from the severe group expressed no

interest in stopping the rituals and all the women in the moderate group were willing to stop the rituals by working to some degree. However, with not much effort was placed on goal attainment.

Figure 1: Daily Preoccupation/Ritual-Free Hours

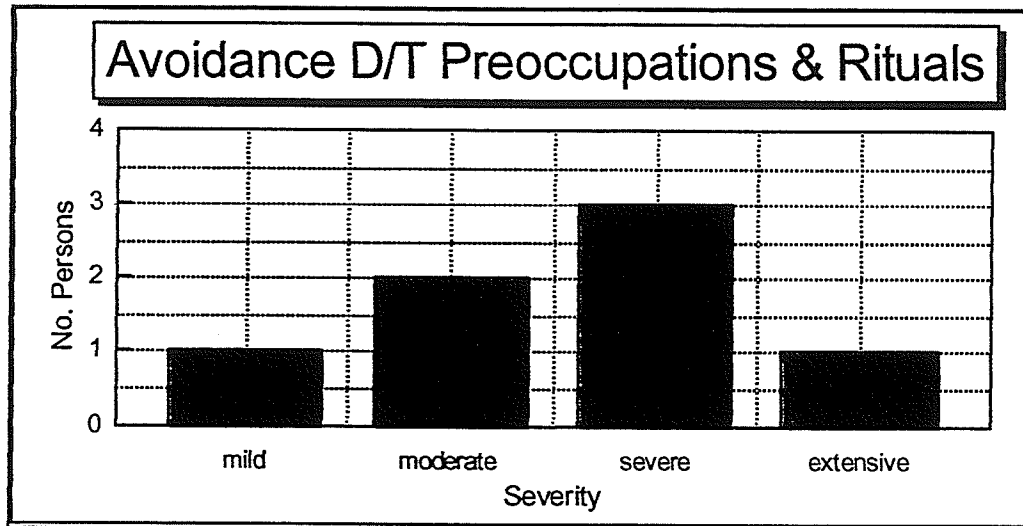


** Note: D/T = Due To

All participants expressed deliberate avoidance [Figure 2] and four (3 severe, 1 moderate) reported severely extensive avoidance of performing tasks or going places out of concern that they might be unable to stop engaging in rituals. It is of note that six participants believed that the rituals performed were consistent with how they saw themselves, that is, an ego-syntonic nature of the rituals (3 severe, 3

moderate).

Figure 2: Avoidance due to (d/t) Preoccupations and Rituals



The mean and the standard deviation scores of the YBC-EDS in a comparative study of this present research and the tool validity research study are presented (Table 4).

Table 4: Comparison of Mean Preoccupation and Ritual Scores

MEAN (STANDARD DEVIATION) YBC-EDS SCORES			
	Preoccupation	Ritual	Global Severity
CURRENT [X] RESEARCH [SD]	14.43 (3.92)	29.14 (6.10)	4.14 (1.12)
REFERENCE [X] RESEARCH [SD]	7.96 (3.24)	6.93 (4.38)	2.86 (1.08)

The mean of the total preoccupation/ritual score was 43.57 (SD 9.65) and the median was 47, out of a maximum possible score of 60. This places the tool validity study scores in relief as they total 24.81. This points to the severity of symptoms and the severity of the illness of the participants in this current study. This coincided with the global severity scores - mean 4.14 (SD 1.1), median of 4, and mode of 3, out of a maximum possible score of 6. As compared to a mean of 2.86 (SD 1.08) in the tool validity study.

It would appear that the moderates in this study group were even more severe than the severest in the tool validity study. The global severity scores also attest to the fact that the members of the adult research group were displaying more effective coping skills as the self-reported degree of distress, the symptoms observed by the researcher, and the functional impairment reported appeared manageable. In the severe group, of the current study, global severity, (that is, the degree of distress reported by the participant, the symptoms observed, and the functional impairment) ranged from severe symptoms limiting function to extremely severe symptoms rendering the individual completely non-functional.

Included in the YBC-EDS is a set of six provisional items for assessing motivation for change, a potentially important predictor of

treatment outcome. These items assess resistance, insight, and desire for change in reference to rituals. The comparison group had low scores which points to the desire for change and less resistance which bode well for treatment outcome. These items were less endorsed as present; indicating resistance, lack of insight, no desire for change in all of the members of the severe group of the current study. Even though the moderate group reported resistance and demonstrated limited insight, they unanimously wished a desire for change concerning the preoccupations and rituals even though they did not seem willing to do much towards attaining that goal. The information derived from the interviews comprised the bulk of the data, which will be discussed below.

Interviews

The young women described the experience of being interviewed as being unique since "no one ever listened to" them. They were eager and willing to share their experiences and were comfortable, excited, and able to express themselves quite well, even though they each used "I don't really know how to explain it" as a qualifier. Adolescence has long been considered a critical period in human development, and the search for an understanding of the adolescent can be traced historically. Early writers such as Rousseau, Francke, and Froebel, directed their interest

toward the education of the adolescent as well as his characteristics (McKeon, 1941). Then in the late nineteenth century, psychologists moulded the Darwinian concepts into psychological terms and firmly established adolescence as an inevitable stage in human development. Before the twentieth century, however, most people thought of themselves as young adults after puberty.

Interviews were initially scheduled at one 15-minute and two 45-minute interviews (totalling 105 minutes) per participant, but ran for an average of one 60-minute and two 80-minute interviews (totalling 220 minutes) per participant with some participants requesting a fourth interview. The teens were easy to converse with and each had her own particular brand of humour; humour, which added to the interest and enjoyment. Data amassed from the 24 interviews with the teens will be examined next, using leader questions as the main categories.

Responses will be discussed as similarities and differences where pertinent.

Meaning of Anorexia Nervosa (AN)

Responses to the question what does AN mean to you?; set the tone for the entire interview. Almost all respondents (6, 3 from each group) agreed that AN was indeed an "illness" and a "problem" (which was personalized, demonstrating ownership and therefore prefixed with

"MY"). However, one teen from the severe group, denied that a problem existed, and instead focused on the fact that the goal was "only to lose weight". All agreed that they were "unable to eat - you just can't".

When asked if "won't" would be more accurate, they all hesitated, but then reverted to the "can't" statement.

Some of the definitions were: "When you're too skinny for your height", "a loss of appetite", "when someone does not want to eat", "a disease of the mind"; and "when someone becomes really thin and doesn't want to gain weight". AN was further defined with these additional components; when an individual "looks sickly"; "is a coping mechanism, how one copes really"; "something that alters your mind and makes you go crazy"; "has a lot to do with control and fear and anger"; and "a reason for being in hospital".

Some quoted and differentiated between "dictionary" and "medical" definitions that they had "picked up" during the course of their illness. Physical status was incorporated, with a note of caution that it was "more than that". A composite of all the teens' similar responses produced this general definition of AN:

An illness symptomatic of several issues, problems, and struggles in life [and as such] it's really how one copes. The not wanting to eat, and looking skeletal are direct results of a diseased mind. Fear, confusion, anger, and not wanting to eat all combine to make the illness as serious as it is.

As per the definitions above, the refusal-to-eat component of AN appeared to be of a voluntary nature, since all pointed out that the loss of appetite was "not a real loss, but a real torture because you want to eat, and think about food all the time". Body size misperception: "I know that I am fat, people are just saying I'm skinny to make me eat and put on weight", and the resultant threats to body image fulfilled the criteria of the DSM IV's (1994) definition since they were all amenorrhoeic.

Life Events at the Time of Diagnosis

This question asked participants to think of when they were first diagnosed and the circumstances surrounding life events at the time. Responses varied, but there were several common themes.

One of the primary emotions was **sadness** ascribed to the inability to fit in; having no real friends, and watching life pass by. Lability of mood with focus on **depression** was a direct result of parental pressures and desires to be thin, in some cases (3) and peer pressure to be popular and thin. Since they were unable to accomplish these tasks, perceived inadequacies were highlighted giving rise to increased pressure to be noticed in other ways hence the pressure to be smart. The depression evolved because of the need "to be accepted for who [they were]", and not what others wished them to be. This was not foreseen as an

eventuality.

Loneliness, abandonment, and isolation was the next set of emotions identified. These emotions were directly related to the unavailability of parents, usually fathers, and or close family members who had moved away. Families having to relocate, hence removing stable supports and friendships for these teens, underscored abandonment issues with the resultant fear of the teens becoming attached to anything that cannot be uprooted.

Friends were also unavailable, that is, "not there for them" when the need existed most, because when these friends were with their other "cool friends" they would be too embarrassed to be seen with the participants. The teens were therefore excluded from the very groups which they so badly wanted to be a part of. This created a great sense of being despised, deprived, and rejected. This was indeed traumatic as these individuals typically took a long time to generate friendships which were long-standing (average of 6.5 years for these teens). These friendships and friends were valued as the teens were "too shy" or "too easily embarrassed" or too "intimidated" to make new friends. Echoes of not being: "good enough" for them; their "type"; pretty enough; able to make conversation; and "sociable" abound. Inadequacies were further revealed by statements such as "I can't go up to people and just start a

conversation with them, I probably wouldn't know what to talk about".

Lack of attention from family and friends. At the time when the diagnosis was made (mean 13 yrs of age, mode 14 yrs), all of the participants felt that "[their] parents didn't notice [them]". The parents' focus at the time was on a sibling, or in two of the cases, on job-related crises. These siblings were experiencing complications ranging from difficult spousal relationships to problems with school work. This was perceived as being unfair to the participants as they were the 'super good' ones who were always being respectful, aiming to please, and being everything that the parents desired.

This lack of parental attentiveness was seen as a necessary evil because the teens stated that the siblings and the parents experiencing job stress did indeed need the support. This new direction however, took the much-sought-after focus away from them.

Attention was also lacking in several instances from peers as "my friends were too busy" to include me. It appeared however, that the friends themselves were busy playing the peer acceptance game of trying to fit in, to be overly concerned with the participants' ill health. Comments such as "you don't look too good" or "you're trying to lose weight or something!" were viewed as perfunctory in nature.

There was little variability in terms of what was happening in the

lives of these teens around the time when they were diagnosed. The themes of isolation, abandonment, lack of attention, sadness, loneliness, and depression prevailed. The prevailing theme was: "no one had time for me, not my parents nor my friends; everyone was busy with someone else". Even though the teens themselves offered reasonable explanations, this underscored the sense of "not being good enough, or interesting enough", and the underlying "not loved or cared for enough" to matter to any one. All efforts were to no avail, hence the one thing that they each had control over was used as a last-ditch effort to refocus and some times focus attention on them. As one individual said, "there was no great tragedy in my life", [indeed] and finished by another, "it was sorta like an experiment. I just decided I didn't wanna eat, it sorta seemed like something to do." For what purpose?

The outstanding theme is lack of attention. This led to feelings of depression and sadness, and abandonment and isolation. The lack of attention coalesced into the feeling that "no one cares". If no one cared, then the teens had to formulate a method by which someone - parents, friends could care.

Living With AN

The question of "how has anorexia nervosa altered your life, if at all?" yielded similar responses. The assailing sense of **impotence** was

contagious. The sense that "no one cared" generated sentiments like, "there wasn't much I could do" to make someone care, "there was nothing I could do" to make someone care, "it didn't make a difference" because no one cared, and "it wouldn't have made much of a difference" because no one cared summed up the emotion. The sense that their hands were tied and that self-induced starvation was the only option was evident. Anything was worth a try.

Sociocultural standards regarding the thin ideal, coupled with some parents' pressure to be thin seemed to have become ingrained. Several individuals were unable to recall how they looked, but think that they were fat based on comments made by parents. Comments such as "you're by no means small, but a rather large girl", and "you'll get fatter if you eat so much" were frequently stated. These comments were voiced by parents who were "fitness freaks", or "naturally skinny"; or by mothers who had eating disorders themselves, or who were "petite and had small appetites"; or mothers who repeatedly said, "when I was your age I had a great figure, what I wouldn't give to be your age again" intimating that "something was wrong" with their daughters' figures. This "something" was usually perceived by the teens as fatty tissue, or fat. This oft times erroneous view, was then internalized.

This view of them being fat, or large was strengthened when the

teens were rewarded via compliments, money, trips, special treats and so forth when they decided to diet in order to lose weight; approval for self-deprivation. This perpetuated the weight loss and resulted in behavioural conditioning. That is, the teens became so conditioned, they were able to predict receipt of gifts. The more predictable the weight-loss leading to gift-giving, the stronger the conditioned response, which gave rise to the expectation.

An example was when one of the teens, at ten years of age, gave up second helpings for Lent. She pointed out that usually people tried not to fight with siblings or engaged in something beneficial to others, but instead made this decision because she "thought it was a good thing to pick" and that she would "definitely be backed up all the way" by her parents.

Others gave examples of not being allowed to make decisions surrounding intake and clothing. Autonomy, independence, and initiative were not encouraged so they began to doubt their own desires and tastes. One teen reported that her mother usually shopped for the teen's clothing and made selections that the mother preferred as opposed to what she favoured. The typical response from the mother when the error of her ways was pointed out was: "What's not to like! I like it!" This contributed to a decreased sense of self, increased

compliance, and maintenance of the status quo at all costs. This made them feel "bad all the time", devalued, as inadequacies were delineated and thus confusion and resentment mounted.

The young women stated that with resentment came the need to belong to self, to be their own person, to be masters of themselves. This set up a confrontational, almost adversarial stance whereby they initially rebelled in secret to gain autonomous choice. This took the form of starving themselves, and at the odd times, consuming high caloric foods. This in itself proved to be highly difficult because it served as a source of internal conflict and great anger because they felt that they had to deprive themselves of food in order to be accepted and approved, yet they so desperately wanted to eat what they wanted in order to be themselves.

