THE LIVED EXPERIENCE OF ANOREXIA NERVOSA: A PHENOMENOLOGICAL STUDY

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by

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Dedicated to

My mom who, starting out on this journey with me, inspired me and stayed with me, spiritually, through to its end. Her faith in me gave me the strength to continue.

My two beautiful children, Tonya and Gerry, who through their unselfish love, allowed me to pursue my goals. Without their support, my dream would never have become a reality.

ABSTRACT

Anorexia nervosa has the highest mortality rate of all emotional illnesses and claims the lives of 5 to 10 percent of its' victims. Despite the plethora of quantitative research on eating disorders, the prevalence of anorexia nervosa continues to rise, and the trajectory of the disorder remains dismal.

In this study, a phenomenological mode of inquiry was used to explore the lived experience of anorexia nervosa. Data analysis was in line with van Manen's Hermeneutic Phenomenology. Six females, nineteen years of age and older, participated in two audiotaped unstructured interviews. Participants were encouraged to speak freely and openly about their overall experience of living with anorexia nervosa.

Through data analysis of the transcripts (interviews) eight themes emerged: the weakened self, a struggle for control, controlled by the illness, concealing the self, consumed by the illness, readiness to change, letting-go while holding-on, and breaking the cycle. The web of interrelationships between these themes allowed the essence of the lived experience of anorexia nervosa to be captured as a persistent struggle to find

meaning in life. Study participants described the development of a connectedness with another as providing a sense of meaning and purpose to their lives, and altering the destructive course of the illness. The findings also emphasized the impetuous nature of therapy (i.e., exerting power and control over clients) in the illness trajectory. The onus is certainly on health care providers to reevaluate current approaches to care and develop a unified treatment model for anorexia nervosa that will be more effective in facilitating recovery from this illness.

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Introduction

Anorexia nervosa is an emotional illness characterized by an intense fear of fatness, dissatisfaction with body image, and the relentless conviction that controlling body weight is a prerequisite for happiness (Garner, 1986). In the past decade the incidence and prevalence of anorexia nervosa escalated at alarming rates, especially among young women (Canadian Mental Health Association [CMHA], 1989; Rosenfield, 1988; Wilfley & Grilo, 1994). It is estimated that 1 in 100 Canadian teenagers develop serious forms of the illness and 5 in 100 develop milder forms (CMHA, 1989). Further projections suggest that from 200,000 to 300,000 Canadian women between 12 and 40 years of age will develop anorexia nervosa at some point in their lives (CMHA, 1989).

As the incidence and prevalence of anorexia nervosa rise, it is becoming apparent that gender and social status will not be granted immunity from this illness (Leichner, Arnett, Rallo, Srikameswaran, & Vulcano, 1986; Paxton, 1993; Ratinasuriya, Eisler, Szmukler, & Russell, 1991). Only four decades ago anorexia nervosa was considered a rare disorder believed to be confined to middle and upper class females. Recent findings indicate that it has increased significantly

in males (Leichner et al., 1986), with estimates around 5 to 19 percent (Hoek, 1991), and across all socioeconomic spectrums (CMHA, 1989; Garner, 1993; Williamson, 1990).

What is most alarming is the growing trend towards an earlier age of illness onset, with signs of the illness present in twelve year olds (CMHA, 1989). Among adolescent girls, there appears to be greater preoccupation with acceptable body weight (Feldman, Hodgson, Corbin, & Quinn 1986). Unfortunately, statistics on the incidence and prevalence of anorexia nervosa are mere estimates, because secrecy, a dominant defining illness symptom, precludes accuracy.

The trajectory and prognosis of anorexia nervosa are dismal. High morbidity rates are associated with such psychological illnesses as depression and affective disorders (Damkberg, 1991), and physiological disorders, including cardiovascular disease, osteoporosis and electrolyte imbalance (Sharp & Freeman, 1993). Anorexia nervosa also has the highest mortality rate of all mental illnesses (Strauss, 1995), with 5 to 20 percent of patients who do not respond to therapy dying (Garfinkel & Goldbloom, 1988). It has been argued that greater efforts must be directed towards early detection and treatment, if we are to

make significant inroads toward improving the health and well being of this population (Crisp, 1988; Garfinkel, Kennedy, & Kaplan, 1995; Shisslak, Crago, & Neal, 1990; Wilfley & Grilo, 1994). The purpose of this study was to develop a greater understanding of the meaning of anorexia nervosa for individuals living with this illness.

Background and Rationale

The proliferation of research over the past few decades has implicated genetic, metabolic, developmental, familial, sociocultural and behavioral factors in the development of eating disorders (Wilfley & Grilo, 1994). The complex interaction of multiple factors constituting the causal base for anorexia nervosa has generated multidimensional treatment regimes. Despite considerable advances, the illness remains highly resistant to successful treatment, especially when it evolves into a chronic illness (Jenson, 1994; Kennedy & Garfinkel, 1992; Shisslak et al., 1990).

The problems posed by anorexia nervosa are apparent from the changing demographics of eating disorders, their increasing incidence and prevalence, and the seemingly ineffectiveness of various treatment modalities under the biomedical model of care. From a review of the literature,

it seems that considerable difficulty exists in clearly differentiating anorexia nervosa from other eating disorders, and deciding whether comorbidity conditions (e.g., depression, obsessive-compulsive disorder, personality disorders) contribute to the onset of the illness or are a consequence of it (CMHA, 1989; Garfinkel et al., 1995; Kennedy & Garfinkel, 1992; Muscari, 1987).

The conceptual and clinical ambiguity surrounding the illness has produced a multitude of risk factors, predisposing symptoms, comorbidities, and treatment modalities. It has been argued that research findings are limited due to conceptual and methodological problems inherent in study designs (Rosenfield, 1988; Wilfley & Grilo, 1994). Most research inquiries have focused on developing reliable and valid diagnostic tools and effective treatment modalities as opposed to prevention and health promotion strategies.

Based on the assumption that prognosis may improve with early diagnosis and treatment, prevention and health promotion strategies have increasingly become the focus of recent research (Childress, Brewerton, Hodges, & Jarrell 1993; Crisp, 1988; Kennedy & Garfinkel, 1992). However, conflicting findings exist concerning the timeliness,

appropriateness and effectiveness of prevention strategies (Crisp, 1988; Paxton, 1993; Shisslak et al., 1990; Wilson, 1993). The development of a knowledge base grounded in individuals' experiences with anorexia nervosa is essential for the provision of quality care by health care providers.

Problem Statement

The position taken by this researcher is that because the early warning signs of anorexia nervosa are not readily discernible to others, even to "expert eyes", the only real access is through some form of phenomenological inquiry. That is, a greater understanding of illness meanings can only be gleaned from an in-depth, thematic analysis of narrative descriptions of those living with anorexia nervosa. Instead of searching for universality in refining diagnostic tools and improving therapies, we should first focus our efforts on grasping an appreciation for the intrinsic, personal side to the experience. Nursing may well be prepared to meet the physiological sequelae of this illness. However, the efficacy of treatment modalities (primary, secondary, and tertiary) will remain limited until the meaning of the lived experience of anorexia nervosa is captured.

Research Question

This study was designed to address the following research question: What is the meaning of the lived experience of anorexia nervosa?

CHAPTER 2

Literature Review

The plethora of literature on anorexia nervosa can be attributed to the contributions from various disciplines (e.g., psychiatry, psychology, nursing, and social work). With few exceptions (e.g., Hilde Bruch's work), limited attention has been given to qualitative inquiry. Most studies which used a quantitative approach were guided by the medical model of care. The vast majority of these studies focused on the identification of factors related to diagnosis and treatment, with lesser emphasis on health promotion and disease prevention.

This literature review provides an overview of relevant theoretical insights, research and clinical findings which capture current understandings of anorexia nervosa. The first section discusses anorexia nervosa as a disorder. Special attention is given to the historical development, current diagnostic criteria, predisposing and precipitating risk factors, associated conditions, as well as treatment modalities and prognosis. The second section discusses qualitative research findings on anorexia nervosa. The third section deals with eating disorders and health promotion strategies.

Anorexia Nervosa as a Disorder

In the past diagnostic thinking about anorexia nervosa was considerably myopic with heavy reliance on single factor causal theories to explain this multidimensional disorder (Bruch, 1973; Garner, 1993). A glance at the historical development as an antecedent, which narrowed the focus of health care delivery to clients with anorexia nervosa, will clarify clinical and academic difficulties experienced in preceding decades.

Historical Profile

Anorexia nervosa is not new to society. Accounts of self-induced weight loss can be traced back to the Middle Ages. One of the earliest writings addressing the signs of eating disorders was by Richard Morton in 1689 (Garfinkel, Garner & Goldbloom, 1987; Maceyko & Nagelberg, 1985; Wilfley & Grilo, 1994). In 1868, the term anorexia, which means "loss of eating or nervous loss of appetite", was first coined by William Gull, in England. Psychological factors were labeled as precursors in the development of anorexia nervosa, but disagreement existed about the nature of these factors.

By 1914, after Simmons discovered destructive microscopic lesions in the post-mortem pituitary gland of some cachexia patients, the term Simmons Disease was uncritically applied to all patients with extreme weight loss. Anorexia nervosa was labeled a physical disorder, and treated as hypopituitary cachexia.

In 1930, Berkman defined anorexia nervosa as a physiological disorder, secondary to psychic disturbance. The psychiatric community now categorized this disorder as compulsion neurosis, hysteria or psychosis. In the 1940's, Waller, Kaufman, and Deutsh introduced the psychoanalytic era. With symptoms based on specific and unconscious fantasies centering around oral impregnation, the treatment of choice was accordingly, psychoanalysis (cited in Coovadia, 1995).

By the 1960's, it became apparent that this treatment modality was ineffective. The modern era of psychological thinking evolved and continues today (Turner, 1990). Major contributions to current understandings of eating disorders have been made by Hilde Bruch, United States; Russell and Crisp, United Kingdom; and Garfinkel and Garner, Canada (Coovadia, 1995).

Diagnostic Criteria

Garfinkel, Kennedy, & Kaplan's (1995) reclassification of the Diagnostic Statistical Manual-III (DSM-III) to the Diagnostic Statistical Manual-IV (DSM-IV) will hopefully identify those individuals with eating disorders who escaped early detection in the past. The DSM-IV outlines the classifications and diagnostic criteria for all emotional disorders (American Psychiatric Association, 1994). One important criteria for anorexia nervosa is the refusal to maintain body weight within the minimal acceptable norms for age and height (i.e., maintenance of body weight below 85 percent of that expected). A second criteria is the presence of an intense fear of gaining weight or becoming fat even when one is underweight. Another criteria is a disturbance in body image (i.e., feeling fat even when emaciated). Finally, the absence of three consecutive menstrual cycles in females is considered to be a significant symptom indicating the presence of anorexia nervosa (American Psychiatric Association, 1994).

Subtypes. There are three subtypes of anorexia nervosa. The restrictor subtype is a label reserved for those who fast from food but do not engage in purging behaviours. In contrast, non-restrictors alternate between

periods of fasting, and binge-eating or purging behaviours. A third label is reserved for those who have an unspecified eating disorder with anorectic features (i.e., meet most but not all the diagnostic criteria for anorexia nervosa) (American Psychiatric Association, 1994).

Behavioral strategies. A number of behavioural strategies are associated with anorexia nervosa to ensure weight loss and/or prevent weight gain. Some of these strategies include, but are not limited to, the following: 1) extreme restriction of food intake; 2) hiding and toying with or disposing of food; 3) compulsive use of laxatives, appetite suppressants, and/or diuretics well beyond recommended dosages; 4) intensive and excessive exercise regimens; and 5) self-induced vomiting (purging)(Haller, 1992).

Gender and cultural influences. Although the forementioned diagnostic criteria are used to diagnose both males and females, some gender differences are apparent in how the disorder is manifested (Eating Disorders Association [EDA], 1988). Men, more so than women, are more achievement-oriented, show more sexual anxiety, appear excessively athletic, and over-value physical fitness, body appearance and muscle strength (EDA, 1988).

In a descriptive correlational study, Olivardia, Pope, Mangweth, and Hudson (1995) investigated select factors associated with eating disorders. Males diagnosed with an eating disorder (n = 25) were compared with a group of women with bulimia (n = 33) and males with Osgood-Sclatter disease (n = 26). All subjects were administered the Diagnostic Survey for Eating Disorders - Revised, the Structured Clinical Interview for DSM III-R, Eating Attitudes Test (EAT), Eating Disorder Inventory (EDI), and an interview schedule on demographic, body image, exercise and dieting behaviours, childhood experiences, and family characteristics. The results indicated that men with eating disorders had significantly higher EAT and EDI scores, and adverse childhood experiences (sexual abuse, poorer relationships with fathers) than men in the comparison group. Although men with eating disorders identified more major mood disorders, problems with substance abuse, anxiety disorders, and dissatisfaction with body image than their male counterparts, they did not differ significantly from women with bulimia. In contrast to previous study findings, there were no significant differences observed between the two male groups on rates of homosexual behavior or gender identity disturbances.

Studies have also documented cultural influences on the emergence of eating disorders (Lee, Ho, & Hsu, 1993; Sohlberg & Norring, 1995). While the drive for thinness is a cardinal sign of anorexia nervosa in Western society, it is not a notable manifestation of anorexia nervosa in other cultures. Lee et al. (1993) conducted a retrospective chart audit of patients (N = 70) with a clinical diagnosis of anorexia nervosa who had been followed prospectively for two years. The findings indicated that food refusal due to fat phobia (41.4%) were less predominant than non-fat phobia (58.6%) (gastric bloating, lack of appetite, fear of food). Non-fat phobic patients had a lower than ideal body mass index (BMI), whereas, fat phobic patients had a higher than average BMI, and exhibited more frequent binge-eating, vomiting, and physical exercise behaviours. The authors concluded that significant cross-cultural differences exist in the manifestation of anorexia (Lee et al., 1993). Lee (1996) criticized the diagnostic criteria for anorexia nervosa as being too insensitive for detecting cultural differences.

Risk Factors

Two types of risk factors play a key role in the

development of eating disorders: predisposing and precipitating. Major risk factors associated with eating disorders identified from the literature include: (a) demographic characteristics, (b) personality traits, (c) family communication patterns, (d) family history of eating disorders and substance abuse, and (e) a history of dieting and biological components (i.e., genetic vulnerabilities, comorbidity with mood disorder, appetite control problems, metabolic alterations) (Crisp, 1988; Muscari, 1987; Shisslak et al., 1990). However, the presence of any one of these factors (precipitating and/or predisposing) is not sufficient for the development of anorexia nervosa. In a recent study of women (N = 35) who had recovered from an eating disorder, Russell, Trierweiler, and Elder (1996) found that subjects gave variable weightings to specified risk factors and identified diverse and complex reasons for illness onset.

Predisposing factors. Demographic characteristics, personality factors, family traits and dynamics in combination with the sociocultural forces have been implicated in the development of anorexia nervosa (Garfinkel et al., 1987; Paxton, 1993; Shisslak et al., 1990; Wilfley & Grilo, 1994). With regard to demographic characteristics,

females twelve to eighteen years of age in middle to higher socioeconomic groups in Western societies are considered to be at greater risk for developing eating disorders than their male counterparts (Fisher, Schneider, Pegler, & Napolitano, 1991; Garfinkel et al., 1987; Hawkins, McDermoth, Seeley, & Hawkins, 1992).

Whitaker, Davies, Shaffer, Johnson, Abrams, Walsh, and Kalikow (1989) designed a cross-sectional study to investigate the eating attitudes and behaviours of high school students (N = 5108) in grades 9 through 12. Data were collected with the Eating Symptoms Inventory (ESI), Eating Attitudes Test (EAT), as well as a demographic and medical history questionnaire. Study findings suggested that although female ESI and EAT scores doubled those of their male peers, students of both sexes with higher body mass indexes were more likely to score higher on the EAT and ESI, engage in binge eating, and experience binge distress. Also, females tended to rely more on multiple methods of serious weight control (72 percent versus 31 percent were dieters, respectively) and have a higher incidence of fasting than males; whereas, males reported more recurrent binge-eating than females.

Leichner, Arnett, Rallo, Srikameswaren, and Vulcano

(1986) used the Eating Attitudes Test to survey students (N = 4659) aged 12 to 20 years in public schools and one university setting. The results identified five percent of males and twenty-two percent of females with potential eating attitude problems. Study findings also demonstrated a higher prevalence of problematic eating attitudes in females, 19 to 20 years of age, with a high body mass index, and living in urban settings when compared with males.

Moore (1990) defined anorexia nervosa as a disorder that usually first appears during adolescence but may surface in middle age. Children as young as nine years of age have been shown to demonstrate a desire to lose weight, believing that their peers perceive them to be fat. When expressions of discontent with feeling overweight are combined with behaviors that lead to thinness at an early age, there exists a strong predisposition for developing an eating disorder (Maloney, McGuire, Daniels, & Specker, 1989; Sasson, Lewin, & Roth, 1995).

