IF YOU KNEW WHERE I LIVED: A QUALITATIVE STUDY WITH PARTICIPANTS IN A COMMUNITY OUTREACH PROGRAM FOR EATING DISORDERS

by

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ABSTRACT

The Community Outreach Program (COP), an occupational therapy-based treatment model for eating disorders, serves adult women who have been repeatedly hospitalized with chronic anorexia and bulimia and who are at high risk of mortality. It provides intensive, individually-focused treatment delivered by a multi-disciplinary team in the client's community. This thesis documents the experiences and reflections of six participants, including clients, administrators, and caseworkers, considering in particular COP's impact on recovery and "quality of life." The adoption of a client-centred perspective to eating disorder treatment and theory constitutes a major contribution of this study.

A multi-method research design (qualitative, ethnographic, feminist, emancipatory) was used to collect and analyze data from interviews and documents from 1996-1997. In setting the context for research, "eating disorders" and "disordered eating" are delineated; as well, incident rates, treatment modalities, and the service framework in British Columbia are described. Program documents provided information about client population, rationale and objectives of COP, and roles and responsibilities of staff. The literature review examines chronicity and iatrogenesis in eating disorders and critiques general causal theories such as biomedical, psychogenic, and cultural etiologies, including limitations of "flight from femininity," family influences, beauty ideals, and fat phobia perspectives. Trauma-based theories correlate disordered eating with sexual and physical abuse, violence, harassment, and stigmatization.

The findings indicate COP's philosophy and model and the interactions between clients and the program enhanced quality of life, decreased hospitalization, and reduced hopelessness and isolation. Qualities of the program philosophy include an out-of-hospital setting, the paradoxical treatment approach (a client-centred activation model), availability and flexibility of the program, and staff skills and strategies. Participants identified qualities of interactions between clients and program staff—particularly activation workers—which enhanced recovery as interpersonal (i.e, consistency, reliability, connection, trust) and intrapersonal (self-awareness). According to participants, treatment was not long enough to promote growth and recovery. The findings demonstrate that relationship quality is important to recovery and signify that effective, responsive treatment must be based on clients'-stated needs and provided in a timeframe determined by clients rather than funders. Self-in-relation and attachment theories are proposed as a key to understanding why treatment failure is frequent and often iatrogenic.

DEDICATION

To the people who continue to struggle to understand themselves and their complex relationships to food and their bodies—particularly to those who have been lost along the way.

To E.F. because she never got to see her words in print

To my Aunty Vivy, my "cookie person," whom I wished could have been here to share these ideas.

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CHAPTER ONE

Problem Statement and Rationale

Those who wish to succeed must ask the right preliminary questions.
Aristotle, Metaphysics, II (III), i (in Coles, 1982)

Introduction

In September of 1995, St. Paul's Hospital's Eating Disorders Clinic and Greater Vancouver Mental Health Services Society began a pilot project to provide treatment for a specific client population of adult women identified as having chronic and unrelenting anorexia nervosa and bulimia nervosa. The project, called the Community Outreach Program (COP), was grounded in an occupational therapy model of rehabilitative practices and was the first of its kind in British Columbia and Canada in treating eating disorders (V. Smye, personal communication, April 27th, 1997). The Community Outreach Program pilot project attempted to address an identified treatment gap for individuals with "severe, long-standing, and complicated anorexia nervosa and bulimia nervosa" (Niblock, 1995). These patients had been repeatedly hospitalized due to medical crises and were at high risk of mortality due to acute physical and emotional complications of their eating disorders. The Community Outreach Program provided intensive treatment services without the use of expensive residential or long-term in-patient hospital facilities. Services centred on client need and were delivered by a multi-disciplinary team at the clinic and by activation workers in the client's community. The pilot project was evaluated as "successful" (Provincial Eating Disorders Steering Committee [PEDSC], 1995b) according to specific outcome measures. The B.C. Ministry of Health gave permission for ongoing funding and development of the Community Outreach Program in June of 1997.

This thesis focuses on participants of the pilot project and their experiences during their involvement with the Community Outreach Program, as this was not included in the formalized outcome measures. The purpose of this work is to examine what participants of the program--both clients and staff members—had to say about the program and its impact on clients' recovery and "quality of life." The thesis attempts to attain information on whether or not the program was successful *according to the participants' perspectives* and why. Staff perspectives were included to provide a parallel report of the experiences of service providers with that of clients. In this work, I have attempted to understand and document what qualities or components of the program have made a difference to the clients' well-being and recovery; to determine what aspects of COP would be beneficial for other treatment programs to incorporate, and to contribute to a more expansive understanding of responsive treatment provision for disordered eating.

This introductory chapter has three components. The first component describes the historical context within which the research problems and questions were asked. It begins by briefly defining eating disorders, discusses the difference between the terms "eating disorders" and "disordered eating," and presents information on incidence rates. Treatment modalities and the general historical development of treatment services in B.C. are then outlined. The second component discusses the development of the Community Outreach Program pilot project including the identified population, rationale and objectives for the program, and the staff roles and responsibilities. The preliminary evaluation results are also presented. The third component of the chapter presents the traditional thesis problem statement, articulates why this research was undertaken, and states the assumptions and limitations to the study.

Historical Context of the Problem

This section describes the context in which this research project is situated. It begins with a history of anorexia and bulimia, defines the differences between "eating disorders" and "disordered eating," and examines the political implications of the use of these two terms. The incidence of eating disorders in the province and the way in which the problem of eating disorders have been addressed (i.e., treatment modalities) are then outlined. Finally, the development of a treatment framework for eating disorders in B.C. is discussed.

Defining the Terms

> *Before we can reasonably be asked to look for the cause of a particular dysfunction or disorder, we must have isolated, however crudely, the dysfunction or disorder in question, and we must be able to recognize it and differentiate it from other syndromes. The very term 'abnormal' implies a principle of classification; we could not look for causes of 'abnormality' unless we had some conception of what we mean by 'normal,' what kinds of deviations we would agree to consider 'abnormal.' (Eysenck, 1961b, in Coles, 1982, p. 3)*

The historical definitions of eating disorders and the subsequent development of treatment services have been based on the observation and description of problem behaviour (nosology) and subsequent attempts to understand the causes of such behaviour (etiology). "Eating disorders" have been identified largely as anorexia nervosa and bulimia nervosa by the medical and psychiatric professions and are discussed as such in the popular media. However, the idea that anorexia and bulimia nervosa are but two points along a *continuum* of "disordered eating" behaviours has been increasingly debated both in and out of the medical and psychiatric arenas, particularly by feminist theorists and social commentators. The historical context in which current nosology and etiology of eating disorders have arisen are discussed to provide a basis for understanding how and why treatment has been implemented.

Anorexia nervosa, while a seemingly recently acknowledged health issue, is by no means a new disorder. Silverman (1997) documents how Morton (1694), Marcé (1860), Lasegue (1873) and Gull (1874) all described patients with physiological symptoms of anorexia (meaning "without appetite") in relation to psychological conditions ("nervosa"). Brumberg (1988) and Bynum (1987) provide historical accounts of self-starvation in relation to religious devotion and/or political resistance. Bemporad (1996) and Silverman (1997) note that early physicians understood the psychological implications of self-starvation (i.e., unrelated to food scarcities or physiological malfunction) and treated patients with early precursors to modern pharmaco-therapy (stomach plasters, aromatic bags, and encouragement to increase food intake).

Bulimia (meaning "oxen appetite") nervosa has only recently been named a disorder. Binge eating and purging behaviours had previously been noted in the medical literature but were thought simply to be a symptom of anorexia. By the late 1970's, however, bingeing and purging symptoms were more frequently noted in non-anorexic and non-emaciated individuals and, thus, "bulimia nervosa" was distinguished as a separate syndrome (Russell, 1979). The last thirty years has seen much research literature focused on the epidemiology of anorexia and bulimia and a continual refinement of the diagnostic criteria (Fairburn & Beglin, 1990; Fairburn & Garner, 1986, 1988; Garner & Fairburn, 1985; Garner & Garfinkel, 1988; Hsu, 1990, 1991,1996; Mizes, 1985; Nylander, 1971; Pope, Hudson, Yurgelon, Todd, et al. 1984; Pyle, Mitchell & Eckert, 1981, 1983; Russell, 1970, 1979; Strober, 1981; Strober & Katz, 1987; Theander, 1970; Willi & Grossman, 1983).

Both anorexia and bulimia are disorders characterized by severe disturbances in eating behaviours and in perceptions of weight and body shape (American Psychiatric Association [APA], 1994). Clinical diagnoses of anorexia and bulimia are made in accordance with the American Psychiatric Association's *Diagnostics and Statistics Manual (DSM)*. According to the latest edition, (*DSM-IV*, APA, 1994), anorexia is distinguished by severe food restriction and/or food refusal, significant weight loss, and an accompanying fear of weight gain despite severe emaciation. Frequently, individuals with anorexia refuse to maintain a "minimally normal body weight" (APA, 1994) and fear a loss of control in relinquishing their restricting behaviours and food rituals. Bulimia nervosa is marked by the repeated consumption of food and the compensatory behaviours employed to avoid weight gain. These may include self-induced vomiting, laxative and diuretic misuse, obligatory exercise, and/or food restriction as a way to "undo" the food consumed in a binge phase. However, both anorexia and bulimia have diverse and multiple symptoms that encompass behavioral, psychological, and physiological characteristics (Harper-Guiffre, 1992).

In 1980, a third category, Eating Disorders Not Otherwise Specified (ED-NOS) was presented in order to provide coding for disorders that did not meet the criteria specific for anorexia or bulimia. Individuals were being observed in clinical settings who were considered to have "sub-clinical" forms of eating disorders (Garner, 1985). For example, ED-NOS is diagnosed if an individual has significant weight loss but remains within a normative weight range; if all criteria for anorexia are met except amenorrhoea (in females); or if the criteria for bulimia are met, but bingeing and purging occur at less frequent intervals. Van Wormer, (1994, p. 291), states that the creation of this third classification was a result of "considerable pressure from the eating disorders treatment industry" to include a category which would permit insurance reimbursements for individuals with disordered eating behaviours who did not fit the strict diagnostic criteria for anorexia or bulimia.

Obesity is not included in the *DSM-IV* because "it has not been established that it is consistently associated with a psychological or behavioural syndrome" (APA, 1994, p. 539). Rather, obesity is considered a physiological dysfunction or condition and is included in the

International Classification of Diseases (World Health Organization, 1992). Obesity is generally defined as a body weight 20% or more above stated "ideals" of insurance actuarial tables (Rothblum, 1994). As Rothblum (1994) states, "In Western society, it is universally believed that the causes of obesity are eating too much and exercising too little." Although the healthcare industry and governmental agencies strongly emphasize that obesity is a health risk, research demonstrating a link between weight and various health risks is being challenged (Eisen, 1997). As obesity is not defined as an "eating disorder" in the medical and psychiatric fields, it has not been researched, treated, or discussed in the same context as other eating disorder behaviours.

Statistics on anorexia and bulimia consistently indicate that 90-95% of those with a diagnosable eating disorder are female. While eating disorders are being increasingly identified in men and, in particular, young boys, feminists have stated that anorexia, bulimia, and other forms of "disordered eating," are related to the experience of gender and gender role expectations in culture. This discussion will refer to the incidence and impact on females only given that the majority of those diagnosed with an eating disorder are female and because of the limitations of this thesis. However, it is acknowledged that the impact of eating disorders has deleterious effects on male well-being also, which may or may not be similar to the impacts on females.

Diagnostics: "Eating Disorders" or "Disordered Eating"

The term "eating disorders" has become politically controversial. Feminists argue that the dominant, allopathic (i.e., focuses on alleviating symptoms) medical model that defines "eating disorders" as strictly anorexia or bulimia fails to acknowledge the larger continuum of "disordered eating" behaviours, perceptions, and feelings that most women experience on a daily basis (Bordo, 1993; Brown & Jasper, 1993; Orbach, 1992; Women's Therapy Centre Institute, 1994). It has been estimated that 1-5% of women are affected by anorexia and 2-18% by bulimia according to rigid APA diagnostic criteria (Garner, 1985; Zerbe, 1993). However, it has been argued (Bordo, 1993, Orbach, 1992) that these statistics reflect only the most extreme end of the continuum of disordered eating behaviours and, thus, the numbers of women affected are much higher.

According to feminist critiques, while only a subset of women meet criteria for anorexia and bulimia; compulsive eating, obesity, widespread dieting, and body dissatisfaction are also disordered relationships to food and the body and occur so frequently among females in Western culture as to be "unremarkable" or "normalized" aspects of femininity (Orbach, 1992). A frequently cited study by Wooley & Wooley (1984) surveyed 33,000 readers of *Glamour* magazine and found that 75% of the participating women were on a diet, though only one quarter were overweight and one third were actually underweight. Research shows that emotional factors such as the drive for thinness and the influence of body image on self esteem effect a majority of women throughout North America (Nylander, 1971) and a growing body of research (Attie & Brooks-Gunn, 1989; Hesse-Biber & Marino, 1991; Houn, 1994; Killen & Taylor, 1996; Mintz & Bentz, 1988; Rossotto, Rorty-Greenfield & Yager, 1996) suggests that weight-preoccupation, body image dissatisfaction, dieting, and self-esteem issues can lead to more serious forms of eating disorders such as anorexia and bulimia. Therefore, it may be difficult to distinguish succinct categories of anorexia and bulimia from more normalized disordered eating activities which become more progressive over time. Therefore, the clinical use of "eating disorders" can be viewed as myopic because it focuses on only the extreme of a wider continuum of disordered eating behaviours. In doing so, there is a failure to isolate and differentiate a "disorder" from "normal" behaviour; and, thus, according to Eysenck's quote which opens this section, precludes the development of an appropriate etiology and subsequent interventions.

Feminist theorists (Fallon, Katzman, & Wooley, 1994; Orbach, 1978, 1982, 1985, 1986; D. Russell, 1995; The Women's Therapy Centre Institute, 1994) prefer the term "disordered eating," arguing it more accurately reflects the *continuum* of problematic behaviours. Furthermore, "disordered eating" attempts to depathologize anorexia and bulimia by questioning the pervasive normalization of activities such as dieting, compulsive exercising, cosmetic surgery, etc. Feminist arguments echo the early work of Szasz (1960) and his recognition of the "social role of the patient," emphasizing that a discontinuous view of eating disorders (vs. disordered eating) obscures the social and cultural determinants of women's generalized distress about food and their bodies. Thus, this view limits the development of a wholistic and effective treatment and prevention framework. Finally, in terms of funding and research, how a problem is defined largely determines how the problem will be addressed. Certainly the response to eating disorders/disordered eating in B.C. is evident of this in that funding and treatment has focused largely on anorexia and bulimia in medical settings. For the purposes of this discussion, the term "disordered eating" will be used to denote the several forms of disordered relationships to food and the body encompassed by anorexia, bulimia, obesity, compulsive eating, weight preoccupation, dieting, etc. The term "eating disorders" will be used when speaking strictly of anorexia and bulimia although the understanding is that anorexia and bulimia are only two points along the larger continuum of disordered eating.

Coles (1982, p. 24) states, "Successful treatments in medical specialities is typically considered to be dependent upon recognition of the cause(s)." Prognosis studies indicate that relapses for eating disorders such as anorexia and bulimia are high and that there is a large subgroup of women with eating disorders who appear to be "treatment resistant" (Garner, 1985;

Zerbe, 1993). Halmi, Eckert and Marchi (1991) found that only 14% of patients with anorexia did well in a ten year follow-up study while Mitchell, Hoberman, and Pyle, (1989) and Mitchell. Soll and Eckert (1989) found one in four patients were considered "treatment failures." In addition, anorexia has the highest morbidity rate (15%) of any psychiatric disorder (APA, 1994; Fallon, Katzman, & Wooley 1994; Women's Therapy Centre Institute, 1994) with one-third to one-half of premature deaths a result of suicide (Hsu, 1991; Theander, 1985). I suggest that the lack of success in the treatment of anorexia and bulimia would indicate mis-recognition of the causes of eating disorders.

While the research literature repeatedly states that the causes of eating disorders are multi-determined and multi-faceted (Brownell & Foreyt, 1986; Harper-Guiffre & McKenzie, 1992; Shislak & Crago, 1994), the lack of an inclusive classification of eating disorders has been problematic in developing treatment, determining funding for research and services, and planning prevention and intervention strategies. When eating disorders are identified as only anorexia and bulimia, this limited identification fails to address the scope of the problem and, thus, has implications for understanding causes and implementing interventions. In this section, the changing nosology of eating disorders—from anorexia to bulimia and EDNOS—has been discussed. It has also been noted that obesity and other forms of disordered eating are not included. Only a small subset of women fit the criteria for diagnosable eating disorders despite the fact that disordered eating is so widespread as to be considered normative. For this thesis, the concept of what is "normal" is important to defining what is viewed as problematic and what interventions must be implemented. To further expand the concept of identifying the problem, the incidence of eating disorders will now be addressed.

Incidence Rates

Eating disorder services in B.C. have been developed in reaction and response to increased awareness and identified need. Research statistics show an increased incidence of anorexia and bulimia. This has led to questions whether this is due to better identification and diagnosis than in previous decades, or to an actual increased incidence of eating disorders in the population (Hsu, 1990, 1991, 1996; Jones, Fox, Babigan et al., 1980; Kendall, Hall, Hailey et al., 1973; Szmuckler, Eisler and Gillies, 1986; Theander, 1970; Treasure, 1992; Willi & Grossman, 1983). While opinions differ, there is general agreement that despite increased public and professional awareness of anorexia and bulimia, there is an increasing number of women and men being affected (Bordo, 1993; Fallon, Katzman and Wooley, 1994; Harper-Guiffre, 1992).

There are no specific figures for the numbers of people affected by disordered eating in the province as no epidemiological studies have been done to date. In addition, there has been no agreement on the definition of the problem (e.g. eating disorders or disordered eating) to make a meaningful beginning to such a measure. The 1996 Provincial Health Officer's Report (1997) indicated that while 46% of British Columbians are within a healthy weight range, 26% are considered to be at risk because they are overweight and 9% because they are underweight. While men are more likely to be overweight than women in B.C., 40% of women are actively trying to lose weight at any given time and 1-5% of women suffer from eating disorders (p. 53). Studies on anorexia and bulimia from Sweden (Theander, 1970), the United Kingdom (Crisp, 1965; Russell, 1970,1985), and the United States (Jones, et al., 1980) estimate that one in ten women struggles with anorexia and one in five with bulimia. Using strict *DSM-IV* criteria to diagnose anorexia and bulimia, Hsu (1990) estimated that 0.1% of adolescent and young adult females are afflicted with anorexia and Fairburn & Beglin (1990) estimated that 0.9% struggle with bulimia. Using these percentages as reasonable estimates of incidence, the *Provincial*

Eating Disorder Task Force Report (McCreary Centre Society, 1989) estimated that in B.C., one in six females and one in fourteen males has anorexia or bulimia. However, these are considered conservative estimates given the secrecy and shame that usually accompany these behaviours (Fallon, Katzman & Wooley, 1994; National Eating Disorder Information Centre [NEDIC], 1988). Furthermore, these estimates do not include women identified as "Eating Disorders-Not Otherwise Specified" nor those affected by more general disordered eating behaviours. So while awareness and recognition of eating disorders has increased significantly since the early accounts of Marcé and Leségue, the actual incidence of eating disorders seems to be growing.

Treatment Modalities

In B.C., treatment modalities for disordered eating have followed the establishment of treatment modalities world-wide. These are based on the burgeoning research findings and etiological theorizing of the past thirty years and have been generated almost exclusively from a medical perspective that determines anorexia and bulimia as the only clinically-recognized problems needing to be addressed. Treatment has also tended to be medically- or psychiatrically-focused and this occurs for several reasons. First, general practitioners and physicians are often the "first point of contact" (Provincial Eating Disorders Steering Committee [PEDSC], 1999, p. 33) for persons concerned with weight and physical health. This is further enhanced by the "medicalization" of the weight loss and diet food industries which often use medical nursing staff and medical language to authenticate their services. Second, starvation from persistent food refusal in spite of a readily-available food supply, or a continued denial of hunger and/or fear of eating and weight gain despite low body weight, are considered pathological and, therefore, require psychiatric intervention. Third, the effects of prolonged anorexia and bulimia have profound physiological effects that seriously impact physical health (Zerbe, 1993). Subsequently, people are brought to medical clinics and emergency wards and treatment is initiated in the medical system as it tries to meet patient needs. Fourth, because earlier symptoms along the continuum of disordered eating are normalized and overlooked within society, anorexia or bulimia may have developed to more advanced stages and require more intensive medical and psychiatric intervention. Fifth, medical and psychiatric services are covered under the Medical Services Plan of B.C. and are, therefore, more easily accessible than non-medicalized services such as counselling or psychotherapy. Sixth, a specialization of eating disorder treatment has occurred as treatment settings have shifted from general medical units to specialized clinics. The literature (Garner, 1985; Morgan, 1977; Vandereycken, 1993; Yager, 1992) and anecdotal reports (PEDSC, 1999) have indicated that general nursing staff are reluctant to work with eating disordered patients. Garner (1985) cites Russell's findings about the reluctance of healthcare nursing staff to nurse patients who "refuse" to return to health and the subsequent hopelessness of careproviders because of their "failure to cure" patients using standard nursing approaches. Finally, the medical-psychiatric model holds a privileged, legitimized, predominant position in Western culture (despite recent and on-going critiques of the model's limitations and oversights with women's health [Bordo, 1993; D. Russell, 1995]). These seven factors have influenced how treatment for anorexia and bulimia has been entrenched in a medical/psychiatric model and how funding, research, and treatment practices are centralized in this treatment modality.

As medical treatment has been the primary mode of intervention, treatment programs have historically been located within hospital settings. Patients with anorexia and bulimia were hospitalized for long-term renourishment and medical and psychiatric stabilization, then released from hospital. With traditional programs, adherence to an allopathic medical model meant that "full recovery" was achieved by treating the symptom of weight loss or psychiatric dysfunction. Full recovery was expected within a medical/psychiatric approach as weight restoration was viewed as the symptom needing correction. A patient's restoration to *physical* health was achieved by having the patient make sufficient weight gains and changes in eating behaviours (no food phobias, restricting, nor purging). This "achievement" was attained through behaviour modification techniques in early programs and through cognitive behavioral approaches in later, more progressive, programs. Treatment programs have been known to be rigidly-structured and to employ strict rules around behaviour. For example, clients were required to meet weight gains in order to have access to their personal belongings, to attain "passes" to leave the ward, or to receive visitors (Orbach, 1986). Treatment was provided only in the hospital setting and programs were usually of a short duration (aside from lengthy re-feed admissions for severe anorexia and bulimia), with few follow-up resources in the community. Some eating disorder programs provided family education and support, particularly in the treatment of children, but with limited budgets, not all programs could provide such services. In summary, there are several reasons why treatment is dominated by the medical/psychiatric model: physicians are the first point of contact for weight issues; the seeming absurdity of self-imposed starvation and the physiological and psychological effects of starvation require medical/psychiatric attention; anorexia and bulimia may be at more advanced stages before they are recognized; the B.C. Medical Services Plan provides insurance coverage for medical and psychiatric services; specialized settings and staff are required to deal with eating disorders given reluctance of clients to "return to health;" and the privileged, legitimized authority of the medical-psychiatric model in Western culture contribute to this approach.

Treatment modalities follow etiology. Restoration to health is viewed as a restoration of weight and thus, treatment had tended to focus on arresting the symptoms of anorexia and bulimia. In-hospital treatment settings have relied on behavioural modification techniques and cognitive behavioural programs to do so, with little support for family or attention to other influences or causes on the development of an eating disorder.

Historical Development of Services for Eating Disorders in B.C.

Providing treatment for the number of people affected by anorexia or bulimia has been challenging. Prior to the 1950's, anorexia was considered a rare disorder and treatment varied from practitioner to practitioner as relatively few cases were seen the consulting room (Orbach, 1986). Increased identification and incidence has resulted in a greater demand for services. With recent and increased recognition of these disorders, the provincial healthcare system has been unprepared to address the problem in B.C. By the 1980's, physicians, dieticians, psychotherapists, social workers, support group and front line workers, and other healthcare providers reported increasing numbers of people requesting services and increased caseloads which numbered in the thousands (McCreary Centre Society, 1989). Few healthcare practitioners had knowledge, training, or experience in addressing eating disorders and few programs, resources, and services had been established to meet the ever-increasing demand. The few trained and skilled service providers with experience in the field reported "burn out" from working in a state of crisis for the past ten to fifteen years (PEDSC, 1999). While British Columbia has been on the forefront of eating disorder research and service development in Canada, existing and newly developed facilities and programs had been filled to capacity since inception.

In B.C., as in other Western centres, it soon became apparent that attending solely to the medical challenges of eating disorders was insufficient to dealing with the complexity of anorexia and bulimia. Several patients were cycling repeatedly through programs and practitioners and treatment centres were inundated with new and repeat patients. In addition, previous treatment programs may not have been effective in facilitating recovery, thus services have been used repeatedly that were intended for single use. The popular media were more frequently reporting deaths due to eating disorders.

In 1989, an Eating Disorder Task Force was established in B.C. to examine the alarming problem of eating disorders in the province and to make recommendations to address the issue. The Task Force concluded that eating disorders were occurring in all regions of the province, were known to be chronic (i.e., without intervention, they could extend over many years), and that both service providers and those requiring services were continually frustrated by the lack of availability and the uneven distribution of services. The Task Force urged the Ministry of Health to act immediately to set up a provincial coordinating body to develop guidelines and a framework for services. The Provincial Eating Disorders Steering Committee (PEDSC), with consumer and family representatives, hospital administration, clinical program staff, and community agencies from across geographic regions was formed to oversee the activities and development of a provincial services program.

Developing a Provincial Treatment Framework

The B.C. Ministry of Health established principles to guide service development. These were: (a) residents from all regions of the province would have access to services, (b) services were to be age-appropriate, e.g., children, adolescents, and adults require services geared to their specific developmental and social needs and (c) resources were to be used efficiently by ensuring provision to as many individuals as possible without duplicating services (PEDSC, 1996). A treatment framework for eating disorders in B.C. followed other North American and U.K. trends.