Feelings of being numb and "once I got my eating disorder, I didn't feel as bad about things anymore" were frequently voiced. The eating disorder was substituted as a pacifier, it would have to make things better. The idea was that parents and friends would have to pay them some attention now that they were ill. Anger mounted, but may be offset by being acknowledged that they do exist. This served as even a facade of control, as some of their energy was redirected elsewhere. That is, in meaningful interactions with others. Who would know that I am

so scared and "terrified" inside that I might lose control? No one will. "All I have to do is keep a tight hold on things". This had an almost desperate quality to it, a perfect match for the feelings evoked. This self-imposed facade of inner-strength was much needed.

All participants agreed that AN had wrought changes. One individual summed up the changes as AN "becoming" her life. "I don't have a life anymore, everything revolves around it. From the time I wake up even when I dream, I'm dreaming about food". Others cite 24 hour per day preoccupations about food, as indicated earlier in the YBC-EDS results. Still others mentioned faster, more effective methods of burning calories - extra sit ups, pacing, or even a further resolve to not eat.

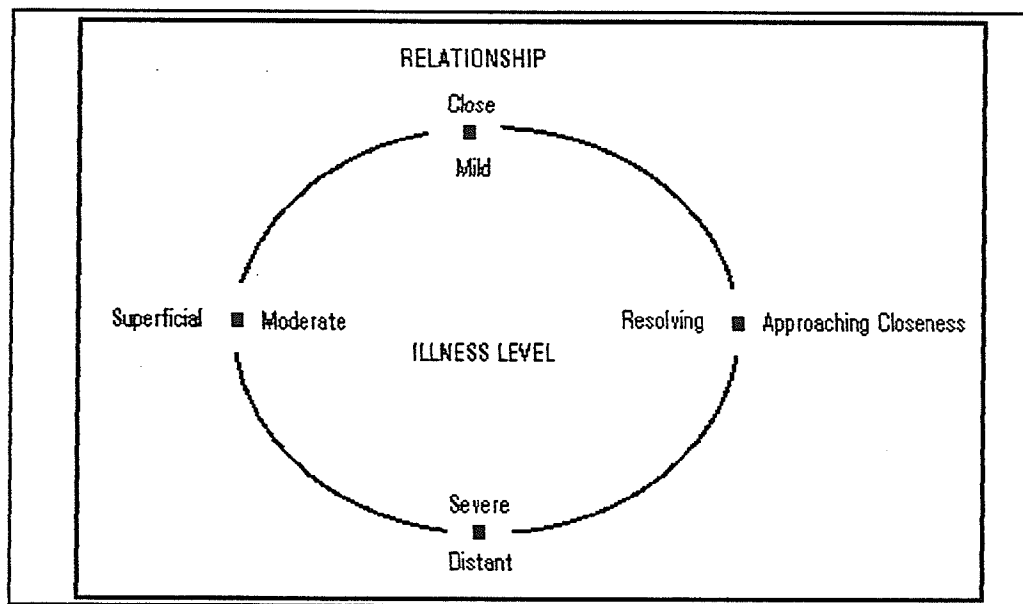
Role of Friends

It has been theorized that adolescence sees the teen conforming to an acceptance of peer group standards and that peer friendships are gaining in importance. The peer group usually consists of the same-sex friends; however, the adolescent has an increased interest in the opposite sex. Responses regarding roles that friends played in their lives were tallied and are presented next.

Five of the participants had solely same-sex friends, with six of them wishing "things would change" so that boys would be included.

even though fearful of this change. Friendships were typically long-standing, and cycled through close, superficial, and distant episodes. Figure 3 displays the relationship between the severity of their illness and friendships as described by the young women and conceptualized by the researcher.

Figure 3: The relationship between Illness and Friendship



There existed a positive correlation between illness and friendship, that is, the more severe the illness the more distant the relationship. This was mainly due to the draining nature of the rituals and preoccupations associated with the illness and hence withdrawal due to fatigue.

Friends were sometimes viewed as true friends, foes, tormenters, and

competitors.

Friends viewed as true friends were usually the true sole support system; the people who knew exactly what they were going through and were "there" for them. These were the friends who kept in touch with the mothers of these teens, by telephone or visits, when they were hospitalized and often times were the sole non-family visitors to the hospital.

Friends as foes were the friends whom they had latched on to in grades three to seven due to propinquity and necessity, because "you had to have friends to fit in". These friends were accomplishing the tasks of adolescence and were more advanced developmentally, hence perceived the AN teens as dead weights around their necks. Several teens recalled being bullied and ridiculed, "made to feel bad". The pecking order was established. The girls spoke of the hatred that existed amongst the members of their group of "friends". However, because they were viewed by their peers as a group of misfits, and "rejects", they had to remain together as the unwritten rule amongst teens in general is "you have to be a member of a group" and they did not wish to further stand out. The teens however, were too daunted and "scared" at the prospect of starting new friendships, (and "lacked the determination") as they were socially inept; "too shy"; "too boring", and

had "failed miserably" following several attempts at friend-making.

The teens either "hung around" on the fringes of the "way cool" people, (or gazed at them from a distance) who allowed them tantalizing glimpses of the world in which they would "die" to live. This group constituted the friends as tormentors. The "in" type of people with whom they could become friends "if only" they were pretty enough, sexy enough, skinny enough, and trendy in dress. These friends always seemed to pose the question, via actions, why are you hanging around us, you are such a loser?

Friends as competitors constituted the largest group. It was here in fact that most reported that "part of the problem started". This group would typically have one or two dieters who would compete with each other in not only weight loss, but rate of loss as well. That is, it was not good enough to lose 2 kg, but it would be great if those 2 kg were lost in four days, for example. "Fat jokes" would be carelessly tossed around as well as intimate details of parties they attended; relationships with boyfriends, and tales of fun things they did with their other companions. The goals of these information sessions were to: i) establish to the others in the group that "they had a life" which was exciting and apart from them, hence validate superiority and involvement; and ii) increase self esteem and self worth with the statement: I am liked, I am

attractive.

When these goals were accomplished, the feelings of insecurity, being excluded, impotence, and the inability to do anything right emerged. It was time to take action. The "I'll show you syndrome" surfaced in the teens and was manifested by "if I can't do anything else, I'll diet, and I'll show them that I am good at this!" This became life's mission.

To summarize, friends were usually of long standing and were divided into four groups (friends, foes, tormentors, competitors) with the most preferable ones being the true friends or supporters, who knew exactly what the teens were going through. This was so most of the times because the friend also had an eating disorder. A positive correlation existed between the severity of the illness and the type of relationship, whereby closeness was undesirable at points when the illness was too severe to sustain same. This was due to the draining nature of the rituals and preoccupations associated with AN.

Family Functioning

Theoretically, the overall family goal during the teen years is to allow the adolescent increasing freedom and responsibility to prepare her for young adulthood. Although each family member is viewed as having individual developmental tasks, the family unit as a whole is

also seen as having developmental tasks. These include: provision for individual differences and needs of family members; establishment of shared responsibilities; strengthening of communication skills; and formulation of a workable philosophy of life as a family. The families were small, averaging four members.

The question posed was, "to whom are you closest in your family and why?" The overwhelming response was "mother"; with only one participant being noncommittal, but stating that her mother knew her best. The second choice of three individuals was sister. The pattern appeared to be sister eventually, as the teens aged. All participants felt that their mothers were more understanding, more supportive, and more sympathetic to their needs, and thus with regards to their illness. Some felt that this held true because AN is a "woman's issue" and there was no way dads would be able to understand, mostly because they did not care to.

Some of the mothers themselves were either diagnosed with eating disorders (3), or were concerned about their weight (6), preferring to be slim. Most mothers exercised regularly and monitored their intake carefully. All participants described their mothers using a combination of these adjectives: petite, slim, skinny, skinny for her age, and tiny. Conversely, the dads were described as being husky, tall, real big.

football-player-type, big, fitness freak, and beer-bellied.

Even though the majority of participants described their parents and siblings as being "kinda supportive", all participants reported familial difficulties in the following areas. **Parental Hypocrisy** and the anger it generated abounded. Instances such as the removal of bathroom scales while the teen was at home in an effort to remove the "obsession with weight" and the resultant temptation "because it influences you", were quickly seen for what they really were. This, because upon return from hospital, the teens found that bathroom scales had been returned to the bathroom and had been in use. The parents were then perceived as being dishonest, unfair, overly concerned with their own weights and charged with excessive exercising and monitoring of caloric intake. Hence the confusion over the double standard as the teens were instructed non-verbally to not emulate their parents.

The families were described as being "mixed up" or "screwed up", "more uptight than others", different, "something is wrong with us". Secrecy was a recurring theme, in all family interactions which were portrayed as "everybody talking about each other, but hiding stuff from each other".

This secrecy stemmed from older siblings and/or parents not revealing pertinent information regarding family members. For

example, withholding information that mom or older sister also had an eating disorder. This in effect excluded the teen and contributed to the feeling of not belonging and being isolated.

The teens themselves also engaged in secretive behaviour; exercising in the early morning hours so as not to be seen, and having meals at other than meal times in order to conceal the content and amount of meals, in an attempt to avoid the negative comments. This also served as a barrier.

Parental Control was another area of conflict. Full parental control, that is if the teens were compliant with parents' wishes, apparently translated into parental happiness. Fathers were seen, in many cases, to be the "bad" parent due mainly to issues of running the "household" with a too firm hand; "control freaks" was the reference made. "Dad, the controller" would inspire sneakier, less obvious behaviours regarding eating habits whenever he was around. Or, as in one "humiliating" instance, parents hid food from the teen in order to assist her with controlling her intake, but all other members of the family knew where the food was hidden.

Household here also included the parental relationship. The teens' perception was that mothers, to a large extent, were in a subordinate position; never seen as equals, and never treated or regarded as such.

Working outside of the home was not a factor. Apparently all major decisions were made by the fathers who solicited a token response from the mothers. This information was then passed down to the children, but done under the guise of a "discussion".

References were made contrasting the parents' levels of control. Mothers were referred to as the emotional ones, the ones with the temper, the ones who swore, and the ones who yelled and screamed during parental arguments. Fathers on the other hand, never yelled or screamed, but always spoke calmly and rationally, and walked away when their points were made. This somehow gave the impression that mothers were under-controlled (out of control), and the fathers, over-controlled (in control).

Parental control enkindled feelings of hostility, anger, ineptitude, weakness, helplessness, inadequacy, frailty, and generalized being "mad". Mad here defined as "always mad", all feelings coalesced and became mad, resulting in a possible "explosion from madness".

Paternal Aloofness was another source of discontent. Claims that the family did nothing together or barely did anything together were frequent. These families typically did not dine together, partially due to the engineering by the teens, who stated that "quality family time" was non-existent.

These families were frequently not only physically separate, but demonstrated some elements of a disengaged family. One would find each family member physically separated and attending to own concerns throughout a typical day. Say at eight in the evening, mom would be either doing the dishes or her nails or hair; dad would be in his den doing work from the office, or other task associated with work; sibling-1 would be upstairs in his room listening to music; sibling-2 would be walking the dog or out doors some place; and the teen would be downstairs doing school work.

One teen said that one day of each weekend was usually set aside for family activities: like going to the museum, bowling, hiking or for a family drive. These family drives were described thus: dad would fully concentrate on his driving, mom would admire the scenery, sibling-1 would play a portable computer game, and the teen would write down the licence numbers of passing vehicles.

Outside of the control exerted as described above, it appeared, fathers had no other involvement in the teens' lives much to their chagrin and vexation as this was perceived to be "being ignored". Sentiments expressed in regards to fathers included: very unfeeling, like a stone, like a rock, never shows his feelings, passive, not empathetic or sympathetic, selfish, self-centred, insulting, uncaring, and superior. One

teen passionately explained it thus:

It's like he doesn't care about me. He doesn't care about how I feel or what I say. He just doesn't care [voice broke]. He just cares about himself and whatever I think and whatever I feel are nothing. He pays for the groceries, he bought me a [pet], he buys my clothes and I have a roof over my head and that's good enough. What else do you expect from me! He is not that great a father. He's like a rock.

Contrastingly mothers were seen as overly involved. They were perceived by their daughters to demonstrate their love and the teens could always "feel" this love. One participant related that her father frequently told her he loved her, but he had to be content with "you too" as a rejoinder as the love was not felt. Apparently there was no action to support the verbalization.

Mothers fulfilled their supportive role even though they were sometimes "screwed up and unhappy". When the participants were asked if they thought that their fathers were aware of their mothers' unhappiness, they unanimously indicated the contrary. One individual stated that her mother was always tired because she worked so hard keeping the house tidy and preparing meals et cetera, and was absolutely certain that her father was not cognizant of the fact even though this has been occurring for years.

Mothers, seen as too emotional, were often chastised for their warmth. Loving hugs and kisses were never in short supply and the

teens all found this "annoying and too much". Mothers were usually confidantes, and were the only confidantes for six of the teens. This however, was sometimes difficult as in two of the cases, mothers expected their teens to be their sole confidantes in return. This created role and boundary problems. The difficulty cited was that these mothers would confide intimate details regarding their unfulfilling sex lives and the roles that their fathers and/or mothers' boyfriends played. As one teen said "I am a kid, I don't need to know" and another, "I was 10, I didn't even know what sex was".

Another point of note is the role of the extended family. Apparently paternal aunts and uncles, especially aunts were considered to be interfering. They had to know what was "going on"; that is, causation and mechanisms utilized for maintenance of the illness. Maternal grandparents, especially grandmothers, tended to blame the mothers of the teens for the illness. An individual recalled being extremely upset following grandma's departure after a visit where she clucked, and shook her head and stated that "we all have our crosses to bear, I guess this is yours". She was even more incensed when a letter turned up naming mom as the culprit for encouraging the disorder. This was seen as inaccurate and meddlesome.