A later age of onset has been associated with chemical dependency or psychiatric illness (Hsu, 1990), and the changing role of women in society (Gremillion, 1992). Certain personality traits have also been implicated in the development of anorexia nervosa: low self-esteem, with or

without depression (Silverstone, 1990); a tendency towards obesity (Ponto, 1995); distorted body image; feelings of loss of control; the presence of a strong need to give to others; feeling guilt or shame when trying to please oneself; perceived general ineffectiveness; and a drive to achieve perfection (Muscari, 1988; Shisslak et al., 1990).

According to Minuchin, Rosman, and Baker's (1978) work on family functioning, transactional patterns play a key role in the development of a sense of autonomy and personal identity. When family interaction patterns are characterized as enmeshed or disengaged, the child's sense of control over psychological and bodily functioning may be compromised, and, therefore, place him/her at greater risk for developing psychosomatic illness (Minuchin et al., 1978). Johnson and Flash (1985) also identify family interaction patterns that place high emphasis on overprotectiveness and less on self expression, as significant risk factors in the development of eating disorders. Anorexics, for example, often have a history of family relationships which impede autonomous growth (Bruch, 1973; Muscari, 1988; Rosenfield, 1988). In some instances, these families may very well present the image of being the "perfect family".

Additional family risk factors include: female dominated or only/last child families; emphasis placed on achievement and physical appearance as opposed to emotions or feelings (Canadian Mental Health Association [CMHA], 1989); families with a psychiatric history of eating disorders, and/or affective disorders (Johnson, 1995; Muscari, 1988); and, father's behavior towards daughters at puberty (e.g., rejection or teasing may translate into shame and self-disgust about one's body) (Sanford & Donovan, 1984). Rorty, Yager, and Rossotto (1994) also suggested that a history of physical, sexual or psychological abuse increases an individual's susceptibility to eating disorders.

Sociocultural influences are also believed to play a significant role in the development of eating disorders. Garner and Garfinkel (1980) designed a cross-sectional study to compare the eating attitudes and behaviours of professional dance (n =183) and modeling (n = 56) students with women of the same age and social class diagnosed with anorexia nervosa (n = 68), attending university (n = 59), or music school (n = 35). The Eating Attitudes Test (EAT) and Hopkins Symptom Checklist were used during data collection. Women in the dance and model groups had significantly higher

EAT scores than either the music or university students. In addition, a significant positive correlation between eating attitudes and psychological symptoms were found in the anoretic and dance groups but not the university group. The authors concluded that cultural emphasis on thinness combined with other predisposing factors "are forcing a certain number of vulnerable adolescents below a threshold which triggers anorexia nervosa" (p. 655).

Powerful messages are being sent to young people by media images that promote thinness (e.g., television advertisements, diet ads, fashion magazines), movie stars that equate thinness with power and success, and society's overall preoccupation with thinness and weight loss. You can never be "too thin" or "too powerful" is the message that the media has successfully instilled in the minds of Western society (Smead, 1985).

In a descriptive correlational study, Tiggemann and Pickering (1996) investigated the relationship between type of television programs viewed, body dissatisfaction, and the "drive for thinness" in ninety-four high school girls (mean age = 15.5). Subjects were asked to complete the Drive For Thinness subscale of the Eating Disorder Inventory, and record television programs watched during the previous week.

The results demonstrated a strong correlation between body dissatisfaction and video content (e.g., fitness) and television programs (e.g., sports, soaps), and the drive for thinness and music videos.

Gender socialization differences is another component of sociocultural influences which have been implicated in the development of anorexia nervosa, particularly in females. Boys grow up learning that individual accomplishments will positively affect how others respond to them. Conversely, girls are often valued for their looks - the source of most positive feedback (Jasper, 1990). Gender socialization "teaches us how to act and behave separately as women and men, and about the different roles that we are expected or required to play" (Friedman, 1995, p. 34).

Precipitating factors. Reynolds (1995) noted that "there is substantial evidence that dieting is a major risk factor in the development of an eating disorder" (p. 1257). The dieting cycle is prompted by perceived plumpness, negative comments from significant others about one's weight and possibly depression (Garner, 1993; Hsu, 1990; Loader, 1980; Orbach, 1982; Roth, 1992; Williamson, 1990). Dieting and body image concerns as precursors in the development of anorexia nervosa have been documented in numerous research

studies (de Castro & Goldstein, 1995; Mellin, 1992; Muscari, 1987; Paxton, 1993; Ponto, 1995).

Hill, Oliver, and Rogers (1992) surveyed dietary restraints, self-esteem, body satisfaction and body figure in a sample of young girls aged nine (n = 84) and fourteen (n = 86) from the same school. Study findings identified dieting restrictive practices in a significant number of nine year olds. In addition, approximately 40 percent of those who dieted in both age groups were not overweight. Motivation factors stimulating dietary actions had little to do with actual body weight, and seemed to be related to perception of body shape (Hill et al., 1992). Similar findings on dieting and weight/shape concerns in elementary school children were reported by de Castro and Goldstein (1995), and Mellin (1992).

Fisher, Schneider, Pegler, and Napolitano (1991) investigated the relationships among eating attitudes and behaviours, self-esteem, anxiety, and health-risk behaviours in a sample (N = 268) of students (mean age = 16.2). Students from grades 9 through 12 were administered the Eating Attitudes Test, Rosenberg Self-Esteem Scale, State Trait Anxiety Inventory for Children, and a questionnaire on select health-risk behaviours. The findings revealed a

moderately, positive correlation between eating attitudes and self-esteem, anxiety, and weight attitudes. Further, most of the health-risk behaviours (smoking, substance use, sexual activity) depicted a low but significant, positive relationship with eating attitudes and self-esteem.

Participation in competitive sports and careers emphasizing thinness (e.g., modeling) are additional factors identified as precursors to the development of anorexia nervosa (Warren, Stanton, & Blessing, 1990). Ballet dancers are considered to be a high risk group because of the attention given to maintaining a slim physique (le Grange, Tibbs, & Noakes, 1993; Szmukler, Eisler, Gillies, & Hayward, 1985).

Adolescents, struggling to find their own identity, are faced with the additional pressure of conforming to acceptable peer norms. Persons teased or ridiculed by their peers are at greater risk of developing poor self-image (Cash, Winstead, & Janda, 1986). The combined effect of low self-esteem and the need to be accepted by peers, especially in grades 5 to 7, is believed to be the driving force behind the development of eating disorders (Thompson, Coovert, Richards, Johnson, & Catterin, 1995).

Additional factors considered responsible for

increasing women's susceptibility for anorexia nervosa include irregular eating habits, such as binging or emotional eating (Crisp, 1988), and major life changes and/or stressors (e.g., parental separation or divorce, puberty, leaving home, or commencing post-secondary education). However, Garner (1993) cautions that ineffective and inadequate coping skills underlie many of these precipitants.

Anorexia Nervosa and Associated Conditions

The complexity in the treatment and diagnosis of anorexia nervosa is further confounded in the presence of: a) alcohol and substance abuse, and b) premorbid and comorbid emotional disorders. Several authors estimated that up to 25 percent of clients with eating disorders have associated alcohol and drug abuse problems (Goldbloom et al., 1992; Lesieur & Blume, 1993; Peveler & Fairburn, 1990; Watts & Ellis, 1992). Clinical manifestation common to persons with eating disorders and substance abusers include: (a) loss of control, (b) preoccupation with the abused substance (e.g., food or alcohol) (c) seeking relief from inner emotional pain, (d) secrecy about behavior, (e) denial of the problem, (f) persistent abuse of the substance (e.g.,

food or alcohol) despite adverse health effects, and (g) non-compliance with treatment regimens (Haller, 1992; Hamburg, Herzog, Brotman, & Stasior, 1989; Hsu, 1990; Watts & Ellis, 1992).

Anorexia nervosa may be either the primary diagnosis with a comorbidity of an affective disorder, or the secondary diagnosis in the presence of other psychiatric disorders such as depression, schizophrenia or personality disorders (Mann, Wakeling, Wood, Dobbs, & Szmukler, 1983). In secondary or atypical cases, persons who present with clinical manifestations reflecting the diagnostic criteria for anorexia nervosa, without body image distortion, generally respond well to treatment once the primary diagnosis is treated (Coovadia, 1995). The coexistence of these forementioned associated diagnoses are variables which often cloud clinicians' diagnostic judgments and alter the course of treatment for anorexia nervosa.

Treatment Modalities and Prognosis

Anorexia nervosa is laden with a multitude of complex and intricate factors which must be considered in order to enhance the efficacy of treatment modalities. The treatment of eating disorders varies considerably depending upon a

particular clinician's theoretical preference. The intricacies and pathogenesis of eating disorders and the generalization of counselling-therapy strategies often become secondary to the clinician's practice model (Bruch, 1973; Roth, 1992). Even with recent advances in the treatment of eating disorders, the importance of the interplay of biological, psychological, familial and sociocultural variables in its development and continuance has not received adequate attention. Researchers have yet to achieve a consensus, or develop a unified theory, on eating disorders (Garner, 1993; Gwirtsman, 1993; Haller, 1992; Irwin, 1993).

Treatment modalities, whether in-patient or out-patient based, consist of one or more of the following: psychoanalytical (Goldbloom & Kennedy 1988); cognitive-behavioural (Garner, 1988); experiential-expressive (Hornyak & Baker, 1989); psychopharmacological (Goldbloom & Kennedy, 1988); psychoeducational (Garner, 1988); or group, individual, and family therapy (Meades, 1993; Strauss, 1995). The decision to treat on an in-patient or out-patient basis, which includes day programs, is determined by the physical and mental status of the client. For example, it is common practice that when a person presents a danger

to herself/himself in terms of weight loss of more than 25 percent of body weight (i.e., according to the DSM-IV), is non-responsive to out-patient treatment, or demonstrates severe emotional distress (i.e., suicidal feelings and ideation), the clinician prefers in-patient treatment (Hamburg, Herzog, Brotman, & Stasior, 1989).

The prognosis for anorexia nervosa is dismal (Garfinkel & Goldbloom, 1988; Haller, 1992). One in ten cases will result in death from starvation, cardiac arrest or suicide. Poorer recovery rates are associated with greater weight loss, older age of illness onset and longer illness duration (EDA, 1988). Success rates are much higher following early diagnosis and treatment (Patterson, 1995).

Summary

Research on anorexia nervosa as a disorder under the medical model of care has resulted in the (a) development of diagnostic criteria and instruments (i.e., Eating Disorder Inventory by Garner, Olmsted, & Polivy, 1984), (b) identification of risk factors associated with the onset of anorexia nervosa, and (c) acceptance of anorexia nervosa as a disorder. Although the growing research base on anorexia nervosa has increased health care providers' awareness of

the complexities involved in the diagnosis and treatment of this multidimensional disorder, limited efforts have been expended on identifying an anoretic's perception of living with the illness. Until a deeper understanding of the meaning of health and illness in this population is captured, Anorexics will remain in a constant struggle to restore the self that was damaged long before illness onset.

Anorexia Nervosa as an Illness: Qualitative Insights

To date, qualitative research insights into the meaning of anorexia nervosa for persons living with this illness is limited. A few studies were found in the literature that stressed the importance of understanding illness meanings in order to successfully treat anorexia nervosa.

Hilda Bruch's contributions from her life-long work with Anorexics are documented in her writings (e.g., The Golden Cage, The Enigma of Anorexia Nervosa, 1977; Conversations with Anorexics, 1988). Bruch has been foremost in proposing that deficiencies in ego development during the first few years of life result from faulty interactions with the mother. The child is often paralyzed with a sense of ineffectiveness, which is central to the psychopathology of the disorder. Because the self is

experienced only in response to the demands of others, personal pleasures are minimized. Based on clinical interpretations of anorexia nervosa, Bruch argued that therapeutic success would remain elusive unless autonomy, over-conformity, self-esteem, and illness meanings are given attention in treatment modalities.

Santopinto (1988) used a phenomenological approach to study the meaning of the "relentless drive for thinness" for two Anorexics. Three concepts evolved from the thematic analysis: 1) withdrawing-engaging - entering into relations with others and the world while seeking protection through concealment; 2) persistent struggle - conflict between the drive to pursue the desired body-state of thinness while feeling bitter and doubtful about doing it; and 3) imaged self - one of thinness that somehow remains elusive. Santopinto's (1988) study findings conflicted with those from other phenomenological studies (Binswanger, 1958, and Boss, 1963, cited in Santopinto, 1988) which depicted the lived experience of the anoretic as one of despair and helplessness grounded in the past without a clear sense of the future. Santopinto (1988) argued that the anoretic's imaged self is longed for, not feared or dreaded: "Ever aware of the was, one moves toward the will-be, choosing

opportunities that expand horizons of meaning" (p. 33). This author stressed the importance of focusing on both particular and universal aspects of therapeutic interactions.

Turner (1990), in a theoretical perspective on the phenomenology of anorexia nervosa, depicted loss of appetite or refusal to eat as an act intended to defy societal expectations and break communication ties between the person and society. Creating a parallel between loss of appetite and loss of speech, Turner stressed that success with therapeutic interventions is highly dependent on identifying "the conditions under which an anoretic patient can be given a voice" (p. 165). This author argued that given the evolution of anorexia nervosa from a complex interaction of diverse processes (i.e., cultural, social, familial and maturational), successful diagnosis and treatment requires a multidisciplinary perspective that is capable of grasping the variant conceptual levels of the illness.

Moreno, Fuhriman, and Hileman (1995) designed a qualitative study to explore factors contributing to positive outcomes in group therapy. Content analysis of the data revealed that group members identified emotional connectedness as the most salient variable in therapy. Van

den Broucke, Vandereycken, and Vertommen (1995) also used a triangulated approach to identify anorexics' relationship patterns. Although data from the quantitative measures failed to detect significant differences between control and study groups, the self-reporting methods did reveal relatively low levels of openness and high levels of intimacy problems in the study group.

In summary, many researchers and clinicians recognize the complexity and multidimensional nature of anorexia nervosa. The problems posed by failure to achieve true emotional connections with others emerged as a recurrent theme in theoretical and clinical perspectives on the experience of living with anorexia nervosa. However, more qualitative studies are needed to capture the "essence" of living with this illness to facilitate health promotion efforts.

Eating Disorders and Health Promotion Strategies

Social, cultural, political and economic forces have had a significant impact on the slow evolution of health promotion and illness prevention programs. The multidimensional nature and complexity of eating disorders have led numerous authors to conclude that such programs are

sorely needed if we are to combat escalating prevalence rates (Crisp, 1988; Paxton, 1993; Piran, 1995; Rosen, 1989). Currently, researchers are increasing their efforts in developing health promotion and prevention programs for pre-adolescents. However, following an exhaustive review of the literature no studies were identified that focused specifically on health promotion programs for individuals diagnosed with anorexia nervosa or other eating disorders.

Despite the apparent political readiness for addressing primary prevention in health, limited attention is given to the efficacy of health promotion programs for eating disorders (Crisp, 1988). Shisslak et al. (1990) and Rosen (1989) used quasi-experimental designs to evaluate the effectiveness of health promotion and illness prevention programs with high school students. Both studies demonstrated a treatment effect for knowledge but not eating behaviors or attitudes. These authors concluded that study findings were limited by using quasi-experimental designs, and recommended time series designs for future research in this area.

Paxton (1993) designed a time series design (1 month, and 12 months) to deliver a health promotion and illness prevention program to grade nine high school students. The

content and design of the research was based on the recommendations of previous authors (Crisp, 1988; Shisslak et al., 1990). Study findings failed to detect a treatment effect for eating behaviors and attitudes. Paxton suggested that the efficacy of health promotion and illness prevention programs might be enhanced by targeting younger students.

Murphy and Dale (1995) conducted a pilot study in a rural high school to identify eating disorder concerns and the need for health promotion programs. Pretest findings on the susceptibility of students for developing eating disorders were comparable to national statistics. Younger students (grades seven and eight) reported less symptoms than grade nine students (fourteen and fifteen years olds), but older students had greater knowledge about eating disorders. A health promotion program was developed in response to study findings. Although changes in eating habits and attitudes were not assessed, post-test scores demonstrated an overall increase in knowledge levels for all grades (three weeks following the structured session). The authors concluded that health promotion programs should target junior high school students, and time series designs used to monitor behavioral and attitudinal change (Murphy & Dale, 1995).

Moreno and Thelan (1993) used a quasi-experimental design to address the efficacy of a health promotion and illness prevention program developed for grades 6 and 7 students. The experimental group demonstrated increased knowledge, and had healthier attitudes and intentions about dieting and weight. Piran (1995), in a time series study of an elite competitive ballet school (high risk population), reported comparable findings. Similar findings were also reported by Neumark-Sztainer, Butler, and Palti (1995) from a quasi-experimental design with high school students (N = 341). However, these authors acknowledged that significant behavioral changes were noted only in students who did not have an eating disorder.

Porter, Morrell, and Moriarty (1986) showed a significant change in eating attitudes and behaviors in students aged nine to sixteen, according to the Eating Disorder Inventory (EDI). Teaching strategies (e.g., art, dance, music and film to "inoculate" against the drive for thinness) were identified as prerequisites for altering eating behaviors and attitudes in this population. However, generalizability of the findings is limited because participants were at low risk for developing eating disorders.