Currently, individuals who require specialized treatment or intensive care are sent to the eating disorder programs at St. Paul's Hospital (for adults) and B.C Children's Hospital (for children and adolescents) for acute care services. These two tertiary facilities in the province have a concentrated majority of healthcare funding for eating disorders services. They provide specialized in-patient treatment units, day treatment programs, and residential facilities. Tertiary programs also provide support to regional teams via telephone consultation, on-site education, and by assisting with regional program development and evaluation. Specialized tertiary care beds address the physical complications of severe starvation and purging. This type of care is intensive and costly and there have been limited numbers of beds available. Currently, there are 8 beds for adults and 3 beds for children at the tertiary care centres for use by the province. In order to access the limited tertiary care facilities, patients must be referred by their physician for assessment to determine the severity of the client's eating disorder and their prioritization for admission. Before the development of a provincial eating disorder program at St. Paul's Hospital and B.C. Children's Hospital, specialized tertiary care beds were initially established within medical and psychiatric units of larger hospital sites in the Lower Mainland (Sunnyhill, Shaunessy, B.C. Children's, and St. Paul's hospitals). The "New Directions in Healthcare" reform (Vancouver Health Board, 1995, 1996) that began in 1990's insisted that local resources be developed in all regions of the province ("regionalization") to provide "closer to home" treatment (Vancouver Health Board, 1995, 1996) and to link treatment programs with existing community services. As a result, specialized beds and eating disorders programs were established in regional hospitals (e.g., Victoria, Vernon, Prince George, Trail, Cranbrook). Smaller geographic centres continue to accommodate tertiary patients in their psychiatric units until admissions can be made to the tertiary care programs in the Lower Mainland.

As demands for tertiary services and wait lists for assessments at these centres began to grow, it was evident that secondary services needed to be developed. Secondary programs consist of diagnostic assessments, psychoeducational groups, nutritional counselling, limited one-on-one counselling, family therapy, and/or support groups. Most secondary services are of shorter duration than tertiary care and are offered more frequently. Secondary services are more cost-effective as group formats allow for services to be provided to many people at the same time. Arguments have been made for the benefits of group treatment over individual treatments (Piran, Langdon, Kaplan, et al. 1989); however, one criticism from both service users and service providers is that complex, individual, emotional, and psychological issues can not be addressed in a short-term group format (PEDSC, 1999). Ideally, secondary services address the treatment gaps for those with anorexia or bulimia who do not require intensive hospitalization, but who still require treatment to stop their behaviours. Secondary services are also used to monitor the status of those who had previously received care in the tertiary centres and to address the needs of those with anorexic or bulimic behaviours that do not meet the *DSM-IV* criteria. However, in B.C., secondary services have become 'stop-gap' measures to respond to the overflow of people who require tertiary care yet are unable to be admitted due to a shortage of beds. In outlying regions, secondary services are also used for patient assessments when travel to the Lower Mainland is difficult. Due to the increased need and lack of available services, a "trickle down effect" has been created where those requiring more intensive services are being assisted at a secondary level of care, and those who should receive secondary treatment are left without access to appropriate services (PEDSC, 1999).

The "trickle-down effect" is also acute at the primary level of treatment. Health funding has been largely reserved for tertiary care services and some secondary care. This has meant that programs with primary or prevention initiatives have been left to volunteer, grass-roots, consumer groups or private agencies with fees for services. In addition, those requiring services but who cannot access secondary or tertiary care are being seen at the primary or preventative levels where services are inadequate to meeting the need of someone with more serious disordered eating. This provincial framework, therefore, has difficulty providing adequate care at the necessary levels for those with eating disorders

Limitations to the Provincial Treatment Framework

Although services for anorexia and bulimia have been responsive, they have not been delivered as a unified single-system of care, rather tending to be fractured and fragmented. While tertiary services are well-established in 2000, further development of regional linkages, early intervention and preventative initiatives is necessary. Regional programs require much more support to allow the proposed Ministry of Health policy of "closer to home" ideals to be meaningful and to decrease the reliance on the tertiary care centres. Currently, primary or preventative services are under-funded and heavily reliant on community and volunteer labour (PEDSC, 1999). In 2000, the provincial framework for eating disorder services continues to be developed by the Provincial Eating Disorders Steering Committee, although at the time of this writing the Ministry of Health is implementing a full review of all provincial eating disorder programs and the Steering Committee itself.

Controversy continues as to whether the existing focus and development of services appears to meet the needs of those with eating disorders (PEDSC, 1999). Certainly services have been developed where none were before, but there continues to be demand for more extensive services than has been provided, particularly development of prevention and early intervention services. There is no data available on the service needs of people with a variety of disordered eating behaviours (particularly compulsive eating), as their problems do not fit the criteria for study, much less for access to services. Private practitioners and consumer-based agencies provide most services to this group with little funding nor available personnel for needs assessments or outcome measurements. Furthermore, the provincial framework does not address nor recognize people with subclinical or disordered eating problems, which only emphasizes the limitations of current service provision. Thus, the lack of a comprehensive nosology and etiology occurs because of the continued myopic identification of the problem and this results in a lopsided prioritization of funding.

Another limitation to the provincial framework is evident with the emergence of a special client group—individuals with severe and prolonged eating disorders. Despite the heavy prioritization and funding of acute/tertiary services, there is a treatment gap for this population of patients. Despite having accessed all existing services in the province, they have not responded well to treatment and have treatment needs that have not been met by existing services. A fourth, or "quaternary," level of intensive care was suggested for development to address the severity of their needs and their histories of repeated admissions. Pressure was applied to the Ministry of Health to fund out-of-province treatment if special services could not be provided in-province. The Ministry of Health worked to quickly create a program to address the special needs of this group. A pilot program, the Community Outreach Program, was begun.

Development of the Community Outreach Program

This second section of the chapter discusses the development of the Community Outreach Program (COP) pilot project and provides a detailed description of the client population it was designed for. The rationale for and objectives of the program are identified from existing program documents and the roles and responsibilities of the program staff are outlined. Finally, the results of the pilot project's preliminary evaluation are presented.

Identified Client Population

For many women with anorexia and bulimia, hospitalization marks the nadir of their eating disorder and they are hospitalized only once. Once medically-stabilized, they are admitted to clinical out-patient group programs or discharged. For other women, neither individual psychotherapy nor group treatment programs prove effective. Their eating disorders become more entrenched, and their physical and emotional condition worsens over time (Bruche, 1978; George, Weiss, Gwirtsman & Blazer, 1987; Orbach, 1986, 1992; Sesan, 1994). Women invited to take part in the COP pilot project were identified as having "unrelenting" anorexia and bulimia, had required numerous and costly hospitalizations either in long-term in-patient facilities and/or to emergency rooms, and had histories of a resultant poor "quality of life." Once treated and discharged, they often lost the crucial weight gains they had made in hospital, their health quickly deteriorated, and they were readmitted within the following months in acute medical and emotional crisis (V. Smye, personal communication, April 27th, 1997).

Most of the pilot project participants had had anorexia and/or bulimia for more than a decade; others had lived longer with their eating disorders than without. They had difficulty functioning independently or effectively in the community, and for many work or education was repeatedly disrupted due to poor health and repeated hospitalizations. Many of the women could not afford nor sustain independent living and resided with parents, lived in group homes, or relied on social assistance or long term disability subsidies. The effects of their eating disorders socially isolated them. The women reported that many of their food and weight rituals (shopping, hoarding, purging, exercising, etc.) dominated their daily lives, impaired employment, and made relationships difficult. Some feared functioning in public and/or experienced clinical anxiety or depression. The women had few friends and less extensive support networks to rely on. Their financial distress and social isolation both contributed to, and was a result of, their anorexia and bulimia. Furthermore, these women were at acute risk of death and did not appear to be benefiting from existing tertiary services.

Rationale for COP

A "revolving door" of treatment had developed for this particular group of service users and they required a significant concentration of healthcare resources in their individual treatment. They had difficulty sustaining longer-term health and because of their subsequent declines were often given priority for tertiary services because of their acute symptoms. They occupied treatment beds designed for and in demand by less acutely ill patients for prolonged periods of time, consequently lengthening wait lists for tertiary services (V. Smye, personal communication, April 27th, 1997).

A few individuals who were at extreme risk of death and who were not responding to existing intensive services in B.C. had received financial support to attend quarternary care treatment in the United States. There were initial positive outcomes from these intensive residential programs: the women achieved substantial health improvements, were no longer at risk of dying, and were able to break the cycle of hospitalization. However, the costs associated with such treatment programs were high (admissions varying from $25,000-30,000 (US) per month), and the longer-term outcomes of such hospitalizations were unknown (Geller, 1996). It was presumed that a significant percentage would most likely relapse over time and continue to require ongoing treatment services in B.C.

The design of the Community Outreach Program pilot project arose from the preliminary findings of discussions, meetings, and focus groups, organized between the provincial eating disorders program administration, Vancouver Richmond Health Board, community services organizations, and service users and their families. This group, the Eating Disorder Community

Planning Working Group (EDCPWG) began work in October 1995. From their meetings they found that this particular patient group had difficulty making the transition from institutional living to community living, and suggested a number of reasons why transitioning from hospital care to community may have proved difficult (Niblock, 1995). First, repeated hospitalizations and the unsatisfactory rotation through available programs was experienced as a failure for these patients and attributed to low self-esteem and feelings of hopelessness. Second, for those women with support from family and friends upon discharge, most family and friends could not provide the intensive level of support or care required. In addition, family and friends, themselves, experienced tremendous distress and anxiety from repeated hospitalizations and crises of the service users. Third, there were few adequate community resources to support someone with a severe eating disorder. Community care providers often chose not to work with this client population, expressing their lack of skills and experience with treatment of severe eating disorders, the long-term service provision necessary, their frustration with their perception of the client's "resistance" to recovery, and their fears regarding the high morbidity rates of the client group. Fourth, support groups and self-help groups designed as adjuncts to therapy or as early-intervention services were inadequately equipped to deal with the medical and psychiatric emergencies that arose from participants' severely-compromised health. In addition, such programs were never designed nor intended to be the sole means of support for this client group and their extreme hopelessness and despair proved difficult for volunteers to manage (PEDSC, 1999).

The Community Outreach Program was proposed as a preferred option to addressing the needs of these individuals rather than sending them out of province or developing expensive quarternary care facilities in the tertiary centres. The intention or rationale for developing a community outreach program was to reduce healthcare costs and foster the necessary supports for these individuals to make the eventual transition from institutional living to community living. The pilot project was designed and would become a component of the existing framework for adult services (see Appendix A) if shown to have a positive outcome.

Objectives of COP

According to the proposal for the Community Outreach Program and correspondence between the service providers and the funder, the objectives of COP were to improve the "quality of life" for these clients and to reduce their hospital usage. In addition, the program aimed to encourage and to develop the support needed by these women (and their families) to pursue independent living—away from hospital and in their community. COP was innovative as it emphasized a "contextual" approach to service delivery and sought to address the complex social and interpersonal relationship issues that kept this client group institutionally-dependent.

There were a variety of strategies employed to improve quality of life and to decrease hospitalization that reflected the basic values and beliefs of COP's philosophies. The first noticeable difference was that program participants were now "clients," rather than "patients." This signified a more active role for the participant in her healthcare and was intended to recognize the inherent power dynamics in previous service user/service provider relationships. Second, a "client-centred" approach was used to encourage the client, with the support of the team, to take an active role in decision-making about her healthcare and lifestyle priorities. In contrast to the group formats and group-defined protocols of previous programs, this client-centred approach required a highly individualized program responsive to the client's own defined needs. Third, quality of life issues were to be addressed by adopting a "harm-reduction" approach. In other words, full recovery, or a "cure," was not expected and abstinence from disordered eating behaviours was not a condition of treatment—a significant paradigmatic shift from previous treatment programs. The program adopted a stance of symptom-tolerance and accepted the client's current health status and abilities while she learned to address quality of life issues. Fourth, an occupational therapy model of rehabilitative practices was used. Instead of concentrating efforts on weight gain and stopping negative eating behaviours, efforts were made to focus and establish treatment goals on aspects of life outside of an eating disorder. An occupational therapy format was to encourage success (rather than repeated failure) by assessing the current skill levels and resources of the clients, thoroughly planning goals, and breaking goals into manageable, achievable steps. The goals varied widely for each participant but tended to fall into what was identified as three broad categories: emotional (including vocational and educational pursuits), leisure (including recreational activities and hobbies), and nutritional or food issues goals (Niblock, 1995). The intent of the program was to assist clients in living *with* their anorexia or bulimia, to focus on improving their quality of life, and to decrease their dependency on hospital. The program was tailored to meet the specific needs of the clients and delivered by a team of service providers, especially, through the use of "activation workers."

Activation workers were instrumental to the service delivery of COP. They were to provide frequent contact, or "outreach,' with the client and to facilitate her linkage with the community. This frequent contact helped, foremost, to decrease isolation. It also facilitated the movement of the treatment setting to outside of hospital. Contact and services that were traditionally provided in hospital now occurred in the client's personal environment—where she lived daily with her eating disorder. Furthermore, activation workers assisted the client in connecting with potential community service providers and, in doing so, provided supported experiences for both the client and the service providers. At the most basic level, this included liasing with the client's family physician regarding her health status (with the client's permission) in order to facilitate continued medical support when she left hospital and eventually transitioned out of

COP. Other links were made with private counsellors or community mental health teams. In this way, COP hoped to remove the barriers these women had been experiencing with attaining services as they moved out of hospital and into their communities.

Community linkages also meant supporting clients to increase their independent living and decrease their social isolation. Each women's skills, unique fears, concomitant disordered eating behaviours, limited social or self-care skills, and limited social networks restricted her ability for independent living and increased the likelihood she would be reliant on hospital care. The program attempted to help these clients acquire the skills necessary to facilitate the development of personal and social support.

Roles and Responsibilities of Community Outreach Program Staff

The Community Outreach Program took a multi-disciplinary approach to meeting the needs for this client group. The program staff included three activation workers, an occupational therapist, a nurse, a clinical dietician, a psychologist, and a social worker. There was access to the SPH Eating Disorders Clinic's medical internist and psychiatrist. The roles and responsibilities of these team members, as described in the appendix to the proposal for funding (Niblock, 1995, p. 7) are outlined:

> - the activation worker's primary responsibility was to deliver the client-centred program to the client. One activation worker was assigned to each client and contact with her ranged from a few hours per week to several hours per day depending on the needs of the client. Areas of support for the client might include meal support or preparation, identifying and increasing leisure activities, and the development of coping strategies.
>
> - the occupational therapist conducted assessments of COP participants social and occupational functioning and participated in developing plans to "activate" clients. She had little contact with clients, but rather acted as a consultant to the team around the development of goals and objectives.
>
> - the nurse's primary responsibility was the day-to day operation of the program pertaining to client care and staff support (i.e., case management). She acted as a liaison

between COP and other aspects of Eating Disorders Clinic and with community resources. This was especially important for clients from outside the Lower Mainland in their transitions back into their home communities.

- the dietician conducted nutritional assessments, menu planning, and provided one-on-one nutritional counselling for clients. The dietician provided home visits where necessary and helped clients to identify nutritional goals (i.e., inclusion of "fearful" or "forbidden" foods).

- the psychologist provided individual therapy sessions for clients who were without a private practitioner or community mental health team therapist. She also provided individual counselling for participants who were from outside the Lower Mainland and assisted in arranging required psychological support for those clients upon leaving the program. The psychologist consulted with the COP team around therapeutic issues and case management, and she conducted testing, and data collection and analysis.

- the social worker worked closely with clients and their families where a continuing or long-term issue needed to be addressed. In addition, the social worker assisted clients and their families in developing a better understanding of eating disorders and increased the family's involvement in the treatment process where appropriate.

- a medical internist monitored the medical status (i.e., body weight, blood work, etc.) of COP clients.

- a psychiatrist provided drug management and crisis intervention when necessary and acted as a resource person for team members with regard to care and case management concerns.

In addition, a training and education component was developed for the COP team members to ensure that they were current with respect to treatment and care issues relevant to eating disorders and rehabilitation practices.

Clients met with the COP team in weekly meetings, but mostly worked one-on-one with the activation worker on their goals. Initially, team meetings were scheduled once a week for all program participants, but in keeping with the program ideals of client-centred care, individuals in the program identified how much contact they wanted with the team. Some clients arranged team meetings for once per week, others once per month. During team meetings, daily and weekly progress notes were recorded and entry and outcome measures for each client were taken to monitor the progress in attaining the program's objectives and the client's goals.

COP Pilot Project Preliminary Evaluation

Initial evaluations of the pilot program indicated substantial improvements for six of the clients. (Seven women had begun the pilot; one woman committed suicide in June of 1996.) The evaluations showed successful outcomes in increased nutritional and emotional health, as indicated by nutritional and physical assessments utilizing standard medical testing, and by participants' scores on the Hopelessness Scale (Beck, 1975) and Quality of Life Questionnaire (Frish, 1994). Of particular importance to the funder was the significant decrease in hospitalizations for the clients. During the pilot program, their hospitalizations decreased by an average of 75% (Geller, 1996; PEDSC, 1995b). Based on these tangible ("hard data") results of increased nutritional and psychological health and the decreased hospitalizations, the Community Outreach program was deemed "successful" by the Ministry of Health officials, hospital administrators, and program staff, and permanent funding for the program was granted to the provincial programs for its continuation.

Problem Statement and Rationale for Thesis

This third section of the chapter presents the traditional problem statement and rationale for this thesis. The need and purpose for this study are articulated and the assumptions and limitations of the research are identified. Finally, terms used throughout the study are defined.

Problem Statement: The Questions

Assessments of the COP pilot project program were provided by participants formally, via tests and surveys and, informally, through contact with COP's program staff during daily contact and scheduled team meetings. While these informal assessments may have been recorded in progress notes and conveyed through personal anecdotes, there was no formal documentation or detailed inquiry into the participants' personal perceptions of what was working effectively for them. Consequently, although COP staff, St. Paul's Hospital and Greater Vancouver Mental Health Services Society administrators, and the Ministry of Health deemed the pilot project successful, the voices of the COP participants had not been heard or included in the evaluation process in an extensive and detailed way. I was interested to hear the evaluation results in the words of the participants. Did they perceive the program as having had a positive outcome in their struggle with anorexia and bulimia and, if so, how and why was this program successful in their opinion? What did participants find effective in the COP that they had not found in previous treatment programs? Although these questions were perhaps discussed briefly in the program's group sessions and measured by a survey questionnaire, I was interested in exploring what the participants of the pilot project had to say in extensive and conversational interviews. I wanted to inquire—in a dialogical format—what were their experiences in the COP pilot project and what aspects for the program impacted their struggle with disordered eating. The research question was, "In your experience, have you found the Community Outreach Program to be successful (or not) in your recovery from your eating disorder—and how?"

Rationale: Who is this Research For?

The purpose of this study is to increase the understanding of what enhanced or inhibited recovery from an eating disorder for COP participants and what increased their quality of life. The decrease in hospitalizations for these women who had little success in previous treatment programs was one indication that COP was successful at some level. The first reason for conducting my research has to do with finding out if, how, and why this program is successful—why the revolving door of hospital admission, re-feeding, hospital release, weight loss, and readmission (Sesan, 1994) has been altered.

Second, a thorough examination of the Community Outreach program, from the perspective of the participants, may provide a source of information regarding community-based healthcare and disordered eating that has been previously unrecognized and unrecorded. Are there important aspects to the care, support, and treatment of an eating disorder that a client-centred and community-based intervention provides? Are there some aspects of treatment that can only be provided at the community level, or in a blending of community and institutional care? Does the setting, quality, and length of contact between clients and program staff (particularly activation workers) contribute to significant change? Outreach programs have been done with other people with serious mental health issues (Niblock, 1995), however, such programs are new to the area of disordered eating.

A third reason for doing this research—particularly from a qualitative perspective—was that few qualitative studies with individuals with eating disorders have been done. Much of the research in eating disorders has been undertaken from traditional research paradigms, focusing on clinical/medical aspects of treatment and the quantitative measures. While quantitative measures are useful in evaluations, I believe it is necessary to get the participants' views of the program in their own words rather than fitting their experiences to scaled survey items.

Fourth, there have been recent and on-going critiques of traditional "theory-centred" and "theory-driven" research (Alcoff, 1991; Clifford, 1982; Hammersley & Atkinson, 1983; Lather, 1986, 1991; Le Compte & Goetz, 1982) which challenges traditional research paradigms on its tendency to do research *on* rather than *with* people (Lather, 1991). It has also challenged the presumed authoritarian stance of the researcher and "false consciousness" of research subjects (Lather, 1991; Weedon, 1987). Much of the existing research on people with eating disorders has tended to maintain traditional modes of hierarchical and politically-oppressive "rituals of speaking" (Alcoff, 1991, p. 12). Susie Orbach (1992), a feminist psychoanalytic therapist exemplifies the challenges to traditional treatment paradigms at a 1992 conference of clinicians:

> We must try to understand what is going on in the heart and the mind of a woman who is engaged in voluntary starvation. A hunger strike, which is after all what is at work in anorexia, is an act of the most extraordinary courage and the most extraordinary desperation. Unless we face the fact of the hunger strike, unless we decipher its aims, unless we commit ourselves to understanding what cause the anorectic is fighting for, we commence treatment on spurious ground ("Eating Disorders in the '90's," Side B)

I agree with Orbach that in traditional treatments and theories of disordered eating, the need to decipher the protests behind "hunger strikes" have often been ignored, and oppressive rituals of "speaking for others" (Alcoff, 1991) are maintained. Thus when participants' stories are not asked, or are asked but not documented, they do not enter the realm of legitimized findings upon which further recommendations and developments in the field are made. I hope that honouring the COP participants' stories, creating a space for their points of view, and the resultant documentation will contribute to a more woman-centred and client-centred perspective and more inclusive understanding of disordered eating. I also hope that this research will encourage an expansion of the repertoire of methods presently used in the field (Sesan, 1994; Streigel-Moore, 1994).

Fifth, I wish to influence the theories, treatment practices, and public health policy regarding eating disorders in the province. Private facilities or counselling may be beyond the financial reach of most individuals. Public programs are developed only when there is a strongly-identified need and the political will and funding to address it. What *clients* say is effective in treatment is of vital importance in determining treatment program development and determining funding. For example, if the research with COP participants indicates that women overcome severe forms of disordered eating by being supported in their daily lives and addressing their communal and social realities, then the gaps in services at the community level will need to be addressed. If those who have the most severe disordered eating problems and have been admitted to *every* tertiary care program in the province do substantially better when more wholistically attended to, then the aim and practice of existing tertiary care programs may need to be re-examined and re-evaluated. Furthermore, the growing incidence and severity of eating disorders may indicate the need to address the everyday issues that women experience in their daily lives—the places that they live—in order to prevent further progressive health problems. Certainly feminist research on women's health continues to emphasize that women's well-being is greatly impacted by the broader social and cultural factors (the social determinants of health [Morrow and Chappell, 1999, Covington, 1999]), including gender, poverty and violence, and cannot be reduced to problems originating within the individual. I would like this research to provide information on a contextual approach to service delivery and the findings used to advocate for policy changes in women's healthcare that address the social determinants of health. I see this work as a continuation of the work of feminist therapists in the healthcare field and a contribution to the body of knowledge and work being generated by qualitative researchers. I hope this thesis will contribute to a growing body of work that is non-medically-oriented, which questions and challenges the traditional conceptualizations of the etiology, development, and treatments of eating disorders (Sesan, 1994; Wooley, 1990), and which, at this point, continues to be marginalized in the field of eating disorder research, funding, and publication (Streigel-Moore, 1994).

Finally, while this research work will be for the completion of my degree and will contribute to my personal and professional growth, I sincerely hope that it will be of significance to the participants. In providing a space for them to speak about their experiences and knowledge, in listening intently to their thoughts and concerns, and in creating a public document to record their testimony, I hope they will derive some personal benefit. At the simplest level, I hope there may be comfort in that what they have contributed may have some impact on future treatment for everyone who struggles along the continuum of disordered eating.

Assumptions

The assumptions I bring to this work have been influenced by my experiences. I am interested the theme of support, and hypothesize that the way in which support is provided is significant to changes being noted with COP participants. Activation workers are providing support to participants (a novel healthcare intervention) based on participants' self-defined goals. This type of supportive work may promote recovery and healing from eating disorders.

Given that much support work has traditionally been done by family members, friends, volunteer and grass roots community groups in B.C. (Canadian Association of Anorexia Nervosa and Associated Disorders [ANAD], 1995; Gardner & Schmidt, 1995; PEDSC, 1999;) and that this work is largely unpaid and usually performed by females, the value of support has often been underappreciated and/or rendered invisible (Waring, 1996). The focus in healthcare funding on the "value of services based on outcome measures" (Vancouver Health Board, 1996) means that a large portion of support work may not be recognized, measured, nor funded in accordance with the outcomes they provide. Therefore, I also assume that this non-valuing and invisibility contributes to a lack of funding for organizations and programs that provide such support services in the community and may explain the lack of community support services in general.

Third, I assume that the continued concentration of healthcare funding on medical interventions has obscured and perpetuated the devaluation of this support work. Therefore, it is important to define what "support" means in this context and to determine if support is a useful construct for the participants in their experience of recovery. I hypothesize that the focus on restoring "health"—based on a medical perspective of "health"—has been an additional contributing factor in the historic problem of inadequate treatment programs for this particular client group. Clients' "failure" to recover in previous treatment programs may be due to the failure of the medical/psychiatric model to define and thus address the "problem." I will attempt to provide some description of the value of support as articulated from this project and will attempt to provide a new understanding of the problem of disordered eating.

Finally, I assume that the perceptions and experiences of the research participants are valid. Reinharz (1992) notes that "believing the interviewee" is a controversial idea because social research typically involves a certain amount of deception and because science relies on scepticism" (p. 28). However, I believe it is imperative in feminist research to begin by believing the participants. Should a conflict between "belief and disconfirmation" (Reinharz, 1992, p. 29) arise, it necessitates returning to participants for further discussion—a task of the data analysis process. Miller (1983) notes that a power differential in interpersonal relationships may cause a doubt of perceptions, and I recognize that the researcher-participant relationship has inherent power dynamics. However, for the purposes of this study, participants' perceptions are believed to be indicators of their real experiences.

Limitations of Study

I acknowledge four limitations in conducting this research. First interviews were conducted by myself, the researcher, alone and are therefore limited by personal perceptions and selective attention. In identifying the researcher's status within the research field, using open-ended questions, and providing a detailed description of the research and data analysis processes (see

Chapter 3), I hope to illuminate the personal biases and limitations I bring to the work and the limitations inherent in conducting feminist, ethnographic research.

Second, with regard to sample size, only three of six COP program participants, one of three activation workers, and two of seven COP team members were interviewed. Therefore, research participants may provide information that may or may not be typical of the experiences of other COP participants and personnel in the program. To counter this, I have provided detailed profiles of research participants limited by confidentiality and the protection of their anonymity.