Parental Insensitivity was a common theme. Frequent parental

comments concerning the teens showing more than ideal weight and parents unfavourably comparing the teens' appearance to their own in teenage years were voiced. Preferential treatment of a sibling was noteworthy. All felt that parents had favourites, which they stated "should not be because it splits up the attention" parents give to their children and "it sets up competition" and a hierarchial structure is created giving rise to isolation and splitting or separateness.

Six of the participants stated that their fathers were in every instance critical. Phrases such as "doesn't understand, always hurt my feelings, never smiles, never listens to me, never shows his feelings, jokes at the wrong time and always about serious things" were common. One teen, angrily stated that her father frequently reminded her that he "did not have enough money to pay for a funeral". Comments such as the ones stated above generated much anger and the desire to indulge in physical violence: whether to "just smack him" or "hit him over the head with a bat" was frequently threatened. This was usually said in even tones, and was noteworthy for lack of venom or other definable emotion, and rather in a matter of fact manner. One individual clarified by saying that the father is so "unlovable that no one cares for him", but guilt played such a pivotal role that they amended the feeling. After all, "seeing he is the father, there should be some form of caring as opposed

to harshness".

Words such as beastly, s--t-head, ass----, pig, annoying, thinks he is always right, and a know-it-all were commonly used in reference to fathers. One individual stated that she did not like talking to her father because "he'd get a little mad because I was harming myself" and he did not like to see it, but he just did not understand" was echoed by several who stated that their fathers concluded that the teens were "selfish". This finding in relation to fathers was not reflected in the literature reviewed.

Words and phrases used in connection with mothers included: shows concern, shows love, more emotional, more supportive, she knows not to say anything because it makes it worse, sweetie, wants me to be happy, really messed up, never happy, and has a messed-up life herself. It is remarkable that even though it was felt that mothers cared about them, they still expressed that no one paid much attention to them.

Leisure Activities

This question was phrased as "what do you do for fun?" Most people repeated the word, and gave the matter some thought prior to responding. Only one individual was spontaneous in her response. Even though she had a long list of outdoor games, the games were entirely a one-person event.

Leisure activities were usually solitary or parallel in nature. This underscored the fact, they claimed, that they did not exist for many, and again, "no one paid any attention" to them. Watching television and video tapes, and listening to music were popular. Talking on the telephone was mentioned several times, but the individuals admitted that it was "not much fun really" because they were either not called often enough or did not have anything to talk about.

Dancing was a favourite, listed as number one for three of the girls. These teens were the three oldest of the sample. It seemed to liberate them somehow as they were able to lose themselves either by donning cloaks, that is costumes, or becoming intoxicated, if it was in public, or by performing in private. This performance had an imaginary audience as self-confidence was lacking. Writing poetry or maintaining a journal was another favourite. This contained expression of thoughts, deepest fears, and feelings that they were usually not able to vocalize. The poems were classified as addressing weird, scary themes pertaining to death, vampires, and physical disabilities. Two of the girls were models and even though they found it stressful, liked the idea of dressing up. The performance element was again present.

School Life

The question "how has school been for you in the last few years?";

produced similar responses from six of the participants. Academic life had apparently been the one area in their lives in which they were able to successfully compete with peers. But even in this however, they felt defeat, because with this came ridicule. Phrases such as "nerd" and "the shy, quiet one without a life" were common.

Even though all participants were on hiatus from school numerous times due to illness, six were A or A+ students and consistently made the honour roll annually. While this boosted their self-confidence, "it was still not good enough" because "what's the use being the smartest? I am a nerd, I have no friends, and I don't look good". The internalization of others' perceptions now formed their sense of self; the fat, ugly, friendless nerd was not someone with whom they could live. Thoughts of death and wishes to be dead were frequent. As one participant stated: "it was not necessarily suicidal thoughts, but more of the nature: why am I here on earth? If I were dead I would be out of all this misery. I would not have to make these decisions regarding food. Nobody cares anyway if I live or die, I am nobody and I'm useless!"

School was viewed as a place in which they were forced to be with peers on a daily basis. It was here that unfavourable comparisons were made. Some would "look at the skinniest girls and say I want to look just like her". Others would take it a step further and would wonder at

the individual's intake and how favourably it compared to theirs. One individual described her typical day at school thus:

If I'd go to school from the hospital, I'd have to have breakfast, lunch, snack, supper, and a snack. And all day I would just obsess about what I ate all day and how much I would have to exercise, all day. I don't know how I concentrated on school work. And I dreaded the next meal and I dreaded the last meal and I was always comparing myself to the kids in school. I just, I would be so tired because of that mental obsession would just tire me out so much that sometimes I think I couldn't do it anymore.

A typical day however, if the individual was not in hospital varied slightly. Breakfast consisted of cereal soaked in minute amounts of 1% milk; lunch was usually water or diet coke, "which has only 1.5 calories", they quickly added. Or often times, nothing. When questioned by concerned friends, the response was typically that they had already eaten or had had a large breakfast. Supper often was a puffed wheat cake or small amount of apple juice. Some did not drink juices however, because they are "too filling and too high in calories".

At school, English was the favourite subject of all participants, with additional courses like nutrition and fitness to round things off. Three (from the severe group) favoured the sciences, the others "something creative" like music or art.

Career aspirations varied. All of the participants had almost a need, and a definite drive to pursue their education beyond high school (one participant was in first year university) that is, community college

or university. The venue was tied to the desire "to be away from home and its influence" and to a lesser extent, for smaller student-teacher ratios. "A crowd can be so intimidating", because it is a larger group of peers with which to compete, hence greater pressures as opportunities to interact increase and social ineptitude are highlighted.

Career goals ranged from being a veterinarian to an astronaut, and included music and art. One participant was interested in pursuing studies in writing children's literature, but her parents wanted her to be a "kind of helping person" like a nurse or a psychologist. This was rejected however, as she firmly believed that such jobs "stem from a need to be needed by others". She did admit that even though "giving people good advice" was a strength, and made her feel needed, she was not sure if she had the "qualities that it would take to be caring and sensitive" as she saw herself as "abrupt, somewhat like my doctor".

A career as an astronaut was chosen by a member of the severe group the individual who appeared, for much of the groupings, to be an "outlier". That is, she expressed different thoughts, feelings, perceptions, and beliefs from any other member of the sample. This atypical individual did not qualify her response except to say that "it would be kinda neat", and "that's been my dream for a long time", sounding as if it had been given much thought.

Coping Skills

'Soliloquizing' and 'litanizing' took second and third places after the actual eating disorder as methods of coping. **Soliloquizing**, was defined by the researcher as the constant non-verbal pep talks participants gave themselves, the unspoken reflections that were necessary to keep them focused on goal attainment. **Litanizing**, was defined by the researcher as the ritualistic repetition of phrases and key words that served to ground participants in their faith; supplication to the gods to keep them strong.

Soliloquizing not only kept the teens focused, but provided a plan of action. One individual who required tube feeding stated that she had to "fight somehow in little ways" as she would feel very guilty if she just gave in and made everything happen the way in which the nurses and doctors wanted. She stated she had to be "extra bad" to herself. This would include pacing for an extra two hours, or if that opportunity did not arise, thinking for an extra two hours. Typical thoughts would be:

I'd torture myself and say that am never ever gonna eat again. I'd think about all the food I love that I'd never ever eat again. I'd plan that when I get older am gonna tube feed myself until I am 75, and then I'll eat a little bit or something (chuckles). Or you know, that I will wake up at four in the morning when the nurses aren't checking on me and I'll do 40 sit-ups.

Litanizing was a useful tool for keeping the teens grounded and firm in their desires. The words "angry", "mad", "hate", "control", "care", "love" were used repeatedly. The most popular phrases were "I'll show

you", and "I'll prove it to you". The most frequently used word was skinny, it was used to describe every facet of the illness, and was indeed a true litany, as exemplified in the following passage.

Like I remember I felt so pressured. I remember thinking that I didn't want to lose weight to be normal. I wanted to be skinny, skinny, skinny, skinny, skinny, so that I'd be skinnier than my mom or skinnier than any of my friends, even the skinniest one. That's what I wanted to be. Like there was no limit to how skinny I wanted to be.

Other coping skills employed were: a) control, that was use of food and eating as a weapon to promote emotional closeness; b) secrecy and denial, that was if it is kept hidden and not spoken of, it did not exist; and c) disdain and mockery. Control and secrecy have already been discussed. Disdain and mockery were fully utilized in recounting memorable discussions with adults who thought they either knew it all (and of course knew nothing) or were just utterly "clueless", but thought they needed to speak and be heard anyway. It is interesting that this was directed towards only adults.

Situations which employed the use of mockery would be healthcare professionals, especially dietitians and doctors, providing information regarding altered care plans. The concept that the doctor and nurse were working in their best interests was extremely difficult to embrace because these professionals had never experienced the illness and even if they had, "no one understands" and "all they want to do is fatten me

up anyway". No amount of second and third hand knowledge placed the professionals in good stead because "it wasn't them and it wasn't their body and they are all liars anyway". Apparently adults were not to be trusted because they "always went back on their word", they always say things won't change and will remain the same, but they never do. "Adults don't really care who they hurt as long as they get what they want". The central question was whose best interests were being served? The teens certainly did not feel it was theirs.

Accurate mimicry of others' tone of voice and mannerisms was very common, although it was not possible to check the accuracy of the content. All the comments mimicked were negative, and the teen usually felt that the adults' efforts did not meet their need. The teens' "games" of one-upmanship, manipulations, and coercion were common. The adults in these vignettes came across as insincere, bullying, "know-it-alls", and the most frequent sentiment was "stupid".

One teen recalled an incident where several frustrated family members were discussing her case:

Oh, she's such a smart girl, you'd think she'd know better. Why doesn't she just eat? She could be so many things, why is she doing this? Some of them could be brave enough to talk to me and some other ones I could hear them, like they think because I was skinny, I was deaf.

As if this was not bad enough, in her estimation, her father would

give this following response:

My dad would repeat what the doctors would say. They say this or they say that; she's very angry or whatever, but my mom would say more or less that she wasn't sure why am doing this and say she's just really upset.

Needless to say, she preferred her mother's response as her father thought "he knew it all". "This is why she's doing this and if we work on this then she'll get better. And I'd have to show him it was not so!" Her tone conveyed disgust, dislike, asperity, and great use of mimicry, with of course relish with regards to showing him his 'error'.

One other individual recalled being rewarded consistently for losing weight and was monitored at meals towards this end. Questions such as: "Are you sure you're still hungry?" were frequent. If the response was yes, her mother's response would be "maybe you should wait 20 minutes; it takes 20 minutes for it to click into your head that you're full". This relation was laced with sarcasm, ridicule, and heavy emphasis on mimicry.

The data appeared at times to have an "outlier", that is, an individual whose perceptions, beliefs, feelings, and opinions seemed to be far different from the others in the sample. This individual was one of the members of the severe group. She met the criteria for inclusion in that group. There was however an age gap, even though length of illness was on average with the other participants, and comorbidity

factors such as a personality disorder were present.

The data just shared from the interviews will now be discussed on its own merit and as it resembles or differs from existing theories.

CHAPTER FIVE

DISCUSSION

*"When I was a boy of 14, my father
was so ignorant I could hardly stand to have
the old man around.
But when I got to be 21, I was astonished
at how much he had learnt in 7 years".
(Mark Twain, 1835-1910)*

Adolescence extends from the beginning of sexual maturity to the achievement of independent adult status. In Leo Tolstoy's *Anna Karenina*, the teenage years were "that blissful time when childhood is just coming to an end, and out of that vast circle, happy and gay, a path takes shape". In her diary, written as a teenager, Anne Frank observed that:

My treatment varies so much. One day Anne is so sensible and is allowed to know everything; and the next day I hear that Anne is just a silly little goat who doesn't know anything at all. Oh, so many things bubble up inside me as I lie in bed, having to put up with people I'm fed up with, who always misinterpret my intentions.

The sentiments expressed by Anne Frank were frequently echoed by the teens in this study, misinterpretation of intentions being the prime one. It has been said that certain established patterns of relating, behaving, and how the world is experienced may make one vulnerable to the illness AN.

This chapter will further discuss the findings related to

vulnerability, stressors and comparison with associated theories, and coping strategies utilized. The chapter will conclude with a schematic representation of the teens' experience of the illness AN. Vulnerability, defined by the researcher as the capacity of the teens for being hurt or damaged due to perceived anxiety, strain, tension, and burden will now be reviewed.

VULNERABILITY

The participants in this study shared their personal experiences, thoughts, feelings, and reasons for their behaviours as they apply to AN. As teenagers struggling to accomplish the developmental tasks of adolescence, living with this devastating illness can only be immensely difficult.

Signs and Symptoms

Reported first signs included great weight loss, irritability, insomnia, restlessness, dizziness, amenorrhoea or cessation of menses, weakness, and "pale colour". This is consistent with the literature. In all of the cases, the parents became alarmed at the rate of weight loss. Even though some parents encouraged this weight loss, it still came as a surprise when they saw their teens' bony frames. Mothers were in attendance for the assessment/diagnosis in all cases, fathers less often. This also cemented in the teenagers' minds, that since the fathers were

not present, they did not care enough to be.

Three of these initial assessment/diagnoses were done by mothers' therapists. Substance usage and depression in parents of individuals with AN are also consistent with the literature. These mothers required therapy for various reasons which included: divorce counselling, substance usage, and depression. These three comprised the moderate group. In speculating, was it possible that these mothers were more attuned to their daughters' needs and/or moods owing to the fact that they were receiving psychotherapy at the time and may have therefore offered some form of assistance?