In summary, the discrepancies evident in the findings from health promotion intervention studies highlight the complexities associated with providing treatment to clients with anorexia nervosa. The effectiveness of health promotion interventions can best be assessed by relying on frameworks that capture the multidimensional aspects of this illness. In addition, appropriate study designs must be used to track the efficacy of interventions over time. Crisp (1988) noted that prevention is a form of intervention directed towards altering the natural history for the better. Primary prevention means intervening before problems with eating disorders surface. Study findings suggest that greater success is achieved with early detection and intervention. Education started at the elementary school level will provide a sound knowledge base to facilitate the formation of healthy attitudes and behaviors (Paxton, 1993).

Discussion

From the literature review, it is evident that there is a dearth of research which focuses on the experience of living with anorexia nervosa. The paucity of research in this area was also noted by others (e.g., Santopinto, 1988).

In contrast, there is an abundance of quantitative research studies that focus primarily on epidemiological, diagnostic and treatment variables. As well, many of these studies have been plagued by methodological and conceptual problems. Rosenfield (1988) stressed the importance and urgent need for more quasi-experimental and longitudinal designs, as well as "rigorous qualitative research to investigate a human response about which very little is known" (p. 51).

Considering the unknown origin of anorexia nervosa, the absence of a unified theory, lack of culturally sensitive diagnostic tools, atypical presentations of the illness and the presence of confounding comorbid conditions, it comes as no surprise that the diagnosis and treatment of anorexia nervosa continues to mystify clinicians. The positive direction provided by recent insights into preventive approaches and a greater willingness to use health promotion strategies is acknowledged and supported by a number of authors (Crisp, 1988; Muscari, 1987; Paxton, 1993).

The diagnosis and treatment of anorexia nervosa, in the past, has been dominated by the biomedical model of care. The term "disorder" is accepted without question by clinicians despite knowing that the pathogenesis of anorexia nervosa extends far beyond the scope of its biophysical

sequelae. Most clinicians recognize the interplay of multiple factors in the onset and trajectory of anorexia nervosa. Without a unified multidimensional model to guide treatment, significant intradisciplinary and interdisciplinary differences regarding appropriate modalities will continue to exist. The prognosis for these clients will remain dismal until precedence is given to their needs.

Gremillion (1992) argued that dominant treatment modalities of the past failed because consideration was not given to all relevant variables (e.g., social, physiological, familial, cultural). This author also noted that the discipline of psychiatry has been largely unsuccessful in treating anorexia nervosa because it poses a challenge to "psychiatric epistemology as well as the social milieu in which both illness and explanation are embedded by reproducing certain core cultural values and meanings of the illness" (p. 58). In view of the fundamental concerns and limitations of current research and the need to enhance the efficacy of health care for anorexics, an investigation into the lived experience of the illness is a plausible effort that will facilitate early detection and treatment.

CHAPTER 3

Methodology And Methods

Methodology means "pursuit of knowledge" and in research refers to the mode of inquiry used by the investigator. As a method in the human sciences, phenomenology focuses on grasping and then rendering the logic of the lived experience without distorting it. The goal of phenomenology is to provide a "description of the experiential meanings we live as we live them" (van Manen, 1994, p. 11).

Methodology

Phenomenological research is concerned with the concepts of (a) rationality, (b) intentionality, (c) consciousness, (d) original awareness, and (e) essences (van Manen, 1990). Rationality in human science operates on the assumption that experience is intelligible and meaningful to those who live it. The powers of thinking, insight, and dialogue allow one to understand the world from the perspective of those who live it. Rationality is an expression of faith that we can make things understandable to each other (van Manen, 1990).

Hermeneutic Phenomenology

This study used van Manen's (1994) hermeneutic phenomenology method to capture the lived experiences of women with a diagnosis of anorexia nervosa. The following steps were taken by the researcher in this study: a) turning to the phenomenon of interest; b) investigating the experience as it is lived, not as it is conceptualized; c) reflecting on the themes which characterize the phenomenon; d) describing the phenomenon through the art of writing and rewriting; e) maintaining a strong and oriented relation to the phenomenon; and f) balancing the research context by considering part and whole.

Turning to the phenomenon. Phenomenology inquiry is driven by a commitment of turning to an abiding concern. This commitment of never wavering from thinking a single thought is the practice of "thoughtfulness". This approach to the phenomenon allows the researcher to concentrate on the whole as opposed to its parts. The research question guides the inquiry and the explication of one's assumptions and pre-understandings of the phenomenon which, in turn, direct the researcher's orientation to the phenomenon of interest (van Manen, 1994).

Investigating the experience. This step refers to the importance of being strongly oriented to the nature of the question. The "taken for granted" and "the given" are held in abeyance in order to enter the world of the person under study (i.e., the anorectic). The researcher investigated the lived world of anorexia nervosa through: (1) therapeutic skills acquired from clinical experiences in mental health "to truly hear" the messages being conveyed by study participants; (2) experiential descriptions capturing the "lived worlds" of eight women with a diagnosis of anorexia nervosa (i.e., two in a pilot study, and six in the current study); (3) reflective accounts of the human experience of anorexia nervosa from diaries and journals (cited in Banks, 1992; Turner, 1990), books such as "The Golden Cage" and "Conversations with Anorexics" (Bruch, 1977, 1988) and "When Food is Love" (Roth, 1991), and a poem, "If Rivers Could Run Backwards" (unknown anoretic author); (4) the researcher's journal writings during data collection and analysis which provided deep reflection and insight into the phenomenon; and (5) a review of other phenomenological studies (e.g., Hepworth, 1994; Moreno, Fuhriman & Hileman, 1995; Santopinto, 1988; Staples & Schwartz, 1990; Sutton-Edmands, 1986; Van den Broucke, Vandereycken, & Vertommen, 1995) to

create greater insight into how lived experiences may be interpreted.

Phenomenological reflecting. Phenomenological reflecting refers to trying to grasp the essential meaning of that which has been articulated. The analysis was directed towards "recovering a theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work" (van Manen, 1994, p. 78). By using the line-by-line approach as described by van Manen (1994), the researcher reviewed and studied the lived-experience descriptions while searching for common themes.

Composing linguistic transformation of each transcript systematically facilitated the development of interpretive narratives that explicated the meaning of the text while remaining true to the essence of the lived experiences. Following repeated revisions of interpretive summaries, the information was compiled into categorical properties according to the common themes and then labeled. This process helped the researcher identify gaps in the data which were subsequently clarified and augmented in a second interview with participants. Insightful conversations with members of the thesis committee concerning the themes, was also beneficial in gaining a deeper understanding of the

text. Reflecting on these themes in alliance with the forementioned pathways of investigating the text, the researcher was able to isolate the incidental from essential themes which articulated the meaning of the lived experience.

Describing the phenomenon. The main function of the phenomenological description is to provide "a reliable guide to the listener's own actual or potential experience of the phenomenon" (Speigelberg, 1965, p. 673). As such, it "describes the original of which the description is only an example" (van Manen, 1994, p. 182). A powerful phenomenological description allows one to "see" that which was not seen before in terms of depth of meaning of the lived experience.

The description of the phenomenon of anorexia nervosa was articulated through the art of writing and rewriting of the text. Writing allowed distancing from immediate involvement with the things in the world and allowed one to externalize what was, in some sense, internal. Writing united the researcher more closely with the lived world of the anoretic.

Strong/oriented relation to the phenomenon. While assuming a strong orientation to the phenomenon, the

researcher became engrossed with the original question in order to gain access to lived experiences and to ask the subject "what is it like?" (van Manen, 1994). Even with a strong orientation to the phenomenon, description is just one interpretation, and does not negate the possibility of another complementary, richer, or deeper description.

Balancing. Phenomenological themes may be conceptualized as the experiential structures which make up an experience. Themes are the parts which fit together to make up the whole. Each theme is interconnected and dependant on the other. The researcher constantly measured the overall design of the text against the significance that the parts must play in the whole structure. In the art of writing and rewriting the text, one can lose a sense of direction and fail to capture the essence (whole). It was, therefore, necessary to pause and step back, look at the total or "the given", and try to identify how each part contributed to the whole.

Methods

van Manen's (1994) phenomenological approach was used to guide the inquiry into and the analysis of women's experiences in living with anorexia nervosa. With this form

of inquiry, the researcher is viewed as a scholar of human science research and the phenomenological method as "scholarship" (p.29). This section will present a detailed overview of the methods used in this study.

Participants

The population of interest was women who met the diagnostic criteria for anorexia nervosa, or relevant subtypes of this eating disorder. Study participants met the following inclusion criteria: (a) female, (b) out-patients, (c) English-speaking, (d) nineteen years of age and older, (e) living within 100 km radius of St. John's, Newfoundland or Kentville, Nova Scotia, (f) physically and emotionally stable (i.e., clinical competency was assessed by attending psychiatrist in Newfoundland, and clinician in Nova Scotia), and (g) participating in health promotion activities, such as group or individual counselling.

A phenomenological inquiry lends itself to fewer participants, as interviews yield vast amounts of narrative data for analysis (Dukes, 1984). Although small sample sizes are normally adequate, subjects were enrolled into the study until no new descriptions and/or themes emerged from the data. Six participants were recruited for this study.

Procedure

Potential participants were selected through consultation with professionals (intermediaries) working with the Health Care Corporation of St. John's, Newfoundland, and Valley Regional Health, Nova Scotia. Potential participants who met the inclusion criteria were contacted by the intermediaries to: (a) inform them of the study, (b) determine their interest in participating, and (c) obtain permission for the investigator to contact them. Three of the nine contacted refused to participate because of concerns that talking about the past would cause an illness relapse.

All study participants chose to be interviewed in the researcher's office. Interviews were scheduled after clinic hours to maximize comfort and ensure confidentiality. A detailed overview of the study was presented, and informed, witnessed consent was obtained prior to the first interview (see Appendix A).

The first interview of each participant was audiotaped and lasted approximately ninety minutes. Participants were asked to describe their experiences with anorexia nervosa, and open-ended questions used to prompt or clarify statements (see Appendix B). With phenomenology, the

researcher's question guides the mode of inquiry and the subject's commentary, in turn, guides the reflective questions posed by the researcher (van Manen, 1994).

During the second interview, two to three weeks following the first, each participant was asked to confirm an interpretive summary derived from the text of the first interview. Insightful questions were asked to clarify identified gaps in the text. One participant also agreed to review the thematic classification generated by the researcher, adding further richness and support to the emerging themes. The phenomenological writing of the text was edited based on feedback from this participant, and a third interview arranged for further understanding and confirmation of the thematic analysis.

Ethical Considerations

Permission to conduct this study was granted by the Human Investigation Committee (HIC), Memorial University of Newfoundland (see Appendix C), and the Research Committee at Valley Regional Hospital, Western Regional Health Board, Nova Scotia (see Appendix D). Letters of support for the study were also received from psychiatrists (see Appendix E) and administrative personnel (see Appendix F) at the Health

Care Corporation of St. John's.

For ethical reasons, the HIC at Memorial University, required that the attending psychiatrist address the competency level of potential participants prior to intermediator contact. Study participants from Nova Scotia were evaluated for clinical competency by the attending clinician. Provisions were also made for an independent clinical competency assessment of Newfoundland subjects according to specified criteria (see Appendix E).

During the initial telephone contact, the researcher outlined possible risks and benefits, the purpose of the study, and the voluntary nature of participation. Upon receiving verbal agreement, an interview time and setting was arranged.

At the initial interview, issues of concern were clarified; and written, informed consent obtained for participation and audiotaping in the presence of the researcher and a witness. Participants were informed that they could withdraw from the study at any time and refuse to answer any questions posed by the researcher; and that their transcripts would be read by the thesis supervisor and one committee member. To assure participants of the confidentiality of disclosed information, all were informed

that: (a) codes as opposed to names would be used to identify transcripts and corresponding audiotapes; (b) direct quotes would be used to support the emerging themes but the use of interview numbers and omission of identifying markers (e.g., physicians, health care facilities or therapists) would ensure confidentiality; (c) audiotapes would be erased following a review of transcripts for accuracy; and (d) interview transcripts and consent forms would be kept in a locked filing cabinet accessible only to the researcher and thesis supervisor.

Although participants were reassured that there were no expected risks, it was stressed that certain interview questions could potentially elicit uncomfortable memories. Particular attention was given to participants' verbal and non-verbal responses during the interviews, and reminders were interjected to address only those issues they were comfortable disclosing. All questions asked by the researcher were received by the participants as non-threatening, and all commented on how comfortable they felt in revealing their lived worlds to the researcher.

As well, the researcher has eighteen years of clinical experience in the area of mental health, has completed a practicum in counselling at Memorial University's

Counselling Centre, and is presently a mental health clinician in the province of Nova Scotia. Based on this background, it was anticipated that risks to participants would be minimal. If the researcher detected maladaptive coping, the interview was to be terminated. In addition, the emotional status of each participant was assessed before terminating the interview. All were encouraged to contact the researcher if any concerns or questions surfaced.

Data Analysis

Immediately following each meeting, the researcher transcribed verbatim the audiotaped interview while carefully noting nonverbal information recalled. Each transcript was read and reread to grasp what was "being said". This approach allowed the researcher to dwell with the data, and acquire a deeper meaning about the lived world of anorexia nervosa.

The researcher made all possible efforts to bracket any thoughts, feelings, preconceptions, and beliefs about the phenomenon under study. The use of a "detailed approach", as outlined by van Manen (1994), during thematic analysis facilitated identification of what was being revealed about the phenomenon. Through reading and rereading of each

sentence in the text, the researcher explicated the themes and meanings. Theoretical sampling was used to obtain representative slices of data to support the conceptual themes emerging from the data.

The thematic coding of each text was also conducted by the thesis supervisor. Following analysis of the first four interviews, a meeting was held between the researcher and thesis supervisor to discuss the identified emerging themes. This meeting ended with a consensus on the thematic analysis process and the emergent themes. As the themes were clarified through the process of writing and rewriting, the researcher was able to grasp a better understanding of the text. Eventually, the descriptive commentaries reflected an hermeneutical interpretation of the text which provided a meaningful context for the thematic statements.

Towards the end of the data collection period, the text of two participants was also coded by a committee member. Another meeting was held to discuss the emergent themes and dialogue with the phenomenon. This discussion was followed by a period of deeper reflection, and rewriting of the text to capture the essence of the lived experience of anorexia nervosa.

Reliability and Validity

It is difficult to achieve the same degree of reliability and validity with qualitative research as in quantitative research. Although reliability in phenomenology is more readily attained than with other qualitative modes of enquiry, van Manen (1994) indicates that the only generalizability allowed in phenomenology is "never generalize" (p. 22).

Qualitative enquiry is evaluated in terms of credibility, fittingness, auditability, and confirmability (Krefting, 1991). Credibility was established by having participants review the summary of their interview. Study participants read their interpretive summary, written to reflect the emerging themes, and readily identified the descriptions as their own.

Credibility and auditability (consistency) is reinforced through member checks (Hoffart, 1991). Two researchers experienced in qualitative analysis (i.e., thesis advisor and committee member) read the transcripts and conducted a thematic analysis of the text. Discussions confirmed and refined the themes, and helped clarify the meanings emerging from the text.

Fittingness (applicability) of the findings is ensured

by recruiting participants who are good informants (i.e., clearly articulate the "lived experience" of anorexia nervosa). Study participants were good historians who provided rich data to facilitate insight into major themes.

Confirmability (neutrality) is achieved through credibility, auditability, fittingness and bracketing. The researcher used bracketing to promote objectivity and limit potential bias by recording thoughts and feelings during data analysis. Credibility, auditability and fittingness were enhanced by having participants confirm their summaries, through member checks, and by having articulate and open informants.

CHAPTER 4

Findings

What is it like to live with anorexia nervosa? What forces act upon and nurture the growth of this illness? These questions are explored from the perspective of six women who have lived with anorexia nervosa.

This chapter is divided into four sections. The first section presents a brief overview of study participants. The second section describes the themes that emerged from the phenomenological analysis of the text. The third outlines the interrelationships among the themes. The final section captures the essence of the lived experience of anorexia nervosa.

Introduction to Participants

The women who agreed to participate in this study had been living with anorexia nervosa for a period of six to eighteen years. The time interval varied from time of onset of the eating disorder to actual diagnosis and treatment. The duration of the disorder, as well as the age of onset and timing of diagnosis, were key variables associated with prognosis.

Recovery is defined as maintaining a stable weight and

not actively engaged in restrictive behaviours (e.g., excessive dieting and exercise, medications); whereas, prognosis refers to the probable course of the disorder and the prospect of recovery (Bruch, 1988; Reiff, 1990). Based on this criteria for illness stability, all were considered to be at different points in the recovery process with prognosis potential varying from good to poor.

One participant, a single woman pursuing postsecondary studies, had a family history of both eating and obsessive compulsive disorders. Initially diagnosed with the non-restrictor form of anorexia nervosa in early adolescence, she was subsequently reclassified as the illness progressed to restrictor subtype. From her own reports, she had been living with this illness for approximately ten years. Although never hospitalized, she had extensive involvement with health care professionals over the years. She is currently considered to be in the recovery phase. Her prognosis is rated fair to good.