Third, the research is also limited by the nature of the relationships established with participants, particularly given the confidential nature of the subject matter. Participants may or may not have felt comfortable speaking candidly with me. In addition, personal contact with some participants was limited.

Finally, the number, length, and continuation of interviews was limited by finances, time requirements of the graduate program, and geographic constraints of the interviewer. The health status and/or availability of the researcher and the COP participants also contributed to limitations on this research.

Summary

This chapter has defined anorexia, bulimia, and other disordered eating behaviours; briefly discussed the controversy in the field in using terms such as "eating disorders" and "disordered eating;" and examined the historical development of services in British Columbia. A description of the Community Outreach Program and a discussion of its objectives has followed. The problem statement, the rationale, the assumptions and the limitations to this research have been articulated and the terms to be used in the thesis are defined. Chapter Two provides a review of the related literature. Chapter Three describes the methodology of the study, the subjects, the interview and data collection procedures, and the method of data analysis. Chapter Four presents the findings from the data collected and Chapter Five offers an thematic analysis of the data, draws conclusions and implications, and makes recommendations for continued refinement of disordered eating programs design, for the development of health policy, and for further study.

CHAPTER TWO

Literature Review

> *Workers in the field [of eating disorders] are free to choose the kind of explanatory model which they find appealing and useful, and their choice is likely influenced by their personal history, their training, and probably also by the kind of patients they see. Campbell, (1995, p. 51).*

Introduction

In this chapter, I discuss the research and treatment literature on chronic eating disorders and the multidimensional model of causal theory. The chapter has four sections. The first section looks at issues of chronicity including definitions, prevalence, the course of chronic eating disorders, and prognosis. The second section discusses the implications of iatrogenic treatment on the issue of chronicity. The third section presents an overview of causal theories, including the biomedical model, the psychogenic model, and the sociocultural model. Finally, trauma-based theories of eating disorders are discussed as a possible application of current knowledge that may provide a more comprehensive understanding of eating disorders etiology and perhaps more effectively influence treatment interventions and recovery.

Chronicity

The *DSM-IV* (APA, 1994) describes chronicity in many psychiatric disorders as existing after a period of 2 years or more. Researchers in the area of eating disorders, however, have differing opinions regarding chronicity as anorexia and bulimia are often prolonged disorders, even with individuals who make a complete recovery. Chronicity implies that the illness or disorder afflicts a person for a long period of time (Theander, 1992) however, this does not necessarily mean that an eating disorder, even a chronic one, is incurable. Theander (1970) found only 15% of patients recovered in less than two years. According to estimates, only 20% of eating disorders become chronic whereas the rate of good outcomes or recoveries varies from 40-60% with remaining patients (20-40%) having intermediate outcomes (Russell, 1992b). Therefore, the most severely chronic eating disorders—defined as a continuous illness of 15 years or more—are seldom encountered and clinicians with a special interest in eating disorder treatment are likely to see only a small number of these patients.

Theander (1992) states that in order to avoid "an unnecessarily pessimistic outlook," the label "chronic" eating disorders should be reserved for people whose illness is a very long-standing and continuous for more than 15 years. He suggests that patients who have been ill for a very long time but less than15 years should be referred to as having "protracted" eating disorders. Yager (1992) prefers "intractable" eating disorders, and notes there is both volitional and unvolitional intractability. He describes intractable forms of eating disorders as those where there are unremitting core symptoms with persistent psychological, behavioural, physiological, or social impairments; repeated relapses and clinical instability; and complicating, comorbid conditions (e.g., depression, anxiety). Yager also notes that some people may have intractable eating disorders yet still remain high functioning despite severe ongoing symptoms while others may have fewer symptoms *per se* but still remain socially-impaired. According to Yager, volitional intractability is where the patient is treatment avoidant and attempts to maintain their eating disorder symptoms, while an unvolitional intractability occurs when the patient is unable to recover despite her best efforts, good motivation, and excellent treatment. Clients with chronic eating disorders in the Community Outreach Program had both intractable (volitional and unvolitional) and protracted eating disorders.

Chronicity has been difficult to assess given the dearth of long-term follow-up studies. Although over 60 follow-up studies have been conducted throughout the world (Russell, 1992), most follow-up studies were conducted only 5 years after treatment. This is due to the nature of what is being measured—the effects of the practitioner's treatment vs. the long-term outcomes for clients. While Morgan and Russell (1975) recommend a minimum period of 4 year intervals for follow-up to monitor the course of illness, many researchers look to measure treatment efficacy and prefer, as Vandereycken and Pieters (1992, p. 194) do, to measure outcomes at shorter intervals "because treatment effects will obviously diminish over time and life events will inevitably interfere, we are not directly interested in outcome in the long term (after 5 years of more)." Truly long-term follow-up, therefore, is only beginning to be acknowledged in the research literature; thus, present findings on long-term outcomes may be limited in scope.

Twenty-year follow-up studies have been done with anorexia (Ratnasuriya, Eisler, Szmuckler, et al., 1989; Theander, 1985; Vandereycken and Pieters, 1992) however, comparable studies have not been done with bulimia. Results from the 20-year follow-ups highlight the limitations of studies more intermediate in duration. For example, when Russell (1992b) compared outcomes from his 5-year follow-ups with a 20-year follow-up, the results were less favourable than he anticipated. Death rates rose to 15% by the end of twenty years and the majority of patients with poor outcomes at 5 years had poor outcomes at 20 years, and one third were improving. Conversely, those with good or intermediate outcomes at 5 years had a 20% relapse rate at 20 years. Russell found an average relapse rate of 12% at 20 years which is concurrent with Theander's (1970) study. Russell also found a low correlation between patient weights at 5 years and at 20 years which he believes suggests that patients' body weight is less reliable an indicator of long-term recovery than when looking at recovery in the intermediate measure. (This is an important finding because much of treatment and successful outcomes has traditionally been aimed at weight restoration.) A more positive outcome of Russell's work was that partial recoveries were still possible even after patients had been ill for over 15 years. This contrasts with the views of others that recovery is not possible after 7 years (Dally, 1969; Hsu, 1980; Schwartz and Thompson, 1981, Steinhausen and Glanville, 1983). In Theander's (1992) long-term outcome study of 37 patients who had been ill for 6 years of more, he found 19 patients (51%) recovered after illnesses that had lasted 6-11years. Unfortunately, nine patients (24%) died and six (16%) continued to have serious eating disorders with some subsequent deaths after 18-40 years.

Long-term studies also provide significant information on relapses. Relapse is frequently seen immediately or shortly after treatment. However, Theander's 20-year follow-up studies found that relapses may also take place later, sometimes after a remission of 10-15 years. Relapses usually occur after an obvious life crisis (such as family death, divorce, or miscarriage). Theander (1992) also proposes that women who are admitted with late onset eating disorders are likely to have had an eating disorder (perhaps undiagnosed) at some earlier point in life, suggesting that these late onsets may, in fact, be relapses occurring at later stages of recovery (Dally, 1984; Ziolka, 1978 in Theander, 1992).

Russell (1992b) notes that a great variability in outcomes of eating disorders may be due to the natural course of illness and thus implies the need for further longer-term outcome studies to better ascertain recovery rates. Russell (1992b) found studies indicating that only 13% of patients recovered within 2 years compared with 56% recovery rate after 5 years. Theander (1985) reported a 15% recovery rate within 2 years but this rose to 33% after three years. Other reports indicate that a return to normal weight was achieved by 38% of patients at the end of the 2nd year, 67% after 4 years, and 70% after 10 years (Russell, 1992b). Theander (1992) notes claims that most of the variability in outcomes in eating disorders may be due to the natural course of the illness: "anorexia nervosa and bulimia nervosa will usually remit spontaneously; it is uncommon to see the full syndrome of either disorder after the age of 40" (p. 215). Tolstrup

(1992) states with 40 years of clinical experience that, "at the start of any treatment there exist both the chance of cure and the risk of death or chronicity. A large number of patients are cured within a few years, but the therapist's pride should also contain a portion of professional humbleness in the realization that he or she has presumably been instrumental in promoting a spontaneous recovery" (p.). Tolstrup also claims that patients who do *not* recover within a few years need long-term support and a modification of treatment goals to inhibit the tendency for eating disorders to become chronic or fatal—"at any rate, help in living an acceptable life with the disease....Time, patience, and consistency probably are the most effective elements in the treatment of this enigmatic disease (p. 237).

If variability is due to the natural course of the illness, then what seems to influence chronicity in eating disorders? What determines poorer outcomes? The research describes many correlative factors but provides no causal explanations. Vandereycken and Pieters, (1992) found that "noncoopertative" patients in their study seemed to belong to a more seriously disturbed subgroup: "they were older, more often married, show[ed] a longer duration of illness with a more pronounced clinical picture (lower weight, more bingeing and/or purging, more additional mental disturbances, poor functioning at school or work), and they [had] been hospitalized more often before their present admission" (p. 190). Russell (1992b) found similar features. His patients were older at the age of onset with the worst outcomes when the illness began in mature women or in prepubertal children. His patients had a longer duration of illness, a history of previous psychiatric treatment, and were at lower body weights when referred for treatment. Russell also found that they reported poorer adjustment in childhood and disturbed family relationships. Prognosis was more serious in very young children with eating disorders (Russell, 1992b). Herzog, Rathner and Vandereycken (1992) claimed the following to be predictors of less favourable outcomes: longer periods of illness before first admission; a higher age of onset, disturbed family relationships, and extreme weight loss upon admission (which also correlated with increased mortality). Yager (1991) categorizes intractability factors as: (a) the nature and intensity of the eating disorder symptoms, (b) the patient's temperament and personality, (c) coping styles, (d) quality of social supports, and (e) enduring attitudes such as marked depression, compulsions and/or substance abuse. Theander (1992) provides some qualitative remarks on patients with chronic eating disorders from other studies and remarks:

> Chronic patients lead an isolated and restrictive life. Their anorectic attitude and behaviour have become ingrained, and the sufferer seems to identify completely with the role of being an anorexia patient. The following quotations supply a good description of the patient's situation: "The peculiar attitudes of such patients towards food virtually become features of the personality"... "Anorexia nervosa has become a mode of existence. The desire to be thin and the dread of becoming fat have taken on the leading and controlling role and imprison the patient in her body"... "...The individual anorectic's lifestyle...may become incorporated with the individual's coping mechanisms and way of life. Sadly, for some this may be the only adaptation that they can make to life"... (Theander, 1992, p. 216).

While there are some defining characteristics of those who comprise a chronic eating disorder population, it must be kept in mind that there is uncertainty as to what accounts for unexpected turnarounds in health (Yager, 1991)—"hopelessness can never be predicted with complete certainty" (p. 374).

Iatrogenesis

Treatment may also influence the course of eating disorders in both positive and negative (iatrogenic) ways (Vandereycken and Pieters, 1992). Much research has attempted to elucidate what aspects of treatment promote recovery. Garner (1985) looks at what aspect of treatment do *not* promote recovery—and may, in fact, do harm. "Iatrogenesis" refers to any adverse condition resulting from the application of treatment by a physician or allied health professional as well as the failure to provide adequate care when it is warranted" (Garner 1985,

p. 701). Iatrogenesis has received more attention in the general medical literature for many years, but less in the literature on eating disorders.

Garner (1985) speculates that iatrogenesis is not an isolated phenomenon but is a common ingredient in many patients' descriptions of received treatment. Most iatrogenesis is a result of lack of knowledge and misguided assumptions about the nature of eating disorders and lack of self-awareness of care providers. For example, Garner (1985) notes the powerful negative reactions eating disorder patients elicit in care providers including strong feelings of aggression in the therapist and therapeutic pessimism. Brotman, Stern, and Herzog (1984) found that patients with anorexia nervosa tended to generate more anger, stress, and helplessness in medical residents than did chronic diabetic and chronically obese patients. Psychiatric and pediatric residents reported significantly more negative affect than those in general medicine wards and all of the psychiatry residents believed these negative emotional reactions directly influenced the quality of care delivered to anorexic patients (Garner, 1985). When the additional stress of inadequate number and scope of services, lack of funding, staff shortages, wait lists and wage disputes of the current health care climate are added to this situation, the ability to provide therapeutic contact is likely even more compromised for eating disordered patients.

Pessimism can be iatrogenic. Goldner, Birmingham, and Smye (1997) write about the principle of beneficence (i.e., the intent to benefit a patient) in health care ethics and state that beneficence is "most poignant" in reference to those with chronic anorexia. They cite a case in Canada where care providers believed that treatment for a 22 year-old woman would be futile and thus decided not to provide treatment. A review of the case upon her death found that the lack of specialized treatment services seemed to have influenced the determination of her case as futile. They report a similar scenario in Britain and state that the "powerful emotional impact of severe anorexia nervosa upon patients, families, and caregivers can influence judgements of the potential benefit of treatment. It can be difficult to maintain a balance between extremes of overexuberant intervention and therapeutic nihilism" (p. 453).

There can be several ways in which treatment can be iatrogenic. What is a main factor in iatrogenesis is the lack of awareness of the impact of treatment when generated from a lack of understanding of eating disorder etiology. The next section will provide a brief overview of etiological theories and examine the iatrogenic implications of theses theories.

General Causal Theories of Eating Disorders.

The search for causal explanations of eating disorders is actually a search to identify how and why an eating disorder develops, what has gone "wrong," and an attempt to correct and prevent the behaviour from happening. A review of the research literature found that there is no widespread agreement on what causes an eating disorder nor a strategic approach to developing an explanatory model (Campbell, 1995). As was noted in Chapter 1, this is further complicated by the fact that there is also no agreement on nosology, i.e., what constitutes an eating disorder or what are we looking to explain.

Tolstrup (1992) states that eating disorders are a disease that involves all the essential physical and mental functions: nutrition, weight, growth, menstruation and other sexual functions, social contact, mood, sleep and physical activity—with the consequent social complications. Therefore, a causal explanation is not a simple task. Campbell (1995) highlights the special challenge that eating disorders present to causal theories because of the implications of the individual's conscious choice. In addition, eating disorders are "difficult to sharply demarcate from variants of normal eating behaviour in a society beset with changing cultural preferences about diet and body shape and that they predominantly affect women in western culture at a time when the majority of doctors have been men" (p. 50). G. Russell (1977) proffers that a causal explanation must be visualized as a series of "circular interactions" between multiple factors and insists on the need for a "flexible etiological frame of reference" (p. 363). Moore (1998) states that eating disorders are a cultural expression of oppression that cannot be decontextualized from race, class, sex, and gender. In general, researchers concede to a multi-dimensional model of causality in an attempt to address the multiple factors (genetics, physiological and psychological vulnerability, and sociocultural influences) that interact in the development of an eating disorder.

Theoretical models have attempted to answer whether eating disorders are a result of biological dysfunction, a psychogenic problem, or a culturally-induced disorder. The theoretical explanations provided from each of these perspectives influence treatment modalities because, as Strober (1987) remarks, treatment is predicated on the practitioner's acceptance of specific etiologies. Criticisms of current causal theories centre on the paucity of empirical evidence to support these models and the possibility that present theories may be more likely to explain the *maintenance* of an eating disorder rather than the cause (G. Russell, 1995). This first section begins with an examination of treatment predicated on the biomedical model of eating disorder etiology with focus on bodily dysfunction. A more contextualized approach of the psychogenic, or psychological vulnerability, model follows. The influence of sociocultural factors is discussed and the contributions of feminist analysis to this cultural model are presented. Finally, the possibilities that trauma-based theories may provide to understandings of causation are examined. The advantages and criticisms of each of these perspectives and the implications on chronicity and/or iatrogenesis are also discussed.

Perspectives of the Biomedical Model

Biological vulnerability, which looks at genetic or physiological predisposition of individuals to developing eating disorders, has been the basis of the biomedical model of etiology. Denise Russell (1995) uses the terms "biomedical model" and "medical psychiatry" to describe the "loose grouping of theories and practices" based on two assumptions: (a) "that there is a distinction between madness, mental illness, or disorder on one side and sanity or normality on the other;" and (b) "that the causes of mental illness or disorder are biological and treatment should be in that realm" (p. 1). Biological psychiatry, as Masson (1986) and D. Russell (1995) note, is the dominant form of psychiatry in the Western world with a pervasive "aura of certainty which makes challenge difficult" (D. Russell, 1995, p. 1). The biomedical/ psychiatric model operates paradigmatically with a certain primacy and authority within Western culture (Bordo, 1993; Ehrenriech & English, 1978) and its values and assumptions have been largely unquestioned and unchallenged prior to the feminist movement. The biomedical/psychiatric model's view of eating disorders is a "mechanistic" one (Moore, 1998) with *illness* arising from physiological malfunction and resulting in physiological disturbance or pathology. Eating disorder research from this perspective attempts to isolate biological fault and has tended to examine genetic vulnerability, neurochemical imbalances, organic brain dysfunction, and the effects of starvation.

For example, eating disorders have been attributed to hypothalamus disorders because of the observation, in 1914, that "pituitary inefficiency" led to severe weight loss and which "set the stage" for neuroendocrinal approaches to understanding and treatment of anorexia that continue today (Silverman, 1997, p. 6). In this approach, eating disorders are caused by malfunction of the neuroendocrine system which controls the hormones effecting bodily function and metabolism (D. Russell, 1995). The hypothalamus is involved in the control of appetite, satiation, sexuality, hormones, and emotion. Because of changes observed in the menstrual cycles of women with eating disorders (particularly amenorrhoea) and decreased sexual desire (common in women with anorexia or at low body weights) (Zerbe, 1993) this became a primary area of research.

Denise Russell (1995) argues that hypothalamic changes may indicate bodily responses to environmental change but does not necessarily indicate a biologically-based problem. Major endocrinal disturbances have been linked to body weight and nutrition levels found in subjects who restrict their food intake even in the absence of major weight loss (Fichter and Pirke, 1990). There is increasing evidence that long-term, repeated, or prolonged dieting/semi-starvation have deleterious effects on brain physiology, and thus hormonal functioning (Keys, Brozek, Henschel, et al. 1950) and negatively impact concentration, irritability, depression, compulsive behaviour, and memory.

Research on body image distortion syndrome (BIDS)—a disturbance in size awareness—was thought to link perceptual and cognitive problems with anorexia and bulimia (Bordo, 1993). BIDS was considered a visuo-spatial problem, a perceptual defect, and a brain-function impairment, possibly a result of inadequate infant development (Bordo, 1993). Studies measuring body image distortion confirmed that woman with anorexia and bulimia had significant body image distortions, seeing themselves as obese when they were actually emaciated. However, Thompson (1986) found that 95% of control subjects "free of eating disorder symptoms" also overestimated their body size as 25% larger than they actually were. There was little distinction between the degree of "normal" or "pathological" distortion in eating disordered and non-eating disordered women, therefore, eating disorders were unlikely a result of cognitive perceptual dysfunction. Findings on starvation show negative impact on cognition (concentration and memory), however, once weight is restored these abilities return to normal.

Impacts on Treatment Approaches of Biological Vulnerability Perspective

The belief that eating disorders are bodily breakdowns that result in weight loss, amenorrhoea, BIDS, or depression implies an equally reductive solution: restore brain chemical equilibrium and/or increase body weight to reverse symptoms. Strategies for treatment of eating disorders have used behaviour modification techniques, tube-feeding and medication to induce appetite, restore weight, and correct neurochemical imbalance. Garner (1985) reviews the efficacy of these programs.

The hospitalization for a patient with an eating disorder was seen as a 'last resort' prior to 1975, and if hospitalization was required, its primary purpose was to assist patients with weight gain (Sesan, 1994). However, hospitalization to restore weight began to be central to inpatient and outpatient programs and gained priority over psychotherapy across North America and the United Kingdom. This fit with the expectation that malfunction was due to weight loss, therefore the eating disorder could be "cured" with weight gain. Research has repeatedly indicated, however, that weight restoration is not an indicator of success as short-term weight gains have produced few long-term healthy outcomes (Russell, 1992b). Hospitalization to restore weight does not address underlying psychological and sociocultural issues that accompany an eating disorder, as demonstrated by low success rates. In addition, the determination and steadfast will of patients to restrict or refuse food has presented serious challenges to traditional medical treatments (Garner, 1985; Goldner et al., 1997; Silverman, 1997). Increasing calorie intake, whether through inducing appetite pharmacologically or by forced feedings, have been fraught with physical, psychological, moral, ethical and legal complications (Goldner et al., 1997)

Garner (1985) notes that tube-feeding is used *often* (italics in original) by 12.6% of psychiatrists and 6.5% of psychologists in America and suggests its use may "reflect the desperation or anger on the part of the clinician to take definitive action with the anorexic patient" (p. 708). Garfinkel and Garner (1982) summarized that the dangers associated with tube feeding centre on the fact that it is almost always unnecessary, can have significant physiological effects, and should only be used as a potentially life-saving measure. In addition, it represents a direct intrusion into the gastrointestinal tract of someone already preoccupied and misguided about bodily functions and may be perceived as an assault or act of hostility which may contribute to the person's low self-esteem and sense of worthlessness. If it occurs without the patient's cooperation, it is likely to create mistrust and a heightened feeling of loss of control.

The role of medication is an area of controversy, considerable interest, and is often an economically-based treatment decision. According to an extensive review of the studies evaluating the short- and long-term efficacy of various medications in anorexia and bulimia (Raymond, Mitchell, Fallon and Katzman, 1993), the use of medications alone have limitations in the treatment of anorexia and bulimia. Garner (1985) claims that a poor understanding of eating disorders and the treatment of isolated symptoms without understanding the wider context of core pathology of eating disorders has been evident in many pharmacological approaches. For example, drugs are prescribed to attend to the effects of constipation, sleep disturbances, poor concentration, amenorrhea, bloating, water retention, and mood disturbances without the recognition that these symptoms are often the effects of starvation. Anti-depressants, anti-psychotics and neuroleptic drugs are prescribed to induce appetite ignoring the fact that clients often report ravenous hunger and terrific fear of losing control over their hunger. Drug therapy is a desired option because medications are easier to dispense than psychotherapy and more cost-effective (Russell, 1992b). The efficacy of drug treatment has often been measured by the rapid rate at which the patients reached target weights, however, no long-term follow-ups indicate that weights were maintained. Drug treatment has been applauded for the ability to increase weight gain in the short term but certainly not on the basis of any decrease or alleviation of psychological effects of an eating disorder (i.e., BIDS, obsessiveness, compulsivity, depression, anxiety, low self-esteem or perfectionism) (Raymond, Mitchell, Fallon and Katzman, 1993). Follow-up studies also indicate the difficulty of maintaining patients on drugs because of bothersome side effects, and some purging may make some antidepressant medication dangerous. Finally, the research also shows that even when patients maintain successful medication after the trials, they have tended to relapse into disordered eating behaviours within 6 months (Raymond et al. (1993). Raymond et al. (1993) suggest pharmacotherapy should be an adjunct to psychotherapy and not the primary mode.

Advantages of the Biomedical Perspective

One of the strengths of the biomedical model is the awareness and understanding it has fostered regarding the phsyiological and psychological effects of starvation. Epidemiological studies point to dieting as a major precipitant of eating disorders (Beaumont and Russell, 1995; Campbell, 1995; Hsu, 1990; G. Russell, 1995). The research shows that many women with anorexia and bulimia have extensive histories of dieting prior to their diagnosis of a clinical eating disorder (Hsu, 1997). Fairburn and Cooper (1984) claim that all eating disorders start with dieting behaviour. Hsu (1997) says "the prevalence of eating disorders occur in direct proportion to the prevalence of dieting behaviour in a given community" (p. 509). Nutritional deprivation, brought on by dietary restriction (i.e., dieting), has been shown to result in changes in hormonal or neuroendocrinal functioning, can interfere with satiety cues, the perception of hunger, and the body's hunger stimulus response (Eisen, 1997). Dieting also decreases the body's metabolic rate, burning calories more efficiently, thus impeding long-term weight loss and increasing further dieting practices (Eisen, 1997). Dieting is the one common component of all the major etiological theories.

Dieting behaviour is rampant in Western culture and an entire generation has been exposed to it (Poulton, 1997). Sixty-five percent of eleven year-old girls worry that they are too fat while 80% reported they diet (Larkin et al., 1996). Fifty percent of women aged 14-18 years believed they were obese and forty-five percent were actively trying to lose weight (Day, 1990, in Larkin, Rice, and Russell, 1996). Two-thirds of adult women are dieting at any given time and despite the commonly-held belief that aging allows women to escape the social pressure to conform to the thin aesthetic, dieting is practiced by elderly women in care facilities (Orbach, 1992), while Beck, Casper, and Andersen (1996) observed a late onset of clinical anorexia and bulimia in women aged 40-70 years of age. Dieting, therefore, is an activity found across the female age-span and is an accepted part of female development in the Western world.

Dieting is promoted as a preventative measure. Public health messages chastize the over-weight population for its flagrant disregard for weight-related diseases (Bordo, 1993; Poulton, 1997) despite extensive medical evidence that dieting doesn't produce long-term results and has tremendous impact on physical and psychological well-being (Cleary, 1999). From the 1980's to the present, the average diet prescribed by the weight loss industry is between 800-1600 calories per day. Wolf (1993) compares this with 600-1600 calorie per day restrictions that Dutch authorities allowed for food rations (and which they characterized as a level of semi-starvation) during the German occupation of 1940, (pp. 194-5). She also notes that the minimum daily intake required to sustain human functioning in the Treblinka concentration camps during World War II was 900 calories per day. In other words, as Wolf (1993) reveals, to embark on a typical diet in the West is to undertake self-starvation.

A second contribution of the biomedical perspective is the ability to address the physical complications of starvation. Evidence-based research has carefully documented and described methods of safely re-feeding and restoring weight for clients. For example, the urge to binge and purge will persist as long as the client remains at a sub-optimal weight (Garner, 1985). In terms of iatrogenesis, Garner (1985) reports that some treatment programs recommend statistically normal body weights for those whose natural weights may be higher. Therefore, a tremendous contribution is made when the scientific objectivity of the biomedical model can ascertain what an individual's healthy weight may be uninhibited and uninfluenced by unrealistic cultural values regarding shape which serve to maintain an eating disorder. However, the persistent focus on weight in treatment programs is also one of the criticisms of the biomedical model (PEDSC, 1999).