All of the teens eventually saw pediatricians. The rate at which pediatricians referred these teens to psychiatrists varied, with some providing some form of therapy in the interim. It is of note, that three of the four teens who received therapy from paediatricians in the interim, were assigned to the severe group. This might very well point to the resistance by the young women who had decided from the outset that they would not allow themselves "to be cured by a paediatrician who would not listen to [their] issues", but would state "you have to eat". The paediatricians would at times refer the teens to dietitians whom the women stated "would hand [them] a copy of Canada's Food Guide and say 'follow this'. The teens felt that because they were ill,

they "needed to see a shrink" who would discuss their concerns with them.

All diagnoses were made by the initial health care professional seen. The participants all knew they were ill before being seen by a health care professional. Five (this included 3 from the severe group) already knew what AN was and had already self-diagnosed. They reported that they either chuckled or smiled when the official diagnosis was made amidst horrified parental sighs, groans, and indrawn breaths. For all the participants, the word "bingo" was silently yelled as phase one of their attempt to get their needs met was realized. Perhaps they felt that probably their friends and parents would now be more attentive to their needs.

General Understanding of AN

In collating the responses from the seven participants, the following is a summarized version of their definition of AN.

An illness symptomatic of several issues, problems, and struggles in life [and as such] it's really how one copes. The not wanting to eat, and looking skeletal are direct results of a diseased mind. Fear, confusion, anger, and not wanting to eat all combine to make the illness as serious as it is.

Research shows that the goal of AN individuals is usually to lose weight. Various reasons have been put forth, for example, in response to their distorted view of themselves, or in reaction to society's stance

that slim is the ideal. Several individuals studied however, stated that initially, AN was a method of looking good, but later it changed to become self-destructive, a way to hurt themselves, as they perceived themselves being hurt by others. They were highly distressed when people told them that they "looked good". It would have been appreciated at the time "when it was really them", that is pre-AN, but not now. They found it difficult to accept the remark because they considered themselves "unhealthy" and "sick" because of "what they had to do" to remain that way. They also thought that the individuals making the comments were themselves sick because a certain level of concern was expected when people, and not just people, but children, are so ill they want to hurt themselves to be accepted, not to be ignored, and to be appreciated. This in and of itself angered them immensely.

This did not improve matters because some parents apparently encouraged the weight loss and the teens were not only bitterly resentful, but angry as well because "it's a kinda crummy feeling when you try to hurt yourself and people encourage it thinking it's really good". As one teen pointed out, "I'm thinking to myself, you guys dumb or something, like the only way that I'm loved is if I am sick!" This was most concerning because if the self-destruction, the attempt to hurt themselves by starving, was to signal the parents to be more attentive,

to be more aware of their children's needs, but then instead they were being rewarded and encouraged, were the parents then sanctioning "no body", the disappearance of the body and their teens? That was the message the teens received.

This would certainly add credence to the perception that the parents did not care. The underlying theme of lack of attention is now taken to another level. That is, lack of attention is equated with lack of caring and lack of love, because how could caring parents allow their children to hurt themselves?

Adolescents with AN have a fairly uniform pattern of typical concerns. The most striking is the constant preoccupation with food and weight, and the fear of loss of control over eating. Some develop obsessive-compulsive behaviours like checking their weight every morning at 8 o'clock, or exercising at every opportunity.

Their harsh, negative, distorted views of their bodies cause them to focus constantly on the need for weight control. This over-concern with physical appearance usually masks a generalized low self-esteem, and a tendency towards self-deprecating thoughts. Other typical patterns include difficulties with separation-individuation, sexuality, self-control, and intimacy.

Related theories and stressors will be examined next.

STRESSORS

To G. Stanley Hall (1904), the first American psychologist to describe it, adolescence was, as it was for Anne Frank, a period of "storm and stress", of emotional turbulence caused by the tension between biological maturity and enforced dependence. Adolescence is a period in which the social approval of peers is imperative; when pressures for achievement are nerve-racking; when the sense of one's direction in life is in flux; and when the alienation from one's parents is deepest.

Other psychologists have noted that for many, adolescence is much as Tolstoy described it, a time of vitality without the cares of adulthood, a time of congenial family relationships punctuated by only occasional tensions, a time of rewarding friendships, a time of heightened idealism, and a growing sense of life's exciting possibilities (Coleman, 1980).

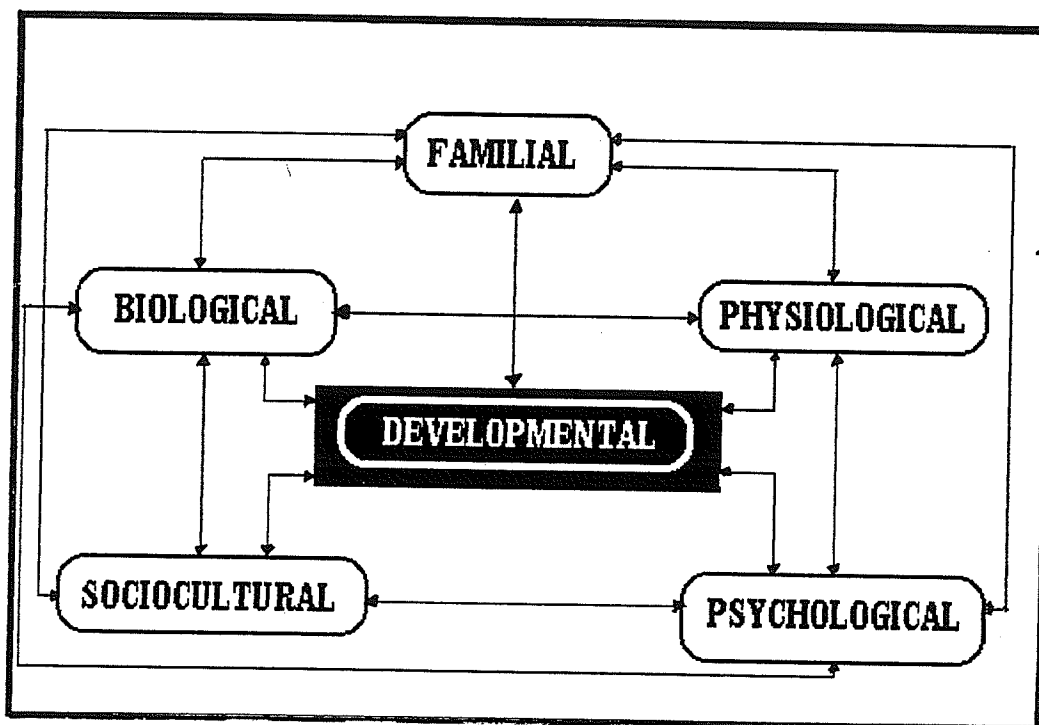
With such conflicting observations, what can one say adolescence is like?

The major developmental tasks during later adolescence are: achieving ego identity, gaining greater independence, forming heterosexual relationships, and displaying interest in both the future and career planning. Peer group allegiance is manifested by clothing, food, and other fads, preferred music, and common jargon. Experimentation with adult-like behaviour and risk taking in an

attempt to prove themselves to peers is common. Sexual experimentation often begins as a result of social exploration and physical maturation. Changes in cognitive functioning may first be evident in that the person moves to more abstract thinking, returning to more concrete operations in times of stress.

The literature suggests a multi-factor model may be needed to address the complexity of AN. A proposed model is presented below.

Figure 4. Multi-feedback system depicting possible causative factors of the illness Anorexia Nervosa



The schematic presentation above, was developed by the writer as a concise way of expressing the complexities and interrelatedness of the risk factors that may contribute to the illness, AN. Each of the following factors: socio- cultural, biological, physiological, psychological, developmental, and familial are closely intertwined and contribute to the retardation or acceleration of the recovery of the AN patient.

These factors are illustrated in Figure 4, as an interconnected multi-feedback system with arrows leading to and from the developmental block. Each of the outer blocks is equally weighed and of equal importance as shown by the symmetry of the diagram. The developmental block on the other hand, is centrally placed due to the great impact which it has on the patient in terms of recovery, as this may influence development positively or negatively which in turn may impact the outer block system positively or negatively. The outer box is representative of the patient and is therefore represented in bolder lines.

The proposed framework captured in Figure 4 above, depicted biological, physiological, socio-cultural, psychological, developmental and familial issues as possible root causes of AN. Biological and physiological issues have been dealt with above and will, to a lesser degree below. The other possible root causes will be examined below.

SOCIO-CULTURAL IMPACT

The participants chose careers like veterinarian science and astronautical studies. The researcher theorized based on the information given that these careers were chosen in order to allow the teens to create their own worlds; worlds over which they will be able to exercise more control. Occupation as a vet will almost entirely remove the human factor as the major area of concentration, and instead focus on the animal; an entity over which more control may be exerted.

A career as an astronaut was chosen by a member of the severe group; the individual who appeared, for much of the groupings, to be an "outlier". That is, the participant who expressed different thoughts, feelings, perceptions, and beliefs from any other member of the sample. Closer examination resulted in this interpretation by the researcher. Being "off in space", created a familiar and revealing picture. This would at best allow for: i) *orbiting* the earth and would satisfy the need for constant motion and to an extent, precluded the desire for self-evaluation and assessment of pertinent issues; ii) *free fall*, translated to be freedom from internal and external pressures and freedom from sovereignty laws, that is parental ownership, to ownership of self; iii) *weightlessness* which would remove the source of conflict as well as rituals and preoccupations, creating buoyancy; iv) *enrichment* of scientific

knowledge, the academic, the area in which maximum comfort existed; and ultimately v) *observation* of objects from above without the interference and distorting effects of "parental earth's and personal atmosphere" which would eventually stimulate development of insight.

Peer Group Issues. Even though the participants were members of one of the four groups where they had friends as foes, tormentors, true friends, and competitors, presented earlier, they still felt isolated, and lonely because for the most part, they felt that they were ostracized not only by the group's other members, but their peers in general. They also felt that they were unable to fit in, and were made to feel as if they did not belong. Initially, they did not wish to be critiqued on their behaviours, and therefore did not participate in any form of group activities when the opportunity presented itself. In the end however, due to the draining and consuming nature of their preoccupations and rituals, they did not have the stamina and therefore did not think that group activities were important enough to want to participate. Furthermore, they did not have the inclination to do so as they found that they were withdrawing more and more.

According to Coleman (1980), the peer group influences the adolescent to a greater extent than parents, mass media, teachers, popular heroes, or other adults. Social relationships take precedence

over family and counteract feelings of emptiness, isolation, and loneliness. Peer groups provide a sense of acceptance, prestige, belonging, approval, and opportunities for learning how to behave.

The teens' experiences of groups was a negative one. It seemed as if all their peers were active participating members of groups. Why did they feel as if they did not belong? Why, they wondered, did no one make the effort to include them in parties, for example? This was taken to mean that no one cared. For all intents and purposes they felt that they did not exist as being important to others..

Even though peer group relations can be theoretically beneficial, the pressure to conform and gain approval may also lead to antisocial behaviour. Participation in delinquent acts may be forced, but provides the adolescent with the opportunity to: a) prove self, b) vent aggression, or c) to gain superiority over members of the group. In this study, this seemed the path they might take to gain approval, acceptance, to be acknowledged that they exist.

One teen who was a member of a group whose leaders always "put [her] down", related that the "leaders" often boasted about their other "cool friends" and parties they attended. She decided that losing weight might be a sure way to get some attention. She managed to capture the feelings thus:

They always bullied me, but I stayed in the group because I didn't have the determination to work that hard to get into another group. At the time they were competing with each other, dieting and who could lose more weight, so I thought, well they are dieting now and I can't do anything else, so I'll diet and I'll show them that I am good at this.

She managed to prove herself, vent aggression, and gain superiority over some in the group; all by being the individual with the greatest weight-loss. She reported "they started being a little bit more nice to me. I think they were sorry for me." Albeit, temporarily, because as she lost more weight, they paid her even less attention and interaction dwindled to nothing.

Theoretically, the peer group helps the adolescent define personal identity as she adapts to a changing body image, more mature relationships with others, and heightened sexual feelings. As a variety of new behaviours are tried within the safety of the group, new ideas are incorporated into the body image and self concept. Since the seven teens interviewed were rejected by their peers, the ability to gain a high degree of social skills, and form relationships necessary for the adult culture was adversely affected. This is consistent with the literature.

Statements about being too shy, or boring, not able to form conversation, or an inability to go up and speak to people were frequently expressed. Several of the girls remarked that being smart meant nothing if they were unable to have and maintain a group of

friends.

Leisure Activities. "Everybody's doing it" is seemingly a strong influence on the adolescent's interests and activities. Leisure activities such as sports, dancing, reading, listening to the radio or stereo, talking on the telephone, daydreaming, experimenting with hairstyles, cosmetics, and new clothes, or just loafing or "hanging out" are favourites of the typical teen.

The participants were not members of a group of friends, but instead saw their mothers as their closest friend. They were not the typical teen and did not gain the skills necessary for some of the activities favoured by other teens, like applying cosmetics, "hanging out", and experimenting with hairstyles. They frequently bemoaned the fact that if they were adept at these things, they might be able to enhance their looks, be more comfortable around boys, and gain the expertise in shopping for themselves by shopping with their peers instead of their mothers.

The three oldest participants stated that dancing was their number one leisure activity. They however, enjoyed dancing in public only if attired in costumes. Could this mean that they were becoming more comfortable with their bodies? And had they come to the realization that they could also derive pleasure from their bodies? Talking on the

telephone, an all time favourite, was not a leisure activity for any of the teens because it was their experience that teens who talk with each other via telephone talk about the same things (clothes, boys, dating), and that it "was boring and they did not have enough to talk about anyway". One must also take into consideration that they had no experience in these areas, so may have had little or nothing to contribute, hence devalued conversations of which they could not be a part.