A second participant is married with no children, and is currently working in the health care field. From her reports, the illness started in early adolescence. Although she has lived with anorexia nervosa for seventeen years, she was not clinically diagnosed until three years ago. This

woman also has the clinical diagnosis of obsessive compulsive disorder. She has been actively involved in individual and group therapy and hospitalized on two occasions. She is currently considered to be in recovery, and her prognosis is fair.

A third participant, a single woman working as a receptionist, still lives at home with her mother. There is a familial history of alcoholism. Based on her reports, eating disorder problems did not surface until her early twenties. She has been living with anorexia nervosa for eight to ten years but was not diagnosed until eighteen months ago. Hospitalized at the time of diagnosis, she has been receiving out-patient therapy since discharge. At this stage of her illness she is not considered to be in recovery. Her prognosis is fair to poor.

The fourth participant, a single woman pursuing postsecondary studies, is still living at home with her parents. There is a familial history of eating disorders. From her reports, the illness started in early to mid-adolescence. Diagnosed with anorexia nervosa six years ago, she has received various forms of treatment but has avoided hospitalization to date. Her prognosis is fair to good, and she is currently "on the road to recovery".

A fifth participant is married with two children and is a clerical worker in the public service sector. This woman was diagnosed with clinical depression in late adolescence and hospitalized for treatment at this time. Although she reports having lived with anorexia nervosa for about eighteen years, she was not clinically diagnosed until two years ago. Her exposure to health care professionals and formal treatment for an eating disorder problem has been quite limited. She is considered to be in the recovery phase of her illness, with a good prognosis.

The sixth participant, a divorced woman with no children, works in the food service industry. First diagnosed in early adolescence, she has been living with anorexia nervosa for seventeen years. Since the onset of her illness she has received extensive therapy. This woman has experienced several relapses and continues to oscillate between periods of recovery and acute illness episodes requiring hospitalization. Her prognosis, to date, is poor.

Thematic Analysis

This section presents a detailed discussion on the themes identified from the thematic analysis of the interview transcripts of six women living with anorexia

nervosa. Although presented separately to highlight different aspects of the lived experience, the themes are interrelated and interdependent with each flowing into and overlapping with the other. The eight themes identified were: weakened self, a struggle for control, controlled by the illness, concealing the self, feeling consumed, readiness to change, letting-go while holding-on and breaking the cycle.

Weakened Self

The image of the weakened self unfolded as participants reflected upon the onset and trajectory of their illness. Webster's (1988) dictionary defines weaken as "to lose or cause to lose strength or vigor". Synonyms for weaken include debilitate, undermine, cripple, and disable. As used in the current context, this suggests that study participants never really acquired an adequate sense of self.

Within the narratives conveying the experience of living with anorexia nervosa, frequent reference was made to early childhood experiences that undermined development of adequate feelings of self-worth and self-esteem. Self concept is how we see ourselves - the value that we place on

all of the parts that make up and shape our personhood. Self-esteem is the feeling component of self concept and is a statement about how much a person likes the self. If high value is placed on beauty and thinness, then feelings about the self will be influenced by the degree to which an ideal image is achieved.

Participants used words like "always shy", "low self-esteem" or "never liked myself" to describe earliest memories about themselves. One woman stated:

> I always had a body image problem . . . . Like, I've always thought I was too fat. Always. Not pretty enough. Too fat. Always. Ever since I can remember.

She recalled a crying episode at her seventh birthday party which was prompted by wanting to look like her close friend: "Why can't I be pretty like that? Why can't I be skinny like she is?" How does a child of seven develop low self-esteem and be reduced to tears because she does not feel pretty enough?

Maslow's hierarchy depicts a linear progression through the lower basic needs (i.e., food and shelter, safety and security, love and belonging) to higher level needs (i.e., self-esteem, self-actualization). For persons living with anorexia nervosa, attainment of lower level needs becomes a

persistent struggle. A child's cry at an early age, as described above, reflects an innate response to inadequate fulfilment of basic needs (i.e., lack of food, shelter, safety, security, love or warmth). The important question is which of these needs were not met during her childhood and, equally important, how did she learn to equate the basic needs of survival with beauty and thinness?

When children are deprived of love and affection, the turmoil and physical/emotional pain leaves them weakened - the core of their personhood altered by the severed bond. When forced to separate from her parents at an early age because of physical and emotional abuse from her mother, while another sibling was allowed to stay at home, one woman experienced feelings of rejection:

> But she didn't keep me! . . . And I remember that [*brother*] was allowed to be there [*home*] and I wasn't. They wanted him but they did not want me. . . . I've got a lump in my throat now. It's hard. It's hard.

The passage of time has not ameliorated her grief. Because positive comments received from others were primarily expressed in terms of how attractive she looked, she began to define her self-worth in terms of external appearances.

> I always felt like I had to be pretty. What would I do if I wasn't? They wouldn't love me. They wouldn't have anything good to say about me. Because they never

said anything else other than that.

As a child she learned to devalue her self-worth and moved into the outside world without adequate skills to form meaningful relations with others.

To trust is to have faith in, to believe in, to confide in, or to commit to someone the responsibility of care. Without a strong foundation for trust, a person's ability to trust themselves and develop close and meaningful relationships, which always contain an element of risk, is severely hampered. One woman spoke about not feeling bonded or connected to another:

> I never felt connected to anyone. I have always been moving around at work but I never connect . . . . The only one I did connect to was a two year old child (*pause*). She had cancer (*longer pause, no eye contact, no change in voice tone*). And she died.

The impact of not feeling connected was conveyed through the lack of emotional expression in her words, voice tone, and body expressions. Her emotional growth was somehow damaged, leaving her searching for a sense of who she was and meaning in life.

A synonym for connection is attachment. Attachment is derived from the Middle English "attachen" and the old French "attacher/estachier" which means to fasten.

Attachment projects the image of something, although not tangible, that is very strong and powerful, allowing one to become whole.

Interaction patterns within families impeded autonomous growth and healthy separation of these women from family members. Some talked about family dynamics as controlling (i.e., "dictated", "very religious", "regimentally ruled"). One woman described parental control thus: "We were not allowed to go out after school; we had to come right home." The lack of connectedness and restrictions on interactions within and outside the family unit erected barriers to healthy separation and, ultimately, the attainment of autonomous existence.

For those who talked about family relationships as being "really, really close", there was a definite sense of overconnectedness. Webster (1988) defined close as the degree of commonality among associated elements whereby there is no deviation from the original. As described by certain participants, family relationships appeared to reflect "complete enmeshment". The growth of the self and individuality are lost when one becomes a mere shadow or reflection of the other.

When not allowed to assume responsibility for

independent thinking or autonomous actions, the person moves into the outside world full of fear and uncertainty. The voices of two women echoed this:

> I hate family reunions. I hate it when all my family is home. Being sick has kept me home. So I envy them [*family members*]!

> I want to leave home but I am so scared. Scared that it [*anorexia*] will come back [*tearful*].

As these women talked about close relationships with significant others, the emotional pain of not being able to sever family ties and move on with their lives was apparent. Today, both women are living at home and still dependent upon their families for the basic necessities of life - safety and security. The intense family closeness appears to have left these women in "a body without a voice".

Women who were socialized within either close or distant families learned not to talk about their feelings, thoughts or emotions. There were no guideposts or markers to help with the mastery of socially acceptable means of expression.

> I don't know how to talk on that level [*about feelings, fears, thoughts or opinions*].

> Growing up we were a close family but we never talked about our feelings! . . . I always kept things to myself. I was always scared of hurting someone else! Or, they would say it was no big deal.

Feeling inadequate and worthless in social interactions with peers, these women were preoccupied with hiding and protecting themselves from others. To avoid hurt, or to receive confirmation of feelings of inadequacy, social activities were restricted or only superficial relations formed (i.e., not have "tight friends"). One woman made the following comment about her adolescent years:

> All the attention was on her - I was nothing. I was - like - not there! . . . I was so small. Like I felt like I was so small.

It was almost as if she was saying that others would not like the "real" her (i.e., I do not like me, so how can others like me?). There was an obvious lack of trust in herself (i.e., not feeling safe or secure with the self). This inability to connect was echoed by others in comments about friendships: "I could not correspond with them."

In some ways, these women exhibited child-like features (i.e., insecurities and fears especially when faced with emotional stress) as they talked about feeling "like a child". A poignant example of this was one woman's description of a dispute with her husband:

> When I got home, he was shaking a finger at me and I just snapped! I snapped! I don't know! I think I only weighed 80 pounds. I snapped! I felt like he reached into my **little** chest and tore my **little** heart out and threw it on the floor. I could see

> my **little** heart going across the floor. I did not talk to him. I had nothing to do with him. I called Mom to come and get me. She said to hang in, it was the holidays. Well, I was shot!

Child-like judgments were also evident from participants' categorizations of behaviours within the family, society or themselves as being either good or bad, right or wrong. This kind of moral reasoning or dichotomous thinking is characteristic of children.

Emotional reactions to the pivotal role played by family interaction patterns in illness development were manifested in diverse ways (i.e., anger, denial or without feeling). One participant conveyed anger through voice tone and body posture as she spoke of her battle "to get even" with her parents: "I rebelled, I got pregnant and I was glad to get back at them". In contrast, another became tearful and denied that her mother's earlier preoccupation with body image could be a contributing factor in the development of her eating disorder: "It was not my mother's fault . . . consciously, I don't remember her being preoccupied about her weight." Another participant appeared to be working on forgiveness and tried to rationalize what had happened by placing events in a meaningful context: "Alcoholism was his control and anorexia is my control".

When a true bond of affection and friendship is forged with another, growth and development is nurtured - like the seed planted in rich soil and exposed to warmth and sunshine. As these women told their stories about living with anorexia nervosa, each described a weakened sense of the self which began in early childhood. Without a strong base for growth and development, they wandered aimlessly while engaging in a persistent struggle with daily living.

Struggling for Control

The intense fears about not being able to control things (i.e., external controls too powerful for the self to feel "in-charge") were echoed by all the participants. Webster's (1988) dictionary defines control as "holding steady or in check; to regulate". Control is a learned behavioural response. A two year old child exhibiting temper tantrums learns, with appropriate discipline, that such out of control behaviours are not acceptable. As a child moves through the various stages of growth and development, s(he) becomes more in tune with how the self interacts with the environment and learns how to control self-gratification impulses.

At a very young age, these women had fears about not

being able to control things in their lives. Some talked about parental control, tactics concerning diet, and eating habits. One participant talked about feeling fat and used the word "mortified" to describe her reaction to being forced by her mother to join an established weight reduction program. As she talked about having to associate with adults (i.e., "I was the youngest; I did not want to be there."), her fears about having no control over her life was evident. Later, she acquired a liking for the program and was driven by its secondary gains:

> I was losing weight and that was good . . . all the compliments and everything that goes with it . . . I think that was the first time that I did and I was successful at doing it.

Her self-concept was boosted because this structure gave her the confidence to incorporate dieting behaviours into her daily routine. She had learned a means of control, which allowed her to feel good about herself. However, when her mother observed an adequate weight loss, she once again resumed control of her daughter's weight and forced her to withdraw from the dieting program.

A second participant talked about early memories of her mother's reactions and behaviours towards her eating habits:

> I never did eat much. My mom would get after me to eat breakfast. I never liked eating before

> that. My mother literally sat on me to make me eat. Going to school she would pack a lunch and I would not eat it. [*long pause*] I never [*pause*]. Like if there was another way to live, eating would not be in my life. I always said that.

Ironically, one woman was forced not to eat and another forced to eat; both learned to reject food in their struggle for control.

Family interaction patterns also elicited a negative impact on eating behaviours. One woman placed her problems with control and the use of restrictive behaviours to manage stress within the family context.

> In Grade six, like I remember it as if it was yesterday. My mother and father were going through a divorce/separation. There are seven in my family . . . . It affected us all differently. It affected me by not eating. It was stressful and the only way I could deal with stress was not eating . . . . Then in high school the exams came and the only way to deal with the stress of exams was not eating. I was scared to gain weight! I felt in control [*pause*]. I felt it was helping me deal with the stress. I felt better when I did not eat. This monster is all about control.

Following a stressful period in her life, she learned that doing without food eased her anxiety and left her with a greater sense of control.

Others' comments about body image provoked intense anxiety and heightened feelings of worthlessness. Because of low self-esteem, some were unable to accept constructive

criticism or place it in an appropriate contexts: "Some good legs to walk on. Meaning they were quite solid and chunky legs!" One participant's worst fear was that no matter what she did, it would never be good enough.

> They told me to lose weight. So I was really upset. I was like really upset. So, I started doing the exercising and all that stuff again. I used to exercise probably two to three hours a day . . . . I'd just exercise an hour more. I kept adding on hours that I wouldn't normally exercise.

Self-esteem and self-worth were equated with being thin; the beginning preoccupation with body image. Heightened feelings of fatness were eased only by a strict exercise and restrictive dietary regime.

For another participant, feelings of worthlessness and fears of rejection were lifted after a weight loss during an hospitalization for depression. Positive feelings about herself were also reinforced when someone took an interest in her. She perceived her thinness as the reason for the attraction: "The first time I ever felt good about myself".

Without a strong inner core, these women were forced to rely on information from others to judge their self worth and identity. This inner struggle for control and acceptance led them on a life long journey of trying to please others:

> I do too much for everyone. I basically do not know how to look after myself. If I don't do it, I feel guilty about it. So, I push it to the extreme limit when I can't do anything for myself. I am constantly, going: that little energized bunny on TV, that's me. I keep going and going. And on nothing. I basically put all my energy into making him live. I didn't realize I was slowly killing myself to let him live.
>
> I always did things to please others. I feel guilty when I do things for myself.

Feelings of inadequacy and low self-worth propelled them to seek confirmation of their value from the pleasures received from doing things for others.

Without a sense of self (i.e., "controlled all my life") and struggling to be accepted (i.e., "I was not worth it"), these women learned from parents, and to a lesser extent society, that thinness meant goodness. Perfection and acceptance could be attained through thinness.

> Well, growing up . . . people would say that I was - you know - pretty or whatever . . . but I did not believe it. [*short laugh*] . . . . Never did, never will . . . and, I always had this thing about my body - that it had to be a size five. It just - if it wasn't - cause where I'm kind of tall - size five would be the size I wanted to be, no matter what right? I didn't care what I had to do.
>
> It was kinda brought to my attention by my parents that I was a bit heavier than I should be. I remember going shopping with my father . . . . And I ended up with a larger size . . . when I came home my mother was really upset . . . . And you know they had to go back!

All of these women subsequently came to operate under the delusion that body image was the most successful expression of self-worth and the only way to receive attention, praise or acceptance.

Restrictive behaviour practices were learned through friends, family, and the media.

> I heard about it [*restrictive behaviours*] at work.
>
> Weight was always a big thing in my family.
>
> The rest of my bothers and sisters were very heavy. I was always scared to put on an ounce of weight
>
> Then I guess with television, newspapers, and magazines . . . this be thin paraphernalia and all that stuff.

Armed with the essential knowledge on the "how-tos" of restrictive practices, these women now had the means to expression and control.

Self appraisal was rated in terms of feedback received from others following the use of restrictive behaviours (i.e., dieting and exercise) to promote an ideal body image. Positive feedback often provided a needed boost for low self-esteem feelings: "They all told me I looked good. I felt great!" These women had learned from outside the self that dieting and restrictive behaviours did bring happiness

and some control into their lives: "I had control. It was the only way I could control."

Periods of oscillating between weight gain and loss dictated how one felt about the self. Weight gain was accompanied by a bad mood:

> I hated the way I looked. I hated it. I - like - I did not want - I just did not want to look at myself. [*And with weight loss*] I felt great.

Self-worth could be measured on the bathroom scales: "I would weigh myself all the time."

Participants identified specific behaviours and cognitive measures that allowed them to feel in control (i.e., "I used diet pills, laxatives and diuretics"; "I could not purge so I had to stop eating"). Having never felt a good sense of control over their lives, when control was demonstrated through exercise and diet they felt stronger and more secure in dealing with stressful life events.

> It was like always something going on. Something in the family - stress! It was always stress that brought it on. I'd get up in the morning and see that I gained weight. And oh, . . . the scales I was always on them. We had to throw them out of the house. I go towards diet pills, laxatives, or walk sometimes. It was nothing for me to walk ten to fifteen miles a day. I felt great then. I'd think I had it all off and then I'd feel great!

The intensity around diet and exercise restrictions was

often accompanied by a strong drive to achieve high grades in school or excel in careers. For some, developing a competitive spirit and an intense preoccupation with being strong willed generated in-control feelings.

Since strength and control were thought to be gained from denying the body food, these women measured another's weakness against similar standards (i.e., eating food). For example, some participants repeatedly enticed others with their culinary skills and watched them eat, or chose careers that involved analysing or preparing foods; however, none chose to be connoisseurs of food.

> Can you imagine I took pastry cooking with an eating disorder. I loved baking and cooking for my sisters and brothers. I loved seeing other people eat! . . . But to sit and eat it, is a whole different ball game! . . . When I am tense I can't eat! . . . I can't even look at it.

Another participant talked about cooking meals for her family (all obese) and achieving control by just sitting at the table picking her food.

> I was sitting down with them and I was eating some. It was hard! It was hard! It took a lot! I found, if I am cooking for someone else, I will sit down and pick. But when I am alone, it is not worth cooking for one person. It's not worth it.