Limitations of the Biomedical/Psychiatric Perspective

Medical and psychiatric treatment has been criticized for being reductive and for focusing on weight and body fat percentages. The belief perseverence that individual biological malfunction is the cause of eating disorders ignores contextual possibilities such as underlying psychological issues, interpersonal dynamics, and environmental causative factors. The primacy, centricity, and authority of the biomedical perspective are also under criticism in the field of eating disorders and particularly with issues of chronicity.

Given that most of the medical/ psychiatric treatments have been developed, tested, and studied in the last twenty-five years, many women diagnosed with eating disorders have received treatment in accordance with this perspective. It appears that with intractable eating disorders, the biomedical/psychiatric model has failed to provide adequate interventions to prevent or address chronicity in a growing number of these patients. The *Needs Assessment of*

Eating Disorders Services in B.C. (PEDSC, 1999), reported that failure to adequately address the issue of eating disorders has resulted in a "revolving door of treatment" for those with eating disorders and may actually have contributed to increased chronicity. Also, the majority of healthcare dollars has been and continues to be spent on addressing the acute care needs of chronic populations in highly medicalized settings. At best, the centralization of research and treatment in the medical/psychiatric milieu can be viewed as a serious attempt to address those most at need with the few funding dollars dedicated to eating disorders. At worst, the iatrogenic development of a chronic population requiring specialized services can be viewed as self-serving, ensuring that research, funding, and treatment remain within the acute care setting. D. Russell (1995) says that "in diverting our gaze...medical psychiatry colludes in the maintenance of the subordination of women, belying its value and neutrality" (p. 95).

The biomedical/psychiatric model often fails to address social, historical, familial, and cultural factors in the development of eating disorders and tends to pathologize the individual, treating her without context or reference to the emotional world within her and the social world around her. Instead the focus must be shifted to examining the social context and the interpersonal relationships within which the aspects of disordered eating occur so prominently among females. The tendency to blame the individual or her body's malfunction requires re-framing and re-examination. The suggestion that the focus of investigation must move to the social setting and social dynamic has fostered psychogenic explanations for the development of eating disorders.

Psychogenic Model

The psychogenic model acknowledges the complexity of disordered eating and attempts to account for psychological factors that predispose individuals to disordered eating, including family dynamics and the social role expectations for women. Feminists have contributed much to this model, insisting that the individual woman or her family cannot be examined without holding in context the profound impact social and cultural pressures have on the development of eating disorders. The psychogenic model sees familial, social, and cultural factors as the catalysts for predisposed individuals who are "at risk." It differs from the biomedical model because it views the development of eating disorders as a result of or a response to interpersonal interactions rather than a biological or organic dysfunction. Again, psychological presdispositional theories may be more descriptive of the effects of an eating disorder rather than the cause. An overview of the findings and the more common psychogenic theories of eating disorder etiology are presented.

Family Dynamics and Social Pressures

The psychogenic model looks at the dynamic interactions of the individual and her environment. From studies and case histories of women presenting with anorexia and bulimia, psychological profiles and risk factors have been surmised. The research has indicated that women at risk for developing an eating disorder tend to have: perfectionistic tendencies (Leung, Geller & Katzman 1996), low self-esteem, an inability to maintain healthy interpersonal boundaries, (Crisp, 1997), a morbid fear of fatness, difficulty in identifying or expressing emotions (alexythemia), impulsivity (Lilenfeld, Kaye, Greno, et al., 1997) and compulsive behaviours or thoughts. More recently, the maturational process or any transitional event (i.e., marriage or onset of puberty and menopause) are considered at-risk factors (Crisp, 1997). Welch, Doll, and Fairburn (1997) suggest that certain "life events" play a role in precipitating the onset of anorexia and bulimia (i.e., loss or threatened loss, such as illness or death of a parent or of an intimate relationship, or general disruptions which involved a threat to a female's sense of bodily integrity or safety, such as moving, a change in family structure, significant physical illness, pregnancy, physical or sexual abuse). In addition, a history of sexual abuse or trauma is believed to put women at risk an eating disorder (Schwartz & Cohn, 1996; Wooley, 1994) and Schmidt, Tiller, Blanchard, Andrews and Treasure (1997) found pudicity (a sexual shame or disgust) was specific to triggering the onset of anorexia. One of the more popular overarching psychological theories is the "flight from femininity" (Bruche, 1973, and Crisp, 1980).

Flight from Femininity

Anorexia and bulimia were originally believed to affect mainly adolescent and pubertal girls who were at the biological threshold of adult female development. Early clinicians Bruche (1973) and Crisp (1980) advanced the "flight from femininity" theory which continues today. They hypothesized that anorexic and bulimic behaviours are the pathological avoidance of female sexual maturation. Clinical observations show that low body weight prevent or repress menses and, therefore, prevent the possibility of pregnancy. Furthermore, the extreme thinness associated with anorexia "desexualizes" the female body, erasing hips and breasts and, in advanced cases, reversing or repressing mature female development. They believed that such behaviours resulted in a physical transformation that unconsciously allows a young woman to refuse to take up the role of an adult female, and an adult female to defer from the expectations and responsibilities that accompany adult femininity (particularly sexuality and motherhood). A women's fear of fatness was interpreted as the psychosexual expressions of anxieties regarding fear of pregnancy or attracting male sexual attention (Bordo, 1993; D. Russell, 1995). Weiner and Stephens (1996) state that the avoidance of adult weight and shape can be seen as a method used to avoid sexual activity, sexual maturity, and sex-role conflicts.

Feminist theoreticians and researchers interpret eating disorders from a perspective that considers the impact of gender (the social construction of female identity) on the etiology of an eating disorder. For example, feminist criticisms of the "flight of femininity" theory have been based largely on the lack of gender and power analysis in this theory, namely its failure to ask *why* women would, consciously or unconsciously, reject femininity. In her groundbreaking feminist critique, Orbach (1986) definitively challenged this theory. She notes that it is not *any* body that is being rejected, but specifically a *female* body.

Orbach (1978) states that the cultural values regarding femininity are at the root of an eating disorder. The lack of control women have in their public and private lives is directly related to their need to control their body size and shape and their food intake. As food and the body are the two forums in which women have traditionally been sanctioned with some degree of control, authority, and autonomy, Orbach suggests it is in these forums in which issues around power, control, visibility and value are seen. Orbach criticizes the suggestion that anorexia and bulimia are unconscious attempts at "wish fulfillment" (i.e., avoiding adult responsibilities) because it renders the woman childlike and delegitimizes the meaning or possible protection her eating disorder symptoms provide. Orbach (1992) notes that the "flight from femininity" theory and its ensuing treatment models dismiss the woman's or girl's opinions and behaviours; deem her immature, manipulative, or inappropriate in her desires; and make the "meaning she assigns to her own body beyond consideration" ("Eating Disorders in the '90's", Side B). Others have suggested that the desire to transform the body through anorexia or bulimia are not attempts to repress desire or to avoid femininity, but are responses to perceived or actual threats of attack on female bodies (Larkin et al., 1996; Schwartz & Cohn, 1997).

The unwillingness and strong resistance of women with anorexia and bulimia to gaining weight has been well documented (Crisp, 1980; Garner, 1985; Goldner, et al., 1997). The belief that women with eating disorders have "pathological" desires to "flee" adult femininity has influenced the development of treatment practices. Weight gain and psychotherapy are used to bring this unconscious conflict into conscious awareness in order to assist the women with her difficulty in transitioning to adult femininity. In an extreme example, Russell (1992) described how breast enhancement surgery was used as an incentive to gain weight for an anorexic patient so that she would "feel more feminine."

In B.C, when a woman's refusal to comply with treatment puts her at physical risk, the Mental Health Act (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1996) allows physicians to declare her psychologically incompetent and empowers law enforcement to bring her to hospital against her will. The patient's behaviours and attitudes are deemed self-harming and indicators of underlying pathology that permit the state to override her authority over her own body. Once in hospital, failure to comply with demands to eat and gain weight have resulted in forced-feedings, forced medication and sedation, forced bed rest, and supervised meals and bathroom visits. In addition, behaviour modification therapy has been employed using varied strategies: removal of personal belongings as "consequences" of transgression of "the rules," rewarding good behaviour with "points" to obtain "passes" which allow for greater liberties such as visitors, television, or permission to leave the facility and eventual release.

Orbach (1992) states that interpretations and interventions based on the "flight" model assume a hierarchical stance where, "treatment begins on spurious ground: she knows not what is best for her, we [the practitioners] do" ("Eating Disorders in the '90's", Side B). Such treatment, Orbach (1986) says, has more often been "enforced incarceration" and she condemns the ideological dogmatism behind such treatment practices:

> In civilized hospitals throughout the United States and England, doctors are perfecting ever more elegant techniques to bypass women's mouths and push

> food into their stomachs. The general consensus is that the patient has recovered when the normal weight is reached and appropriate sex role functioning is achieved (1992, p. 7).

Orbach (1992) adds that simply overriding the woman's resistance can "recreate the fear of loss of control and impingement that may have been the seedbed for such behaviours in the first place" ("Eating Disorders in the '90's", Side B). She proffers that efforts must be directed to understanding and inquiring how the eating disorder behaviour serves to preserve a woman.

Criticisms of the Psychogenic Model

Main critiques of this aspect of the multidimensional model is that it frames the issue of etiology as an individual pathology and never questions whether an eating disorder is a *healthy* response to the pathological cultural expectations of adult femininity. It assumes that only certain predisposed individuals are at risk because of a psychological constitution that renders them vulnerable to sociocultural pressures (Garner, 1985). In addition, this perspective assumes there is a discreet delineation between *normal* and *pathological* and what is being defined as pathological is rather commonplace when compulsive exercise, fasting, gastric bypass, liposuction, and other cosmetic surgeries are considered (Orbach, 1992). Feminist theoreticians suggest that eating disorders may be logical, understandable, responses to the pathological social conditions that shape individual female psyches and behaviours and make developmental transitions so difficult.

Family Influences

In addition to individual factors, the psychogenic model has also noted family characteristics that may predispose women to eating disorders. These include: controlling mothers, absent or weak fathers, family enmeshment, early parentification of children, and/or negative relationships between mother and daughter (Rabinor, 1991). Dynamics of family interactions cited as risk factors for an eating disorder are: intrusive or over-protective parenting, the history or presence of mood disorders or substance abuse (Hsu, 1997) and the type of parental care a child has received, i.e., detachment of parent, parental antipathy or indifference (Hernandez, 1995) or touch deprivation (Grupta and Schork, 1995). Intrafamilial sexual abuse (Baldo, Wallace & O'Halloran, 1996; Baldo and Baldo, 1996), particularly by a close male relative (Mullen, Martin, and Anderson, et al., 1993) has been linked to a greater likelihood and more serious manifestations of eating disorders. Evidence suggests that women in families that have a history of disordered eating attitudes and behaviours (i.e., place exceptional priority and greater importance on food, shape, and eating) are at risk for developing and eating disorder (D. Russell, 1995). Hsu (1997) and Brown (1989, 1997) found women with anorexia and bulimia had a history of family obesity or fat oppressive attitudes (i.e., "fat phobia"). Family factors have been understood as contributing to the development of eating disorders in the following ways: the female internalizes the family's fear of obesity; she has difficulty negotiating separation and autonomy within the family; she attempts to establish a different identity than the mother's or other family members'; and/or she attempts to avoid unwanted sexual contact (to be discussed further in trauma-based theories). In this view, eating disorders are not seen as an individual dysfunction, rather the family is viewed as the "environment" that contributes to its development. In terms of intervention, the woman or girl and her family are treated as a unit.

Criticisms of Family Influences Perspective

Criticisms of this conceptualization, however, emphasize that when contemporary psychological theories of eating disorders do not consider the social construction of gender their contributions to the field are limited. When eating disorders are viewed as responses to the interrelational dynamics associated with enmeshed families and dominant mothers and absent fathers, there is a failure to examine how families, mothers, and fathers are transmitters of sociocultural values and beliefs regarding family roles, gender, and the dynamics of power and control. Families themselves are impacted by cultural expectations around gender and relay these to the daughter. When issues regarding dependency, autonomy, perfectionism, or femininity are seen as concerns only for certain psychologically-vulnerable individuals and families, this perspective fails to examine how dependency, autonomy, and perfectionism are socially-constructed, socially-sanctioned, and socially-perpetuated by all families (Orbach, 1992; Covington, 1999). The familial and cultural emphasis on independence and autonomy mirrors the cultural emphasis on independence and autonomy. For example, Belenky, Clinchy, Goldberger, et al. (1986) found that "women's way of knowing" which emphasizes connectedness, interdependency and relatedness, runs counter to the cultural expectation of autonomy and independence. Karpman (1992) states that eating disorders occur in families where there is silence and denial about family losses and traumas. Rather than physically- and psychologically-vulnerable, Wooley (1991) sees women with eating disorder as "the strongest links in the chain" because they hold and articulate the family's underlying and unexpressed emotional pain. Eichenbaum and Orbach, (1983a, 1983b) suggest this is because daughters with eating disorders are likely to be hypervigilant to others' needs and less aware of their own, becoming particularly sensitive to the family's pain and to, therefore, "act it out."

Advantages and Limitations to the Psychogenic Model

The advantage of the psychogenic model is its tendency to look at social interactions and the larger context of the family and culture. It also attempts to find the psychological meaning or significance behind an eating disorder and to more carefully acknowledge the continuum of disordered eating. Limitations to this model centre on its scope of examination on its implication of the sociocultural influences on the individual and the family. The values a culture subscribes to are internalized by the family, and the family, in turn, inscribes these onto the child. In general, and the lack of analysis about political oppression is another criticism of this model. It is these wider cultural values which are examined in the following section.

Cultural Influences on Development of Eating Disorders

The influence of culture has been used to explain from a wider perspective, the causes of eating disorders. The changing roles of women, the prevailing cultural ideal of beauty, (Steiner-Adair, 1994), and the pursuit of thinness (Garfinkel and Garner, 1982) are considered factors of development. This model attempts to examine how desire is created within the individual and the social milieu to attain what seems to be valued.

Cultural Ideals of Beauty and Fat Phobia

The ideal of feminine beauty as it has been represented in the media is of a "thin, white, young woman with no visible imperfections" (Kilbourne, 1994, 1996). Media analysts report that 95% of images of women are of a body type that occurs naturally in only 5% of the female population (Kilbourne, 1994, 1996; Bordo, 1993; Gilday, 1992). Thus what appears as a "normal" body-type, simply by virtue of its visual pervasiveness, is actually an anomaly. This body "type" is exemplified in Barbie and beauty pageants where the ideal is difficult even for contestants to measure up to. The *New York Daily News* [Ryan, 1998] reports that 40 of the 51 1998 *Miss USA* contestants (18-26 years old) had had breast implants prior to competing.) While fashion purports to expand the beauty ideal to include women of color, the facial features or body types are often based on existent white values of beauty (Bordo, 1993, Thompson, 1994a). Bordo (1993) is critical of the way in which plastic surgery is touted as an "individual preference" and an act of self-determination when in fact the language used, (i.e., "to 'correct' a 'Jewish nose' or a 'black nose' pp. 263-4) ignores the racial implications of what is deemed "beautiful." Furthermore, media images (white or non-white) increasingly rely on technologies such as computer imaging and airbrushing to create *perfect* images which are not even human (NEDIC, 1988; Gilday, 1992).

Such ideal body types have been linked to the cultural fear of fatness, the stigmatization and discrimination of fat people, and increased fat phobia in Western society (Brown, 1997; Bordo, 1993; Steiner-Adair, 1991). Fat phobia is internalized early. Six year-old girls in a Toronto study said they did not want to put on their bathing suits because they felt "too grotesque" (Orbach, 1992). Preschoolers in a British study would least like to have a fat child as a friend (versus one of a different ethnicity, one who had lost her hair from chemotherapy, or one with a physical disability) saying the fat child was "stupid," "lazy," and "ugly" (Cleary, 1998). Young women in a *Glamour* magazine study reported they would rather lose weight than have success at work or in their personal relationships, or an increase in their financial status (Bordo, 1993). A survey in *Psychology Today* (1998) found that 89% of women respondents said they would like to lose weight and 39% of these said they would gladly sacrifice 3 years of their lives to be the weight they wanted.

The belief that only white, wealthy, adolescent girls were at risk for developing and eating disorder had been refuted. Increased globalization and accompanying media exposure to this beauty standard has been shown to influence body image perceptions and weight loss practices worldwide. For example, television was only recently introduced to Fiji and eating disorders and dieting are on the rise. Researchers found that Fijian girls who watched television 3-4 nights per week were 50% more likely to describe themselves as too fat" or "too big" and 30% more likely to diet than girls who watched less television ("Study finds TV trims," 1999). Lee (1998, 1999) has noted changes in attitudes and behaviours in Mainland China since the "reunification" of Hong Kong. Dieting, eating disorders and suicidality are increasing as television use has expanded and increased the exposure to Western images of beauty and roles for women. Most women report being affected by the prevailing aesthetic of thinness, the unrealistic cultural values regarding shape (Kilbourne, 1994), and the pervasiveness of fat oppressive attitudes and discrimination (Brown, 1997). Moore (1998) claims that these contribute to "an enforced feminine script that emphasizes thinness and controlled food consumption." The extensiveness of such tremendous body disparagement and women's determined pursuit of the ideal body is evident in the multi-billion dollar per year diet and weight loss industries, diet food industries, fitness and health clubs, and cosmetic and plastic surgery industries.

The "pursuit of thinness" model has been criticized for several reasons. First, it reduces the portrayal of women to one of vanity (Moore, 1998, Bordo, 1993) rather than examining the pervasive pressure to meet this expectation of femininity. As Larkin, Rice & Russell, (1996) state, "The unrelenting pursuit of thinness is a compelling but not necessarily the most salient factor underlying the eating and body image disturbances experienced by many women" (p. 112) Second, it implies that women and girls simply need to resist the social pressure to diet and shore up their self-esteem against the onslaught of media images. Treatment, then, would require increased media awareness and resiliency in girls and an emphasis and focus on awakening females to the pressures of cultural standards in order to "cope more effectively." This situates the responsibility on the individual to tolerate the effects of sociocultural expectations without looking to change the larger social values and context that have such devastating psychological impacts. The onus is on females to adjust to the cultural onslaught of misogynistic message concerning ideals around weight, shape and role expectations.

Feminist academics suggest that the onus should be on society and consumers to require drastic changes from the corporate senders of such messages questioning the misplaced onus of responsibility. As Streigel-Moore (1994) states, "to ignore and to fail to address the cultural values that, when ingested, make women "sick" is iatrogenic." Although most women are impacted by these media messages, not all develop a full-blown eating disorder. Murray (1999) and Beaumont and Russell (1995) found that a critical stance toward media messages may be necessary for preventing an eating disorder, however it is not sufficient to promote recovery from an eating disorder.

Advantages and Limitations of Sociocultural Perspectives

The advantages of the sociocultural perspective is its greater contextual approach and analysis of gender in the cultural milieu. However, the model does not provide an explanation as to why all women do not become afflicted with anorexia or bulimia. A more recent criticism of the feminist contributions to this model is that the role of gender is elevated to exclude other systemic pressures that impact women, such as the extent of violence and the impact of racism, poverty, heterosexism, and class differences. Moore (1998) states that the effects of social oppression and systemic violence on the individual must be examined in order to that create an opportunity to understand the highly personal and sociopolitical meaning of disordered eating symptoms. The model has tended to reduce "cultural factors" to descriptions of the experiences of white, upper to middle class women and girls and the majority of research has been focused on this specific demographic.

Lee (1998, 1999) challenges the ethnocentrism of the diagnostic criteria for anorexia and bulimia and the assumption that the morbid fear of fatness is universal. Orbach (1999), Rice (1996) and Szelekley (1988) suggest the effects of increased globalization, consumerism, and modernity be examined. Thompson (1992) found that African-American and Latina women she interviewed were consistently under-diagnosed and misdiagnosed for eating disorders, which led to greater severity at intervention. Moore (1998) notes how the effects of race, class, poverty, sexual, and cultural differences have not only been overlooked in the research on women and food problems, but how racism, classism, heterosexism as *systems of oppression* [italics in original] have been neglected factors. She notes:

> The body has been a terrain of racialized, sexualized, and classed power negotiation through enslavement, indentured labour, imprisonment, rape, reservations, segregation and genocide. Oppressive experiences are a site to examine how the 'idealized body' interacts with the 'hated body' (p. 7).

Feminists insist that practitioners and theoreticians acknowledge both the individual's unique experiences and the sociocultural context in which these experiences are mediated. They propose that treatment of disordered eating requires immediate intervention in the social realm. Treatment frameworks must include and not ignore the need for concurrent social change—to address, as Steiner-Adair (1994) says, the social conditions that make women sick.

Trauma-based Theories

Trauma-based theories provide another possibility for understanding how culture impacts the development of an eating disorder. Trauma-based theories view eating disorders and disordered eating as survival strategies or coping mechanisms developed in response to crisis or overwhelming stress (Schwartz and Gay, 1996), including developmental and transitional events (Crisp, 1997). However, feminists have suggested that more external, socially-imposed traumas such as violence, harassment, stigmatization (Larkin et al., 1996), racism (Thompson, 1994), heterosexism (Brown, 1997) and institutionalized oppression are at issue (Moore, 1998; Rice, 1996; Wooley, 1994a, 1994b). There is strong evidence to support this argument.

Sexual and Physical Violence and Abuse

Correlations have been found between women who have a history of incest, sexual abuse, and childhood physical abuse and the presence of an eating disorder. High prevalency rates of child sexual abuse have been observed in women presenting with anorexia and bulimia. For example, Moore (1998) reported in her review of the literature that the prevalency of reported child sexual abuse in women with eating disorders ranged from 6-66%. Palmer and Oppenheimer (1992) state that prevalency rates tend to cluster around 30% and De Groot, Kennedy, Rodin, et al. (1992) report a 25% rate in Canada. Moore (1998) reported the following statistics in her literature review of violence and eating disorders:

- Inpatients have higher sexual abuse rates than outpatients (p. 3).
- Sexual abuse history was the trauma that African-American, Latina, and white North American women most frequently related to the development of their eating problems, including compulsive eating and obesity, in addition to anorexia and bulimia (p. 5).
- 61% of white North American women with eating disorders had been sexually assaulted before their 18th birthday and, on average, were ten years old when they were first abused. The reported age of onset for their eating disorders was *after* their first experience of sexual abuse (p. 5, italics in original).
- A national U.S.-based study of 3006 women found that those with bulimia had experienced higher rates of rape, sexual molestation, aggravated assault, direct victimization, and current and lifetime post-traumatic stress syndrome (p. 6).
- Women who experienced past extrafamilial child sexual abuse reported bingeing, vomiting, fasting, and using diet pills more frequently than those who have not (p. 6).

The link between eating disorders and sexual or physical abuse has been interpreted as an effort to control the body or to transform it *because* the body was the site of the abuse. Others suggest that the weight loss that accompanies an eating disorder is an attempt to disappear or to dissociate from the abuse. Weiner & Stephens (1996) found evidence to support trauma-based theories of eating disorders with "sexual barrier weight." A graphic analysis of the histories of sexual trauma of 42 women with eating disorders showed that fluctuations in body weight followed sexually significant life events. Women with eating disorders avoided weight points at which past traumatic sexual events had occurred. Thompson (1992) says women of color in her interviews reported trying to change their body size and shape in an attempt to protect themselves from violence and believed doing so would make them less vulnerable to sexual attack. Schwartz and Cohn (1996) state:

> For the woman, eating influences body size, interferes with "feminine" development, and quite literally can decrease the probability that a man will "abuse" her or that she will have to deal with her "bad" sexual urges or incapacity to say "no." For other women, the body becomes the only reason a man would approach since they feel so internally damaged. Making the body attractive (i.e., thin) becomes an obsession, the only way to escape being alone (p. xi).

Prevalency rates of sexual abuse in women with eating disorders are consistent with rates of sexual abuse in the *general* female population and in those with psychiatric diagnoses of mental illness. Larkin et al. (1996) remark that incest and childhood sexual abuse are extreme forms of violence that are "depressingly common" (p. 14). Thirty to forty percent of women, in general, report early experiences of sexual violation (Larkin et al., 1996). Therefore, Connors and Morse (1993) question whether correlations between eating disorders and sexual abuse are meaningful given that both occur so predominantly for women and girls and reviewers in the area of eating disorders and sexual abuse note that not all children who have been sexually abused develop eating disorders. However, while child sexual abuse is neither necessary nor sufficient for the development of eating problems, it does act as a contributory factor and may account for the extent of generalized disordered eating behaviour.

Childhood physical abuse has received less attention in the literature than childhood sexual abuse (Reto, Dalenberg and Coe, 1996; Rorty and Yager, 1996) and has yet to be fully investigated. Childhood violence history predicted both the presence and severity of bulimia (Bailey and Gibbons, 1989; Reto et al., 1996) while Schmidt, Tiller and Treasure (1993) found that 25% of women with bulimia and 3% of women with anorexia reported histories of physical abuse. Hernandez (1995) studied over 2900 school-aged girls studied and found those who were physically abused were significantly more likely to report eating disorders. Brown (1997) describes how the role of food may be used in abusive contexts including: starvation, force-feeding, forced ingestion, emotional abuse during meals, the use of food as rewards or bribes following abuse, and the use of foods in sexual acts. Given these circumstances, food may simply become unpalatable and aversive or the individual may develop a complicated relationship to food—it may be a provision to which she is not accustomed to having access to, to having control over, or to which she is entitled.

While childhood sexual and physical abuse (Larkin et al., 1996) may be the most frequently documented connection between violence and food issues, they are not the only ways in which violence against women is perpetrated. Women experience many forms of violence: stranger assaults, violence in intimate relationships, acquaintance rape, emotional abuse or neglect, and incest. The research suggests that the widespread extent of body image disturbances, disparagement, and dieting may be linked to the many forms of violence women experience and which go unnoticed and unreported simply because of their everyday pervasiveness. For example, Danielson, Moffitt, and Caspi's (1998) research found that two-thirds of subjects who had experienced severe spousal abuse had elevated rates of anorexia and bulimia. Anecdotal reports of women who have left violent relationships show that verbal and physical attacks are focused on the body (Moore, 1998) and women report dieting or embarking on strenuous physical exercise programs after an abusive episode, or upon leaving an abusive relationship (Researcher's Fieldnotes, 1998, 1999). This behaviour is interpreted in various ways: as a protective measure to gain physical strength; to distance from the abused "self" by reshaping the body, to become more pleasing to the abusive partner to avoid future attacks, or to become more attractive to future partners (Researcher's Field notes, 1998). Leighton (1989) noted that eating disorders are also linked to children who have observed their mothers being abused.