Theoretically, leisure time with the peer group is important for normal social development. More time is spent away from home, either in school, other activities, or with peers as greater independence is successfully achieved. School is a social centre which not only provides the opportunity for abstract learning, but also provides recognition from others which leads to a determination of group status based on success in the teens' cases, in scholastic activities.

The findings from the socio-cultural context pertaining to this study are: a) the teens experienced groups negatively and were 'members' of groups of friends who were perceived to be true friends (rare), foes, tormentors, and competitors; b) illness levels were positively correlated to relationship. That is, the more severe the illness, the more distant the friendship; [Refer to Figure 5] in previous chapter c) dancing was

the favourite leisure activity especially for the older teens signifying perhaps that they were becoming more comfortable with their bodies, and the realization that the body can also give pleasure; d) that their mothers are their best friends and confidantes; and e) the idea that "no one cared", and the feeling that they did not exist led them to diet and show themselves that they are not worthless, but in fact can be good at something other than academics.

PSYCHOLOGICAL/DEVELOPMENTAL IMPACT

Keniston (1975) describes cognitive development of adolescence as proceeding through a complex transition of dualism, such as a simple understanding of right and wrong and either-or of an issue, to an awareness of multiplicity, a realization of relativism, and a more existential sense of truth. This stage involves being very aware of inner processes, focusing on states of consciousness as something to be controlled and altered, and thinking about the ideal self and society.

Self-concept and Body Image. The development of self-concept and body image is theoretically closely akin to cognitive organization of experiences and identity formation. The adolescent cannot be looked at only in the context of the present; earlier experiences have an impact which continue to affect. Many of the mothers of the participants were described as being petite, small, and slim, and therefore perceived, by

their daughters, to be in direct contrast to the teens' statures and frames. In combination with enforced reduced servings, rewards for losing weight, and "chubby jokes", few of their earlier experiences were helpful. The teens rarely felt good about their bodies and themselves, therefore negative feelings about the self and the body prevailed.

Other factors contributed to the formation of self-image, and subsequent perception of body and self. Factors such as: a) degree of attractiveness - they all thought they ranged in looks from ugly to average; b) size - 6 (3 from each group) thought they were "really fat" and needed to lose at least 10% of their current weights; c) physique appropriate to gender - several mothers described them as large or big-boned, therefore they perceived themselves as not being feminine d) degree of identification with the same-sex parent - all felt that mothers understood and were supportive, and e) level of aspiration and ability to reach ideals - all of the teens desired education beyond high school with a professional focus ranging from veterinarian to astronaut. This contrasted sharply with their mothers who were predominantly housewives (5 out of 7).

The body is part of one's inner and outer world and many of the inner world experiences are based on stimuli from the external world. Physical changes in height, weight, and body build cause a change in

self-perception, as well as how the body is used. The body then acts as a source of acceptance or rejection by others. Since the teens felt that they had not gained much acceptance from neither parents nor peers, an attempt was made to compensate for real or imagined defects via academic success in order to enhance prestige, and most importantly, weight loss, so as to not be ignored.

The achievement of the ideal body, (so demanded by the society and the culture) was the ultimate goal, and self-devaluing resulted since the body was experienced as defective, inferior, or incapable. Since the adolescents feared rejection and were over-sensitive to the opinions of others, they retained and later reflected upon these impressions. Thus they developed a negative self-image, and motivation, behaviour, and then eventual life style were also incompatible with social expectations.

This resulted in low self-esteem, and unstable self-concept. The teens felt dependent and believed they were so unique that no one had ever experienced what they felt? They still believed that everyone was watching or being critical of their physical or personality characteristics. This is consistent with current research.

Reports that people were watching and commenting that "look, that girl has anorexia and see how much weight she has gained since last week" were common. Of course, no consideration was given to the fact

that these strangers knew not who they were and never saw them before. One teen reported that a sibling might also be developing an eating disorder. This not only created the sense of urgency that she had to do something about it, but produced the fear, that she did not want her to have an eating disorder because "I want it to be mine. Like I don't want to share it with her". Egocentricity has remained fixed.

Emotional Development. Emotional characteristics of the personality cannot be separated from family, physical, intellectual, and social development. Emotionally, the adolescent is characterized by mood swings and extremes of behaviour. Emotional development requires an interweaving and organization of opposing tendencies into a sense of unity and continuity with an end result of psychological maturity.

In this study, a number of issues may have interfered with identity formation:

1. Telescoping of generations - with many adult privileges (example: being a party to the discussion of sexual difficulties between the parents) are granted early so that the differences between adult and child are obscured
2. Rapid changes in the adolescent subculture and all society with emphasis on conforming to peers

The developmental crisis of adolescence is identity formation versus identity diffusion. Identity means, the individual feels he is a specific unique person, emerging into adulthood. Identity formation results through synthesis of biopsychosocial characteristics from sources like earlier gender identity, parents, friends, social class, ethnic, occupational and religious groups (Erikson, 1963).

Identity formation is enhanced by having support not only from parents, but also from another adult who has a stable identity and who upholds sociocultural and moral standards of behaviour (Murray & Zentner, 1985). Since the teens believed they received support only from their mothers and that adults in general were untrustworthy, dishonest, and frequently made promises that they were unable to keep, the opportunity for identity formation was diminished.

Since the previously mentioned developmental crisis had not been successfully negotiated, then a discomfort with personal identity existed.

Statements such as:

I don't know what I am, I don't know who I am anymore, I don't know what my personality is. I can't tell it seems like I can't find myself. It's just like now ... I've discovered myself and didn't know myself then and I know myself now. I'm starting to get an idea of who I am and not really because for so long I associated my identity with a body, if I kinda lose my eating disorder, I feel like I'm losing my identity.

demonstrated the difficulty with identity formation and personal

identity. The values, beliefs, and guidelines given were internalized. Parents were now needed much more for support and direction as the teens now experienced difficulty with decisions regarding what is considered acceptable and unacceptable behaviour.

Theoretically, identity formation implies an internal stability, sameness or continuity, which resists extreme change and preserves itself from oblivion in the face of stress or contradictions. It implies emergence from this era with a sense of wholeness, knowing the self is a unique person, feeling responsibility, loyalty and commitment to a value system. The three types of identity are closely interwoven.

1. Personal identity - what the person believes the self to be.
2. Ideal Identity - what the person would like to be.
3. Claimed Identity - what the person wants others to think he is.

Identity diffusion resulted, since the adolescents failed to achieve a sense of identity. Feelings of self-consciousness and doubts and confusion about self as a human being and life's roles prevailed. Impotence, insecurity, disillusionment, alienation, inability to initiate action, and vacillation in decision-making predominated. Behaviour at school, with peers, and in sexual contacts was distorted.

The real danger of identity diffusion looms when a teen finds a negative solution to the quest for identity. She gives up, feels defeated,

and pursues antisocial behaviour, since "it's better to be bad than nobody at all". This was reflected in the reasons for the great desire to maintain their illness.

I just felt like nothing. Like I wasn't anybody except an anorexic, that's it. If I can say nothing else, I can say I have an eating disorder. That's who I am.

If I got better then I'd be nobody. Then I wouldn't even have anorexia. Then what would I be? Then I'd be fat and ugly and I wouldn't be anyone.

I feel like I wanna get rid of it [AN], but in other ways don't, because I feel it makes me unique and special. Cos it would be worse than a nightmare for me to be average. I mean I can't be and I don't wanna be average [said with distaste].

Identity diffusion was more likely to occur since the teens had close contact with an adult who was probably still confused about his/her own personal identity and who it appeared was in rebellion against society.

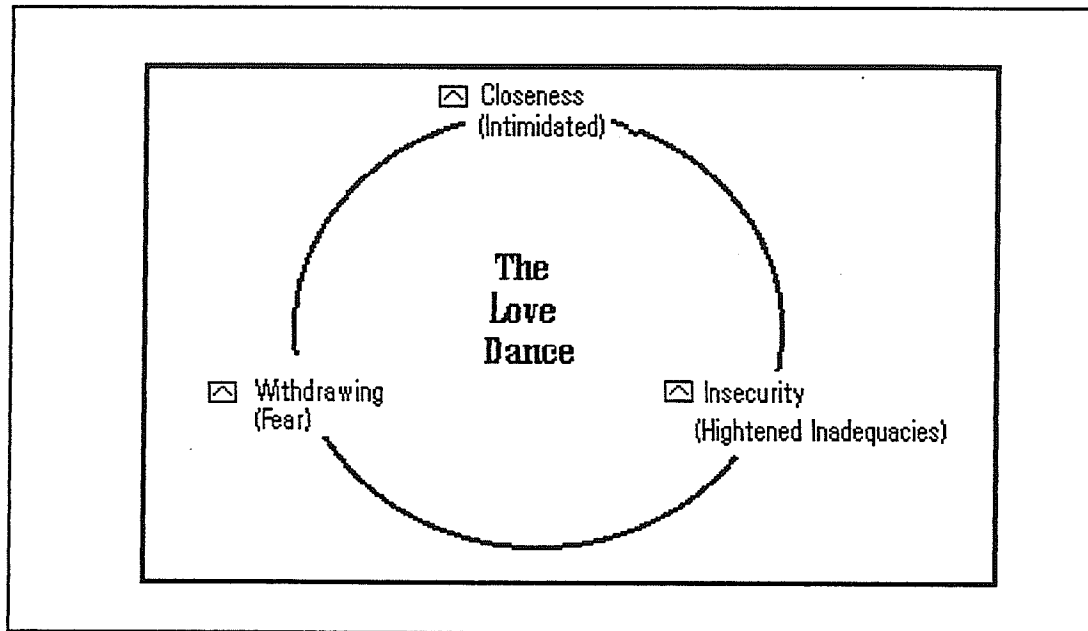
Sexuality Issues. When dating begins, the emphasis is first on commonly shared activities. Later the emphasis shifts to groups of couples, then double dates, and finally single couples. With each step, the goal is to learn more about, and become more comfortable with the opposite sex, as well as acceptance of self.

Only two (from the moderate group) of the teens had ever had

boyfriends or been out on dates. Another four dearly wished for these experiences and fantasized about their behaviours on dates, but were apprehensive about and avoided, what they perceived to be, adult behaviour, fearing loss of uniqueness, and the pain of being harmed physically and emotionally by entering adulthood. This was seen as a direct result of being told too many graphic intimate details about their parents' sexual relationships at an early age. As this was mostly negative and painful and not placed in proper context, the teens were terrified of intimacy and all it entailed. The literature frequently referred to this fear of intimacy, but the reasons cited above have never been provided.

The dating teens typically did a love dance [Figure 5]. That is, after several months of dating, emotional closeness usually gave rise to the desire for physical closeness by the boyfriends. This was extremely intimidating for the teens as emotional closeness translated to mean being "hurt" physically and emotionally and increased the risk of "being two-timed". This was their perception as some parents used affairs to cope with familial stress. This has impacted formation of trusting relationships. Physical closeness meant that boyfriends would now be able to see their bodies which heightened their sense of inadequacy and increased their level of insecurity.

Figure 5. The Love Dance



This insecurity led to withdrawing as a method of coping to avoid being hurt and avoid the sharing of the information that they had an eating disorder. The fear that the boyfriends would not only see their less than perfect bodies, but would know that their weight was "not natural", increased the rate of withdrawal. They would from hence forth be only friends and nothing more. This cycle repeated itself with each new relationship and continued until the teens were comfortable with their bodies and a positive self-image gained.

Sexuality, in its broadest sense of the theory, includes a search for

identity as a whole person; role behaviour of men and women; attitudes, behaviours, and feelings towards self and each gender; relationships, affection, and caring between people; the need to touch and be touched; and recognition and acceptance of self and others as sexual beings (Tauer, 1983). One of the greatest, almost constant preoccupations, of the adolescent is sexual feelings and activities due mainly because of environmental, physiological, and hormonal influences.

Findings of this study pertaining to the psychological/developmental impact were: a) that telescoping of generations has occurred, with the teens being privy to information regarding parental sexual difficulties - same not placed in proper context. This has resulted in the teens being terrified of intimacy and all it entails. To off-set this, they hope, they engaged in what the researcher terms "the love dance". Since physical and emotional closeness are avoided at all costs until such a time when they are satisfied with their bodies, this dance and its changing partners may be perpetual; b) egocentricity has remained fixed; and c) AN defines them in their perception that they are nothing but good anorexics.

FAMILIAL CONCERNS

Communication difficulties was the most frequently occurring problem identified by the teens.

Communication Issues. Family communications must aid the process of problem solving rather than hinder. The problem therefore was that the communications that did occur, for a variety of reasons, did not result in problem solving. On the content level, verbalizations did not convey a clear understanding of what the teens meant to say, especially if confounded by dissonant body language.

Tone of voice, sarcasm, and mimicry may have accentuated difficulties by conveying heavy affect or great insistence on the rightness of what the teen was saying and the necessity for all others to agree. The teenagers were frequently interrupted by others, usually their fathers, before they were finished. They were responded to with a change of topic as though they were not heard. It was the perception that their points of view was never aired, much less heard and taken into account. Consequently topics were not pursued because they were not understood, differing points of view were not adequately discussed, and plans were not made because disagreements were not resolved. The family then remained stuck in its dysfunctional state.

Given such a state of affairs, family relationships deteriorated. The teens consistently reported that they felt disrespected (emphasized), misunderstood, and alone. The majority of teens responded by further withdrawal or greater insistence, or heavier affect in an effort to be

respected, but instead succeeded in escalating the unproductive cycle. Distance between family members increased, and control issues and power struggles ensued. Caring and investment in relationships decreased. Frequently, sentiments such as "no one cares", "what's the use?", "why bother?" were voiced. The need for new patterns of communication thus became evident.