Another participant repeatedly emphasized that she was not bulimic because she was strong enough not to eat. Another

indicated that she was jealous of people who weighed eighty pounds and wanted to be like them because, "They got the will power not to eat."

The lived world of these women reflected images of one who is unable to identify inner strength and regulate the stressors that accompany daily living. Without a well developed sense of self, all were left to rely on feedback from others to judge their self-worth. As they struggled to live a meaningful life, they learned that restrictive behaviours enhanced their sense of control over stressful events and boosted their self-esteem.

Controlled by the Illness

When dieting becomes an obsession, everything else revolves around it. Obsession from the Latin word "obsidere" means to besiege or to have an unreasonable compulsion, idea or emotion causing preoccupation. All of these women had learned to engage in restrictive behaviours to measure self-worth and gain control: "The thinnest I could be was the best that I could be." As they became obsessed with restrictive behaviours, they withdrew from a world where they felt no control.

As participants became more and more obsessed with

their weight, dieting continued to be monitored (i.e., "I weighed myself all the time, 10 to 15 times a day.") and exercise hours increased to buffer caloric intake. All of these women talked about studying calorie books and using a cycle of intense exercising (e.g., "I exercised like crazy.") to rid the self of the caloric intake. To eat was a sign of failure and a weakness that was visible to others: "Then when I see what I'm eating, I feel so bad, like I am a failure." As stressors increased out-of-control feeling states, some incorporated additional restrictive measures (e.g., diet pills, laxatives, purging, and diuretics) to regain control and pursue their quest for an ideal body image: "In high school I tried diets, diet pills, laxatives, exercise. I am still fanatic about exercising . . . I have tried it all. I have done it!" Others sought control by developing a relationship with someone reflecting their ideal body image (i.e., "tall", "thin", "absolutely gorgeous"). However, this type of relationship crushed their self-esteem and created further inner turmoil.

Cycles of severe food restrictions, excessive exercising and over-the-counter remedies followed by binge-eating, purging or starvation exposed the body and the mind to potential lethal insults. As one participant noted:

> Binges, where I had to eat something . . . would last for that moment, then I would be depressed. . . . Then I would have to starve myself again.

This intensified out-of-control feelings and pushed her anxiety to the point where the only effective relief came from engaging in restrictive behaviours: "I told myself I was strong and I had to do it. I had to be strong enough to stop to do it *[eating]*!"

When relapses were experienced with restrictive activities, this confirmed their image of themselves as weak. Periods of being unable to maintain high level dieting (i.e., "lost control of it") were labelled as "falling-off" or "binge eating" and evoked intense dislike for the body (i.e., "I looked horrible."). Some of the women described the physical pain consequential to their body's reaction (i.e., "severe abdominal cramping", "dizziness", "unable to stand") to high doses of laxatives, diuretics or diet pills, as well as exercise and dieting. Yet, the drive to engage in restrictive behaviours to boost feelings of being in control took precedence over their physical health (i.e., "I did not care."; "I had to do it.").

Two of the women talked about the presence of medical problems and the effects on the body and mind:

> I had a lot of medical symptoms before - but it was when my periods started to go - like I was tired - always having headaches - fainting. I had to be moved [*area of work*].
>
> I was dizzy, I was passing out, I could not stand up for long periods of time, which I had to do in school. It was. [*long sigh*] I was tired. It had control over me. I felt like that I just had to do it.

The measures chosen to facilitate feeling "in control" eventually progressed to "take control" as cognitive or thought processes also became affected:

> I could not even talk clearly . . . I was not allowed to answer the phones any longer because the customers could not understand what I was saying.

Even when such extreme points were reached, there was a strong denial that there was a problem. However, due to the presence of external signs of something being wrong, it became exceedingly more difficult to conceal the illness.

As these women became more and more controlled by the illness, fears about not being good enough for social interactions enhanced feelings of worthlessness: "I never felt as good as them." The end result was enhanced anxiety feelings which drove them deeper into the relentless pursuit of thinness and the struggle for greater control. However, each measure instituted led them further away from the real world and a step closer to the unreality of restrictive

behaviours.

One participant talked about her experience at modelling school and the decisions she was forced to make in order to reduce anxiety.

> I didn't want to talk about it [*weight*], because I was afraid they would ask . . . . I was too big to be there . . . . Not pretty enough to be there . . . . So I quit . . . . I felt better after that.

All of the women echoed similar remarks about their inability to cope with the demands of weight restrictive measures: "The only thing I could do was to stop eating. It was the only way I could control things."

For these women, the experience of living with anorexia nervosa was described as a struggle for control while simultaneously being controlled by the illness. The continuous struggle for self-control escalated when increased feelings of inadequacy and heightened anxiety states were relieved by additional restrictive behaviours. As control over self-imposed restrictions waned, the struggle to conceal the illness became more difficult.

Concealing the Self

Concealment is derived from the Middle English term

"concelen", the Old French "conceler", and the Latin "concelare", which means intensive measures to hide. The strong preoccupation with concealing restrictive behaviours was associated with: (a) fears of rejection - the major driving force behind projecting an image of strength or normalcy; and (b) holding on to unreality to protect the self against reality.

Fears about being rejected by others if they became aware of the desperate measures used to achieve control is captured in the following statement:

> It would be humiliating for anyone to know that was how I was trying to control my weight. I never would have told a soul.

The importance of appearing normal and being accepted by others necessitated secrecy concerning restrictive behaviours. Breaking the concealment would be comparable to admitting inner weakness and differentness.

The drive to conceal was almost as intense as the obsession with restrictive behaviours. One participant became tearful as she talked about why her parents could not know about her eating disorder:

> My parents did not see me, they did not know what I looked like. [*pause*] I did not want them to worry about me.

In the early stages of the illness, concealment was

possible as family and friends perceived dietary and exercise habits to be normal behaviours. For some, the lack of routine around meals eased the burden of concealing aberrant behaviours:

> I never ate dinner . . . . I just pretended I had dinner. I'd make the plate look dirty and sometimes like I'd just throw it out. I'd just tell him I ate at work.

These experiences provided positive reinforcement and increased feelings of control. As restrictions became more pervasive and weight loss increased, the struggle to keep the secret became more difficult: "I wanted him to see me eating. I needed him to think I was eating."

A great deal of time and energy went into devising plans to convince others that they were "normal". Situations had to be cognitively appraised ahead of time for their conduciveness for concealing restrictive behaviours (i.e., location of bathroom in terms of audibility regarding purging; eating with friends prior to class but possibly drawing negative attention to the self by having to leave to purge). Others described food games to conceal restrictions (i.e., "pushing the food around"; "throw it out if I could . . . when no one was looking"; "get up from the table . . . and distract").

Denial that a problem existed helped these women project an image of normalcy. For one woman, denying allegations about restrictive behaviours made by her friends allowed her to continue the struggle for control and acceptance. Although hospitalized several times for depression, antenatal problems and deliveries, none of the health care workers considered an eating disorder problem. Her family doctor, whom she visited regularly for check-ups, and her family also failed to notice the extreme weight loss or address the issue. Because she was successful at hiding restrictive behaviours and her weakened self, she believed that she was strong and in control.

The intensity of the obsession with restrictive behaviours left some with no time to dwell on real world issues.

> One day he was there, the next day he was gone; I was devastated.
>
> My parents are so happy, now . . . . When I found out about their separation I was not going to go home! I just lost it!

Seeking to escape a world which constantly reminded them of personal weakness, they entered a world dominated by control through preoccupation with thinness.

Even at the point of extreme emaciation, these women

saw themselves as fat. This altered body image is conveyed in the following passage:

> I could not figure out who this person [*on the picture*] was. Even when my sisters said: Look at it . . . I said who is this? I don't remember anyone being there. They said: It's you! [*pause*] I looked horrible, I looked terrible and I didn't recognize myself!

Despite using drastic measures to gain control through weight loss and concealment of these behaviours from others, self-esteem plummeted.

As stressors increased and higher doses of restrictive behaviours were required to alleviate the pain, there was a constant preoccupation with thinness: "It [*food*] was always on my mind." For all these women, hiding the secret allowed them to remain in control and escape rejection by others. Successful concealment also helped them deny that a problem existed, even in the presence of medical problems. Ultimately, the dual obsessions (i.e., restrictive behaviours and concealment) became too powerful, weakening perspective of reality and heightening their feelings of living a meaningless existence.

Feeling Consumed

Feelings of "being consumed" by the illness were

expressed either implicitly or explicitly by all of these women. To consume is derived from the Latin word "consumere" which means to take completely or to take up intensely. The synonyms for consume (e.g., devour, dissipate, demolish, destroy, waste), when applied to a person with anorexia nervosa, conjures up an image of someone being eaten up and left with a sense of "nothingness".

As the person progresses from feeling in control to being controlled and then consumed, the illness is objectified or seen as separate from the self (i.e., "You are consumed by it."; "It consumes you."). One woman gave a vivid description of moving from a period of feeling good about herself and life in general (i.e., first three years of marriage) to being controlled by her husband and then consumed by anorexia nervosa. When faced with marital stressors, she found it difficult to cope with the magnitude of external controls.

> I felt like his puppy dog on a leash and every time he would tug me back when I would be out too far . . . . I was not supposed to be sick. I was supposed to take care of him . . . . I didn't realize I was slowly killing myself to let him live . . . . He took my freedom . . . . Then he almost took my life. I went two years without eating. I lived off chocolate bars, tea, coffee, and water. That is the only way I could have control. I did not care any more.

Each time she experienced a relapse it became more difficult to find a safe place because the struggle became harder: "It's a battle and I am losing." The illness eventually progressed to a point where she felt consumed by out-of-control feeling states:

> Living with anorexia is like having a monster inside of you. It consumes you. You can't escape it. Like it has complete control of your whole life. It wants you to do one thing and your body wants you to do something else. This monster takes over. It's very hard! It has all the control; you have none.

The depths of her struggle to gain control through restrictive measures escalated to the point of zero tolerance for food: "Like the sight, the smell of food made me vomit. I could not go to the grocery store."

Other women spoke about the paradoxical nature of anorexia nervosa. What at first seemed to be a means to achieve control, later became a catalyst for enhancing fears and insecurities. The false sense of security brought by self-control through restrictive behaviours rapidly dissipated and was replaced by feeling consumed by restrictions. For some, it became extremely difficult at times to separate the real from the unreal (i.e., dreams about eating or blowing a diet evoked panic attacks).

> I wished I could eat because all day I thought about food and I'd even dream about food and eating it. And

> I'd wake up and think that I had ate - and being all anxious because I thought I had eaten and blown my diet. But then realized I didn't, you know, so it was, it was always there.

Another woman talked about being consumed by the illness as she struggled to gain control of her life. Ultimately, restrictive behaviours escalated to the point of total preoccupation with food: "I just decided I was not eating." Her belief that denying the body food would bring control is also evident as she talked about the painful experiences of raising her children:

> Anorexia nervosa consumed me *[pause, eyes cast to floor and voice low]*. I missed out on a lot of my children's younger years. I could not cope. I had to be strong. I had to stop eating [*eye contact and tone increased*].

When consumed by the illness, there was a total preoccupation with restrictions. Still, during a pregnancy, to ensure the safety of her unborn child, she was able to exercise some control over restrictive behaviours: "I didn't eat a whole lot but I did eat." In the early stages of illness it seems that she could still exercise some control over restrictions. This sense of control could not be recaptured, however, when she described feeling consumed by the illness: "I could not even care for my children." Her perceived inadequacies as a person forced her to relinquish child-care responsibilities to her parents.

It appears that feeling consumed by anorexia nervosa destroys or dissipates the core or the essence of personhood - self-identity. Many of these women reached the point where restrictive behaviours were no longer effective in controlling anxiety and feelings of worthlessness. What remained upon awakening each day were the pains of the past and the constant inner struggle with finding meaning in life.

Letting-Go While Holding-On

Once the illness had progressed to the point where it became difficult to hide restrictive behaviours, the concealment was broken. The skeletal prominence as well as the food games were visible to others. Yet, all participants continued to deny having eating disorder problems. When confronted about weight loss and restrictive behaviours, they resisted the allegations and accused others of not really understanding their situation: "I'll never speak to you again if you don't stop."

Emotional reactions were classified as "shocked" or "angry", words common to grief reactions to a loss. Shock is derived from the French word "choquer" which means to strike (with fear), or a violent collision or impact. One

participant described the intensity of her fears following a break in concealment and subsequent weight gain: "It was like I was hit with a Mack Ton truck."

Finding it difficult to "let-go" of the only effective means of control they had, all participants refused to accept the fact that they needed professional help. To do so would be a reaffirmation of their perceived weakness. Despite using descriptors such as shock to describe reactions to others' confrontations about restrictive behaviours, altered body images and thought processes forced them to "hold-on".

In all instances, the breaking of the concealment intensified the drive to gain control. When psychological or physical controls were instituted by others to curb aberrant behaviours, some of these women became obsessed with overcoming the barriers and regaining control through restrictive dieting.

> I felt I was even more insecure after that . . . maybe, cause she told me that people were watching me. So my self-esteem shot even lower. It was crazy. And then I went nowhere! . . . I got more sick . . . My eating habits . . . I don't know. They got worse.

Other women talked about the inner turmoil and pain experienced from being forced to eat:

> I cried and cried all over my meals.
>
> I felt like they were ganging up on me. Bringing me places I did not want to go. Forcing me to eat, forcing me. That was really, really bad. They could not understand [*pause*].

Being forced to eat was taking away the control; the only means of dealing with life's stressors. Most external controls had a negative impact and only served to intensify anxiety and inner turmoil. A few reached the point of not caring who was aware of the restrictive behaviours: "No, I just did not care!"; "I did not want help."

However, with the concealment broken, these women were left without the "in-control" feelings provided by restrictive behaviours. In a sense, they were stripped of a constant and trustworthy means to achieve happiness, leaving them completely defenceless in a foreign world. The focus was still on regaining control (i.e., enhanced preoccupation with restrictive thoughts, devising ways to evade barriers, and ultimately achieving even greater highs).

With the developing awareness that restrictive behaviours were causing a great deal of pain for family members, many became anxious and felt guilty. Enhanced conflict between self and others' needs/concerns diminished

feelings of inner control because the timing and type of restrictive behaviours were limited to those easiest to hide: "I'd eat when I was at home because I knew when I went back to school I'd stop eating."

The lived world of anorexia nervosa often left these women feeling out-of-control. Unaware of how to stop the inner pain and turmoil, they again relied on others to dictate a course of action. One woman's fear of self-harm led her to accept the psychiatrist's referral to a psychologist. However, treatment was initiated while operating under the delusion that this might help her "stay thin forever". Her refusal to accept the diagnosis of anorexia nervosa also prevented her from initially seeing possible benefits from being admitted to a psychiatric unit. However, as her anxiety intensified she realized that support was needed to control suicidal thoughts and severe restrictions.

The perceived insightfulness of others, or feeling connected to another who understood, provided the glimmer of light that slowly began to pierce the "veil of darkness" that threatened to engulf them. These women described the impact that connecting to another person had on their lived world (i.e., jogging and sharing feelings, or being a role

model by seeking help) as critical events which allowed greater acceptance of the self. Supportive behaviours by significant others were perceived positively and provided them with the incentive to deal with their illness.

Denial was still present because of the difficulty accepting that others could have access to their perceived identity - a weak person. The process of letting-go while holding-on to the restrictive behaviours which dominated the lived world was clouded by fears and insecurities. Ultimately, connecting to another person provided a bond of trust and a vision of strength and security.

Readiness for Change

What facilitates change in a person with anorexia nervosa? The women in this study talked about the importance of challenging restrictive behaviours and accepting help from others. They also emphasized that readiness to change had to come from within the self. Critical to feeling ready to change was the increased ability to form a "bond of trust" with another.

Participants talked about the readiness to change period in terms of a turning point in their lives. While some felt set free from protective shells (i.e., wanting to

be less dependent on another and developing more confidence and assertiveness), others became more selective over friends. Still others started thinking about what they really wanted in life (i.e., having children meant moving to reduce destructive effects on the reproductive system; or, having a career required completing a university degree). Without a sense of readiness to accept help, efforts by significant others (e.g., family, friends, or health care workers) were perceived as either threats to control or feeding the drive to regain control: "It got worse after that [*breaking the concealment*]"; "I did not want their help - I did not care."

Some women experienced critical events that provided a breeding ground for change. The positive effects derived from becoming pregnant were described by one participant thus:

> If I had not have gotten pregnant [*long pause - silence*] . . . I would not be here today. I thank God for that.

The sense of life within gave this woman a purpose for living - a mother-to-be. The focus changed from a preoccupation with food to caring for the needs of an unborn child.

For a second woman, connecting with another was

preceded by the jolt from a CAT scan report that revealed she had extensive osteoporosis. The concrete, tangible picture of her damaged bones "opened her eyes" to the reality of the destructive effects of her restrictive behaviours. Subsequently, she met someone who brought a glimmer of hope into her life: "I connected with her"; "She helped me find myself."

When successful in forming a meaningful attachment with another person, these women felt truly connected for the first time in their lives: "I felt like a person"; "I realized that I was a person"; "I connected with her"; "She helped me find myself." The beginning steps, in the transition from feeling emotionally empty to feeling connected, were described in terms of a dawning or recognition of one's self-worth.