Harassment and Stigmatization

Larkin et al. (1996) propose that harassment and stigmatization have a role in the development of disordered eating. From their anecdotal research they were able to connect a history of being teased about physical appearance to the occurrence of an eating disorder, particularly the "gendered nature" of teasing. Research with adolescent girls in Ontario subjected to on-going verbal and physical attacks from male age-group peers in their schools (i.e., grabbed, pinched, groped, and fondled as they passed through hallways) told of the impact of verbal and sexual harassment in their self-loathing of their body parts (Larkin et al., 1996, p. 16). Harassment also came from adult males who "leered" or made sexualized comments on young adolescent girls' bodies. Larkin, et al. (1996) postulate that leering is "a process used by males to select those females who will be the target of their future sexual and abusive comments and behaviors" (p. 21) and is so commonplace as "to signify girls' passage into womanhood" (p. 21). Harassment serves to remind girls that they are "always at risk" (Larkin, et al., 1996, p. 21) and a girl's attempt to alter her body may be an attempt to "achieve safety as well as to avoid humiliation" (Kaschuk,1992, p. 202). Larkin et al. (1996) contend that sexual harassment is more than an *act* of objectification that leads to feelings of disgust and inferiority and is a *process* whereby the female body is "marked" and visibly displayed. In addition, Larkin et al. (1996) delineated a connection between harrassment, stigmatization and disordered eating stating that:

> Stigma is "the physical mark or attribute from which people are conditioned to recoil, consciously or unconsciously, in an attempt to protect themselves from that which they cannot understand or control, from possible taint or infection" (p. 17).

Stigmatization is often communicated non-verbally and is experienced and "*felt* viscerally, immediately, directly" in the body through registering others' physiological reactions (Larkin et al., 1996, p. 17, emphasis in original). Feminists have noted that the social stigmatization and discrimination against fat people, and particularly fat women (Brown, 1997), serves as a "cautionary tale" (Gilday, 1992) to all women to uphold and adhere to the cultural aesthetic of thinness. Females develop a learned hypervigilance (P. Kitchener, personal communication, January 23, 1998) to prevent exposing their imperfections. The social sanctioning and collusion with sexual harassment means that the only way a woman can escape stigmatization is to remove herself from interactions with the larger world. Controlling the body through disordered eating can be viewed as a means to avoid stigmatization, to embrace the safety of conformity, and to remain connected with the social world.

Trauma-based theories are often linked to the examination of "dissociation." Dissociation is a common characteristic and defense mechanism of sexual abuse and emotional or physical trauma (Schwartz and Cohn, 1996). Dissociation is seen as a "style" of escaping and avoiding overwhelming thoughts and emotions (Reto et al.,1996). The Boston Women's Health Collective (1998) explains dissociation in lay terms as "...a process that produces an alteration in a person's thoughts, feelings, or actions so that for a period of time, certain information is not associated or integrated with other information" (p. 171). Therefore, perception, connection, lack of bodily integration, and memory—previously attributed to cognitive-perceptual dysfunction in the medical/psychiatric model—may be a result of female traumatization. Several authors have provided theoretical and anecdotal accounts of dissociation at work with individuals presenting with eating disorders (Reto et al., 1996; Root, 1991). Eating disorders have been viewed as another form of dissociation and one of many possible responses to abuse.

Trauma-based theories of eating disorders provide a framework for why and *how* an eating disorder may develop in a woman. Uncomfortable emotions or somatic sensations may be overridden by the constant obsessing about food and the body. The energy needed to deny hunger might actually prevent victims of abuse or assault from feeling or thinking about anything other than food (Schwartz and Cohn, 1996). Thompson (1992) has also observed that food may be the most readily accessible, easily accessible, and socially sanctioned "drug" children and adolescent girls can obtain for self-soothing or to obliterate uncomfortable feelings.

Feminist contributors to the multidimensional model recognize the role of violence, abuse, harassment and stigmatization. With these forms of trauma, the relationship to the self, the body, and the world are fractured and disturbed. Suggested treatment for woman with abuse issues involves developing other, less destructive, coping mechanisms and recognizing, validating, and preventing the extent of violence to which women are subjected. For example, the rates between abuse and eating disorders may be underestimated and under-reported. Child sexual abuse is not easily assessed and often missed in intake and treatment. Wooley (1994a) states that in order to truly understand the scope and influence of sexual abuse, a trusting relationship with the client must first be established. Others suggest that sexual and physical abuse issues may surface only after the eating disorder has subsided and the client has sufficient ego strength and experience with new methods of coping (Larkin, et al., 1996; Miller, 1996; Moore, 1998; Schwartz and Cohn, 1996; Wooley, 1994a). Thus the onus is on those providing interventions to make women safe in the therapeutic relationship, on society to become aware of the prevalence abuse, and to change the everyday practices that effect girls and women with physical and emotional devastation.

Advantages and Limitations to Trauma-based Theories

The trauma-based model focuses on the sociopolitical realm. It claims that women's struggles with food and body are rooted in the culture's systemic violence and oppression of women. This perspective attempts to explain eating disorders and other problems that affect women as responses to the social conditions that shape individual and collective psyches. Because of their traumatic nature, these responses can be expressed through dissociation (the splitting of the body from the self) and by the expression of physical and mental symptomology. The feminist model looks beyond the individual woman to situate her within a social context. Orbach (1978) suggests that eating disorders are a response to the "trauma" of being female in a misogynistic culture: the role of femininity and gender is not only extremely problematic but must be central to any theoretical understanding and treatment of eating disorders. To ignore the implications of gender perpetuates the tendency to "blame the victim" and pathologize the individual and the family without accounting for the influence of socialization and patriarchal values on individuals and families. As Catherine Steiner-Adair states, "If we look at eating disorders as expressions of a body politic rather than a body pathological, the symptoms become a statement about the enormous difficulty of growing up female in the current culture..." (Dellebuur, 1997, p. 66).

Finally, there is a biological base to trauma that may appeal to proponents of the biomedical model. Levine (1997) looks at the effects of "the frozen residue of energy that has not been discharged or resolved" (p. 19) and its long-term, debilitating effects found in symptoms of Post-Traumatic Stress Disorder. *Time* magazine (Nash, 1997) noted new developments in infant and brain research that shows how environmental experiences effect neuropathway development, particularly in the early years of life. A lifetime's experience of varying degrees of trauma may likely have a profound physiological effect on women's bodies and brains.

Using trauma-based theories would acknowledge the way in which disordered eating has benefited women because it allows them to survive experiences of systemic violence. A distinction between "madness and mental illness" and "sanity and normality" in the individual becomes much less clear when the larger social forces of oppression and violence are acknowledged. It is important that a framework for understanding eating problems examine the "myriad forces that shape women's experiences of their bodies" (Larkin et al., 1996) and encompass the ways in which sexism, racism, and other systems of oppression affect an individual's relationship to food and her body (Thompson, 1992). Moore (1998) states that an examination of systems of oppression must lead to a reconsideration of current etiological models of eating disorders, as to address eating disorders as "unidimensional and as individual pathological responses to a thin beauty ideal does not address the issue of justice" (p. 9). Interventions must address the ways in which gender, race, class, sexuality biases and the role of power and oppression are inherent to treatment and that health care systems work to change these.

How does one develop coping mechanisms against social-wide violence? If being female in the culture leaves women at risk for abuse then, like anti-smoking and drunk-driving campaigns, culture-wide prescriptive attitudes about the ideal body and the extent of violence against women need to be changed. Troop & Treasure (1997) suggest that since most women are exposed to violence, research should begin to look at what allows some women to escape disordered eating behaviours, i.e., to look at characteristics of resiliency rather than vulnerability. Trauma-based theories still require further development to provide a sound causal explanation for the etiology of an eating disorder.

Summary

In this chapter I have described several perspectives on eating disorder etiology, the impact on treatment, and the strengths and limitations of each. I suggest that the medical/psychiatric perspective must be decentralized. Its dominance in the treatment of eating disorders and the allocation of financial investment in this model need to be reexamined and reallocated. The biomedical/ psychiatric model insists on focusing on individual bodily dysfunction rather than examining and reflecting on the sociocultural perspectives that influence the development and treatment of an eating disorder. I question who is best served by continuing to distinguish between clinical diagnoses of pathology while refusing to acknowledge or address how sociocultural and institutionalized violence influences and defines pathology. Many symptoms once thought to be the causes of eating disorders are now viewed within the medical/ psychiatric model as "secondary" to starvation, and thus the primary priority is to "correct the starvation state," while noting that, as Goldner et al. (1997) state, "Individuals with anorexia nervosa are more reluctant to accept those components of treatment that support increased food intake, weight gain, and reduced physical activity" (p. 450). I believe that working to understand and defuse this resistance or "hunger strike" (Orbach, 1986) is imperative, must be accomplished, and can only be done within a larger cultural context.

Some aspects of the multi-dimensional model have perpetuated the idea that individual women are predisposed to disordered eating without consideration of the extensiveness of the sociopolitical context within which eating disorder develops. Proponents suggest causal theories can be reduced to attitudes around beliefs in families and society relating to the cultural ideal of beauty, the changing roles of women in Western culture, and the pursuit of thinness as protection against fat phobia and the desire to flee adult femininity. However criticisms of this centre on the failure to acknowledge the politics and power of systemic forces in the development of an eating disorder. Trauma-based theories attempt to explain how the prevalence of eating disorders and disordered eating may be accounted for by the extent and degree of violence women have experienced and continue to experience in a misogynistic culture. This perspective suggests that eating disorders are powerful strategies employed in an attempt to avoid, to resist, and to oppose this violence. A more extensive analysis of systemic oppression and disordered eating is needed. If eating disorders were viewed as a "survivalist" response to the pathological circumstances of women's lives, the onus for change would rightfully belong to the sociopolitical realm. In addition, there need to be research and theories that are more culturally sensitive and culturally specific. This will help provide a wider understanding of the precursors and concomitants of eating disorders and assist in tailoring treatment programs to personal etiologies (Moore, 1998). The purpose of this chapter was to situate my work within a changing understanding of what disordered eating is about. The next chapter will look at the methodology used in conducting this research, then will be followed by the findings and results of the study.

CHAPTER THREE

Methodology

Introduction

This chapter presents a description of the methods used to collect, analyze and present the data. In describing the collection of the data, this chapter discusses the use of multi-method research principles that guided the project, the rationale for using this methodology and the trustworthiness and ethical concerns in conducting the research. A general description of how this research project was established and how contact with the Community Outreach Program was made follows. This chapter also elucidates the methods of data collection and analysis.

General Description of Multi-method Research

The practices and principles of four research paradigms shaped this research: qualitative, ethnographic, feminist, and emanicipatory methodologies. Multiple research methods were used in an attempt to gain a contextual comprehension of the Community Outreach Program and of the meaning of the experiences for the women involved. I will briefly describe each of these four research methodologies and give my rationale for their use in the study.

Qualitative Research Methodology

Qualitative research de-emphasizes the traditional quantitative paradigm of positivism and experimentation. Instead, it stresses the importance of "process rather than outcomes, context rather than specific variables, and discovery rather than confirmation" (Merriam, 1988, p. xii).

In qualitative research, the rigorous measurement necessary to quantitative experimentation can impede the construction of powerful categories of analysis, limiting the development of new knowledge; in fact, the very richness of data is often reduced away (Lather, 1986; LeCompte & Goetz, 1982; Merriam, 1988). Qualitative methods involve naturalistic observation and a sensitivity to the "intrinsic structure and qualitative patterning of phenomena studied" (Striegel-Moore, 1994, p. 446). It is a "hypothesis-generating" practice rather than a "hypothesis-testing" practice (Merriam, 1988) which can potentially produce significant variables that may have been neglected in previous methodologies (Striegel-Moore, 1994).

I chose a qualitative research approach precisely for its emphasis on innovative discovery and descriptive quality of experience. As it was unclear as to what were the aspects of the Community Outreach Program that created effective change for participants, I anticipated that a qualitative focus could permit new information to emerge. Most eating disorder research has been undertaken from a traditional quantitative perspective and has tended to consist of empirical studies that often omit significant interpersonal and experiential information. Sesan (1994) found that the few qualitative and clinical case studies done in eating disorders tended to rely on positivistic traditions. Striegel-Moore (1994, p.446) warns that the potential cost of using a limited range of methodologies, such as in the field of eating disorders, are diminished validity and a narrowed vision because "methods determine to an extent the kinds of questions we can ask, and...limit the kinds of answers we may find."

Ethnographic Research Methodology

Ethnographic research uses techniques of naturalistic observation, researcher participation, archival analysis, and open-ended interviewing (Reinharz, 1992) to "elicit cultural knowledge, [provide] detailed investigations of social interaction, or a holistic analysis of societies"

(Hammersley and Atkinson, 1983). Ethnographic principles encourage recording, interviewing, analyzing, and interpreting research data in a way that honours participants and distorts or exploits their participation as little as possible. This is accomplished by carefully recording the phenomena that occur in the research site and by attending to the researcher's experiences while "in the field" of study. This counters the positivistic belief that the researcher be a detached, objective observer separate from the field (Lather, 1991).

Ethnographic practices were used in this research in an attempt to directly access the perspectives of Community Outreach Program participants. The program's success had been measured economically by clients' decreased hospitalizations, and statistically by clients' increased nutritional and psychological scores. There had not been any detailed inquiry with the participants, themselves, as to whether they deemed the program successful and, if so, why. I felt that the quantitative measures used to evaluate their psychological and nutritional well-being, did not provide information about what aspects of the program seemed to have made a difference from the participants point of view. I hoped that by carefully documenting my observations of the program, by interviewing and conversing with participants and staff, and by looking at archival information about the program, I could access previously unrecorded and unrecognized qualities that seemed to support change and recovery.

Feminist Research Methodology

Ethnographic principles and methodology have been used in feminist scholarship to "continuously and reflexively attend to the significance of gender as a basic feature of all social life... [and] to better understand the social realities of women" (DiIorio, 1982, in Reinharz, 1992, p.46). Feminist research analyzes gender relations and the dynamics of power and oppression and applies this analysis toward social change. Feminist theory recognizes gender bias as an inherent aspect of all human inquiry and, therefore, concentrates on the influence of gender in the inquiry process. In feminist ethnographic research, this includes having the researcher monitor herself through self-conscious reflexivity and to understand human behaviour through the examination of context (Streigel-Moore, 1994). In addition, feminists have noted the way in which patriarchal assumptions and biases have impacted women's physical, emotional, and economic security (Waring, 1996).

Feminist principles and theory were central to this study because, as Fallon, Katzman & Wooley (1994, p. ix) state, "one may speculate about the role of gender in many conditions, but in the case of eating disorders, where nearly all sufferers are female, it is beyond debate." Striegel-Moore (1994) claims that much psychological research has been ahistorical and acontextual in its approach. Using a "gender lens" (Ministry of Women's Equality 1995) to view and conduct this research has been essential as gender has not been made explicit in much of the research on eating disorders. Bordo (1993) contends that the fact that gender-biased models continue to dominate both the theory and treatment of eating disorders speaks to an unconscious and unintentional collusion in the conditions that make women more vulnerable to disordered eating. As Steiner-Adair (1994, p. 381) states to healthcare providers in the field:

> Healing requires... [taking] a clear stand against the cultural norms and values that sicken women. This process challenges the assumptions of traditional, non-feminist therapy that therapy is apolitical; it hints that, on the contrary, any therapy of adaptation risks being iatrogenic.

Striegel-Moore (1994) proposes that eating disorder research take a contextual approach by moving away from the individual as a unit of analysis to the larger social systems and strongly suggests that the implications of research findings must be considered and implemented for change in social systems.

Emanicipatory Research Methodology

Emanicipatory research practice employs strategies and techniques designed to limit and prevent the "perpetuation of oppressive rituals of 'speaking for others'" (Alcoff, 1991). Research is conducted via "invitation" to the research site (Haig-Brown, 1992) where collaborative relationships with participants are established. There is a valuing of the energy and trust participants provide the researcher and thus, reciprocity—giving something back to participants—is an important aspect of this paradigm. This approach also recognizes the need to involve participants in as many levels of the research as possible in order to verify the congruity between participants' experiences and the researcher's recording and interpretation of events. Finally, the researcher's "status," or biography, is made explicit as her position undoubtedly influences the research process and findings.

Recent and on-going critiques of traditional positivistic "theory-centred" and "theory-driven" research has found it to be benign at best and unethical at worst (Alcoff, 1991, Lather, 1991, 1986; Le Compte & Goetz, 1982). In my early forays into the field, I found eating disorder research to repeatedly contain many offensive and "oppressive" (Alcoff, 1991) characteristics: research subjects' voices were obscured from the data, their behaviours were decontextualized and labelled pathological, and there was little or no examination of gender or ethnocentric bias. I did not want to replicate these types of studies, so I chose to use the methodologies described above to gain a more in-depth and respectful understanding of the perspectives of COP participants and the program.

Reliability, Validity, and Trustworthiness of the Data

Critiques of qualitative/ethnographic research centre on issues of reliability and validity, however, the contributions of qualitative research lie precisely in its differences from positivistic research. Qualitative research attempts to find a theory that matches the data versus finding data to match the theory. It aims for comparability—describing constructs and characteristics so clearly that they can serve as a basis for comparison to other groups (Le Compte and Goetz, 1982). Qualitative methodology also aims for translatability, i.e., the methods, categories, and characteristics of phenomena are detailed and identified so that comparisons to other projects can be made from the findings (Le Compte and Goetz, 1982).

Threats to reliability are high in ethnographic research given the uniqueness of the research situation. Research is conducted in natural settings (versus the contrived clinical settings of positivistic research) which preclude the use of standardized controls. It focuses on natural occurrences rather than the manipulation of variables essential to experimental design. Le Compte and Goetz (1982) suggest ways in which reliability can be increased in ethnographies: external reliability can be enhanced by reporting details of the researcher's status position and how research participants and settings were chosen; by specifying social settings, circumstances, and social contexts in which data is gathered; and by specifying the precise methods of data collection. In addition, the choice of terminology and methods of analysis should be based on clearly delineated and explicitly identified assumptions and metatheories. Such detailing reveals the context of the research to others attempting to replicate the work. Internal reliability is enhanced by mechanically recording the data; using participants to confirm and verify observations and to determine theoretical constructs for analysis; using peer examiners or colleagues to verify conclusions and theoretical constructs; and triangulating the findings between groups.

Validity is the strength of qualitative and ethnographic research (Merriam, 1988). Le Compte and Goetz (1982) argue that the value of research is recognized by the validity of the findings. From the perspective of emancipatory research, Hayes (1989, in Le Compte and

Goetz, 1982)) frames the issue of validity in terms of whether or not the research contributed to positive changes for the participants. Lather (1991, p. 68) uses the term "catalytic validity" to refer to the degree to which the research process re-orients, focuses, or energizes participants in what Friere (1973) calls "conscientization"— knowing reality in order to better transform it.

There is a high internal validity in qualitative ethnographic research because the researcher spends a great deal of time in the field versus the lab setting (Le Compte and Goetz, 1982). The use of interviews is a process that allows for greater closeness to a participant's own understanding than is found with the more abstract instruments used in positivistic research (Lather, 1986). The focus and emphasis on documentation enhances internal validity by attending to issues such as the history and maturation of participants or programs, observer effects, the selection and attrition of group members, and the way in which the group or program changes over time (mortality). The "disciplined subjectivity," or self-monitoring, of the researcher exposes all phases of the research to continuous questioning and re-evaluation (Le Compte and Goetz, 1982). As the process of how conclusions were made is chronicled throughout the project, the problem of "spurious conclusions" is limited (Le Compte and Goetz, (1982). Documenting the process by which the text is created is essential to qualitative ethnographic methodologies because, "the most rigorous reading... is one that holds itself provisionally open to further deconstruction of its own operative concepts" (Norris, in Lather, 1991, p.85).

While this research was conducted using sets of principles and methods of inquiry (rather than selecting one specific methodology), it rested on five fundamental principles: the recognition that research is not value-free but "politically uninnocent" (Apple, in Lather, 1991, p.vii); the need to privilege women's lives and experiences and to place this at the centre of theory and method (Maracek, 1989); the attention to language and the recognition of power as a primary tool of analysis (Brown, 1994); the understanding that scholarship must necessarily be connected to action (Reinharz, 1992; Freire, 1973); and that reflexivity and reciprocity are integral and inherent to ethical research relationships (Lather, 1991). This research was conducted with attempts to meet these principles.

This has been a general description of qualitative, ethnographic, feminist, and emancipatory research principles and practices that were used to conduct this project. The purpose of working from these perspectives was to add to a growing body of work that questions and challenges traditional conceptualizations of eating disorder etiology, development, and treatment (Sesan, 1994; Wooley, 1990) and that continues to be marginalized in terms of research direction, funding, and publication (Striegel-Moore, 1994). My intent was to add to existing knowledge and to bridge marginalized and mainstream theoretical understandings of disordered eating. These principles and techniques are inherent to the general description that follows of the specific actions taken to conduct this project.

General Description of Research Project

This section of the chapter documents the researcher status position, how the research project was set up, research protocols, and how research participants were selected. The researcher status outlines the way in which my public and private positions influence my role as enquirer and impact the research process. The set-up of the project details the research protocols and the ethics approval process. How research participants were selected chronicles the way in which confidentiality, informed consent, and voluntary participation were attained.

Researcher Status

Lather (1991) says, in order to "attempt to deconstruct the way in which our own desires as emancipatory enquirers shape the texts we create," it is necessary to talk about the researcher and the way in which her history influences what is brought to the research. There were a variety of reasons why I initiated this research work. They are closely related to and complexly layered with who I am, what I do, and to my personal beliefs and values.

As a graduate student within the Faculty of Education, I chose an individual study program that focused on disordered eating and women's psychology. I chose an individual study program because I did not find a traditional clinical or counselling psychology program to have the critical approach I felt necessary to supporting my growing understanding of sociocultural influences on eating disorders. I felt strongly that it was important to look at disordered eating and women's psychology within a cultural context, not just within the individual and/or the family. To this research, therefore, I brought a perspective that was "outside" a traditional counselling program or curriculum of study—neither part of the clinical community nor necessarily ascribing to the medical model.

As a full-time practicing therapist, I work from the perspective of honouring a client's defenses, believing that what the client reports is not only true for them, but that many of the problems that people bring into therapy are the result of sexism and cultural oppression (Sesan, 1994). I carried this perspective to my research hoping to convey my willingness to not only believe that what the participants had to say was true for them, but valid given the way in which gender, class, ethnicity, and the social construction of identity intersect with experience. This remains congruent with my belief and practice that my role as a feminist therapist is to work with the experiences, desires, and needs of clients "by focusing on their understanding of situations" (Lather, 1991, p. x).

Lather (1991) uses the term "praxis" to discuss the dialectical tension between action and reflection, noting that reflection without action is mere verbalism and action without reflection is mere activism. As a praxis-oriented practitioner, I was concerned with how efforts to 'help' can "perpetuate relations of dominance" (Apple, in Lather, 1991, p. ix). Therefore, I endeavoured to make my work meaningful to participants and to illuminate and deconstruct the power relations inherent to our research relationship, as I do in the therapeutic relationship, as much as possible. This requires continued self-examination and reflection upon my actions and a commitment to consciousness and intentionality in my interactions.

In addition, I had struggled with bulimia for 5 years during my undergraduate degree, which had been preceded by 11 years of disordered eating. I did not receive inpatient or outpatient treatment as I did not meet the *DSM-III* (APA, 1987) criteria for medical attention. However, I would have met the criteria soon enough as my eating disorder progressed rapidly within the next six months. As services were scarce, only the most severe cases were addressed in the public healthcare system. The labelling of what was or wasn't considered an "eating disorder" was based on arbitrary measures, however those measures determined who did or did not receive treatment. I sought private therapy in 1991 and took another three years to recover to health. My treatment experiences have been the impetus for looking beyond the traditional medical model for alternative understandings of what is occurring with an eating disorder.

Without access to services, I had began to conduct my own "research" to better understand my eating disorder. At that time, I found most information to be clinically-based and quantitative and did not find information that made sense of my experiences until encountering feminist psychoanalytic works (Orbach, 1978) and autobiographical self-help texts (Roth 1984, 1988). These works began to connect my experiences within a larger sociocultural context and identified a continuum of disordered eating that my dieting and bulimia fit within. Rather than viewed as isolated incidents—dieting considered normal and encouraged, bulimia deemed pathological and incomprehensible, these texts provided an alternative understanding to the one offered by the medical/psychiatric profession. My experience has brought a personal awareness of disordered eating to this work that may not be available to others who have not experienced an eating disorder.

My status as a researcher—the personal, professional, and public stances I occupied within this field while conducting the research—has impacted my work, influencing the questions asked, the approach taken, my access to the research site, and the analysis of the data. When I began this work, I was a volunteer with ANAD (Association of Awareness and Networking Around Disordered Eating, formerly the Canadian Association of Anorexia Nervosa and Associated Disorders). For eight years I was a support group facilitator, a board member, chair of the research committee, and president of the organization in 1998. As a representative of ANAD, I occupied a position on the Provincial Eating Disorders Steering Committee representing the interests and concerns of consumer groups and attempting to complement representatives from provincial Ministry of Health clinical and administrative settings. My role of bringing the concerns of grassroots 'consumer' services and the problems consumers faced regarding recognition, funding, etc., gave me grounding from a perspective other than traditional treatment programs. As one of the first consumer representatives on the Steering Committee, I brought my personal and professional experience of eating disorders to the policy table. My position as committee member allowed me to develop a clear picture of service provision in the province and to observe the rationale and method by which funding for services is determined.

This work in the field also gave me personal contact with people who later became associated with the Community Outreach Program. Prior to conducting the research, I had had personal contact with clinical and administrative staff of St. Paul's Hospital Eating Disorders Program and, often via the support groups, clients of the program. Therefore, my public positions with ANAD and the Provincial Eating Disorders Steering Committee gave me background and access to the field—an "insider" position—that other researchers may not have.

I first heard of the Community Outreach Program during a Steering Committee meeting in September of 1995, as the committee made recommendations for funding the program. Much of the preliminary archival material I had access to was from personal minutes and notes recorded during the Steering Committee meetings. I may have been provided access to other archival information—program proposals, letters of request for funding—because of my familiarity with the program and my working relationships with the Eating Disorders Clinic's administrative staff as a member of the Steering Committee. It is possible that the way in which staff made themselves available for interviews and supported my proposal and project was also enhanced by my existing relationship with the St. Paul's Eating Disorders Clinic.