Theoretically, the overall family goal at this time is to allow the adolescent increasing freedom and responsibility to prepare her for young adulthood. Although each family member has individual developmental tasks, the family unit as a whole also has developmental tasks. These include: provision for individual differences and needs of family members; establishment of shared responsibilities; strengthening of communication skills; and formulation of a workable philosophy of life as a family (Janzen & Harris, 1986)

Family Structure. According to Janzen and Harris (1986) communications contribute to the shaping of family structure, and family structure in turn serves to shape the patterns of communications. Other problem aspects of structure identified by the teens will now be examined.

Changeability. Family structure should not be so rigid that it prohibits variability and change. The converse should also hold true.

However, the teens did not find the structure of their families sufficiently stable to provide for dependability and predictability nor to give adequate guidelines by which they could be clear about expected roles and behaviours. For the family to function properly in whole and in part, subsystem boundaries, roles for individuals, and rules of the system need to be clearly defined without being permanently fixed, and subject to change as the needs and demands of individual members and the family as a whole change. These families typically did not achieve clarity about boundaries, roles, and rules in the interest of stability therefore the central task of allowing the family to change as needed was not accomplished. This is consistent with the literature.

Hierarchy and Subsystems. Family systems and individuals function best when the parents provide leadership, direction, and rules of behaviour for the children. Consider this situation in which the parents were constantly fighting over the lack of consistent treatment practices of their teen's illness whenever they were together. The father would exchange unpleasant greetings with the mother, which signalled distress and the teen would intervene by misbehaving. Apparently having learnt from the mother that yelling was a method of being heard, the teen would join her mother "and yell at him because I always take her side, no matter what" (the concept of triangulation). This was

a form of inappropriate parental subsystem interference. This would claim the parents' attention and prevent them from having to deal with each other, and all would be protected from the open conflict of the parents. This sequence of events was structured within the family's transactional patterns and most likely would only change if the basic structure of the family was changed by the initiation of alternative patterns of interaction.

Similarly, it is sometimes necessary to protect the subsystem of children from unneeded involvement of parents. This was evidenced by repeated parental intervention in disagreements between children and making decisions for them regarding the issues involved. The parents' intrusion was a violation of the protection of the subsystem boundary which should prevent interference from outside of the system.

Intervening therefore, did not allow the teens the opportunity to learn how to negotiate and settle disagreements within the sibling subsystem.

Rules. Family transactions are also governed by a set of covert rules within the family structure (Nichols, 1984). The manifestation of these rules was observed in various ways depending on the family members involved and the context in which it occurred. One teen pointed out that "there was a little set of rules" in her family and members "just knew exactly what to do and what not to do to get what we wanted cos

I'm not used to getting what I want through healthy ways". Even though the rules were restrictive, they were at least predictable, and as such provided some security.

Such rules focused on the dependence of family members upon each other or the joining of members to protect each other. One teen described it this way:

With my mom he would always be crabby when he came home and just all stressed out and yelling at us and snapping, and she would kinda keep him in line. She would just say, 'you're being like a loser, look what you are doing. [name] you're getting out of control' We'd just team up on him so he had to act differently, like not take it out on us, you know.

Boundaries. The balance between separateness and connectedness among family members is important as the family carries out its various functions. Boundaries surround not only the subsystems, but also the individuals as well, and serve to regulate the distance between both individuals and subsystems.

Boundary difficulties were seen when distance between individual family members was not properly regulated by boundary protection. This most often took the form of extreme closeness or extreme distance in interpersonal relating among members. These extremes of boundary functioning are identified as enmeshment and disengagement.

A state of disengagement enveloped the family systems as a whole of all the girls in the moderate group and one from the severe group.

Activities were so individualized among them that they each developed a microcosm of their own. This made for decreased communication within the family and increased contact with others outside the family circle, resulting in members being so separated from each other that boundaries became overly distinct. Since there was a decreased sense of belonging shared by those involved, the teens attempted to act independently, but because of the enmeshment with mom, and the facilitation of immaturity, they were unable to act independently. With this loss of autonomy the teens lacked the ability to be able to explore, take chances, and solve problems that would normally fall within their range of activity and hence experienced great difficulty adjusting to change under stressful circumstances. Individual subsystem boundaries will need to be strengthened in order to restore autonomy.

Enmeshment. As pointed out earlier, Minuchin (1974) emphasised the necessity of clear subsystem boundaries for proper family functioning. Maintaining a clear boundary presumes a state of permeability which allows members of a subsystem to have contact with others, allowing members to perform necessary functions without interference from others.

Frequently, in the mother-daughter relationships [fathers typically "did not know that (we) existed"] movement across boundaries was not

allowed, closeness in relating within the subsystem became central and enmeshment followed. All teens named their mothers as chief confidante. Two cited difficulties with roles in regards to their mothers' inappropriate disclosures. Comments such as:

We were just always closer, it's just that we don't have a normal mother/daughter relationship. She treats me more like a peer, an equal. I don't know what my role is. It's hard to respect somebody as a parent when you are all of a sudden their equal...Your kid doesn't need to know about your sex life and stuff like that especially when I was younger. She'd tell me way too heavy problems and issues and I ended up being her support system, her counsellor, an adult and I was a kid... our relationship is screwed up.

Also, consider the mother and daughter who over time have turned to each other for emotional support and understanding, have gradually shut out the father and label him as an outsider. All teens stated that they could never talk to their fathers about anything, but found it easy to speak with their mothers. One teen recalled that her talks with her mother usually denigrated father's character by "cutting him down". This made her feel worse because they were talking behind his back and "he's kinda good person and we're always talking bad about him". Guilt was the prime emotion because he was "ganged upon", treated like an "outcast" and since no one cared about him much, he "must be lonely with no one to talk to".

The boundary between mother and daughter therefore, became

diffuse with no clear separation of roles and identities and a loss of the ability to act individually. They became more and more dependent upon each other and increasingly unable to communicate across the boundary that surrounded them. This developed into an enmeshed state and also represented an intergenerational boundary violation, as both mother and daughter were locked in a common boundary. The presence of disengagement or enmeshment indicated difficulty in the way in which family members perform tasks and carry out responsibilities. This was also consistent with the literature.

Separation/Individuation. Inflexibility on the part of the parents was reflected in their difficulty to rethink their position and adjust their objective for the teens. Frequently, the teens themselves were the perpetrators, as one individual pointed out that she wanted to be "little again" to force her parents "to look after and look out" for her, to "pay her some attention". A wholesome balance, an important factor in the separation process was not attained. Change can only occur when the family understands how it functions in relation to promoting appropriate autonomy for its members.

The separation/individuation process occurs gradually. When the infant crawls away from mother to explore new territory she provides the first test of how distance is to be regulated among family members.

There has to be a willingness to allow children to separate and explore the world around them. The regulation of emotional closeness and distance among family members surfaced in a more observable manner because during mid to late adolescence confrontation is likely around conflicting issues (Nichols, 1985).

Elements of family structure are observable in the communication processes of the family. Who speaks to whom; who listens to whom; whose ideas are adopted; who is put down, shut out, or ignored; and who seldom or never speaks, are all aspects of communications that tell of role, status, power, control, affection, and distance regulation in relationships (Janzen & Harris, 1986).

This researcher's findings were: a) frequent interruptions by fathers, fathers' tone of voice, and teens' mimicry confounded communication which led to a lack of problem-solving. This process resulted in decreased caring and investment, and the impression that they were not respected; b) the teens always "took [their mothers'] side" in the event of an argument between parents, a show of force against fathers who are viewed as cold, hard and uncaring; and c) families of all the members of the severe group and one member of the moderate group were disengaged. Is there a link between illness severity and familial boundaries? The teens claimed that they starved themselves for two

reasons: i) to get the attention that they deserved, and ii) to become child-like and "small" so that they could be cuddled, loved, and cared for. Is the link then, that families that are disengaged engender greater, more serious efforts to bring them together? The young women admitted this was so, and expressed mixed feelings that the illness has brought the family together, but that it appeared as if they had to remain ill to reap the well-deserved benefit because they went as far as harming themselves to get it.

AN, for many, was utilized as a coping mechanism as stated by the teens, a method of surviving. Other methods of management were incorporated in what some saw as a way of "handling things"; that is, their lives.

SURVIVAL TECHNIQUES

It would appear that the moderates in this study group were even more severe than the severest in the tool validity study. Age of the participants might be one of the factors since the tool study group used an adult population. This current study consisted of only adolescents who, comparatively, may have had the illness for a much shorter period and hence possibly less exposure to, and engagement in, therapy. Or is it possible that the participants in this study experienced and displayed more severe symptoms due to the seriousness of the illness? Or have

they not yet learnt the necessary and appropriate coping skills?

All adaptive mechanisms permit one to develop a self, an identity, and to defend the self-image against attack. These mechanisms are only harmful when one pattern is used to the exclusion of others for handling many different situations. Such behaviour is defensive rather than adaptive and distorts reality. Adaptive abilities are strongly influenced by inner resources built up through the years of parental love and guidance. The following were the most frequently used methods of coping. The researcher attempted to capture the mood and the tone of the emotions displayed, hence the terms chosen.

Shrinking. This was a technique that was utilized effectively "to gain attention". The initial goal of some of these teens was to lose weight so that they would be able to wear some of the clothing they wore as prepubescents. Subconsciously they wanted to be "younger or little again" (shrinking). Then they would not have to worry about making friends, and fitting in because it was a difficult task. It also eliminated the need to spend valuable yet unproductive hours wondering: how to dress, what to say, and how others perceived them.

The plan was to get skinny, "almost like a little girl" and just be totally consumed (shrink) by AN, then those thoughts would be inconsequential. They stressed "wanting to be taken care of", "to be

listened to", "to be included" as the ultimate goals. "Maybe if I got really, really, skinny they'd pay more attention to me". This included peers and family, especially parents. When the goal was achieved the sentiment was "it felt kinda neat, all the attention and fuss". This, to them, demonstrated love and caring.

Numbing (a feeling of being numb). Sentiments such as AN "eased" their pain, "helped their depression" because initially, they were "numb to an extent", they were "kinda numb to feelings", "wouldn't feel anything" were numerous. They created their own world, a microcosm, where they were able to think about "food and this and that", a world over which they had some control; a world in which they felt effective, "powerful", and strong.

In their world they acknowledged no emotion, but anger. All other feelings were suppressed, and infrequently feelings such as: fear, sadness, being scared and terrified, and "normal human feelings" were allowed through.

Mimicry. Mimicry, disdain, ridicule, and sarcasm, "acid tongue" was another method of coping. It was evident from relating their life stories that adults were not held in high regard. Adults were viewed as dishonest, untrustworthy, phoney, the all-powerful, know-it-alls who had to be shown that they did not really know much, and were stupid as

well.

Numerous stories were shared where the all-knowing adults were found to be wrong. The teens took great pleasure in not only pointing it out, but would ensure that it would never be forgotten. The rationale for the derision was that these uncaring adults, in age only, were all powerful, had all the control, and who had been on this earth for so long, were missing the basics.

As individuals who made the choice to become parents, they were obligated to provide unconditional love and acceptance, and provide the loving care and attention that their offspring needed. Their inner reasoning seemed to follow their logic. How can you call yourself parents without having mastered the basics? To make matters worse, these super-smart beings were not even equipped to handle the stress in their own lives without "taking it out on us" or cheating.

Why get married if cheating on your spouse is the quickest way in which to handle issues, issues that you created mind you, in your pathetic lives? How can you expect to be trusted? If you are so insensitive and out of touch with people's feelings, and refuse to take the time to find out, how can you be good parents? Clothes on our backs, a roof over our heads, food (gosh I can't stomach that) on the table, is just not enough.

We could probably survive without those, but if we accept that those are the basics, they are the basics that anyone can provide. Parents, your children need more than the physical, the emotional is by far the most important. Give us a little credit for what we know, trust us, acknowledge us, speak to us, care for us, love us. That's all we ask. Afterall we did not ask to be placed, that's how it appears, in this world.

Accepting. After years of attempting to change the way in which they were viewed, some of the teens reluctantly accepted the fact that they were unable to change their parents. It was a slow, painful, learning process. Verbalizations like the following were frequent.

I'm accepting things with my parents that are not gonna change, even though I got a raw deal. I used to think I got shafted so it's their duty to change, it's their duty to be better parents. So when I told them how they hurt me and stuff, I figured they would try harder, but no they won't and they don't. I have to accept that I can't control them and they will continue to be losers.

Accepting that their bodies were "going all crazy", "like the devil was let loose inside" them was also a hard won battle. Fears regarding slowed metabolic rate and subsequent weight gain or slower weight loss were striking. Questions like the reason for "going for 5 days without gaining a pound, but then gain 1 kilo in 2 days" for no apparent reason "because nothing was done differently" constantly plagued them. They have slowly come to accept that the bodies that they have tried so hard to create and their mechanisms, will go awry from time to time because

of years of "not treating [their bodies] right"; and that there's nothing that they can really do about it except take a wait and see approach, and hope for the best.

For those being tube-fed, they would "obsess" about the various methods by which they could burn off the calories that they had assisted the healthcare professionals to add on. This was the feeling because they felt that they obviously had not put up a good enough fight. When it became obvious that their goals would not be realized, they tried to persuade themselves to accept the additional calories. That is, accepting the additional calories without pre-planning and pre-plotting, and devising ways in which to lose these calories, might just be easier. This would be because they no longer would have the additional burden of punishing themselves, if they failed to accomplish their goals.

Anger. The I'll-show-you 'syndrome' predominated. For the most part, it was developed in order to prove to the people who mattered most, parents and peers, that the teens had "will power". The oppressive burden of: powerlessness, ineffectiveness, trying and failing, weakness, coping with perceived parental displaced anger and frustration, self-doubt, and inadequacy was an hourly challenge and served as a well-spring of bile, a bitter taste attesting to the fact that they were "worthless". "nothing". "nobody". Who was responsible for

making them feel this way? Their parents, the healthcare system, peers, strangers, just everybody who "looked down upon" them, and that meant "everyone". In an effort to redeem themselves, they donned the armour of "since I can't do anything else, I'll diet and I'll show them that I can be good at this, that I am worth something".