> I am a somebody. All my life I was made to feel like a nobody. I was moulded by my parents' little world . . . With my first husband it was the same.

Feeling comfortable with the caring behaviours displayed by another person was critical in helping them "connect". This power behind human connectedness is described by Sartre (1956) as: "I see myself because someone else sees me. I experience myself as an object for the other" (cited in van

Manen, 1994, p. 25).

One participant spoke about the importance of unconditional acceptance by others.

> Whereas with the ladies . . . they are letting me be me. I am able to say I like myself a bit better because these ladies are helping me find me. I do not feel intimidated by them . . . . I am really, really comfortable with them and I feel I can be me.

Another talked about her relationship with someone who eventually became her husband. Despite feeling like she wanted to hide or be "invisible" when initially socializing with his friends, as a trusting bond was formed with him she became more secure in social interactions.

> I have to give him all the credit . . . . He talked to me and told me that I could do it . . . . I started to meet a lot of his friends and started to talk to them. I was thinking, "Gee I can do this." I really surprised myself.

The strength and importance of forming a bond of trust with a significant other is captured in the following passage:

> One person and he is extremely good to me. He understands. He doesn't force me. I can tell him anything. He is my best, best friend. He is a gem!

What was most revealing about her description of this relationship was the obvious expression of excitement, surprise and joy when she talked about sharing meals with him: "I pick, but I enjoy it! I enjoy it!" Despite feeling

relaxed and deriving pleasure from eating with someone she had learned to trust, she continued to experience anxiety when eating with others: "But with anyone else I am always stressed. You can almost feel an anxiety attack coming on!"

As care and trust unfolded in meaningful relationships, some acquired the strength, willingness and purpose to challenge destructive behaviours.

> I just woke one day and said I am going to do this today [eat].
>
> I just decided that he must be right. Everything he has told me so far is right, so I decided to try eating.

The critical event, trusting others enough to gain access to the self, provided the impetus to initiate measures which disbursed the holding powers of anorexia nervosa.

When events or relationships surfaced that created the potential for change, they did not always translate into concerted actions that led the person to permanently modify restrictive behaviours. Although a pregnancy provided two of these women with a reprieve from the intensity of restrictive practices, it was not powerful enough to overcome uncertainties and fears about themselves. Anorexia nervosa sat patiently waiting for a vulnerable moment (stressors) when it could launch another attack. For one

woman, the added stressors of being a new mom coupled with marital discord reaffirmed her weakness and provided the rekindling fuel to resume restrictive behaviours.

The breaking of the bond of trust also decreased the desire to change. Each time the bond with another was broken, these women resorted to restrictive behaviours to help them cope.

> It happen so fast! The only way to cope was to stop eating. I shut off from food again.
>
> Like my best friend, my boss, my roommate [*the same person*]. Like my eating disorder is so bad that she would have to run over to the bar and tell them everything!

When confronted with critical events which renewed fears of trusting others, personal identities were once again lost to the powers of the illness.

For all of these women, readiness to change was preceded by a critical event (a connectedness with the self) which gave them a purpose or meaning to fight the battle of anorexia nervosa. By forming a meaningful bond with another, participants learned to trust their abilities to overcome the illness and remove restrictive controls. Readiness to change also held the person in therapy and weakened the strength of the bond forged with the disorder. Success in therapy required the development of greater self-

awareness and faith in their self-worth, and the continued presence of a trusting relationship with another.

Breaking the Cycle

The women in this study very clearly articulated their struggle with breaking the cycle. Confronted with having to shed the protective barriers hiding the weakened self, and accepting the risk of embarking on a journey in search of the elusive ideal self, they were besieged with fears and uncertainties that threatened to engulf them. Without a clear picture of what recovery would mean, they sought refuge in a place where they had more control (i.e., the restrictive behaviours of anorexia nervosa): "I fight every day with it . . . . it is something that I probably will have to struggle with for the rest of my life."

The word break means "to make ineffective as a binding force" or "to disrupt the order" of something (Webster, 1988). When applied to the cycle of restrictive behaviours dominating the lived world of the anorexic, it refers to a change or interruption that is temporary or lengthy depending on the perceived supportive and caring presence of others. All these women voiced two integral forces which

helped break the cycle and maintain a commitment to recovery: a) having someone who understood what it was like to live with anorexia nervosa and, b) the presence of a trusting environment free from external controls.

All had learned not to trust the self or others, and to rely on restrictive behaviours to give them a sense of control over interactions with the outside world. One woman spoke about the contrasting effects of different interactive approaches on her ability to deal with anxiety during and after therapy:

> I go to see her [*psychologist*] probably once every two weeks . . . for about two years . . . She, like, makes me feel really good when I go in, and she does something that nobody else has done with me. She does relaxation techniques and stuff. So, like, a lot of times I'm really anxious and frustrated when I go in but she'll calm me down. And none of them, like the other people that I've seen had never tried that with me before. Like, I would go in and feel anxious, and coming out I would still feel anxious and pissed off.

This woman's insecurities and fears were alleviated by a therapist who helped her relax before dealing with illness issues, and intensified by one who treated her as a "textbook case".

Other women viewed health care workers as having inadequate knowledge about eating disorders. One woman highlighted the differences between effective and

ineffective approaches in terms of therapists' skills and practical knowledge.

> The first lady I saw, she did not have any experience . . . . That idea of measuring things, recording the food, you should never do that with people who have an eating disorder . . . . That was a B-A-D thing to do, cause I was too sick and I really did not want help. The other lady . . . . a soft, spoken person . . . a dietician into counselling . . . . knew a lot about eating disorders. So we worked on both things. How I felt and what I could do to help myself. We always set little goals.

When confronted with ineffective interactions during therapy, all participants experienced increased inner turmoil and sought ways to escape the situation: "You are making me worse. There was no way I would go back; I ran out of his office"; "I did not make another appointment. [*pause*] I just did not feel comfortable."

Breaking the cycle required developing a will to let-go. Reference was often made to changes that altered the course of their lives, and if only temporarily, the illness. "Feeling connected" required finding someone who was not only knowledgeable about and understood anorexia nervosa, but also trained to do counselling.

> She is just like a mediator, a go-between . . . she hardly says anything. Like, she just sits there and if I need time to stop and regroup, she'll . . . stop for a few minutes - just relax, you know.

When furnished with a non-threatening and non-judgmental environment to express fears and concerns, these women felt safe and secure to let-go of the past and explore future possibilities.

Therapists who failed to communicate on a personal and affective level, who conveyed pity or used threats, were perceived as unwilling or unable to understand what it was like to live with the illness.

> It's like he [*therapist*] didn't understand . . . he knew what it was about from reading a book. He didn't know what it was about - living through it. And I would be talking to him and he would make me feel stupid.

> It was his [*therapist*] overall approach. I really don't know what he was trying to do. He was trying to get me on medication. I'm not that kind of person. I was depressed . . . . I said NO!! But he kept pushing, and pushing . . . . Like he kept on saying that if I did not do this that he would put me in the hospital. Threatening me, threatening me, like that . . . . Then, there was one day, there was a fruit-fly, one of those that you can hardly see, going around my head. I was brushing it away and he assumed that I was insane! Like he did not know what I was doing . . . . I dreaded going to see him, honestly.

Such communication approaches reaffirmed and echoed thoughts about the self as being weak - another knock against self-esteem. This only increased the sense of distrust in oneself and others: "I felt like I was a number. I was a number! She was not compassionate. She was cold." Those

women who stayed in therapy described an atmosphere of unconditional acceptance and positive regard: "She listened to me"; "She did not judge me"; "She was interested in me."

Lack of connectedness and feelings of being controlled were evident from words that reflected counterproductive approaches to therapy (i.e., "threats", "scare tactics", "blame", "pity", or "shame"). Some of these women felt that their basic rights, to be treated with respect and dignity, were violated by some members of the health care team. Examples of these negative experiences included:

> He blamed my mom. I hated him . . . . I did not want his help but he was just awful.

> He said to mom take her home and feed her. Sit on her if you have to! He told me that there was no need of me doing this foolishness. From that day on, I did not trust anybody. He was a doctor! I'm like OK, if this is your attitude!

Others talked about receiving mixed messages from health care providers during hospitalizations:

> [*Some*] told me I needed to increase my weight and [*others*] told me to maintain my weight at the current level. I could not do that, I was not eating, I could not maintain this weight.

Others felt that their needs were secondary to the hospital staff's routine: "Talk when they were ready"; "No one ever talked on the weekends."

Many women expressed dissatisfaction with health care

workers who failed to address their anxieties and needs or used controlling tactics. One woman described how her pain and anxiety escalated following a negative experience with a therapist:

> You have to get weighed. You have to! I knew I was going to think I was overweight. I knew if she thought I was underweight, then she would try and get me to eat and eat and eat! No way, not forcing me to eat. CAN'T DO IT! . . . . She put me on the scales backwards and that's how she weighs me backwards. She weighed me, marked it down and did not tell me. Then that week I was at my friend's house and she had scales. I weighed myself . . . . I was so upset. I thought I weighed a little less and I did not.

Others spoke about being forced to record their dietary intake by counting calories.

> She thought that was helping me to show me how many calories could be in me. But it was showing me how this MONSTER could take this and run with it. This monster had a field day with it. Counting calories and the scales.

Use of weighing scales or a counting calorie system as signs of recovery only served to reinforce perceptions that self-esteem was measured in terms of weight.

The voices of these women echoed the importance of getting to know and accepting the self. Some made a conscious decision to throw out the bathroom scales, reminders about the old, weak self. Others learned, through therapy, that wellness was measured in terms of one's

ability to interact with others without having to rely on restrictive behaviours.

The experience of becoming emotionally connected with a person (a therapist and/or another) "opened their eyes" and introduced them to a new form of communication: "I never communicated on that level before"; "I did not know what it meant." Once they were able to see themselves and others in a new light (i.e., trusting self and others), they found the strength to fight the battle of freeing the imprisoned self from the powers of anorexia nervosa.

Interrelationships Among Themes

Phenomenological themes are defined as experiential structures which fit together to form a whole; they are the threads around which phenomenological descriptions are woven (van Manen, 1990). This section attempts to capture the interrelationships among the themes (the weakened self, a struggle for control, controlled by the illness, concealing the self, feeling consumed, readiness to change, letting-go while holding-on, and breaking the cycle) that describe the experience of living with anorexia nervosa.

Filled with memories of physical/psychological rejections (perceived or real) from family and peers, the

pre-anorexic child perceived the unknown as a persistent threat to safety and security. Feeling deprived of a meaningful existence and the ability to trust others, these women were left without a "voice" to communicate their thoughts, feelings, and concerns. The media, society, parental attitudes and behaviours about thinness and food captivated them. Convinced that strength and control were equated with denying the body food, they struggled to attain a positive self-image by controlling restrictive behaviours. Because restrictions helped reduce emotional pain, they were deluded into thinking that thinness would increase their chances of being accepted by others.

Feelings of worthlessness and inadequacy left them unprepared to meet the changes and challenges of adolescence and young adulthood. These women were eager to latch on to something or someone to relieve their inner anguish and feelings of emptiness as they struggled for inner control. Dieting and exercising became the constants - the things that were controllable. Their obsession with, and rejection of, food provided an effective control strategy that facilitated concealment of their weakened selves and escape from reality.

Despite the vigour applied to restrictions, there was

an increase in out-of-control feeling states and inner pain in response to new stressors, enhanced feelings of worthlessness and weakness, and, ultimately, a reduced ability to cope. When restrictive dietary and exercise measures failed, as well as medications, some resorted to more drastic solutions by refusing to eat. As restrictive behaviours began to dominate the lived world, the illness moved to take control.

The concept of control is a paradox. The weakened self, who tasted and loved the false sense of security derived from restrictions, continued to rely on these same behaviours to avoid social contact. Denying or concealing the illness from oneself and others fulfilled the need to be accepted and appear normal. Unable to articulate feelings or reduce fears of rejection, the need to conceal escalated. Although temporary relief could still be achieved by intensifying restrictive behaviours, the dose-response curve was changing to parallel the growth of anxieties and insecurities. As the self became progressively weaker, thought processes also were distorted because of the extreme denial of nutrients to the body. Paradoxically, as anorexia nervosa gained control, these women became more consumed by the illness while desperately struggling for control and

concealment of restrictive behaviours.

Breaking the concealment increased the struggle for control and, ultimately, provided the catalyst, for some, to break the cycle. As medical problems surfaced and the ability to appear normal waned, loss of concealment threatened their control - safety and security. Pressured by concerned others to reduce restrictive behaviours, these women panicked because they were being asked to relinquish the only control that they knew. Still feeling deprived of love and trust and unable to remember a time when they had been content with their lives or themselves, they became extremely fearful of the future.

With the concealment broken and their inadequacies exposed to others, they were confronted with two prospects - start believing in themselves and accept the need to change; or intensify restrictive behaviours and withdraw further from those who could not understand them. All of these women experienced a readiness to change while still struggling with feeling consumed and controlled by the illness. Further rejections and feeling controlled by others could, without warning, tip the balance and send them further and further into themselves and the depths of despair. Their struggle to merge the feeling and thinking

parts of themselves into a meaningful whole was diminished when they connected with someone (e.g., therapist) who accepted and believed in them. As well, the constant presence of a loving, caring significant other was needed to prevent the mind from turning upon itself and once again generating a lethal force that propelled the person along a path of self-destruction.

The Essence

Through formal, unstructured interviews, participants reflected upon and described their lived experiences with anorexia nervosa. Interpretive analysis of the transcripts and confirmation of individual, specific insights with each participant facilitated the grasping of the whole which subsumed all other parts. The essence of the lived world of persons with anorexia nervosa is seen as a persistent struggle to find meaning in life.

Separately, each of the themes that capture the lived experience of anorexia nervosa provide insight into a world that few come to know or understand. This separation is artificial and distracts one from grasping the importance and totality of the whole. When woven together to form a phenomenological description of the lived experience of

anorexia nervosa, the themes portray an image that leaves one silently wondering about an experience with living that is at once elusive to grasp but powerful in rendering its message.

For these women, obsession with food or excessive exercise was an expression of control in a world where they felt no control. Unable to feel good about themselves or in control of their lives, restrictive behaviours and the "relentless pursuit of thinness" gave them a purpose for living: "It was the first time that I felt good about myself." Besides feeling in control, it brought temporary relief from stressors while successfully concealing perceived inner weakness.

Feeling deprived of a reason for living, and not trusting their abilities to interact socially, they avoided situations which required opening themselves to others. Withdrawing while relating impeded meaningful bonding with others - being with others while alone with themselves. Consumed with projecting an ideal image to the outside world, a great deal of time and energy was devoted to trying to please others while concealing the "true" weakened self: "I do everything else for others but this [*anorexia nervosa*] is for me."

The restrictive behaviours, which were learned from and rewarded by others, allowed the person to feel a sense of the self, to reduce the inner pain, and to escape from the world which dictated and reinforced their feelings of worthlessness. As the illness moved to assume control, restrictive behaviours were found to be less effective in dealing with emotional pain and the stress of interacting with others in their world. Moving further and further away from this ideal image of themselves, they became more despondent and consumed with emptiness. While struggling to give meaning to their lives through the pursuit of thinness, they experienced greater pain and anger when confronted with rejections and others' attempts at control. Once again, they received confirmation that they were not good enough and needed to try harder to be truly accepted by others.

Feeling alone and misunderstood, all perspective was lost on how to engage in meaningful relations with others. Moving to let-go of restrictive behaviours, while holding-on, left some without the will to live.

> I know that I'm always going to struggle with it. But like I know that I'll get through it . . . . Like, one time I didn't even care if it did. But now, I don't want it to kill me.
>
> Like, it's hard for me to say it, but I don't know if I would have - probably would've hurt myself or

> something. Because I was kind of feeling like that. Like, I don't know if it's actually feeling suicidal, but close enough to it that I probably would've tried, but not intending to end my life.
>
> And I had his insulin and needle. I was going to [*pause*] But before that I had called my mom and asked her to come and get me . . . . If she couldn't help, the only way to stop this was [*long pause*]. I was bad. I wanted the hurt to STOP . . . . It was not worth it anymore. Life is not worth it.

Conversely, those who were able to connect with a special someone in their personal lives as well as with a "special" therapist were able to begin the task of breaking the holding powers of anorexia nervosa. These connections were seen as the glimmer of hope, the light at the end of the tunnel, that promised to help them bring new meaning into their lives.

> And did you get what
>
> you wanted from this life, even so?
>
> I did.
>
> And what did you want?
>
> To call myself beloved, to feel myself
>
> beloved on the earth.
>
> (Raymond Carver, cited in "When Food was Love", Roth, 1991)

CHAPTER 5

Discussion

Anorexia nervosa is a daily struggle to deal with the deep emotional pain and inner turmoil consequential to the interactional effects of sociocultural, environmental, familial, and personal factors upon the self. This chapter discusses study findings in relation to the current body of knowledge on anorexia nervosa. Commentary is also provided on new insights gleaned from the data and what meaning this has for health care delivery.