My understanding of eating disorders and my experience in working with women with eating disorders also supported my proposal to undertake this research. My volunteer and professional background served to reassure staff that I had some awareness of the sensibility and sensitivity required for working with and interviewing this particular group of women. In other words, in addition to my contact with the program, my lived experience in the field may have provided me with opportunities to do this project that would be unavailable or restricted to unknown or inexperienced "outsiders."

Setting Up the Research

Upon hearing about the Community Outreach Program and its outcomes, I saw an opportunity to enquire into the qualities of the program that were making a difference to these patients and, more importantly, to ask the women themselves to describe this. I discussed the limits and ethical considerations inherent to conducting research at this site with both my clinical and academic supervisors, and developed a verbal proposal to bring to the Community

Outreach Program administrators.

In May of 1996, I contacted one of the program psychologists whom I'd known through my volunteer work, and met to discuss the possibility of doing qualitative research with the new program. Her response was encouraging and supportive, particularly of the qualitative nature of the project. She hoped a more detailed analysis of the subtle and significant changes she saw with participants (but was unable to capture with psychological testing instruments) could be revealed by my work (Fieldnotes, May 1996). She assisted me by providing the forms necessary for SPH ethics approval and gave me a copy of an approved proposal to use as a template. I was grateful to have the copy of the proposal. The language on the form was specifically geared to quantitative, positivistic, experimental research design. The approved proposal gave me some idea as to the expectations of the review committee and I could gear the qualitative, ethnographic research terminology to the requirements of the committee.

I wanted the research to be invitational and felt that any strong reactions, objections, or cautions from staff to my working with these clients needed to be revealed and addressed prior to my entering the field. First I met with the Eating Disorder Clinic's director (June 3rd, 1996) to get approval. The director was supportive of my proposal and also encouraged me to proceed.

Second, I wanted to directly address the COP staff to get both their approval of and feedback on conducting the research. As program staff had the most contact with participants, I felt it was important to hear their concerns regarding the effect my presence may have to their work with their clients. Copies of my proposal were provided for distribution to all members of the administrative and clinical staff. My intent was to give them time to be informed of my intentions and to solicit their feedback on what they viewed as appropriate to working with their clients. I was invited to attend a meeting with the activation workers, a psychologist, nutritionist, case manager, family therapist and occupational therapist. However, this meeting was postponed for one week, as the program was required to address the suicide of one of their clients. At the rescheduled meeting I found the staff to be disheartened, discouraged, anxious, and cautious. There was grave concern that given the closeness of women in the eating disorders community, the distress among the COP participants and other patients in the ED clinic about the client's death, and the tendency toward "competitiveness" among patients, more suicide attempts would be made. The COP staff expressed concerns not only regarding my research proposal, but of their program itself, i.e., was COP actually helping, or did the suicide indicate the program was ineffectual or, worse, implicated in the death (Fieldnotes, June, 1996).

Given the circumstances, there were concerns about the timing of my study. These were allayed by the fact that I would not conduct interviews prior to December 1996. The staff also expressed concern regarding my experience with such a "severe and chronic population," and my possible visceral, visible reactions in face-to-face interactions with "severely-emaciated women" (Fieldnotes, June, 1996). The team was also wary that my research would be an evaluation of the program and staff. I responded that was not looking to "judge" nor blame the program but to solicit information from the participants as to what was helpful to their recovery. I also stated that I thought the COP program may actually help participants deal with this suicide by providing continued supportive contact with them during this sensitive time. This seemed to reassure staff that I was not intending harm to the program, the staff, nor the participants, but rather I was informed and supportive of the work they were doing. In addition, my experience as a support group facilitator with women with severe anorexia and bulimia allayed their fears around my possible reactions to clients.

From that meeting, the team approved my proposal and were satisfied with the ethical considerations I had made for soliciting COP clients to participate in the research. They did recommended that I reduce the length of the interviews from 2 hours to 60 minutes, as they thought clients would be unable to maintain concentration for extended lengths of time given their degree of illness. It also became apparent in the meeting that a political oversight had occurred. I would need the additional approval of Greater Vancouver Mental Health Services Society (GVMHSS), as they were partners in the program. This oversight seemed to provoke some controversy as to the way in which GVMHSS's participation had been forgotten.

Once approval in principle was received from the staff, I submitted my proposal to St. Paul's Hospital Ethics Review Committee and GVMHSS for approval. Approval was received from St. Paul's Hospital Ethics Review Committee on August 19th, 1996 (Appendix C) once their requested changes were made to my letter of invitation, i.e., the size of the lettering. In addition, they required that I inform participants that I would have access to their medical records. This was a protocol I did not feel was necessary to my work. I included this sentence but informed participants at our first contact that I would not be requiring access to their medical records. GVMHSS provided approval on August 20th, 1996; (Appendix D) and I then submitted my proposal to Simon Fraser University's Ethics and Review Committee. Approval from SFU was given on August 22nd, 1996 (Appendix E).

Research Protocols

Ethnographic and emancipatory research practices greatly influenced my desire to conduct the research in a manner as ethical, respectful, and unobtrusive as possible to program participants, the Community Outreach staff, and St. Paul's hospital. Initially, I had wanted to introduce myself and my research to the COP participants in their weekly "Quality of Life" group. This was an on-going support group that disbanded before I began; the group's facilitators noticed the women became more depressed by coming together and hypothesized this was because their poor quality of life was more apparent in a group setting (Fieldnotes, June 12th, 1996). I also anticipated that presenting to a pre-established group would lessen the effects of my position as researcher requesting participation than in a one-on-one setting would, by allowing the participants to hear me and to "check me out" before deciding to participate or not.

As the group was no longer meeting, it was decided by the COP team, the program coordinator, and myself that I would create a package that would be given to each of the six participants during their weekly team meetings by the program coordinator. I designed a "letter of invitation" (Appendix F) to be distributed in a sealed envelope to all COP participants at the end of their weekly team meetings. Staff were instructed to state to clients, in their own words, that the envelope contained information requesting voluntary participation in a research study, the research was independent of the program and SPH, and the COP team would not know who was taking part in the research project unless participants chose to disclose such information.

In my approach, I felt it necessary to be cognizant of how the women are frequently requested to take part in both hospital-based and external research projects. Two other research participation notices were posted at the clinic while I was setting up my research. Therefore, I distanced myself from any association with the hospital or the ED program to permit participants to be as frank as possible in their expressions about the program and to have the qualitative research I wanted to conduct set apart from the experimental research that occurred in the clinic. Therefore, in my description of the research project I included: information outlining the project and how it may be different than previous research they may have taken part in; biographical information about myself; the level of commitment and involvement required; the measures taken to ensure their confidentiality and anonymity; their ability to choose to withdraw at any time from the study; the documentation process; where and to whom the research will be presented and/or published; and where they may contact me should they decide to participate.

The COP team supported this. Should participants decide to take part, they were to respond directly to the researcher as per the instructions inside the envelope (i.e., by returning the notice in the sealed, self-addressed, stamped envelope provided in the package to either their COP team member, to the receptionist at the Eating Disorder Clinic, or mailing it directly to me. This controlled for the perception that the team was involved in the research and, in addition, protected participants' anonymity from the team.

The letter of invitation explicitly informed all involved with my project that the research was independent of St. Paul's Hospital and the Community Outreach Program, and that participation or non-participation would not effect funding, continuation, nor participant admission to the Community Outreach Program. Participants were informed that they were free to refuse to participate or withdraw from the study at any time without any consequence to their continuing medical care. It was very important to me that the respondents choose to come forward on their own accord.

Included in the package was a letter of informed consent (Appendixes G, H) which participants were required to complete, sign, and have witnessed for both St. Paul's Hospital's and Simon Fraser University's Ethics Review committees. A subject feedback form (Appendix I), a requirement of SFU's Ethics review, was given to participants with a contact name of my faculty supervisor, and faculty chair. Contact names of those affiliated with SPH, who would be responsible for the researcher and the project, were printed on the SPH consent form and participation notice. Participants were informed both verbally and in writing, that they could address complaints or comments about the researcher or the research project to these persons.

The letter of invitation also informed prospective participants that an introductory meeting would be arranged to allow them to meet me, ask questions about the project or their participation, and determine whether they wished to continue. Another purpose of the initial contact meeting was to invite participants to contribute to shaping the report and to reassure them they had some control over what was said about them and used in the report. They were also told transcripts of the interviews would be returned for their review and initial analyses would be brought to them for their feedback and verification. All three were enthusiastic about this part of the project and two reported looking forward to having some closure in the research process by being notified of what significance their contributions have had on the project.

All meetings, including the initial meeting, were conducted in locations outside the SPH Eating Disorders Clinic and were determined by the researcher and the participant. This helped to reinforce the independence of the research from SPH and the COP program, suggested that the participants were an important part of the collaborative approach of the research, and increased confidentiality of research participants. Meetings were held in a variety of locations—a neighbourhood bakery, coffee shops, a deli, the researcher's practicum office, participants' kitchen tables, and a neighborhood park. This was in keeping with the ethnographic research approach whereby we attempted to meet in "natural" settings—the places where participants actually live with their eating disorder on a daily basis—versus the clinical settings. The initial meetings were one hour to two hours in length, as determined by the needs and schedules of the participants, and one of the initial meetings became an actual interview.

An interview schedule was required for the SPH Ethics review to be included in participant packages. An authorization to record interviews form (see Appendix J) and an interview schedule (see Appendix K) was constructed and submitted to meet this requirement. The original research question was "Have you found the Community Outreach Program to be a success and why or why not?" This was expanded to include a list of possible questions that could be asked during the interview and a notation that the methodology being used (different from quantitative design methods) permitted the conversational nature of the interview to shape the interview. Participants were given the interview schedule with the proviso, but the schedule was soon abandoned as the discussions took their own natural course.

Finally, in addition to the letter of invitation distributed in October 1996, a notice was posted in the common room of Eating Disorders Clinic, where clients could wait for their individual team meetings to begin. This would allow participants to read the notice on their own, and would also serve as a reminder that participants were invited to take part in the project.

Ethnographic, feminist, and participatory research protocols were followed throughout as I believed that it would be unethical and insensitive to step into private and vulnerable areas of these women's lives without being invited to do so (Alcoff, 1991; Haig-Brown, 1992; Merriam, 1988). I tried to be sensitive to the needs of these women, to balance them with my need to do the research and facilitate and establish a level of trust and safety in the relationship with them.

Selection of Research Participants

Purposive sampling was used to select research participants. Six of the seven original pilot project participants were invited to take part and were given information packages in November 1996. New COP clients were not invited as they had not yet spent significant time in the program to be able to ascertain noticeable change. Three responses were received in late November, early December of 1996, and March of 1997. A decline to participate was received in January of 1997. When the response rate remained low with only two participants having responded by January 1997, a general reminder notice (Appendix L) inviting submission of unreturned responses was placed in the general reception area of the clinic. Three additional packages were provided for distribution in March of 1997 to new COP participants (who had now been in the program for 6-9 months). However, there were no additional respondents.

COP staff suggested that a low response rate was not uncommon, as clients were often preoccupied with their medical "survival" (Fieldnotes, February 1997). In addition, they reported that initiating or maintaining contact with another person was difficult for many of the women to do.

As each of the prospective participants responded, a preliminary meeting was set up to within the following two weeks. With the exception of one meeting, these preliminary meetings were not audiotaped. It was a time for both participant and researcher to meet and for the participant to ask any questions about the process, commitment, focus of the project, etc. None of the participants had taken part in qualitative research projects and were surprised that there were no forms or surveys to fill out. There were many questions, particularly about what we would talk about and what did I want to know. All three reported discomfort with the sound of their taped voices, but said that they would not mind being recorded when asked and completed an authorization to record interviews form. All three agreed to take part in the project and responded they hoped they could "just be of help" (Fieldnotes, June 1997).

In conducting and transcribing the first few interviews with COP clients, I became aware of the inability of the interviewees to separate their experiences in COP from previous treatment experiences. Their eating disorders were a continuous process, without clear delineation of programs, treatments, etc. In addition, I was aware of my gaps in knowledge about previous treatment programs. While waiting for more participants to reply, I spoke with staff to get necessary background and contextual information about the current and previous programs. I interviewed colleagues who were part of the staff—an outreach worker, an administrator, and one of the program's psychologists. These interviews were audio-taped (with their permission) to record the voluminous factual information they provided on historical and practical aspects of current and previous eating disorder programs. Client participants had been informed by the invitation to participate and in initial meetings that I would be speaking to staff. However, confidentiality was maintained—staff did not know which clients I was interviewing nor did clients know which staff participants.

These staff interviews later became an integral part of the research. They provided not only archival information, but also revealed information on interactions with clients, observations of client change, and the staff's own ideas about what was or was not working in the program. During the transcription of these interviews, it was apparent that the staff perspectives were pertinent to the study as I began to compare and contrast their perspectives with the participants. Therefore, I used the staff perspectives to triangulate the data, comparing staff interviews with client interviews and with the archival data. This assisted in constructing the categories of analysis and increased the validity of the findings.

When the response rate from COP clients remained low, with only three affirmative responses received by March of 1997, I sought direction from my thesis supervisor on how to address the data collection. I was advised to merge the contextual staff data with the client data. Had there been a larger number of client responses, I may not have included the staff responses in the analysis, but rather, kept them as contextual data. Therefore, the way in which staff data was solicited was different from the solicitation of client participants.

Staff participants were not intended to be research subjects initially, and contact with them was based on the establishment of my previous relationships with them. Although solicitation was informal, these participants had given prior permission for their interviews to be used in the research. Ethical procedures and participatory research protocols had, as with COP clients, been discussed and agreed to. Therefore, it was not necessary to return to the staff to seek their permission to include them as subjects rather than simply contextual participants. Thus, adhering to feminist, ethnographic, and participatory research principles facilitated the transition of these three interview subjects from background to foreground.

Data Collection

Interviews

Data collection consisted of two types of information—conversational and written. Interviews were recorded from both COP clients and staff in December 1996 to June 1997 and transcribed from December 1996 to June 1998. An interview approach was taken for a number of reasons. First and foremost, I was interested in what program participants had to say about their experiences and wanted their "voices" to be a central focal point of the research. I wanted to document our dialogues—or conversations—regarding how the program impacted their struggle with their disordered eating. I was less interested in continuing further clinical documentation of statistical indicators of client health, program success, or program economic viability. Questions regarding qualitative experiences within the program had previously been asked of participants by a scaled survey form ("Quality of Life Inventory," Frisch, 1994) and in general conversation; however, that was not captured in the program's outcomes. I felt it was imperative to have the COP participants' experiences documented as "an Other" record of program outcome measures and successes—and I believed it was unethical and unconscionable to discuss such outcomes without ever having listened seriously and attentively to the program's participants.

I asked the participants of the Community Outreach Program to evaluate the program in their own words, on their own "scale," by their own measure. I asked them about their experiences in this program and others that preceded it and how things could be different. I asked what it was like to live with an eating disorder. I reiterated that what they had to say was important and that "talk is serious" (Kirby & McKenna, 1989).

All interviews were audiotaped with each participant's prior permission. The interviews were open-ended and conversational (Merriam, 1988). This less-structured format assumed participants define the world in unique ways and that the purpose of such interviewing is to attempt to access the perspectives of the participants rather than those of the researcher (Merriam, 1988). The interviews lasted from 60 minutes to 2.5 hours depending on the time available to the participant and researcher (countering the team's suggestion that participants could not concentrate for longer than one hour). I tried to ensure that interview environments are safe and comfortable for the participants and attempted to defray any costs or impositions inherent in their taking part in this work. I acknowledged my gratitude for their time by buying coffee or bringing flowers to their homes or offices.

Interviews were conducted with Participant A ("Natalie"—all names are pseudonyms created by the participant and/or the researcher) on December 18th, 1996; January 7th, 1997; and April 29th, 1997. Interviews with Participant B ("Michelle") were conducted February 11th, 1997 and February 25th, 1997. Michelle did not show up for a third scheduled interview and did not return subsequent phone calls. Only one interview was conducted with Participant C ("Sara") on March 14th, 1997. Sara did not show for our second scheduled interview, calling to say she had forgotten. Later, she had medical problems that interrupted our ability to do further interviews. In addition, another death had occurred in one of the Clinic's patients. This impacted Sara, as the deceased woman was a friend. We did not schedule further interviews although Sara and I remained in contact with each other in other capacities.

With staff, or the service providers, an interview was conducted with one of the three activation workers ("Amber") on January 20th, 1997. An interview with one of the two program psychologists ("Deborah") took place on May 13th, 1997, although initial contact had been made the year prior. One of several different program administrators ("Christine") was interviewed twice, on January 6th and May 23rd 1997, although there were other informal contacts made in working conjointly with the Steering Committee. The number of interviews conducted with each participant, the dates on which they occurred, and the length of the interviews are shown in Table 1.

Transcriptions

Audiotapes of the interviews were then transcribed. Initially, I had intended to personally transcribe the audiotapes and to return them to participants for their review at the next interview. However, transcribing took much longer than estimated, so transcriptions were returned to participants as they were available. At one point, copies of the audiotapes were made and sent to a hired external transcriber. These transcribers worked within the psychiatric community but had no contact with St. Paul's Hospital. Despite their familiarity with the mental health field, their unfamiliarity with eating disorders and not being present at the interviews proved to create many errors in the transcripts. Subsequently, I returned to transcribing the interviews myself due to both the number of errors and the cost of hiring transcribers. The transcripts of the interviews ranged from 17-53 pages with the average length being 34 pages. All transcripts were returned to participants with copies of the audiotapes for their perusal and verification. Participants were also asked to delete any sections of the interview they did not want me to use in my writing and to provide feedback on the accuracy of the transcripts. There were few deletions to maintain confidentiality and only one participant had a concern with the accuracy of one section that was then reviewed and corrected. All participants received copies of audiotapes and transcripts of their interviews. Upon completion of the project, all audiotapes and paper and

Table 1

Interviews with Participants

Participant	1st contact (by phone)	Initial meeting (unrecorded)	Date of interview	Length of interview
COP Clients				
Natalie	Dec 3/96	Dec 11/96	Dec 18/96 Jan 7/97 Apr 29/97	60 minutes 90 minutes 150 minutes
Michelle	Nov 15/97	Feb 4/97	Feb 11/97 Feb 25/97	60 minutes 60 minutes
Sara	Mar 10/97	Mar 14/97	Mar 14/97	60 minutes
COP Team				
Amber		June 14/96	Jan 20/97	120 minutes
Deborah		June 7/96	May 13/97	60 minutes
Christine		Dec 6/96	Jan 6/97 May 25/97	60 minutes 60 minutes

computer copies of transcripts were destroyed. As a gesture of reciprocity, a copy of the thesis was offered to each of the participants and a copy provided for the Community Outreach Program's records. In addition, all participants were invited to the thesis defense.

The decision to end the data collection phase of the research was decided by pragmatics, and an "exhaustion of resources" (Lincoln and Guba, 1985). I had depleted the personal time and funding I had allocated to the project. In addition, I did not receive any further interest from participants to take part in the interviews. Also, I felt that there was a sense of integration with the data I had collected to date, although I would have welcomed the possibility of interviewing other participants.

Documentation

Documents regarding the Community Outreach Program were requested from personal contacts in the program, but as COP was still relatively new, program objectives, job descriptions, protocols, and policies were still being developed. There were, however, other resources available to me to gather contextual information about the program. These were from the "working group" papers, the development of the proposal for funding, and the written correspondence between the potential funder and the program developers. In addition to these documents, I also kept hand-written fieldnotes in a file that were used as data for later analysis. Data was collected between June 1996 and February 1998. Both sources of information—the documents and the interviews—were essential to attaining a clearer picture of the program's principles, goals and developmental struggles.

A "working group" was established to develop the initial proposal for the Ministry of Health. The Eating Disorders Community Planning Working Group [EDCPWG] consisted of a focus group of clients of the SPH Eating Disorders Clinic, family and friends of clients, community resources such as ANAD and GVMHSS, and the administrators of the Eating Disorders Clinic. The working group "brainstormed" for several meetings to get information on what type of a program would best meet the needs of women struggling with chronic, unrelenting eating disorders. The working group papers consisted of notes taken by a hired policy writer during several of the group's meetings from October to December1995. I had obtained access to these carefully maintained notes, with dates, original outlines, and revised versions of the proposal, through my personal association with the administrator and the policy writer. A second source of information was the final proposal presented to the Ministry of Health. This overlaps with the third source of information—the written correspondences between the Ministry funder reviewing the proposal and SPH administrators who lobbied for the program's funding.

These two types of data (interviews and documentation) gave me a rich and complex view of the program itself. Such an opportunity to attain this information may or may not have been made available to other researchers. My insider status, as well as the access to the policy writer's complete and well-ordered notes and dated drafts of the proposals, provided a source of information about the program likely unavailable to others. From these sources, I was able to ascertain and define for myself some of the terminology native to this program's development which will be discussed further in this chapter.

Literature Review

The literature review was conducted on an on-going basis throughout the production of the thesis. Prior to beginning the proposal, a directed studies course in feminist perspectives in eating disorders and a feminist, ethnographic and qualitative research were completed. While waiting for respondents and conducting and transcribing interviews other articles on eating disorders and chronicity was sought.

As the field of literature on disordered eating was widespread, I focused my search on specific aspects of disordered eating: the biomedical model and the multi-disciplinary model. An electronic literature review search was done using the psychological abstract database, with the keywords "eating disorders" from the year 1990 on. Articles were selected from the printed abstracts and filed by model. In addition, several articles and books were found at the Eating Disorders Resources Centre of B. C., particularly articles on chronicity and treatment.

Four separate literature reviews were done. The first literature review looked at the biomedical model and feminist etiological theories of eating disorders and sought the shortcomings of the former and the advantages of the latter. It was soon apparent that this literature review was too simplistic and grounded in the researcher's personal agenda and history. A second literature review was more encompassing, examining the variety of etiological theories offered in books, research journals, and on-line in an attempt to find a "truthful" explanation of causality. The review provided varied perspectives but offered no conclusive causal explanations. It was soon apparent that this review was overwhelmingly contradictory and dependent upon the hermeneutical perspectives and practices of theorists. The third literature review attempted to provide an overview of causal theories of eating disorders and a more specific and directed focus on chronicity and eating disorders. Throughout the literature reviews, the relationship between theory and treatment practices was obvious.

During the analysis of the data, a fourth literature review began to take shape once the findings emerged into categories. This literature focused more on qualities of therapeutic relationships—in particular, attachment theory—and is incorporated into the final chapter. From the data collected from the literature reviews and from the interviews with participants, a collection of terms were used repeatedly, constituting a "common stock of knowledge" (Haig-

Brown, 1994) held by myself as researcher, the participants, and the program. These were included in the definition of terms in Appendix B.

Data Analysis Procedure

Merriam (1988) states that data collection and data analysis should occur simultaneously in qualitative research. Goetz and LeCompte (1982) say it is the timing of analysis and the integration of analysis with other tasks that distinguish a qualitative design from traditional positivistic research. Merriam (1988) determines three dimensions of data analysis—analysis during data collection, the devising of categories, and theory building. These dimensions are used to discuss the analysis of the data for this research project.

Analysis during Data Collection

Data analysis began during the interviews. The permission for conversations to be "free-flowing" allowed either the participant or myself to direct the interview to any particular topic or area that seemed pertinent or timely. I feel that the first level of analysis occurred here, where a topic was realized and the interview proceeded in its direction.

A second level of analysis began while listening to the audiotapes during transcription or while reviewing those from the transcriber to verify accuracy. As spoken language moves so quickly, a paragraph or statement would have to be reviewed several times in order to get it correct. In essence, the transcripts were analyzed with each re-reading. At this phase of the data collection, I made "observer's comments" (Merriam, 1988), to stimulate critical thinking about what I was hearing or reading. These were recorded in my fieldnotes, or placed in the "working papers" file I had started. I noted questions I wished to pursue in future interviews, topics to be explored in the literature, and marked key words that emerged as I worked the transcripts.

Observer comments were also made as the documents—the working group papers, the final proposal, and the correspondence—were reviewed.

Once the transcriptions were completed and verified by participants, all data was pulled together to create a "data base." In addition to the file of "working papers," file folders were assigned to each interviewee and each category of document (e.g., "program proposals," "trauma-based theories," "research process," etc.) to make locating specific data easier during the intensive analysis stage. Three photocopies were made of each transcript and numbered for easy reference.

Intensive Analysis

This third stage of analysis occurred when I began to look for themes in the transcripts and documents. Each of the three copies of the transcript was read at separate times. For example, I would read only one interview, then take a few days before re-reading it or starting another interview. I would read all the transcripts of one participant at the same time. I then read all of the client interviews together and then all the staff interviews. Sometimes I would juxtapose client interviews with staff interviews. My purpose in doing so was to keep awareness as "fresh" as possible to the data. I wanted to see what emerged from the transcripts and to remain "open" to the data so as not to prematurely arrive at categories and concepts. With each reading, "units of information" (Merriam, 1988 p. 132) were noted--key words were written in the margins and passages of interest were marked with a coloured highlighter pen. Merriam (1988, p. 131) describes this as "holding a conversation with the data."

I examined the highlighted data for commonalities and disparities within each individual's transcript, across participants, and between staff and client groups. I analyzed what was homogenous information—i.e., repeated by more than one participant or was similar in content.

These commonalities were classified into themes. Each theme was then examined for heterogeneity—i.e., the content was different enough to be separate from another theme (Merriam, 1988).

In addition, some themes had evolved during the ongoing literature review and in my daily interactions working in the field. This ancillary process of developing themes was recorded in my working papers and fieldnotes and then brought back into the transcript review process. The themes were recorded on a running list of major ideas while working across the data and were then filed with the working papers. This list later became the basis of categorization.

Developing Categories

"Categorization," linking like themes together from the transcripts, was the fourth level of analysis. As the volume of data was daunting, I returned to my original research question, which asked what aspects of COP seemed to make a difference to recovery. Using the research question as a standard, a profile was compiled for each participant. All highlighted data from the interviews pertaining to the question were entered into the profile and grouped by the preliminary themes identified earlier in the intensive analysis. These themes included items such as "trust," "community location," "consistency of contact," etc., and were colour-coded to correspond with the preliminary themes. This profile was named a "response summary profile." The profiles were completed by comparing one theme to another, then each individual profile was consolidated into a master profile or outline or responses.

In reviewing the master profile, the first category construct emerged as I saw that the data converged around the participants' perceptions of interactions that either enhanced or inhibited their quality of life. The data was re-organized around this construct and each individual's interview responses were entered into a table according to whether it enhanced or inhibited quality of life. At this stage, more distinct properties of the categories that enhanced or inhibited recovery were determined. These categorical properties included "consistency," "reliability," the program "paradigm" or "goals," "location of program," etc.