The urge to fight "sometimes just for the hell of it" and "be as devious" as they could "to piss people off" was almost overwhelming at times, as they wished not to be controlled, but to be able to control some elements of their existence. Since they did not wish to gain weight nor be tube-fed, if they put up a bit of a fight then they would feel better about themselves as they were not just "letting it happen", the guilt therefore would be much less. That is, the guilt associated with contributing to their unwanted weight gain.

Anger, the underlying emotion, was at times so intense that the teens expressed "hatred", and "feelings of almost passing out" and "exploding". The only feeling that was acknowledged was anger, as it ate at them like ferocious cannibals. Anger supplied the source of energy to defy, condemn, and the strength to survive.

Everything was mad and angry. I didn't realize that there were other feelings inside me. I guess it was in cold storage as you said. You don't want to think about anything but being mad and getting even, proper revenge for all the people who hurt you...and making other people mad.

I was so angry and so hurt that I couldn't get approval from my parents unless I was a lesser weight, and I thought I'll show you. You want skinny, I'll give you a skinny daughter and then we'll see how happy you are when I'm really skinny. It was like I was showing them that ... I had will power because they thought I had none and stuff.

The ego is the mediator between the inner impulses and the outer world. It is that part of the personality which becomes integrated and strengthened in adolescence and has several functions. Some of the most important functions are: reasoning, judging, and planning; developing a realization that one's way of mastering experience is a variant of the group's way and is acceptable; mediating among impulses, wishes, and actions and integrating feelings; and maintaining a sense of unity and centrality of self (Lidz, 1976).

Ego changes occur in the teen because of broadening social involvement, widening intellectual pursuits, close peer activity, rapid physical growth, and social role changes. Adaptive mechanisms leading to resolution of frustration and reconciling personal impulses with social expectations are beneficial because they permit the self to settle dissonant drives and to cope with strong feelings.

As discussed earlier, anger was the emotion that drove the illness. It provided the impetus, the energy. Guilt also played a significant role. These two emotions, as they generally appeared together, formed the nucleus, in the researcher's opinion, that kept the essential processes of

AN viable.

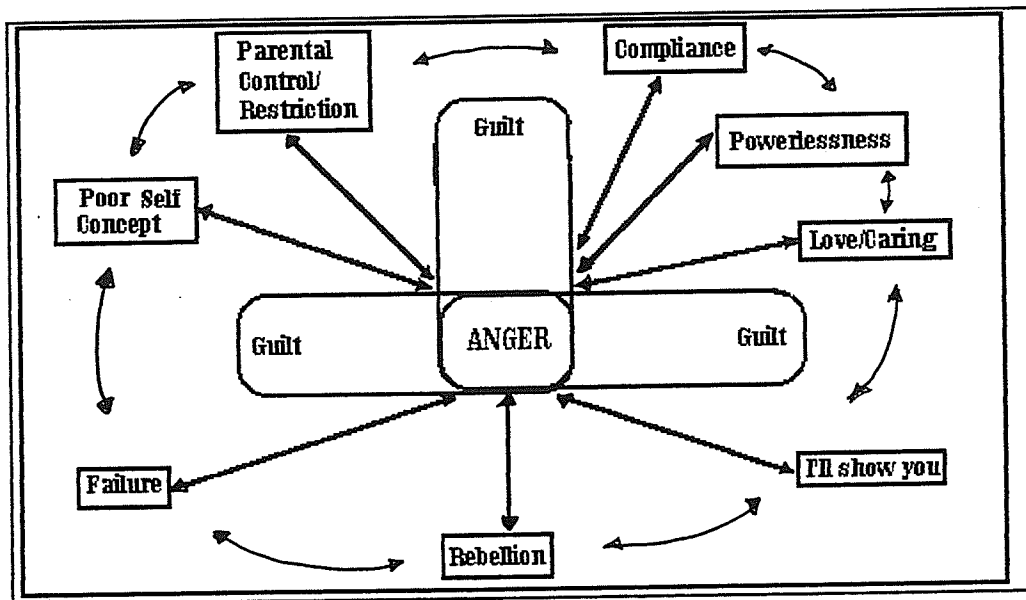
In reviewing Figure 6 [page 130], the guilt/anger dyad is central to the maintenance of the illness, hence its placement. Increased parental control and/or restrictions resulted in hostility and anger as the teen felt that the tight reign on power was just to feed "power-hungry, controlling" parents. These parents were "selfish" and "stupid" enough to base desires on "personal satisfaction" as opposed to the wellbeing of the teen, or the family in general. This anger generated guilt because even though they were bad parents they did provide some of the physical basics.

This led to increased compliance with wishes of parents. Increased compliance came at a cost to autonomy, initiative, and independence. With the parents fostering dependence, this contributed to a decreased sense of self and increasing compliance. High level of compliance coupled with a willingness to please led to feelings of powerlessness.

Lack of power and control, TO be seen as "nothing", "nobody" or not seen at all, left the teen crying out for attention, love, and caring. Since she had been "good", that is compliant with parents' wishes, she had come to expect some form of reward for positive behaviour. When no reward was forth-coming, she felt guilty that she had let down their parents, had failed, again. This made her feel "bad all the time" as

inadequacies were emphasized, thus confusion and resentment mounted as she had done her part.

Figure 6: The Anger-Guilt Dyad of Parent/Child Interaction



Mounting resentment gave way to anger which created the need to belong to her self, to be her own person, to be mistress of her own destiny. She then decided to "show them" (the parents, family, peers, society) that she had the "will power" and the strength. This set up a confrontational, almost adversarial stance where she rebelled to gain autonomous choice. This took the form of starving herself, as this was the only facet of her life, over which she had control [Figure 6].

In rebelling, she decided to lose more weight. This served as a

source of internal conflict because she felt that she had to deprive herself of food in order to be accepted and approved. Yet she so desperately wanted to eat what she wanted in order to be herself. Parents and the world however, remained unconcerned. This was internalized as failure. Impotence set in, this led to anger which generated guilt because "if I did it right they would notice, so it's not really their fault".

Thoughts of I am "nothing", I am "nobody", the devaluing and poor self-concept came to the fore. "I have to lose more weight to be effective", (that is, to be noticed) prevailed. Ironically, loss of weight results in no body, the person she was trying not to become. Depression then set in and now the parents offer their brand of assistance, viewed as control, and the cycle repeated itself.

The Anger/Guilt Dyad (Fig. 6) played a major role in the genesis and subsequent maintenance of AN. Table 5 [Page 131] will place the dyad in the context of the illness AN in general terms and as experienced by the teenagers.

Table 5 captures the stages that the teens endured as individuals diagnosed with AN. Even though all these areas have been covered previously in the paper, further clarification might prove to be useful.

Table 5: Stages of Anorexia Nervosa

STAGES	ATTRIBUTES
FAMILY INTERACTION	Guilt/Anger Dyad of Parent/Child Interaction
TAKING STOCK	Realization : uninvolved + no pals = no life
SEEKING FAME	Assumption : skinny + beauty = popularity
LOSING WEIGHT	Assumption : beauty = skinny
ALTERING MOOD	Realization : skinny + beauty = popularity
WITHDRAWING STAGE	Realization : skinny + isolation = no life
TAKING STOCK 2	Realization : isolation + no life = suicidal thoughts
SEEKING FAME 2	Assumption : skinny + friends = popularity
SELF-STARVING	Assumption : skinny + skinnier = self esteem
CHANGING OPTIONS	Realization : skinny + self esteem = control
IDENTIFYING SELF	Realization : starving = AN = power = me

The family interaction stage was addressed just prior as the anger/guilt dyad. The responses and reactions elicited in the anger/guilt dyad are cyclic and continuous. However, at the point where the teen vowed "to show" the world, including parents, that they had "will power", the taking stock phase was sired. It was also at this time (in their decision to "show" the world) that the rest of the world became involved. Previously, it was predominantly a parent/child issue, with other members of the family playing the minor role of "stealing all the attention".

Following the "I'll show you"/Rebellion phases in the anger/guilt dyad, taking stock stage was the next logical move. Taking stock meant evaluating and assessing their lives with the view of making changes as they saw fit. This involved the realization that they were "uninvolved" in society and had no friends, so this was tantamount to saying that they had "no life".

Having "no life" meant they had to "get a life". In examining the traits of the people who have "lives" they came to the conclusion that they were popular and this stemmed from being beautiful. Beauty meant long narrow face, slim body, and a well made-up face. The seeking fame stage was built on the assumption that if they were skinny and beautiful then the secrets of success and popularity would be theirs.

This was further revised however as skinny and beauty were viewed as synonymous. That is, there can not be one without the other, but skinny "kinda" came first, as one would not be noticed otherwise hence the **losing weight stage**.

However, even though they had lost weight and were now approaching beauty, recall beauty is equated with being skinny, they were still not popular. The **altering mood stage** is realized as depression then set in.

Even though they were skinny, they found that they were isolating and others were allowing them to do so. Recall that there exists an inverse correlation between illness level and relationship, that is, the more severe the illness, the more distant the relationship [Please refer to figure 5]. Thus the **withdrawing stage** where the combination of being skinny and isolated is akin to "no life".

They then advance to the stage where they realize that they are isolated and have no life and are therefore, yet again uninvolved. What of the idea that being skinny would mean friends and therefore popularity? Being at a cross roads again has taken them to the **taking stock 2 phase** where decisions regarding status have to be made.

The change in theory from the 'skinny equals beauty equals popularity' gave rise to a change in concept. The assumption was now

that skinny and friends will result in popularity. The illusive popularity will now be achieved via a renewed **seeking fame 2** stage.

The further assumption that skinny plus even skinnier will give rise to friendships was dashed as the so-called friends could not care less except to state that they were indeed "getting real skinny". Well done! The **self-starving** stage was well on its way. They had finally found something that they were good at, and they would certainly work at it, fine tune it, perfect it. This resulted in a surge of positive regard for self and increased their self-esteem and self-concept dramatically.

With the surge in self concept and the realization that they were good at something also came another surprise. People were taking note, the attention that they desired now came in full flood. This response was overwhelming an "kinda neat", "all the fawning, Gee I just might get the love, caring, and attention" (that I have wanted for so long) finally. The **changing options** stage has brought to the fore that they were in a position of control. I eat even less and they become even more worried, concerned, they must love me. In addition, I have some control over me, over my life.

Now that they had come to the realization that self-starving was the way to go, that the dreaded (as viewed by parents and system) anorexia nervosa had taken root, the goal was to never give it up. After all we

are good at this, we have it down to a fine art, we are finally useful, we are somebody - the power it gave. These powerful persons are us - the little-noticed nobodies.

A great deal of energy, commitment and self-sacrifice was required to continue this system, but was seen as well worth the effort. Indeed the desire to eat became stronger, but had to be quelled. This generated much anger because the teens now realized that they needed AN, to be ill, and sometimes near death to have their needs met. This anger, that fuelled the fire that was the anger/guilt dyad, required no stoking.

CHAPTER SIX

IMPLICATIONS

In reviewing the theoretical perspectives of AN, it became apparent that even though the interrelated factors of psychology, society-culture, physiology, biology, family, and development all play a role in the development of AN, the latter two play a major role as revealed by this study.

Self-reported impairment due to preoccupation was frequently stated. Main preoccupations were weight, shape, appearance and the interventions in which they engaged, in an effort not to seem "average" or unattractive. All participants had specific narrow ranges of ideal weight with three desirous of a 49-51.4 kg weight range. Factors which will impact upon ideal weight, healthy weight, and rate at which they are re-fed during treatment.

The two groups, moderate and severe were homogeneous in most areas, but the severe expressed differences in: i) greater intensity of preoccupations and rituals, and the number of hours spent daily - over 8 hours per day, engaged in same. The severe group also displayed greater avoidance of engaging in activities of daily living, expressed no desire for change in their preoccupation and ritual levels. They also

demonstrated poor insight into their issues. Global severity ranged from 4-6 from a total range of 0-6. These scores coincided with the preoccupation and ritual scores wherein 75% of the severe group admitted that preoccupations severely interfered with social and school functioning.

The families of the members of the severe group were totally disengaged. The teens were therefore unwilling "to give up" their illness as they reaped benefits such as "being fussed over", and "getting loads of attention".

All the participants were closest to their mothers, because the fathers were not amenable to conversation. In fact they all claimed that their fathers did not know, or could not care less whether or not they existed. To this end, feelings of sadness, depression, loneliness, exclusion from family and friends, and isolation prevailed. This was ironic because the more severe the illness, the more distant they became - as they claimed they were now so focused and driven that their entire existence was the illness as opposed to say working on social skills.

AN was viewed as an illness, a symptom of several issues, problems, and struggles. It was also a way in which to cope with problems. Problems and difficulties, they claimed, stemmed from familial and developmental concerns. In regards to their families, issues

surrounding communication and lack thereof; boundaries, that is enmeshment and disengagement; roles; and structure were the main causes. However the perception that the parents were also hypocritical, insensitive, paternally aloof and maternally close were also factors. The fathers' over-controlled manner contrasting to the mothers' undercontrolled behaviour were also concerning to the girls.

This is indicative of the need for familial and individual changes to: allow the teen to be cared for; be regarded in a positive manner; be accepted for who they are, and be loved without the need to harm themselves; and facilitate independence and autonomy. Effective coping skills like anger management and effective communication skills are indicated as well as family and individual therapy to teach and support the family regarding changes required in structure, communication, rules, and boundaries to eliminate the need for the teens to remain ill to have their needs met.