Lived Experience of Anorexia Nervosa

While this study's findings provide new insights into the experience of living with anorexia nervosa, certain components of the themes augment clinical and research findings presented in the literature. The piece of the analysis which provides the greatest support for current perspectives is reflected in the essence of the lived experience for study participants - the persistent struggle to find meaning in life. In the text that follows, themes that depict the strongest interrelationships are discussed together.

Weakened Self and Struggling for Control

As described by the women in this study, the image of the weakened self emerged from the interactive effects of individual, family, and societal factors. A number of authors speak to the importance of these predisposing factors in increasing a person's susceptibility for anorexia nervosa (Garfinkel, Garner, & Goldbloom, 1987; Garner, 1993; Paxton, 1993; Shisslak, Crago, & Neal, 1990; Wilfley & Grilo, 1994). However, the presence of any one or even a combination of these factors, with or without precipitating factors, will not necessarily lead to anorexia nervosa (Russell, Trierweiler, & Elder, 1996).

The weakened self theme portrays the image of a person who has not been successful in developing a true affinity with the self or finding meaning in life. For many of these women, anorexia nervosa surfaced and evolved in response to psychological and emotional problems. Garner (1993) indicated that eating disorders are most likely to develop when low self esteem and negative body images are accompanied by inadequate coping skills.

Within the confines of a family environment that was overprotective or controlling, the women in this study failed to experience autonomous growth and doubted their

abilities to share themselves with others. The important influence of family interaction patterns in diminishing anorexics' feelings of self-worth and suppressing confidence about assuming independence is supported by Bruch (1977), Garfinkel and Goldbloom (1988), and Turner (1990). Bruch (1977) highlighted the key role played by controlling parents in suppressing autonomous growth, and generating feelings of low self-worth and fears of being misunderstood. Turner (1990) emphasized how family communication patterns can leave the anoretic anxious about the self, without a complete sense of individuality, and insecure about communicating with others.

Garfinkel and Goldbloom (1988) expanded the spheres of influence beyond the family to include teachers, peers, and other societal forces (e.g., cultural, media). This perspective is in line with Erickson's (1950) theory on personality development which emphasized the important influence of different social worlds on the person (cited in Bootzin & Acocella, 1988). According to Erickson's theory, successful resolution of conflicts confronting the person at different developmental stages (i.e., trust versus mistrust and autonomy versus shame and doubt) is critical to ego identity formation (cited in Bootzin & Acocella, 1988).

Study participants appeared to have not mastered the core developmental task of learning to trust or feel comfortable with autonomous existence, and entered the outside world mistrustful about sharing their true selves with others (e.g., friends, peers, co-workers). Insecurities and fears of rejection became manifested as "afraid to love" or "afraid to trust". Other authors have linked fears of losing personal control to underlying feelings of helplessness and a sense of personal mistrust (Bruch, 1973, 1977; Garfinkel & Goldbloom, 1988; Muscari, 1987; Santopinto, 1988; Selvivi-Palazzoli, 1974; Turner, 1990; Van den Broucke, Vandereycken, & Vertommen, 1995).

The fundamental psychopathology of anorexia nervosa frequently relates to an intense drive to maintain a sense of self-worth through weight control. Ultimately, for the women in this study, self-esteem became highly bound to external standards (e.g., beauty, thinness, strength) in their struggle to feel good about themselves and gain acceptance from others. In some instances the struggle for control started with a diet that got out of control: "It started out slowly as a diet. The way you are supposed to diet." Other authors have also suggested that the pursuit of thinness may begin with the innocence of dieting to

improve one's body image (Garner, 1993; Hsu, 1990; Muscari, 1988; Williamson, 1990).

Garfinkel and Goldbloom (1988) noted that when eagerness to conform to external standards is fueled by dichotomous thinking style, particular cultural looks or images can be carried to a pathological extreme. Bruch (1977) asserted that the person who chooses to engage in dietary practices is, in this instance, driven by anxiety to prove that s(he) has the ability to do it and to derive some benefits from doing it (i.e., reduce anxiety, and feel good about oneself and superior to others). The paradox is that the anoretic has learned to feel good about the self while being unhealthy.

Controlling, Concealing and Consuming

The weakened self, struggling for control through restrictive behaviours, eventually became controlled by the illness. When these women experienced increases in out-of-control feeling states, their obsession with restrictive behaviours intensified (e.g., laxatives, diuretics, starvation, and increased exercise hours) to rid the body of perceived excesses and regain control. Still in denial that an illness existed, they fought desperately to conceal

restrictive measures but in so doing became consumed by them. The popular concept of "the relentless pursuit of thinness" described by numerous authors embraces these three themes (Bruch, 1977; Garfinkel & Garner, 1987; Garner, 1993; Halmi, 1994; Santopinto, 1988; Staples & Schwartz, 1990; Turner, 1990).

Unable to achieve a true emotional connectedness with another human being, to nurture the development of the self, these women forged a bond with restrictive behaviours to boost their sense of self-worth. As the bond with the illness solidified, it further eroded the weakened self, enhanced fears and uncertainties about forming meaningful relations with others, and left them devoid of a meaningful existence. Santopinto's (1988) concept of persistent struggle describes the anorexic as struggling to achieve an ideal image (the not yet) while losing the self (the now) to the controlling illness. A second concept, withdrawing-engaging, views the anorexic as attempting to form relations with others while hiding the true self.

As the mind and body became depleted of needed nutrients, these women experienced physical problems and altered thought processes (i.e., delusional regarding food and body image). Overwhelmed with feelings of worthlessness

and limited control and security, they found it increasingly difficult to distinguish the real from the unreal and, ultimately, lived in fear of losing their selves to the illness. Garner (1993) noted that as illness severity is enhanced by food deprivation, cognitive functioning and thought processes become delusional (i.e., distorted body image).

Readiness, Letting-go/Holding-on and Breaking

With regard to the theme readiness to change, the women in this study indicated that unless they felt ready to change and were willing to seek help, all efforts from others would be futile and even push them further into restrictive behaviours. When it dawned on them that others knew about their secret, they often reacted angrily to accusations and became adamant in their refusal to seek help. Support for these findings is also found in the literature (Bruch, 1977; MacDonald, 1995; Parkin, 1995; Staples & Schwartz, 1990; Strauss, 1995; Sutton-Edmands, 1986). Bruch (1977) stressed the importance of assessing the anorexic's readiness to change before proceeding with therapy because of the strong resistance potential from fears of distrust and the need to blame others.

The theme of letting-go while holding-on was described by study participants as recognizing the need for professional help while still being reluctant to actually do so because of fears and uncertainties about a future without restrictions. Ultimately, the forging of a trusting bond with another facilitated their acceptance of treatment, and the support and purpose for breaking the cycle and staying on the road to recovery. The women in the current study who stayed with treatment perceived the therapist as a caring, compassionate person who understood and accepted them as a person. It appears that a window of opportunity exists for clinicians, early in treatment, to reach out in a caring manner and connect with these clients. It is also apparent that the concept of connectedness is critical to the healing process. These findings are supported by Moreno, Fuhriman and Hileman (1995) who found that persons with eating disorders rated the emotional experience of connecting with another person as the most significant and meaningful aspect of therapy.

Within therapeutic relationships, these women were able to learn to trust the self, by trusting in others who empathized with them and truly heard their stories, fears, concerns, and struggles. When relationships with therapists

were seen as true equalitarian partnerships, they were able to confront fears about being rejected and become more comfortable with sharing their selves with others. The use of the pronoun "we" to describe interactions with therapists suggested that these women felt some control over the healing process. The importance of establishing heartfelt connections and collaborative working relations with anorexics during therapy is supported by Yager (1992). Wanlass (1996) also stressed the importance of establishing a sense of connectedness among anorexics participating in group therapy because of their problems with self-disclosure and interpersonal distrust.

The Essence

The lived world of anorexia nervosa, as described by the women in this study, was a struggle to find meaning in life. Their stories reflected feelings of rejection and failed attempts to truly connect with others. Moore (1997) stated that: "Meaning is central to life in that it allows humans to make sense of their existence in the face of adversity and chaos, or during times of relative calm" (p. 34).

The lived world of anorexia nervosa, as described by

study participants, echoes empty, meaningless existence. The pain from despair could be seen in their faces as they described periods of not caring anymore and "wanting the pain to stop". Fitzpatrick (1983) stated that: "Those who have no meaning do not continue to live" (p. 295). Frankl (1984) described persons dominated by meaningless feelings as having "enough to live by but nothing to live for; they have the means but no meaning" (p. 165).

It is clear from this study's findings that efforts directed at modifying lifestyles, without addressing the underlying forces that propel the person towards anorexia nervosa, will not be effective in reducing the severity of the illness or facilitating breaking the cycle. When these women came into contact with the health care system, the lack of caring and compassion from nurses and other health care workers served to reinforce feelings of helplessness and lack of personal control. These findings were supported by Moore (1997) who suggested nurses need to see the world from the perspective of their clients. Frankl (1984) asserted that when people discover meaning, they are empowered to rise above the forces that attempt to control their lives. The most important task facing the therapist is to work on "broadening the visual field of the patient so

that the whole spectrum of potential meaning becomes conscious and visible to him" (Frankl, 1984, p. 133).

Revisiting the Meaning of Health Care

Although the multidimensional components of anorexia nervosa have been accepted by most clinicians and researchers, reaching consensus on a unified treatment model remains elusive (Conrad, Sloan, & Jedwabny, 1992; Halmi, 1994; Meades, 1993; Parkin, 1995). Study participants viewed the approach to health care as lacking continuity and often being iatrogenic (i.e., negatively affecting the trajectory of their illness). Family physicians, often the gate-keepers, are overburdened and have limited expertise in diagnosing eating disorders or providing a clear sense of direction for clients and their families.

Becvar and Becvar (1993) note that socialization of children is the process by which one learns appropriate behaviours and ways of thinking. Informal socialization occurs within the family unit, while formal socialization takes place within the school structure. In this study, all participants reaffirm the fact that anorexia nervosa is a complex, multidimensional disorder and that familial and broader societal issues play a role in the onset and

trajectory of the illness. The school environment, therefore, is an ideal forum for promoting healthy living. Teachers' and parents' attitudes on eating, dieting and gender differences affect and mould the child's values, morals and principles.

Study participants also emphasized the need to reorganize the current health care delivery system in order to meet the needs of persons with anorexia nervosa and curtail the self-destructive effects of the illness. Health care workers must look beyond traditional roles to address broader familial and sociocultural issues, and be willing to relinquish control and involve clients as active agents in their own care. All of these women identified approaches reflecting power struggles, such as labelling and blaming, to be counterproductive to health promotion. Gremillion (1992) asserted that the ideology of medicine reaffirms power relationships by labelling, organizing, and constructing "anorexia nervosa as a reified and bounded condition that is removed from cultural ideologies and processes, as an illness entity which can be grasped and fixed" (p. 59). This study lends support to Gremillion's work.

This study's findings also support the importance of

directing health promotion and illness prevention efforts at all age groups. The current emphasis on devising health promotion programs for school-based populations (Childress, Brewerton, Hodges, & Jarrell, 1993; Paxton, 1993; Shisslak, Crago, & Neal, 1990) may well prove to be to be too narrow a focus to curb the escalating rates being observed across all age groups.

CHAPTER 6

Nursing Implications, Limitations and Summary

This study's findings have implications for nursing education, practice and research, as well as for the total health care delivery system. In view of the present economic realities, increased emphasis is being placed on delivering cost-effective programs. While consumers have been asked to assume greater responsibility for their health status, they can also take a proactive role in articulating their concerns about how governments are choosing to allocate health care dollars.

Mental health care services have been considered the poor cousin in health care. Consistently fewer dollars have been allocated to mental health care than any other service (Dellasega, 1991). As the prevalence of anorexia nervosa and other eating disorders continue to rise, governments and health care professionals have an ethical obligation to explore alternative methods of providing cost-effective and quality mental health services to address the specific needs of this population.

Implications

This study's findings highlighted the value that participants placed on the caring, understanding and compassionate role of health care providers. The presence of such a person helped them learn to trust themselves and others. Within the confines of a trusting relationship, these women felt secure enough to challenge old coping styles (e.g., restrictive behaviours) and incorporate new, healthy behaviours into their lifestyles. Unfortunately, none of the participants identified nurses as these special persons who helped them during the healing process.

Where was nursing? Anderson (1995) described nursing as an "invisible" profession. She challenges nurses to work collaboratively in delineating a role for nursing in health care reform and delivery. Further, she recommends that nurses form a united voice that echoes our professional obligation to provide quality care to clients. Other nursing authors also support this perspective (McKay, 1993; Stuart, 1993).

Nursing Education

Nursing educators have the responsibility to educate their students about the meaning and importance of

maintaining a caring attitude while performing diverse roles. Students must develop good listening skills and therapeutic ways of connecting with their clients. Educators should give equal weight to interpersonal as well as technical competencies in facilitating the healing process. Nursing educators are challenged to develop and implement a curriculum to prepare students to meet the needs of diverse populations in a changing health care system.

Dyer, Hammill, Regan-Kubinski, Yurick, and Kobert (1997) present a new paradigm for delivering cost effective, comprehensive mental health care. These authors discuss the Psychiatric-Primary Care Nurse Practitioner program at the University of Pittsburgh which is designed to equip nurses with the knowledge, skills and competencies to deliver primary, secondary and tertiary mental health care to populations. This model could be adapted to meet the educational needs of mental health care nurses which would enhance the quality of care delivery for the eating disorder population.

Nursing Practice

Numerous authors have addressed the role of nursing (primary, secondary and tertiary) in the provision and

management of health care for clients with anorexia nervosa (Brown, 1991; Brown-Sanders, 1987; Cahill, 1994; Childress, Brewerton, Deering, 1987; Conrad, Sloan, Jedwabny, 1992; Deering, Niziolek, 1988; Dickstein, 1985; Halmi, 1994; Irwin, 1993; Lilly, Meades, 1993; Simmons, 1990; Sordelli, Fossati, Devoti, & LaViola, 1996). Despite the increased emphasis on expanding nursing roles to diverse settings, most practicing nurses in mental health are primarily restricted to in-patient units which are governed by the medical model of care.

Based on the literature and this study's findings, there are specific roles and skills which clinicians must master if they are to be active forces in promoting the health status of clients with anorexia nervosa. First, nurses must become aware of their attitudes and beliefs about thinness, dieting, and eating behaviours. Second, they must acquire the necessary knowledge and skills to perform effective counselling and diagnostic assessment (Garner, 1993; Haller, 1992; Hsu, 1990; Williamson, 1990). Third, and most importantly, they must take the time to "get-to-know" the person with anorexia nervosa.

Study participants viewed health care professionals as having limited knowledge about anorexia nervosa and

inadequate counselling skills. Ethically and morally, clients have the right to adequate health care services; and professionals are ethically obligated to be competent. Nursing is very familiar with the importance of gathering data for an assessment - the first step in the nursing process. The assessment must be individualized and directed towards generating information about the problem, and the person with the problem, in order to plan client-focused care (Dickstein, 1985). Accurate and comprehensive assessment of the illness and the usefulness of interventions requires that clinicians become thoroughly familiar with the core features of anorexia nervosa (Garfinkel & Garner, 1982; Garner, 1993). Ongoing assessments and re-evaluations of client needs must occur throughout the course of treatment, and clinicians must be forever cognizant of the important role that connectedness plays (e.g., sensitivity, compassion, interest and respect) especially with anorexics, in promoting health status.

Santopinto (1988) indicated that nurses must foster a sense of interconnectedness with all clients by "being present" to the particular and universal aspects of the relentless drive for thinness. In the current study, all participants talked about the significant impact that

connecting with the self and others had on the outcome of their illness. These women emphasized that when a caring approach was not present during therapy, this had a negative impact on their health status.

Study findings suggest that nurses need to revisit the meaning of nursing care. Jean Watson (1989), in her theory of human care, asserted that nursing has lost its ability to care because of its overindulgence with technology. Study participants did not perceive nurses as compassionate and caring as they were perceived to be too busy with routine. Moore (1997) states: "When nurses can meet people in their experience of pain and are willing to walk with them through that pain, it opens the possibility for the transformative nature of caring to begin to work and for a process of connection" (p. 35). These women talked about feeling comfortable in an environment which provided unconditional acceptance, and safety and security - nursing was not mentioned in this context.

Unified models for health promotion. Participants in the current study articulated that dieting and exercise behaviours started at the onset of adolescence. Concerned that their body image fell short of the ideal, and desperately wanting to connect and gain acceptance from

peers, they embarked on a serious dieting and exercise program. All participants talked about the importance of building self-esteem at a very early age, and accepting personal differences as uniqueness, rather than imperfections.

Because of the declining age of onset of eating disorders and the increasing prevalence in school-age populations, community health nurses need to become more proactive in planning and implementing health promotion strategies that will help offset the escalating rates in this population (Rosenfield, 1988). Nursing must take a leadership role in developing school based health promotion and illness prevention programs. Critical to the efficacy of these programs are collaborative efforts with other disciplines, constant availability throughout the implementation phase for consultation and counselling, and willingness to assume a pivotal role in program evaluation.