A table (Table 3.2) was constructed and all highlighted data from response summary profiles were colour-coded and entered according to the preliminary themes and the overarching or meta-categories of qualities that enhanced or inhibited growth and recovery. While entering the data into the table, I returned to each quote to verify that it fit with the preliminary theme. I reflected upon whether each statement was accurately placed within the theme, if it required movement, or if a new thematic construct needed to be made. In this way, the thematic data was once more cross-referenced with each participant and theme and all data pertaining to theme was grouped together in the table permitting a re-examination of hetero- and homogeneity.

From this table, major categories began to emerge. What was readily apparent at this stage of the analysis were the qualities of interactions that were growth-enhancing or growth-inhibiting diverged into two additional meta-categories. Participants' comments could be divided into those that referred to the program itself, i.e., the structure and philosophies forming the *content* of COP, or those that identified interactions participants had with COP staff or program, i.e., the *process* of COP. A third category—incongruencies between content and interactions—emerged later in the analysis as the "inhibitive interactions" category filled up with participant responses.

Table 2
Perceptions of Interactions that *Enhance* or *Inhibit* Growth and Recovery

Category	Themes/Properties	Enhance Quality of Life	Inhibit Quality of Life
1. Qualities of Program	Program Paradigm	*Individualized format*	*Group Format*
	Program Focus	*Paradoxical approach*	*Focus on weight goals*
	Goal Setting	*Client determines goals*	*Program sets weight goals*
	Location	*Coffee shop*	*Hospitalization*
	Length of Treatment	*Open-ended,* *Client determines*	*Program determines*
2. Qualities of Interactions	Consistency	*Activation worker available at Christmas*	*No service on weekends, holidays*
	Reliability	*Dealing with conflict*	*Avoiding conflict*
	Empathy	*Preparing for exams*	
	Attachment	*Connection with activation worker*	
	Trust		*Treatment ends*
3. Incongruencies	Length of Treatment		*Client vs. funder's need*

These findings and categories were written up in a draft form and sent to the participants for their review and feedback (December, 1999 and January 2000). My intention was to "negotiate meanings" (Lather, 1991) and build reciprocity in this work and thus increase the "face validity" of the project. I invited the participants' critical reactions to my account of their world (Lather, 1991) to serve as a "corrective to the investigator's preconceptions regarding the subjects' life-world and experiences" (Lather, 1991). Of the five respondents (one participant had died by this time), two participants met with me, one contacted me by telephone, and two did not respond to my requests. There were no expressed concerns about the categorical or thematic constructs with the respondents, however, I think that by this point in the project, participants may have felt somewhat removed from the work. In addition, I don't believe an environment was successfully created in which the participants could remain invested in the project. Perhaps a participant-action research model could be more effectively employed. Ideally, developing the themes and categorization conjointly with participants may have proven more interesting and further verified their relevancy, but time restraints and the level of interest of participants did not permit doing so.

Critical Reflections

Some challenges arose during this process of categorization. First, there seemed to be a "confound variable" in that it was often difficult to differentiate between what were participants' historical experiences in treatment prior to COP and what was specifically pertinent to COP. Therefore it was difficult to identify the specific phenomena of a "bounded system" (Merriam, 1988) as in participants' minds, COP became merged with other components in the on-going development of clinical services offered by the hospital. I attempted to clarify this where possible by asking specific questions to participants and obtaining the background information on previous treatment programs.

Secondly, I recognized that I needed to be vigilant about the biases I had developed while conducting the research and working in the field. I had a tendency to interpret participants' responses and had to look at why this interpretative mode was so insistent. I was using my own ideology to interpret what the participants were saying, believing I could understand from their responses what the participants, themselves, could not. Lather (1991) and Willis (1977) describe this as assuming participants' " false consciousness." Lather (1991) defines false consciousness as "the denial of how common sense ways of looking at the world are permeated with meanings that sustain disempowerment" (p. 59). It is important to pay attention to issues of false consciousness as the determinants of women's oppression can be hidden from or beyond participants' immediate awareness. In emancipatory research, having participants come to awareness of their false consciousness can be achieved by "ruptures in patterns of normality so that the pathology of the normal can be seen" (Gorelick, 1991, p. 467). However, assuming participants' false consciousness can be troublesome to emanicipatory theory because it imposes one meaning (the researcher's) on the situation rather than constructing meaning through the negotiation with the research participants. As I had not created conditions suitable to such negotiation, I attempted to limit this interpretative mode by recording these thoughts in my fieldnotes and working papers and, instead, focused on continual verification in repeatedly referring back to the data. This, I believe, made the data less susceptible to my selective interpretation. I also worked with my thesis supervisor to limit this interpretation as much as possible.

In addition, I asked a colleague working in the field of eating disorders to review the table of entries and the categories they were grouped under. I solicited her feedback as to whether she saw the categories as relevant and to verify the 'fit' between each unit of information, the theme, and the category. I also brought the analysis to the participants, asking if the themes and categories were relevant or needed to be changed; however, I did not receive any responses. By recording and analyzing the information in this manner, I was trying to limit what Sampson (1993) has described as the tendency of categorization, or construction of categories, to serve the purposes of dominant groups. I allowed the themes to emerge from the interview data itself.

Verification during Analysis

Internal reliability was enhanced by the use of audio recording equipment to mechanically reproduce the interviews. This allowed an opportunity to repeatedly go back to the interview to verify content and delineate the researcher's interpretation and projection regarding what took place. Inviting research participants to confirm what was recorded and checking back with them to verify themes and categories further enhanced internal reliability. The theoretical constructs for analysis—the themes and categories—were discussed with my thesis supervisor and a colleague in the field. In all, this increased the trustworthiness of the data.

External validity was enhanced by continued self-reflexivity, dialogue with my supervisor via notes and meetings, collegial review, using a working papers file as a journal, and recording fieldnotes. This was instrumental to noticing my biases and my assumptions. The collegial review and the triangulation of the data—administrative staff with activation workers with participants; interview data with documents with the literature review; and the data with my findings with a colleague's review—were also ways to increase trustworthiness, reliability, and validity.

Bias is inherent to any method of inquiry. I intended to reveal my biases clearly and in doing so to delineate the investments I have in doing this work. For example, I found my criticisms of the program most interesting. I tended to view the situation in an adversarial fashion as myself and the clients "against" the program. I found I had a desire to "expose" the program flaws despite initially indicating I was not going to be judgmental. Upon reflection, I think much of this can be attributed to my desire to "help" the COP clients, to become an advocate for them, and to use the thesis as a "vehicle" for their voices. My assumption and experience was that they were physically and politically compromised to do so themselves. (This will be discussed in Chapter Five.) In reviewing literature on feminist research methodology, however, I was reminded of the necessity to value each person's perspective and found I had increasing empathy towards the service providers as my ability to hold their reality emerged. This was easier to do as I noticed a parallel process for all those interviewed. The data was revealing the complexities of transition in women with eating disorders, in a model of treatment, in a research paradigm, and in society.

During much of this project I found myself experiencing profound emotions. I was overwhelmed with sadness and frustration, particularly as the clients continued to struggle with recovery, as deaths occurred, as the program itself was continually changed. Gorelick (1991) writes:

> And when this scientist with a female personal pronoun studies women, she is apt to feel a different relationship with her subjects because she is subject to finding herself mirrored in them, in fact with revolutionary implications for the relationships among observer and observed, theory and experience, science and politics, race and class" (p. 460)

Pre-existing relationships and ones established with participants along the way did have a profound impact on me. I found it difficult to remain detached (although I had anticipated this) and was frustrated by my inability to make change to the conditions that I felt were so obviously needing to be addressed. As an observer, group facilitator, therapist, political advocate and having recovered from an eating disorder, I felt certain that my hypotheses were being validated as I spent time with the participants. As a researcher, however, I felt unable to declare this until I had "proof." And even then, I doubted having "proof" would make change to the politico-economic conditions that seemed to be at the root of the problem.

While re-doing this chapter after the analysis was completed, I had difficulty facing the fear of knowing what I knew—that my hypotheses were supported by the data. I vacillated between confirmation and doubt—of having *a priori* knowledge and having to prove it. I began doubting whether I did "shape" the data to fit my knowledge. This fear was quelled as I returned to review my data and reflect on my analysis methodology. I had grounded myself in the data; I had stuck to what the participants said. And in doing so, I noticed a parallel process with the women, the program, the service providers, the health care system, and women in general living in a hierarchical and patriarchal society. I found reassurance in Lather's (1991) remarks:

> Building empirically grounded theory requires reciprocal relationships between data and theory. Data must be allowed to generate propositions in a dialectical manner that permits use of *a priori* theoretical frameworks, but which keeps a particular framework from becoming the container into which the data must be poured. The search is for theory which grows out of context-embedded data, not in a way that automatically rejects *a priori* theory, but in a way that keeps preconceptions from distorting the logic of evidence (p. 62).

The ability to keep my *a priori* theoretical framework was predicated on my ability to keep this framework open to other possibilities from the data. Lather (1991) suggests that while there is no such thing as value-free or objective research, she argues that there is a need to keep as open a frame of reference as possible to allow the data to generate the propositions. Lewis (1992) speaks of the researcher's authority, or "power to name" and that the researcher must claim and proclaim that authority. This success of this will be discussed further in Chapter Five's discussion of the findings.

Finally, during the analysis of the data, the findings generated the need for further information and, as stated earlier, a fourth literature review began to take shape. In addition, some findings were not pertinent to the research question and instead initiated other questions and ideas for further research. These were recorded for use in Chapter Five.

Developing Theory

The fifth level of analysis, theory building, moves beyond the categories to link them together with tentative hypotheses. This involved making inferences from the data and speculating on the relationships found between categories and the phenomenon studied. As Merriam (1988, p. 141) says, "thinking about one's data—theorizing—is a step toward developing theory." While completing the analysis of the data and presenting the findings, tentative hypotheses or "suggested links between categories and their properties" (Merriam, 1988, p. 142) were made. These were recorded and filed in a folder designated for the writing of Chapter Five.

The data analysis was an effort to organize the voluminous raw information from the interviews and documents into a significantly meaningful account. This required refining the units of information into themes, constructing themes from the categories, and linking the categories together with hypotheses to form a theory. In this way, the theory remains grounded in the data and emerges from it.

Summary

This research began with an interest in ascertaining a qualitative assessment from participants in the success of Community Outreach Program that could coexist with preliminary quantitative results. The premise was that what the women, themselves, had to say was important to any such assessment of the program, should be inquired about, and their responses documented. In this chapter I have presented a description of the research setting and the approaches and guiding principles to doing the research. I have detailed the rationale for the methods and procedures employed in carrying out the interviews and data analysis and discussed the efforts made to enhance the trustworthiness of the data and the process of categorization. Chapter Four presents the findings of the study.

CHAPTER FOUR

Findings

· Introduction

This chapter presents the profiles of the research participants and the anecdotal data from the study. Two groups of participants in the Community Outreach Program were interviewed: three clients of the program and three staff members who worked as part of the interdisciplinary team. In this chapter, the interview question ("What qualities, if any, did you find successful in your experiences of COP?) and the research participants' subsequent answers are discussed. Responses are categorized in terms of aspects of COP experiences from both clients' and staff's unique perspectives that enhanced or inhibited clients' 'quality of life.' These aspects of the program are divided into (a) the qualities of the program and (b) qualities of the interactions between clients and the program. The themes that emerged from the data are discussed and supported using the words of the research participants and are triangulated with the written documents from the COP program where available. The chapter concludes with summary of the findings. The implications of the findings are discussed at length in Chapter Five.

Profiles

The profiles of the research participants have been created from information the participants provided in their interviews or in personal discussions occurring off-tape and recorded in fieldnotes. The profiles provide information about the participant's history with COP and the circumstances of their interviews. The profiles have been reviewed and verified by the participants for use in this chapter. All names used are pseudonyms.

COP Participants

The profiles of the clients begins with Natalie, with whom the longest research relationship occurred, continue with Michelle, and then conclude with Sarah, with whom the research was limited to one interview occasion. The COP clients were asked to discuss their experiences while participating in the pilot program and in previous treatment programs. Their replies centre on how COP had or had not proven successful for them, what they felt enhanced or inhibited their recovery from an eating disorder and what changes they felt needed to be made to the program to make it more effective.

Natalie

Natalie was a 30 year-old single woman living alone in the Vancouver area and was in regular contact with her family who also lived in the Lower Mainland. She supported herself with a provincial social services disability pension, but prior to her disability with anorexia and bulimia, had worked as a receptionist. She was active in a grass-roots advocacy group for people with eating disorders and had recently returned to college.

Natalie had been involved with COP for nine months at the time of the first interview (December 1996). She participated in one meeting (December 11th 1996) and three interviews in total (December 18th 1996, January 7th 1997, and April 29th 1997). The research relationship has continued beyond the scope of the research project to the present time, where a collegial and personal friendship is maintained.

Natalie had attended many treatment programs provided by the provincial Ministry of Health. Her disordered eating behaviour was first medically recognized at 19 years of age, during a two-month hospitalization in 1986 for a suicide attempt. At that time, her eating disorder was comprised of self-induced vomiting, but, in her words, the purging was " treated as secondary" to her depression and was "shoved away, it really wasn't dealt with" (12/18/96, p. 6). She was hospitalized several more times for depression and suicide attempts.

In 1987, Natalie lost a significant amount of weight and was hospitalized for the first time for anorexia. This hospitalization lasted three months and after she took part in a 5-6 month intensive day-treatment group program. Upon completing this program, Natalie quit treatment, travelled abroad and then returned to Canada. Her anorexia remained intact throughout this time. She later was hospitalized 2-3 more times in Vancouver for re-feeding and weight stabilization. Each hospitalization lasted 6-8 weeks. Natalie tried a variety of treatment programs and worked with a number of psychiatrists. She had been admitted to the acute care ward, the day treatment program, and to the outpatient program at St. Paul's Hospital.

Natalie's last hospitalization in the acute care ward occurred in the fall of 1995 during what she described as "a really bad time of crisis" (12/18/97 p. 9). Upon her discharge, Natalie was to enter the outpatient program again. However, she was told "at the last minute" that she could not attend because her skin-fold measures (of her body fat percentage) were too low (12/18/97 p.9). It was suggested Natalie attend the 4-day per-week day treatment program and she began participating in a "readiness" program to prepare her for that admission. Natalie stated she was really not wanting to attend a day treatment program again, and had decided during Christmas of 1995 that she would "try to do it on my own, outside of any program" (12/18/96 p. 4), although she remained on the waitlist for day treatment. During this time, a position in the Community Outreach Program became available and she was invited to meet with the team to discuss any goals she may want to set for herself if she attended COP. Natalie started with COP in April of 1996, at which time the program was funded as a six-week pilot project. Natalie and the team expected she would take part for six weeks only, however, as funding was continued, her participation was extended. She left the program in May 1999.

Michelle

Michelle was 36 years old at the time of the interviews. She entered the COP program in January of 1996 and had completed one year with the program when our two interviews took place (February 11th and 25th, 1997). She lived by herself in an apartment in Vancouver and supported herself with long-term disability pensions from the provincial government and her employee union. Prior to her debilitation with anorexia and bulimia, which prevented her from working, Michelle had been employed in the medical profession. Michelle originally came from another province to attend university in Vancouver. She did not indicate if she had family in the Lower Mainland or what their relationship status was, although in both interviews she spoke briefly of her painful childhood and family experiences which included childhood teasing and stigmatization based on her socioeconomic class and family obesity.

Michelle was diagnosed with anorexia when she was twenty-six but stated that she had been bingeing and purging for at least two years prior to that. A work colleague recognized the anorexic symptoms of Michelle' weight loss and urged her to go for help. According to Michelle, this colleague's friend had died from anorexia and she'd pledged never to ignore the symptoms again. Michelle went to her family doctor and was referred to the internist at St Paul's Hospital. The internist immediately recommended Michelle be admitted to the Eating Disorders Clinic and she was hospitalized in the Long Stay program for 13-14 months in November 1990.

Michelle said she had also attended the provincial residential program, but found living with other residents too challenging after several years of social isolation. In addition, she experienced difficulty complying with the program's strict focus on weight gain and its restrictions on purging behaviours. While Michelle did not indicate other programs she had attended, she did state she had been involuntarily committed to hospital several times for treatment. These hospitalizations were for extended periods of time. Michelle also acknowledged that she had voluntarily admitted herself when "everything is just falling apart and I'm so stressed out I can't cope anymore" (02/19/97 p. 28).

Michelle said that purging was a method she initially employed to control or to maintain her weight after a "binge" or the ingestion of "bad" foods when dieting (02/11/97 p. 9). She had dieted consistently during her teens and early adulthood and purging seemed to present a solution to the dilemma of bingeing and the repeated weight gain. In addition, purging alleviated her fears of becoming morbidly obese like other family members. Michelle said she realized later that she could use purging to lose weight and believed she would stop purging when she got to a weight she was "comfortable" with (11/02/97 p. 10). In retrospect, however, she admits there never was such a weight; purging quickly became the centre of her daily activities (02/19/97 p.13) and a major component of how she spent her time.

Isolation was a concomitant part of Michelle' eating disorder. She worked solitary night shifts and her days consisted of sleeping, eating, and purging until it was time to go to work. She would then fast during her work shift and return home to repeat the binge-purge-sleep cycle. She reported she had few friends and, therefore, decreasing her isolation was a major goal of her work in COP. Michelle linked her social isolation as both a cause and effect of her bulimic and anorexic behaviour. For example, prior to speaking with Michelle in person by telephone, there was difficulty connecting with her. Despite returning the consent form indicating her interest in participating in the research, three phone messages to her went unanswered. Six weeks later, when she did return the call, she stated that her "anorexic thinking" had been active and she found it difficult to break through her isolating behaviours to return the calls despite wanting to take part in the study (Researcher Fieldnotes, January, 25th 1997).

Michelle participated in three telephone calls, one introductory meeting, and two interviews. At the second interview, Michelle's COP team had just notified her that she would need to leave the program within the next 4-5 months. The program began to establish time limits for participation and Michelle was approaching the program's 18-month limit. At the interview, she stated her great distress and anger. Michelle was very concerned with how she would cope with her eating disorder in both the immediate timeframe and in the upcoming five months. She agreed to meet for a third interview but then did not return calls to arrange a time. Three more phone calls were made throughout the following year to inquire as to her willingness to continue however there were no responses. There has been no further contact with her in the subsequent two years. I was informed that Michelle had died as a result of suicide in July 1999.

Sarah

Sarah was 27 years old at the time of our interview in March of 1997. She lived with her family in an upper middle class home in the Vancouver area. She was attending university part-time and had spent many years studying dance prior to her diagnosis. Sarah participated in one interview for this research project and then was hospitalized prior to the next scheduled interview. After this hospitalization, another client from the eating disorder program died and Sarah stated this death had reconstituted some feelings about a friend and clinic client who had committed suicide the preceding year. In her phone call to me, Sarah said she needed "to take a break from everything," including the interviews (Fieldnotes, April 1997). She also stated she had also just been asked to "step out" of the Community Outreach Program; i.e., to take time to assess whether she was ready to take advantage of the COP program's offerings. We maintained sporadic contact the next few years in other community events.

Sarah was diagnosed with anorexia in 1992 at the age of 22. She stated that her friends had discovered she was engaging in bulimia and encouraged her to tell her parents. Sarah was assessed within a month and said she felt very lucky to have such a quick assessment as the wait lists at that time were six months to a year. She speculated that her parent's professional relationships with members of the medical community might have facilitated an earlier assessment. Despite the quick assessment and diagnosis, Sarah saw a program psychiatrist only three times in the following four months. She found this to be of little benefit and the anorexia persisted. In April of 1992 she was told she should be admitted to the 3-month hospital in-patient program. A nursing strike delayed her admission but she was later admitted for two months in the summer of 1992. Following this stay, Sarah was admitted once more for 6 weeks, then admitted again for a 2-3 month stay the following summer (1993). Sarah had also worked individually with several private psychiatrists. Sarah stated she was repeatedly frustrated that, for various reasons, she had been required to work with seven different psychiatrists in the past five years. In addition to psychiatric treatment, Sarah had also attended a general psychiatric residential facility.

Sarah was one of a handful of B.C. residents to request and acquire out-of-province services at a specialized private clinic in the United States. She and her family petitioned the Ministry of Health to cover the costs of treatment because it was felt by the program staff, her family, and Sarah, herself, that the existent provincial programs could not address her needs. The petition was successful and Sarah was approved to attend a 3-month treatment program in the U.S. in 1995. While in the U.S. treatment program, Sarah gained ten pounds but did not meet the weight gains the program protocols required. Despite having looked for a program that specifically did not use tube-feeding, the treatment centre insisted that Sarah be tube-fed to restore her weight. Sarah was reluctant to do so, as previous experiences with tube-feeding had been disastrous failures. However, she complied with their recommendation for two days then demanded to be taken off. With her weight still too low to meet the program's protocols, Sarah was required to withdraw from the program and returned home after only a few weeks. Approximately two months after her return from the United States, Sarah was invited to take part in the Community Outreach Program. At the time of the interview, she had been involved with COP for 15 months, however, Sarah was beginning her "time out" for an unspecified length of time by our second phone call.

The client profiles provide details of how Natalie, Michelle, and Sarah met the pilot program admission criteria. The profiles also describe the persistence of eating disorders in Natalie, Michelle and Sarah's adult lives. Respectively, their eating disorders had lasted 11, 10, and 5 years. All three clients had attended all the available provincially-funded eating disorder treatment programs, in addition to private clinicians, without respite or success. Sarah had also attended out-of-province treatment. All three participants had been COP pilot project program participants and had attended the program for lengths of 9, 12, and 15 months at the time of the interviews and, therefore, were considered appropriate research candidates given their experiences within the program and prior to COP participation.

COP Multi-disciplinary Team Members

The profiles of the staff begin with Amber, one of the first activation workers in the program; continue with Deborah, one of the team psychologists and an original program coordinator; and conclude with Christine, the clinical director of the St. Paul's Hospital ED program who initiated COP.

Amber

Amber was one of several activation workers in COP. She holds a graduate degree in psychology and had been working in the area of eating disorders for several years when she joined the COP team. Amber initially heard about COP when she participated as one of several stakeholders in an inaugural meeting of the Eating Disorders Community Planning Working Group, in June 1995. The description of the activation worker role interested her because it required someone who would be "providing daily support" and offered "more contact, personal contact" (20/01/97 p. 2) than her present work did. After the meeting she inquired about the position and was offered a half-time position. At the time of our interview (January 20th, 1997), Amber had been an activation worker for less than two years.

COP was a pilot project when Amber started. In our only interview, she revealed how novel this program was to the Eating Disorders Clinic. There were no polices or procedures yet formulated and no formalized orientation process for newcomers. Amber reported her training consisted of "shadowing" the existing activation workers for a week "to see what their interactions with clients was like... [and] talked with them about their experiences a little bit and got some direction and stuff" (20/01/97 p. 1). In addition, her training involved "getting a sense of the paperwork necessary to the program" and reading suggested research articles on rehabilitation and working with people with chronic eating disorders (20/01/97 p. 2). When she began work with her first client, Amber was teamed with another activation worker for a few days for additional support. Amber's experience of this time was that the team pulled together to learn from each other as, "There just wasn't anyone really to sit down and do a huge orientation because there really wasn't this concrete model" (20/01/97 p. 2). Amber also remarked how the team members supported each other through these early stages of the program's development.

Amber began working with one client in autumn of 1995 and a second client the following winter. At the time of our interview, Amber had two long-term clients and one short-term client. She identified the difference between these client groups: short-term clients had access to activation workers only and not the entire COP team. Short-term clients were required to have established medical, nutritional, and therapeutic support in their communities, or were in a healthier physical state than long-term clients. Amber stated that carrying a short-term client was designed to provide the activation worker with " a bit of a break from the more chronic, unrelenting [clients]" (20/01/97 p. 5) and to acknowledge the limits of both the program and workers in providing consistent intensive treatment and support. In addition, short-term clients were added to the program to address the wait list for eating disorder services. Amber's 17.5 hour work week was used: in one-on-one contact with her three clients (including travel time); completing the paperwork of charting and recording client progress and activities; joining clinical team members for 3-hour weekly 'rounds' sessions; attending team meetings between clients and the team; educational in-services on rehabilitation models; and responding to after-hours emergency calls. In addition, according to the proposed budget, the activation worker was the lowest paid position for staff members other than the secretarial staff.

In her interview, Amber was asked to discuss her involvement in the COP program and her experiences as an activation worker. Amber related personal information and knowledge of the program's paradigm and model and also articulated her beliefs of what she felt were the needs of the program's activation workers based on her personal requirements during her time with COP. In addition to these general comments about staff needs, Amber expressed what she believed might enhance and inhibit change for COP clients based on her observations of client interactions with the COP team.

The relationship between Amber and myself was facilitated by our mutual involvement in the field. Given our on-going relationship throughout the research process, Amber provided several updates regarding changes to the program since the interviews had been completed which were recorded in the researcher's fieldnotes.

Deborah

Deborah is one of the psychologists in the eating disorder program and, like her colleagues, has been part of the Community Outreach Program in a variety of roles: as program coordinator, therapist, group facilitator, and researcher. At the time of our interview (May 13th, 1997), the majority of Deborah's work had shifted to research although she maintained some clinical therapy time with clients. When she was program coordinator, much of her work had been administrative and included developing program philosophies, policies, and protocols; writing grant applications and reports; addressing the wait list for admission; and making and receiving community provider referrals. As a therapist, Deborah saw 4-5 clients per week. In addition to providing consultation to the COP team, she also assessed clients' 'readiness' to attend the program, and recorded client changes in the program.

Deborah stated that her clinical research work was supposed to consist of 6-7 hours per week. Later it became apparent that the program could use her psychologist time more efficiently as a consulting psychologist, (i.e., administering psychological tests, conducting modules, and providing short-term interventions and one-on-one counselling). Deborah commented that, upon review, her role was also shifted because the program had been unbalanced administratively as COP "just had too many cooks in the kitchen... [and] it just felt like maybe we didn't need so many people 'up there' making decisions" (13/05/99 p.3).