It is of note, that the teens who were offered psychotherapy by paediatricians in the interim, until they were referred to a psychiatrist, were members of the severe group. The desire to "not be cured" by individuals other than "shrinks" and the subsequent resistance to treatment by paediatrician, is an indication that referral practices might need to be further examined.

Compared with the validity scores from the adult group, this study group exceeded them in all areas indicating that this group of seven is quite severe. These foregoing concerns certainly do not bode well for recovery and long-term treatment and will therefore have a great impact. Factors like age and length of treatment might be factors and should be incorporated in expectations of treatment.

Coping mechanisms utilized were soliloquizing and litanizing which not only focused them, but gave them the strength to carry on. Numbing was used as a tool to shield them from the almost constant hurt and pain caused from lack of attention, and being "looked down" upon. Mimicry and disdain allowed them to express their total disregard for the dishonest, untrustworthy, and stupid adults that they encountered as well as provided emotional distancing to prevent or reduce hurt and pain. Shrinking was used in an effort to be noticed, to be cared for, to be protected.

The innovative stages endured, ranged from taking stock to self identity, and provided an easy method of analyzing the ways in which the teens thought and made critical decisions regarding their illness. The decisions were well-thought out, they expressed, and was the means to their end. The way in which to have their needs met, unfortunately because they had to "hurt" themselves to be given their dues.

Anger and guilt were the driving force of the illness. They were responsible for not only the genesis, but the subsequent maintenance. Accepting, as a defense mechanism mainly shielded them from hurt and disappointments as accepting that they were unable to change people, to change how they, the teens, were viewed, could be life-long ventures, and even then, success was not guaranteed. This was also indicative of the need for more appropriate and effective coping skills which may be gained via group and/or individual therapy.

Interestingly, six of the teens were of the opinion that the healthcare system could do nothing for them. This comprised the full complement of the severe group. They opined that therapy helped them to communicate better with their parents, fathers in particular, only if there was a mediator, like during family therapy sessions.

Recommendations

- 1 The teens strongly recommended that supports be put in place for post discharge, in the form of:
 - a) A day program specifically for eating disordered individuals
 - b) Support group of eating disordered individuals, about 5-8 individuals who would meet for about an hour twice weekly to discuss issues and concerns, with a lay person as facilitator.(It was their view that discussions with people who knew first-

hand about the illness might be more helpful.

It was also their opinion that a therapist should sit in on the meetings once monthly to assist with processing thoughts, feelings, and behaviours as the teens are aware of the destructive nature of unhealthy competition amongst and between them

- 2 Specialized skills training - anger management, stress management and effective communication skills prior to and after discharge, since "the work" begins post-discharge and these skills are required to achieve their goals.
- 3 Increased involvement in treatment as they do know first hand what is happening and may be able to make valid suggestions
- 4 Family therapy as a unit; and parental therapy (teach parents how to communicate well and manage anger and life skills)
- 5 Individual therapy for support for a limited period, and then
- 6 A sponsorship program, much like the one utilized in Alcoholics Anonymous programs - where the sponsor's role would be a less formal support role, a confidant(e)

Areas for Future Research

Nursing research on the effectiveness of various behavioural interventions and programs developed for the treatment of eating disorders would contribute greatly to current practice. The studies

performed to date have varying degrees of follow-up and different criteria for outcome which make it difficult to assess the effect of non-behavioural aspects of the treatment programs.

Most clinicians agree that behavioural intervention is necessary for weight gain, but the specific methods that are most effective remain controversial. Critics charge high post-discharge relapse rates and argue that patients who are forced to gain weight are bound to rebel when they leave hospital. The important research question seems to be, how flexible can a program be to maintain effectiveness? Is it better to have a detailed program that leaves no room for ambiguity about the requirements, or to have minimal rules that allow for greater patient participation in decision-making? Since nurses are central figures in the planning and implementation of in-patient behavioural programs, they have important insights regarding the answers to these questions.

Another area of study should be the effect of tube feeding. There is much debate over trauma versus therapeutic value of this procedure therefore long term effects need to be examined. Research studying patients' reactions to this intrusive intervention may provide insights into better care for patients who require the treatment.

CONCLUSION

This study documented the experiences, concerns, opinions, and

beliefs of seven teens who were diagnosed with AN and deemed a valuable study for healthcare professionals who treat individuals with AN. Areas like the meaning they give to AN, peer and family relationships, school, leisure activity, and self-image, not only brought to the fore some very important and previously undocumented issues, but also validated the theoretical underpinning and previous research. Concerns such as their fear of intimacy, quality and quantity of rituals and preoccupations, the relationship between illness level and friendships, and the stages of the perpetuating cycle of AN were developed by the teens and were then analyzed.

A study with a larger sample might demonstrate further differences/similarities between illness levels and age. A multi-centred approach might also yield different responses based on different treatment methods and treatment teams. A longitudinal study might also yield answers to questions regarding the effect that length and type of treatment might have on insight development specifically, and outcome in general.

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APPENDICES



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DIAL DIRECT (204) 787-4587
FAX (204) 787-4547

OFFICE OF THE DIRECTOR OF RESEARCH

January 30, 1995

Ms Lois A. Stewart-Archer

Winnipeg, MB

Dear Ms Stewart-Archer:

**RE: ANOTHER LOOK AT ANOREXIA NERVOSA: THE TEENAGERS'
PERSPECTIVES.**

ETHICS #: N#94/36

The above-named protocol, has been evaluated and approved by the H.S.C. Research Impact Committee.

If your study is receiving funds, please contact the H.S.C. Finance Department for an application for a Specific Purpose Account. It is imperative that you submit a copy of this letter along with your application to: Supervisor, Ancillary Services, Finance Division, so she is aware this has been approved by the H.S.C. Research Department.

**PLEASE NOTE: THIS SPECIFIC RESEARCH ACCOUNT NUMBER CAN ONLY BE
USED FOR THIS PARTICULAR STUDY.**

My sincere best wishes for much success in your study.

Sincerely,

Luis Oppenheimer, MD, FRCS
Director of Research
Health Sciences Centre

cc: Supervisor, Ancillary Accounts
Finance Division
791 Notre Dame Avenue
Department Head

LO/kv





Pediatric Research
Coordinating Committee

820 Sherbrook Street
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Dial Direct (204) -787-2455
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January 12, 1995

Ms. L. Stewart-Archer
Graduate Student - Nursing

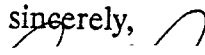
Winnipeg, Manitoba

RE: STUDY: Another look at Anorexia Nervosa: the teenagers' perspectives

Dear Ms. Stewart-Archer,

Your protocol was reviewed at our January PRCC meeting and was approved.

If you have any further concerns or questions, please do not hesitate to contact my office.

Yours sincerely, 

Wade T.A. Watson, MD, FRCPC
Chairman,
Pediatric Research Coordinating Committee

WTAW:ck

The University of Manitoba
FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#94/36

Proposal Title: "ANOTHER LOOK AT ANOREXIA NERVOSA: THE TEENAGERS' PERSPECTIVE."

Name and Title of
Researcher(s): LOIS STEWART-ARCHER
MASTER OF NURSING GRADUATE STUDENT
UNIVERSITY OF MANITOBA FACULTY OF NURSING

Date of Review: DECEMBER 05, 1994; JANUARY 02, 1995.

APPROVED BY THE COMMITTEE: DECEMBER 05, 1994.

Comments: approved with submitted clarification
to the chair

Date: Dec. 16, 1994

<u>Linda J. Kristjanson, PhD, RN</u>	<u>Chairperson</u>
Associate Professor	
University of Manitoba Faculty of Nursing	
	<u>Position</u>

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

ANOREXIA NERVOSA AND CONCERNS

-B-

UNIT MANAGERS' APPROACH FOR PARTICIPATION IN STUDY

Hello, my name is _____. There is a Master of Nursing degree student from the University of Manitoba here. She is a nurse. Her name is Lois Stewart-Archer. She is interested in finding out the concerns of teenagers diagnosed with anorexia nervosa. She is interested in speaking with you because you have been diagnosed with this illness. Would you consider speaking with her? If you speak with her, you are under no obligation to take part in her project.

-C-

VERBAL EXPLANATION OF THE STUDY

Hi. My name is Lois Stewart-Archer, a nursing student in the Master of Nursing program in the Faculty of Nursing at the University of Manitoba. I am conducting a study in order to explore the concerns of teenagers diagnosed with anorexia nervosa.

I will interview you three times, about three weeks apart. Each interview will last for about 45 minutes. You will be asked about the concerns you have about your illness and how it has affected your life. You will also be asked some questions to complete a short form on information about your: age, number of brothers and sisters and their ages, grade completed at school, and concerns that you have specifically about your eating habits and appearance. These interviews will take place at mutually agreeable places and times. The interviews will be tape recorded.

The information which you will provide will be kept strictly confidential and only I will have access to your name and information which may identify you. At the end of the interview, the tape recordings will be typewritten. Your name will not appear on any of the typewritten notes, tape recordings, or form you will fill out. Codes will be assigned to each set of information. All the information which will be gathered will be kept in a locked cabinet for ten years. My research supervisors {Dr. Erna Schilder and Dr. Eleanor Adaskin, professors at the University of Manitoba and Dr. Eric Vickar, Clinical Director of Child and Adolescent Inpatient Services at the Health Sciences Centre) may request to see the interview notes or information I

ANOREXIA NERVOSA AND CONCERNS

have gathered from the forms. Remember your name will not be on these notes and forms. Your name will also not be used in relation to the information gathered in the study report, or any publications from the study.

There are no risks likely to be encountered. Even though information of a confidential nature will be kept as such, if thoughts of, or plans to harm yourself and/or others are revealed during these interview sessions I will have to report this information to your doctor. If you feel uncomfortable in answering any questions during the interview, you are free to: refuse to answer, have the tape recorder turned off, or withdraw from the study.

At the end of the project I will compile the information from all the young people that I interviewed and present it to health professionals such as nurses, doctors, and social workers. In doing this, health professionals may be more aware of what concerns you in regards to your illness. The findings of the study will be summarized and may be published at some time in the future.

Even though you may not personally benefit from the study, the information gathered may, in the future, help health professionals to care for other individuals affected by anorexia nervosa. Your participation in this study is voluntary and you are free to refuse or withdraw from the study at any point without any penalty or risk to any care that you may receive now or in the future.

You may telephone me at _____, or write me at: 771 Bannatyne Avenue, Winnipeg, Manitoba, R3A 1S1 at any point in the study. You may ask me questions about the study at any time and will receive answers.

In order for you to volunteer for this project, you have to be:

ANOREXIA NERVOSA AND CONCERNS

diagnosed with anorexia nervosa; between 13 and 19 years old; medically and physically stable; able to read, write, and understand English; live within the city of Winnipeg; and give your written, informed consent. Your parent/legal guardian will also have to give written, informed consent.

You will receive a copy of this written explanation of the study, as well as a verbal explanation, and the opportunity to ask questions.

-C-

UNIVERSITY OF MANITOBA
FACULTY OF NURSING
DEPARTMENT OF GRADUATE STUDIES
CONSENT TO BE A RESEARCH PARTICIPANT

Purpose

A project is being done by Lois Stewart-Archer, Master of Nursing student at the University of Manitoba to learn more about the concerns of teenaged females diagnosed with anorexia nervosa. I have been invited to be in the study. I will participate with other hospitalized teenagers. My ideas are valuable to the interviewer in understanding my thoughts, feelings, and concerns related to my illness.

Procedure

If I agree to participate, I will be interviewed three times for approximately 45 minutes each time. During the first interview, I will complete a form, answering specific questions regarding my eating habits and appearance, and questions about my background including: my age, the number of my brothers and sisters and their ages, and the grade that I have completed in school; this should take about 30 minutes. The remaining 15 minutes will be used for interviewing. The questions will deal with concerns as I see them, and the interview will take place at mutually convenient places and times. If I agree the interview will be tape recorded. The interviews will be spaced approximately three weeks apart.

Risks/Disadvantages

In answering the questions in the areas identified above, I may experience some loss of privacy. The study is being supervised by Dr.

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Erna Schilder (474 9664) and Dr. Eleanor Adaskin (237 2606), Professors in the Faculty of Nursing, and Dr. Eric Vickar (787 7470), Professor in the Faculty of Medicine. These three people will also have access to the data. However, the interviewer will separate my name from the answers provided on the form and will keep my name coded. The typewritten notes from the recorded interview and the completed form will be kept locked so my confidentiality will be protected. If, however, I reveal plans/thoughts of self-harm or harm to others, my doctor will have to be informed of these thoughts or plans. The study data will be kept for 10 years.

Benefits

Although there is no direct benefit to me from participating, the interviewer hopes to learn more about my concerns regarding anorexia nervosa. I understand that Ms.. Stewart-Archer will compile the information from all the young people that she has interviewed and present it to health professionals. This knowledge may help nurses, doctors, and other members of the healthcare team to understand the viewpoints of teenagers with my illness and incorporate this knowledge in caring for us in the future. The findings of the study will be summarized and may be published at some time in the future.

Questions

The study has been explained to me. I have a copy of the written explanation of the study. If I have further questions however, I may telephone Lois Stewart-Archer at: (204) 787 7676 or write to her at: PsychHealth Centre, 771 Bannatyne Avenue, Winnipeg, Manitoba, R3A 1S1 at any point in the study.

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Rights

I have received a copy of this consent form. My participation in this study is voluntary. I have the right to refuse to participate and the right to withdraw from the study at any point without any penalty or risk to any care I receive now, or in the future. I just have to say so.

Participant's Signature

Guardian's Signature

Investigator's Signature

Date

I would like a summary report of the findings: Yes ☐ No ☐ Please mail the summary of findings to:

Name: _____

Address: _____