Gresko & Karlsen (1994) described the Norwegian program for primary, secondary and tertiary prevention of eating disorders. A comprehensive, collaborative approach, involving all government departments, health care professionals, educators and clients, was designed to combat the rising incidence and prevalence of eating disorders in

targeted populations (e.g., schools, athletics, etc). This model provides a glimmer of hope for developing a unified health promotion model to address primary, secondary and tertiary levels of health care delivery for clients with anorexia nervosa and their families. A similar prevention model in Canada is the HUGS program (Omichinski & Harrison, 1995). This program focuses on healthy living in school age populations. The goal is to modify the pattern of thinking and behaviours commonly labeled as the "diet mentality".

This researcher envisions a comprehensive, school based, health promotion model for anorexia nervosa which reaches across all age, gender, and sociocultural barriers. A comprehensive program, therefore, should include the education of children, as well as their families and teachers. The program should be developed in three phases, with each phase building on knowledge attained from the previous one. The content should be age specific, address all the forementioned aspects of healthy living, and emphasize self-esteem building and personal responsibility for maintaining health.

For optimal effect, the program should be supplemented with learning activities, and educational strategies (i.e., drama, music, film, art, poetry, etc.) which stimulate the

learning process (Porter, Morrell, & Moriarty, 1986). The potential health problems - including health risks related to dieting and the development of eating disorders (i.e., anorexia nervosa) - need to be gently and persuasively presented, but powerful in rendering its message. Such a learning plan would capture the interest and imagination of young people, thereby enhancing and entrenching awareness of attitudes, beliefs and behaviours which constitute a healthy lifestyle.

Nursing Research

Based on this study's findings, a number of suggestions can be made for future research in the area of anorexia nervosa. First, additional qualitative investigations into the lived experience of anorexia nervosa, using participants from various cultural and socio-economic groups, are needed to determine if others manifest comparable lived experiences. Second, greater qualitative research efforts are needed to further our understanding of the role that society's emphasis on thinness actually plays in the onset of eating disorders.

Third, qualitative inquiry is needed to investigate if there is, in fact, a window of opportunity for timely

delivery of preventive health care services for persons susceptible to developing eating disorders. If such a window does exist, it could prove to be crucial in altering the high attrition rates of anorexia nervosa clients. Most importantly, additional qualitative and quantitative research is necessary to provide useful data to help design appropriate and health promotion comprehensive programs.

Finally, research is required to identify the most effective role for clinicians in facilitating positive health outcomes for this target population. The concept of emotional connectedness surfaced as an important force in instigating and keeping study participants in therapy and on the road to recovery. This concept certainly warrants further research efforts.

Limitations

Recent research indicates that persons from all socioeconomic classes may be affected by anorexia nervosa (Nasser, 1994; Leichner et al., 1986). In this study, participants were interviewed at various stages of the illness. The effect of demographic data, especially in terms of martial status and viable births, on the outcome of the trajectory of the illness requires future investigation.

Only women meeting the DSM-IV classification for anorexia nervosa and associated subtypes were recruited for this study. However, the majority of study participants were diagnosed with anorexia nervosa. Further research efforts are needed to investigate the meaning of this illness in a more representative group.

In phenomenological research, the notion of credibility of the findings is enhanced by the selection of participants. Participants must be able to clearly articulate their lived experiences in order to provide rich data. Consequently, study participants tend to be the most articulate, accessible, or high-status members of their group - a problem which Sandelowski (1986) refers to as "elite bias" (p. 32). Because study participants were fairly well-educated and involved in counselling, they were possibly more introspective and self-analytical than women with a similar diagnosis but who have less education or not actively involved in group or individual counselling.

Qualitative research findings should never be generalized. All participants in this study were Caucasian, and held careers in fields which would indicate possession of post-secondary degrees or diplomas. It is possible that women in other cultures and from other socio-economic

classes would express the lived experience of anorexia nervosa in a different voice.

Summary

This phenomenological study on the lived experience of anorexia nervosa used van Manen's (1994) method of analysis to explore the question: What is the meaning of the lived experience of anorexia nervosa? From the data collected in two unstructured interviews with each of the six participants, eight themes were identified as: the weakened self, a struggle for control, controlled by the illness, concealing the true self, feeling consumed, readiness to change, letting-go while holding-on, and breaking the cycle. From the themes, the essence of the lived world of persons with anorexia nervosa is seen as a persistent struggle to find meaning in life.

The findings were discussed in light of the current body of knowledge on anorexia nervosa and provided new meanings for health care delivery for clients and their families. Implications for nursing education, research, and practice were presented as well as the limitations of the study.

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APPENDIX A

Consent Form

School of Nursing
Memorial University of Newfoundland,
St. John's, Newfoundland, A1V 3V6

Consent to Participate in Nursing Research

Title: The Lived Experience of Anorexia Nervosa: A Phenomenological Study

Investigator: Lorraine Murphy
Telephone: 334-2042

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment.

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Purpose of the Study: The purpose of this study is to explore and describe the lived experience of Anorexia Nervosa. By gaining an understanding of the things that are important to help you deal with this illness, the quality of care to other Anorexics may be improved.

Description of Procedures: You are being asked to participate in two interviews which will be conducted at a time and place that is convenient for you. Interviews will be audiotaped (with your permission). During the first interview you will be asked to reflect upon your experiences with anorexia nervosa and share any thoughts and feelings that you recall about it. In addition you will be asked to indicate what you find most helpful and least helpful about the medical/nursing care that you have received. During the second interview you will be asked to read a written summary of major themes identified from the text of your first interview, confirm whether it accurately reflects your experiences with anorexia and medical/nursing care, and provide any information that you consider important for clarifying your experiences.

Duration of Participation: Each interview will last approximately 60 to 90 minutes. Both interviews should be completed within four months.

Foreseeable Risks, Discomforts, or Inconveniences: There are no expected risks from participating in this study. It is possible that certain interview questions may elicit uncomfortable memories. If you find that any questions make you feel uncomfortable about disclosing any disturbing or painful memories associated with this experience, you may refuse to answer them. You may terminate the interview at any time, as well as your participation in this study. The researcher may also terminate the interview and refer you back to your psychiatrist if she determines that you could benefit from additional counselling services.

All information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the principle investigator and thesis supervisor. Your name will not appear on the audiotape or written copy.

Benefits of Participation: You will have an opportunity to express your feelings and discuss your experience with an interested listener. Although you may not benefit directly from this study, your participation may provide nurses and other health care professionals with helpful knowledge to improve the quality of care for persons with anorexia nervosa.

Other Information: Findings of this study will be made available to you and health care professionals upon request. Study findings will be published but you will not be identified. If you have any concerns about the study after reflecting upon the interview conversation, the investigator will be available at all times to address any questions or concerns that you may have about your continued participation.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator, sponsors, or involved institutions from their legal and professional responsibilities.

I, _____, the undersigned, agree to my participation in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

_____ _____
(Signature of Participant) (Date)

_____ _____
(Signature of Witness) (Date)

I,_____, the undersigned, agree to be audiotaped during each interview.

_____ _____
(Signature of participant) (Date)

_____ _____
(Signature of Witness) (Date)

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

_____ _____
(Signature of Investigator) (Date)

APPENDIX B

Interview Schedule

Interview Schedule

Introductory commentary:

I am interested in your experience with Anorexia Nervosa. I would like for you to take some time to reflect upon your experience and tell me in your own words what it is like to live with Anorexia Nervosa. You may share any thoughts and feelings about your illness and/or the quality of medical/nursing care that you have received. Feel free to talk about whatever comes to your mind. At times, I may ask a few questions, just to help you describe your experience to the best of your ability.

Examples of Probes/Questions to Facilitate the Interview

1. Tell me about your average day, living with anorexia nervosa.

2. When did you first realize that you may have anorexia nervosa?

3. Reflecting back can you remember anything, in particular, that would trigger the onset of your illness?

4. What aspects of your treatment do you find most helpful/least helpful?

5. Can you remember any particular thing and/or person that led you to seek help?

6. How do you cope with Anorexia? What helps? What does not help?

7. How do you see people who try to help you? (e.g., family, friends)

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

APPENDIX C

Approval from Human Investigation Committee

Memorial
University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

1997 01 17

Reference #96.138

Ms. Lorraine Murphy
c/o Dr. Christine Way
School of Nursing

Dear Ms. Murphy:

This will acknowledge receipt of your correspondence dated **December 17, 1996**, wherein you clarify issues and provide a revised consent form for the research application entitled **"The Lived Experience of Anorexia Nervosa: A Phenomenological Study"**.

At a meeting held on **January 16, 1997**, the Human Investigation Committee granted full approval of this research study.

We take this opportunity to wish you every success with your research study.

Sincerely yours,

H.B. Younghusband, Ph.D.
Chairman
Human Investigation Committee

HBY\jglo

cc Dr. K.M.W. Keough, Vice-President, Research
Dr. Eric Parsons, Vice-President, Medical Services, HCC

Memorial
University of Newfoundland

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

1997 01 17

TO: Ms. Lorraine Murphy

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

SUBJECT: Application to the Human Investigation Committee - #96.138

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled **"The Lived Experience of Anorexia Nervosa: A Phenomenological Study"**.

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

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

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

Verna M. Skanes, Ph.D.
Assistant Dean

cc Dr. K.M.W. Keough, Vice-President, Research
Dr. Eric Parsons, Vice-President, Medical Services, HCC

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

APPENDIX D

Approval from Research Committee

February 26, 1997

Ms. Lorraine Murphy
Community Mental Health Nurse
Kings County Clinic
Valley Mental Health Services

Dear Ms. Murphy,

On behalf of the Research Committee, Valley Mental Health Services, I want to inform you that the research proposal The Lived Experience of Anorexia Nervosa: A Phenomenological Study has been approved as submitted with the revisions requested.

Please accept our best wishes in the work on your project. The Committee asks that you submit a final report of the project once completed for our records. As well, we would ask that you update the Committee every six months on the progress and status of the project.

Yours truly,

Peter Kiefl
Chair
Research Committee
Valley Mental Health Services
Western Regional Health Board

APPENDIX E

Approval from Psychiatrists

Mercy Above All

St. Clare's Mercy Hospital
LeMarchant Road
St. John's, Newfoundland
Canada A1C 5B8
Phone (709) 778-3111
Fax (709) 738-0080

Sept. 17, 1996

To Whom It May Concern:

Re: **Lorraine Murphy**
Box 87, Mobile
A0A 3A0

This is to certify that Lorraine Murphy has my support for the proposed study, the lived experience of Anorexia Nervosa; A Phenomenological Approach.

Once you have received ethical approval from HIC at Memorial University of Newfoundland, I will facilitate the identification of suitable clients meeting the inclusion criteria for physical and mental competency.

Yours sincerely,

Dr. D.A. MacLaughlin, F.R.C.P.C.

DAMacL/bmc

HealthCare
Corporation of St. John's

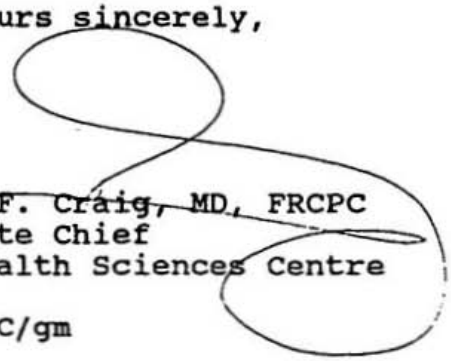
May 23, 1996

Ms. Lorraine Murphy, BN, RN
P.O. Box 87
Mobile, NF
A0A 3A0

Dear Lorraine:

Your proposed study "The Lived Experience of Anorexia Nervosa: A Phenomenological Study" was discussed at the departmental meeting of the Psychiatry Department of the Health Sciences Centre on May 22, 1996. I am pleased to advise you that you have the support of the entire department including my colleagues, Drs. Nurse, Doucet, O'Loughlin and myself, for your proposed study. Once you have received ethical approval from the Human Investigations Committee of Memorial University and The General Hospital, we will facilitate identification of suitable clients meeting the inclusion criteria for physical and mental competence.

Yours sincerely,



D.F. Craig, MD, FRCPC
Site Chief
Health Sciences Centre

DFC/gm

May, 1996

Dr. T. Cantwell
Medical Director,
Waterford Hospital
St. John's, Newfoundland

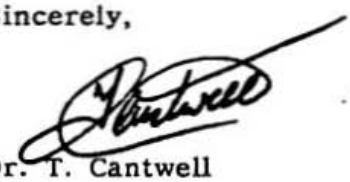
P.O. Box 87
Mobile, NF
A0A 3A0

Dear Lorraine:

You have my support for the proposed study, "The Lived Experience of Anorexia Nervosa: A Phenomenological Study." Upon receiving ethical approval from the Human Investigations Committee, Memorial University, if the need arises, I agree to serve as an independent consultant to evaluate the competency level of possible participants for your study.

With regards to participation in a research study of this nature, I would evaluate competency in the following manner: 1) degree of insight that these women have into their illness, i.e., aware of illness, and accepts the need to participate in treatment programs; 2) understands the purpose of the study and expectations/responsibilities regarding their participation; and, 3) aware of the voluntary nature of their participation and the right to withdraw from the study at any time.

Sincerely,



Dr. T. Cantwell

APPENDIX F

Approval from Program Managers and Division Directors

HealthCare
Corporation of St. John's

1997 02 06

TO: **Dr. C. Way**

FROM: **Eric R. Parsons, MD,CCFP,**

SUBJECT: **Research Proposal**

Your research proposal HIC **# 96.138 - The Lived Experience of Anorexia Nervosa: a Phenomenological Approach"** has been considered by the Research Proposal Approval Committee (RPAC) of the Health Care Corporation of St. John's at their most recent meeting.

The committee has approved your proposal to be conducted at the General , Waterford & St. Clare's Sites within the Health Care Corporation of St. John's. This approval is contingent on the appropriate funding being provided and continued throughout the project and on the provision of regular progress reports at least annually to the RPAC Committee.

ERIC R. PARSONS, MD,CCFP,
Vice-President, Medical Services

ERP/sh
c.c. Linda Purchase, Research Centre

September 15, 1996

Colleen Simms
Program Director,
Mental Health
Health Care Corporation
St. John's, Newfoundland

P.O. Box 87
Mobile, NF
A0A 3A0

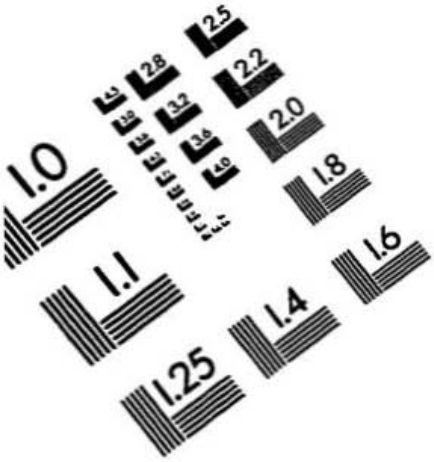
Dear Lorraine:

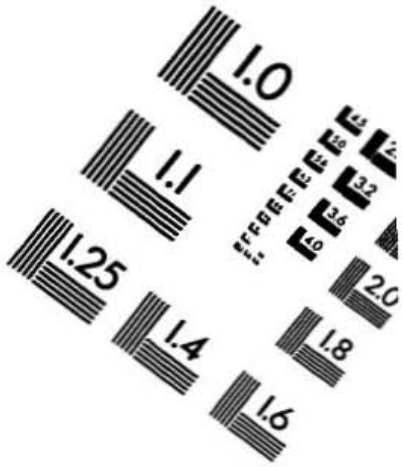
This is to certify that you have my support for the proposed study, "The Lived Experience of Anorexia Nervosa: A Phenomenological Study." Once you have received ethical approval from the Human Investigations Committee, Memorial University, I will facilitate identification of suitable clients meeting the inclusion criteria for physical and mental competency.

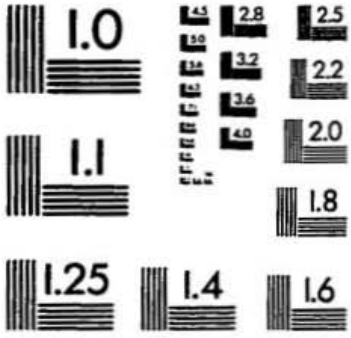
Sincerely,

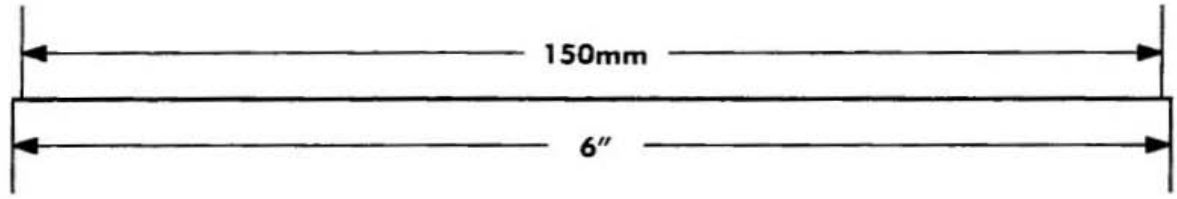
Colleen Simms

IMAGE EVALUATION
TEST TARGET (QA-3)









APPLIED IMAGE, Inc
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Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989