In Deborah's interview, she was asked to address the research question from her perspective of program psychologist, to talk about the changes to COP during the previous six months, and to discuss her thoughts on 'quality of life' changes she noticed with clients she worked with. Generally, Deborah relayed descriptive and factual information about the administrative and personnel changes made to the program, the changes to time limits for client participation, and COP's addition of short-term clients to the program to accommodate the client load. Thus, Deborah's general statements focused on the length of treatment, changing staff roles, and her awareness of client needs.

In her role as research consultant, Deborah focused on the variables that seemed to benefit COP clients in their recovery. She was working closely with the team nutritionist to examine the relationship between clients' nutritional management and their medical and psychological issues—an area in the research literature where, according to Deborah, there is a dearth of actual research findings. At the time of the interview, Deborah and the nutritionist were developing a database to look at trends in nutritional management and the concomitant impact on COP participants. Like Amber, Deborah commented how the newness of the program and its subsequent changes impacted her work as a psychologist.

Deborah also spoke of an awareness of her own personal changes in therapist-client interactions. She described her increased self-awareness and the resultant change in her interpersonal interactions with clients, particularly adopting the stance of "radical genuineness." In addition, Deborah hypothesized that what may inhibit recovery was the length of treatment the program provided. Deborah based this hypothesis on feedback that she received from an international eating disorders conference in April of 1997.

Christine

Christine was one of several administrative staff involved with the program throughout its duration. She is a registered nurse with a 10-year background in eating disorders in both her clinical work and private practice. Christine's interest in eating disorders began with her undergraduate work and she continued to research this topic in her graduate program. One of Christine's particular interests is examining the use of an ethical decision-making model in treatment, i.e., when or when not to force-feed or to commit someone to hospital.

Christine was an integral part of the early Eating Disorders Community Planning Working Group that examined the needs of this particular client population. She was involved in writing the proposal and requesting the funding. She also contributed to the philosophical approach and practices of the program with ideas of empowering clients by using principles of a client-centred approach and harm-reduction model. Designing and setting up the program took much work and time, Christine stated because, "There's no template anywhere. This is the only program of its kind anywhere, so we were kind of flying by the seat of our pants. We don't really know if it's going to work—we hope its going to work! (06/01/97 p. 19)."

Once the program was established, Christine's role shifted to that of a consultant to the project. In addition to COP, Christine worked as a consultant to the Provincial Eating Disorder Program, assisting communities across B.C. to establish standards of care and treatment protocols for people with eating disorders. Christine assisted the COP team with difficult clinical situations by applying an ethical decision-making model.

In her interview, Christine commented that some discussion in the research literature claimed an eating disorder was a protest against the social condition of women, e.g., a hunger strike analogous to the political hunger strikes of Irish protestors. As Christine remarked:

> It's a really hard walk sometimes because a lot of these clients live on that line between life and death. And we don't want to lose anybody. And it's not that we don't want to lose anybody in the St. Paul's program; we just don't believe anyone should have to die. I mean we really believe that very strongly. It's a hard place to be. ... I read an article written by a feminist that said the client is actually being an activist in this culture and if she wants to go on a hunger strike, man, she can go on a hunger strike! And to that I say, "You do not understand anorexia nervosa. No!" Anorexia nervosa is not a volitional hunger strike against an issue; it is not a thought-out piece. We are not going to let a woman die when she doesn't even know that's why she's dying (06/01/97 p. 13-14).

Christine was adamant that recovery from an eating disorder is possible and that the program philosophy be congruent with that.

In addition to the basic interview question, Christine was asked in her two interviews (January 6th, 1997 and May 23rd, 1997) to provide a history of COP and to talk about the conception of the program and where it stood 18 months after beginning. Christine provided the frame and context from which the program grew and then spoke about the many changes and revisions the program had undergone. Christine also postulated her beliefs about this client population based on knowledge she acquired through focus groups conducted prior to the development of COP and in her ten years of experience working with this client group. Her interview responses about the program were descriptive and cluster around the program philosophy and the program model—both historically and presently.

The staff profiles emphasize the staff's intentions to provide factual information regarding COP from their unique perspectives within the program. This factual information was relayed in response to the research question and to questions regarding the program's historical context. Both client and staff profiles assist to situate the findings from the context of each individual, from a within-groups context (client group or staff group), and across-group experiences. The findings are discussed in the following section of this chapter.

Findings

Interview participants had varied perspectives on what aspects of the program were or were not effective. These aspects focused on two areas: (a) the qualities of the program design and delivery—its philosophy and model, and (b) the qualities of interactions between clients, staff, and the program. Both COP client and staff responses focused on these two areas. Clients spoke of their historical experiences of what did not work in previous treatment programs and compared this with their experiences of what did or did not enhance recovery and 'quality of life' with the COP. Staff members spoke of changes they saw happening with clients, the program, and themselves and related these to the program philosophy and model. Additionally, at the time of the interviews the staff were in an on-going process of working to develop an effective and responsive program model; preparing evaluations of the program for the funder and for an upcoming presentation at an international conference; and adjusting to numerous funding and program changes. Their responses were reflective of the program's twin objectives of increasing the 'quality of life' for clients and decreasing hospitalizations for this client group. Findings regarding the qualities of the program philosophy and model are presented first followed by the quality of interactions between clients, staff, and the program that enhance or inhibit quality of life.

Qualities of Program Philosophy and Model

Regarding the qualities of COP that enhanced or inhibited quality of life, participants spoke about the program's philosophy and model. Comments about the program philosophy address three main components: the setting, the use of a paradoxical approach, and the length of treatment. Comments about the program model examine the flexibility and availability of the program and staff, and the skills and strategies employed in carrying out the program philosophy. Respondents remarked on these features.

Program Philosophy:

The program philosophy describes aspects of the program's paradigm, or beliefs and values. These were described in the program documents and were articulated by the program staff and, although less so, by clients. This discussion of program philosophy features the setting of the program, the treatment approach used, and the length of treatment provided. Participants' responses about their experiences both supported and contradicted the program's philosophy of out-of-hospital treatment setting and the use of a paradoxical approach. The program's length of treatment was the feature that participants responded to with the most negativity. The program philosophy is discussed in the following section, beginning with the program setting, followed by the use of a paradoxical approach and the length of treatment.

Program setting.

According to program documents, the Community Outreach Program, as indicated by its name, was to be situated outside of hospital and in the community where clients lived with their eating disorders. The Eating Disorders Community Planning Working Group [EDCPWG] papers (October 25th, 1995) identified the treatment setting as a priority for a new program. The working group stated that a purpose of a new program would be to establish community and social ties that allowed clients to "stay in the real world of school, work, and relationships" (EDCPWG, Patient Focus Group, October, 1995) and to provide opportunities for "community outings, events, and socializing" (EDCPWG, Family Focus Group, October, 1995). According to the Community Outreach Program Proposal (Niblock, 1995), and in keeping with current trends in mental health care, service was to be provided "in the client's own environment, including the home, or in other locales or facilities, depending on the needs and goals of the individual" (p. 2). While no program for individuals with severe and complicated anorexia had yet been developed in Canada, research literature (Reding and Raphaelson, 1995; Marks, et al., 1994, in Niblock, 1995) regarding community outreach programs servicing other psychiatric populations reported that:

> ... Remaining in the community as much as possible while being provided the appropriate care and supports... [resulted in] reduced psychiatric symptoms, increased or improved community and social involvement, reduced stress in family and significant others, daily living skills development, maintenance of social contacts and support networks, and reduced hospital admissions (p. 4-5).

In addition to the improvements to quality of life, a further motivation for a community-based program was the "concern for cost containment of health services" (Niblock, 1995, p. 4). Documentation regarding the development of a new eating disorder program, therefore, emphasized the importance of an out-of-hospital treatment setting.

Clients had much to say about their previous experiences in hospital treatment programs. These remarks were largely negative and demonstrated the advantage of COP's out-of-hospital setting. These responses included the clients' experiences with tube-feeding, previous programs' focus on weight gain for admission or continuation, the client's sense of failure with each re-admission, and their isolation from family, friends and community during long term hospitalizations. Being treated in hospital had been problematic and a hardship for clients, as indicated by their statements below:

> From the very first time I was tube-fed, they said they'd made a mistake. I found that my body just doesn't react well to tube-feeding. I've actually volunteered—gone in to get tube-fed—before I went to [an outside program] so I could get medically-stabilized. I lasted 24 hours voluntarily. It was just—it was too hard. Ten pounds within 35 hours, I think I gained. It hurts and it feels uncomfortable. And its just, emotionally, I can't stand it. The last two times I was here [SPH] that they tube-fed me, they sedated me. I was unconscious. I don't remember. Which

> was supposed to help. It didn't. It just made it worse. Which was when they sort of [said], "You know, our programs aren't going to work for you." (Sarah 14/03/97 p. 20)
>
> I've had a couple of times where I had to go in the hospital to gain [since starting COP], but it's been voluntary, where as before it wasn't. Some of the time [before] it's been where I've had to be certified. Those are just dreadful situations. It's a nightmare. Right away it's just out [of the question] to begin with because you're not feeling well. There's usually something driving you to get to that point [of committal]. So you're stressed out because of that. Then all of a sudden the ability to binge and purge has just been taken away—which is a coping mechanism (Michelle, 11/02/97 p. 25)
>
> When I go to the hospital [now], I really specify where I want to be. I will not go the psych ward unless they put me in as a non-eating disorder patient. Because I don't like it. It's too restrictive. That's what I find with the hospital setting. It's just too restrictive. In COP, you restrict what you do. (Sarah, 14/03/97 p. 17-19)

Being in hospital for treatment had not been a positive experience of clients. Therefore, COP's setting treatment outside of the hospital is appealing. In fact, Natalie indicates that a reason she admitted herself to COP was because of the out-of-hospital setting. Sarah notices how participating in COP and being out of the hospital has an effect on her motivation, feelings, and attitude:

> Another big thing [about taking part in COP] too was that *(whispers)* I didn't have to go back to the hospital again! *(Laughter)* You know it was just the *thought* of that, because the last few times I had been in hospital have NOT been fun. (Natalie, 07/01/97, p. 30)
>
> I really have cut down on my connections with other girls from St. Paul's because I find that it's really competitive. And I find that very tiring. I don't like going to clinic so I've done it so I only go to clinic once a month so [that] I don't have to sit with everyone. Because I find just sitting in the hallway really depressing. I see a lot of the same people there. You see them in the hospital month after month after month after month. I would just be like "Oh!" And how long do you reach out and let it affect you? (Sarah, 14/03/97 p. 15-16)
>
> When I'm feeling really negative, it [hospital] is a really negative place to be. Because everyone is talking about their eating disorder or if they've been in the hospital.... (Sarah, 14/03/97 p. 17-18)

Both Natalie and Sarah find the in-hospital setting aversive because of their previous experiences or because of the way in which hospital seems to perpetuate their negative feelings. Both Natalie and Sarah explain how an out-of-hospital setting was beneficial to improving quality of life: Natalie sees it as a more relaxed and realistic setting; Sarah finds it modifies her understanding of her eating disorder and herself:

> I think that's what has been different. It's completely different than the setting in the hospital—because it is out in society and you go into a coffee place or whatever you are going to do. So the atmosphere is more relaxed. (Natalie 07/01/97 p. 5)

> I do think it is a good program and I think that some aspects of it are *SO* good. It is really freeing in many ways once you get out of the hospital cycle. I want to find some way to validate myself outside an eating disorder because as long as you see your eating disorder in the hospital as a validating thing, you are never going to escape it. Just getting out of the hospital cycle—you can see that you can move forward in your life even if your eating disorder is kind of moving up and down. (Sarah, 24/03/97 p. 25)

Treatment outside of hospital has an impact on participants' outlooks and, in Sarah's example, allows her to consider her life as something more than just a person with an eating disorder. In fact, it allows her to believe she can "escape" her eating disorder.

Participants in the pilot project knew of what they spoke—they had had extensive experience with hospitalizations. An assessment of the seven women who took part in the pilot project found that five had histories of repeated emergency hospitalizations (ranging from 2 to 26 admissions per year), and all had been hospitalized in the eight months preceding COP for a total of 299 days (Geller, 1996). This contrasted with two hospitalizations and 35 days of hospital time used by women during the four-month pilot project.

The program staff respondents also saw COP's out-of-hospital setting as a beneficial feature. Their experience with clients who had had numerous hospitalizations indicated that clients became more isolated and experienced significant upheaval in their lives. Christine and Amber recount:

> Generally people report that being in hospital is a pretty dehumanizing experience. Not because people are unkind or any of those sorts of things but you are separated from what you do, your own place. It's just really difficult. Most people talk about going to hospital as an unpleasant experience. (Christine 01/06/97 p. 5)

> The healing needs to take place in the community.... (Amber 20/01/9 p. 13)

> It wasn't anti-hospital in the sense of "we don't like you guys" it was more around the fears that [hospitalization] creates and the re-feeding process—all of those things that just feel so demeaning and so horrible...I'm sure it must be really awful for people. (Christine 01/06/97 p. 8)

Moving an eating disorder treatment program into a community setting, however, required a transition of hospital-based roles and responsibilities. Deborah noted that the functions the hospital had previously fulfilled, i.e., meal and dietary support, psychotherapy, medical monitoring, family support, etc. would now need to occur in the community. With the development of COP, hospital personnel were required to shift to consultant roles—both to the COP program itself and to community providers. Thus, the locus of control seemed to be decentralized from the hospital and moved into the community. Deborah describes the importance of the activation workers role in liasing between clients, the program, and the community, and remarks on the change for hospital staff to the role of consultants:

> The activation workers being the core workers who have the most contact [with the client] and with the case-coordinator as well, and then the hospital workers as coming in as needed—consulting to the program and also trying to get the functions they serve happening in the community. So basically consulting both within the program and outside the program. (Deborah 13/05/97 p. 2)

Christine views the situation as the hospital staff supporting the client's transition to community care. As the transition is made, the hospital-based staff will move into the community with the client and be present with her as she establishes a new relationship with the community care provider:

> It [transition] is probably preferable in their [community provider's] setting with the client, so the client feels the comfort of you being there, but at the same time

> can sort of get kind of comfortable with somebody else. (Christine 05/23/97 p.3)

> And I'll help her [the client] connect with those people [community providers]. And I want that to happen now because I want her to establish a relationship with this person, [to] gradually wean out of therapy with me—[to] use me as a kind of sounding board if she needs to, here and there—but she needs to move in her life. And that needs to be putting St. Paul's a bit behind her...or a lot behind her. (Christine, 01/06/97 p. 23)

In addition to changes to staff role and function, changes would also occur within the hospital's Eating Disorder Program itself. Rather than use the acute care beds of the Eating Disorders Program, COP clients could be hospitalized for re-feeding and medical stabilization under their family physician's care in the family practice wards. This would free up the acute care beds for those on the wait list for services from across the province. This strategy also fit with COP's philosophy of community treatment while providing added cost containment to the existent eating disorders program:

> We tend not to use the Extra Care beds. We tend to use medical beds or the family practice beds. A couple of them have family practitioners that we can use the family practice unit. And patients don't seem to mind that. (Christine 01/06/97 p. 27)

> The decision usually comes down to [the client's] experience. Some clients prefer medical [support]. Some find they do better in Extra Care because they need that extra help—and just taking their own past experience [into consideration]. So it is much more planned, there's [a] contract; it's got the client's voice in it as well. (Amber 20/01/97 p. 24)

An out-of-hospital setting for treatment appears to be beneficial from the perspective of clients and staff alike. Previous in-hospital treatment experiences have been negative or aversive for clients and therefore, an out-of-hospital location is more appealing. It also seems to encourage client participation and decreases the pathologizing that in-hospital treatment fosters. In addition, it provides cost-containment by gradually shifting treatment responsibility from the hospital to the community.

Christine feels that the role of the hospital in a community treatment program cannot be underestimated given the degree of illness in this particular population of clients:

> With this client group I think it is naive to think that they are not going to need hospital. I think it's naive, in fact, I think it is quite stupid to even design a program for people like this that has nothing to do with the hospital. Because, boy they do get into medical crisis...they do! (Christine, 01/06/97 p. 48)
>
> Now we haven't been able to ignore the medical crises our clients have been in um, we just haven't. Some of them have been in very highly critical situations. (Christine, 05/23/97 p. 18)

However, despite the displeasing experiences of the clients, it appears hospitalization also serves an important therapeutic function. According to the participants' responses, hospitalization also provides a setting for reconnection and increased human contact for some clients. The interview respondents, both staff and clients, found that hospital plays an important role in assisting some women to break their isolation and become reconnected again:

> Sometimes I go into hospital just because everything is just falling apart and I'm so stressed out I can't cope anymore. And I do okay in the hospital and I even do a lot of psychological work in the hospital and I do very well with meeting people. But as soon as I get back home, I've fallen right back into the same situation. The COP program has helped to mediate that a little. (Michelle 11/02/97 p. 28)
>
> I thought to myself, if I go into hospital I'm going to have to eat and, you know, keep it [down]. Why do I have to have the permission—because you sort of get this permission when you get into hospital. You get this permission to eat again. (Natalie, 07/01/97 p. 16)
>
> An average duration of illness is something like sixteen years. In some ways, we've become family. And many of these patients have needed that. ... Some people use the term "institutionalized" and I am not even sure that's true—I think it's just that [hospitalization is] the only real connection they have. Their lives have been lives of isolation and a lot of misery. Finally they have a little bit of hope that life is going to improve a little bit, and that's connected to us. (Christine, 05/23/97 p. 2-3)

Given the degree of hopelessness and isolation that can accompany a chronic eating disorder, hospitalization can provide a surprising benefit.

Providing treatment in the community and outside of hospital is reported to be beneficial to the COP clients. It encourages their participation in the program, allows them to feel more relaxed and encouraged about participation, and provides a more positive experience than previous involuntary committals and forced feedings. While setting the program in the community offsets costs to the Eating Disorders Clinic, it also requires that the hospital move into a consultative role with the community. Program staff are also required to be the "transitional objects" for clients as they become acquainted with community providers and move away from long-tem connections established with hospital-based care providers. Finally, while hospitalization is necessary for this particular group of patients due to their medical instability, it also is a place that enhances quality of life for clients who need to be connected to others again.

Paradoxical treatment approach.

A paradoxical approach refers to the belief and practice that focusing treatment on aspects other than the client's eating disorder behaviours will, conversely, treat the eating disorder behaviours, i.e., to treat isolation and hopelessness rather than focus on the eating, restricting, bingeing and/or purging behaviours. COP's paradoxical approach incorporates three components: a focus on reducing a client's isolation and hopelessness; principles of harm reduction that demonstrate an acceptance of the eating disorder symptoms; and the use activation and a client-centred approach in treatment. Clients reported that when this approach was used, the CO program enhanced their quality of life and assisted recovery.

Focus on reducing hopelessness and isolation.

Hopelessness and isolation were identified as two factors that were predominant for the COP client group. Data from the Eating Disorders Working Group also supported this. A critical success factor for patients identified from the Eating Disorder Community Planning Working Group was "ongoing motivation and [the] instillation of hope," (EDCPWG, Minutes, October 27th, 1995, pg. 4), and "the need to break isolation," (EDCPWG, Patient Focus Group, October 27th, 1995, pg. 4). The staff respondents spoke extensively to this in their interviews, identifying hopelessness and isolation as inhibitive to a healthy quality of life for clients with eating disorders: Deborah describes her findings on pilot project participants who entered the program; Christine comments on how, for this client group, hopelessness and isolation permeate their lives; and Amber states that hopelessness has an impact on clients abilities to succeed in the program.

Deborah describes the results of psychological tests she administered to COP pilot project participants upon entry to the program and how their sense of hopelessness and despair resulted in responses so low they could not be measured:

> It's pretty dismal actually, but what we found in terms of quality of life is that of the ten people who I had data from, nine of them were off the scale. They were so low. This isn't imposing a definition of quality of life on them, it's actually them saying what areas are important to them and how satisfied are they with those areas. It's of the areas that they identify as important to them, how dissatisfied are they? They were not just in the first percentile, but way below the first percentile. So it's a group who at least when they first came into program were pretty dismal about their lives. (Deborah, 13/05/97 p. 5)

In her interview, Christine talks about two clients in particular and her observations that previous community support groups have tended to increase hopelessness for these clients rather than lessen it. She also comments on the hopelessness of participants in COP's short-lived

"Quality of Life" group where, in fact, the group was disbanded because participants felt more hopelessness while attending (Fieldnotes, January 10th, 1997):

> The chronic population—the COP group—they are a good case in point. They need actually to be with a group of people like themselves. Because you know [when they are with others] then they feel SO bad—SO terrible about themselves. It feeds their despair, unfortunately, instead of giving them some hope. (Christine, 01/06/97 p. 38)
>
> What became really very, very, clear from all of the people that were coming [to the Quality of Life group]—including these two individuals that I spoke of [who were at risk of death]—was just the lack of hope that they had for their lives. Real despair about their life. Every single person in the group. There was no exception. (Christine, 05/23/97 p. 4)

Amber notes how this pervasive hopelessness directly impacts participants' abilities to work on and achieve their goals in the program. This is echoed by Sarah's remarks on how being in hospital for several years and continuing to see others like her is so depressing that she isolated herself and refused to attend the clinic at all in her treatment:

> The long-term goal [for clients] is made difficult by the hopelessness—about there being any long-term future at all. (Amber, 01/20/97 p. 9)
>
> I don't like going to clinic so I've done it so I only go to clinic once a month. So I don't have to sit with everyone. Because I find just sitting in the hallway really depressing. (Sarah, 14/03/97 p. 16)

Identifying and addressing hopelessness in COP has apparently benefited clients. In one of her interviews, Christine remarks how hopelessness shifts for clients as they spend more time in the program and how, according to verbal comments that the clients have made to her, the program has improved their quality of life. Her remarks speak to a qualitative assessment of the program rather than a quantifiable one:

> They feel generally, I think, safer. They do report they feel that their quality of life has improved in a sense—that there is more hope, less despair. So, quantitatively I haven't seen that yet. I'm talking purely about conversations with the client. (Christine, 05/23/97 p. 7)

It would appear from staff perspectives that the safety the Community Outreach program provides increases clients' hope, which lessens their despair and isolation.

Hopelessness and isolation are two factors that inhibit the clients' quality of life according to staff perspectives. Although only Sarah is quoted addressing the issue of hopelessness and isolation here, other client respondents commented on hopelessness throughout their interviews. Several COP participant quotes regarding hopelessness and isolation appear later in this chapter and are interwoven in participants' remarks that identify further barriers to recovery. That the COP program addresses the issue of hopelessness and isolation in its program philosophy and model appears to enhance quality of life and, possibly, recovery from an eating disorder, according to the staff comments.

Use of a paradoxical approach.

Previous hospital programs tended to focus treatment on the symptoms of eating disorders. This was to be modified with COP. The Eating Disorders Community Planning Working Group identified that traditional weight-based or nutritional-based programs, so dominant in the medical model of treatment, had not been effective (Eating Disorders Community Planning Working Group, Patient Focus Group, Minutes October 27th, 1995, pg. 4). Patient participants of the Working Group wanted a program which focused on them as whole persons, not just, as Michelle phrased, "a register of body values" (Researcher Fieldnotes, January 25th, 1997). Christine comments on the basic paradoxical approach adopted by COP, where the program stopped focusing on the symptoms of eating disorders, temporarily accepted rather than resisted these symptoms, and assisted directly with clients' quality of life issues:

> [We asked ourselves] should we be doing something that focuses more on quality of life and a lot less on nutritional issues? Would that be more helpful? ... Could we use more of a rehab model and think about just simply accepting that people are

> living with the illness for right now and that we can perhaps help them to take another look at life by looking at the quality of life issues. (Christine, 05/23/97 p. 5)

COP incorporated a paradoxical approach to treatment which insisted that an acceptance of the eating disorder symptoms must be the basis of treatment. COP employed principles of a harm reduction model to accomplish this. In harm reduction, abstinence is not required and instead the focus is on reducing the frequency of risky or harmful behaviours. This was encouraged and supported in COP and, thus, permitted the women to be treated without necessarily surrendering their eating disorder behaviours altogether. Although the women were required to keep themselves medically safe to stay in the program (by voluntary admission for nutritional stabilizing or by attending regular physician appointments), they were not removed from the program if they purged or restricted, as other programs demanded. Both clients and staff commented on the use of harm-reduction strategies and a paradoxical approach. Michelle remarks with enthusiasm about COP's requirements of her. Christine notes that a harm reduction strategy was effective in increasing clients' compliance with keeping themselves healthy and decreasing the time clients were absorbed in eating disorder behaviours:

> There isn't the requirement for weight gain. All they require is that you remain physically safe. (Michelle, 11/02/97 p. 23)
>
> There has to be safety and so the expectation is that people will keep themselves safe. And sometimes that means that you'd have to accept thinking about going and having your potassium infusion and magnesium infusion, or whatever, if your doctor has told you that you are unsafe at that time. So there is the expectation that there would be safety and most people say, "Yes, I would comply with that." We haven't had anybody say no. (Christine, 01/06/97 p. 42)
>
> They have actually minimized the [eating disorder] behaviour—they have pushed and pulled down the hours.... To cut it out completely would be impossible. You might as well live with the fact that that is what the client is doing and try and make it better. (Christine, 05/23/97 p. 20)

Compliance, increased enthusiasm and reduced risky behaviours are evidence of the effectiveness of this approach. The staff talked about their perspectives on accepting the client's eating disorder symptoms:

> The part that I've been using the most from her [theorist, Marsha Linehan's] model is acceptance, seeing acceptance as a point of departure—as the *only* point of departure for change. (Deborah, 05/13/97 p. 7)
>
> To work in this program you have to have—you can't be having an abstinence model. It won't work. I'm not going to say, "Well, okay, bingeing and purging is great." I'm not going to do that. But, at the same time, I'm going to support where [clients] are and give them some tools and strategies and things to help them cope and manage. (Christine, 05/23/97 p .19)
>
> In this group the difference I would see is that people aren't necessarily at the stage of going to become self-advocates because they may or may not want to give up their eating disorder. They may not be at that place. But they may self-advocate around their quality of life issues. So that's good. That's a beginning place anyway. (Christine, 01/06/97 p. 45)

Acceptance of the symptom had tremendous impact on change for clients. Michelle spoke of how this strategy resulted in an increased self-awareness and self-compassion; Natalie stated how looking outside her eating disorder was useful for examining her needs and desires; and Sarah remarks on how COP's focus away from weight issues allowed her to participate:

> Unfortunately, the [residential] program is kind of like a roller coaster, whereas the COP program, they just take you as you are and you do as you can. (Michelle, 11/02/97 p. 23)
>
> For me, the difference between the COP program and any of the other programs that I've been in [is] they seem to recognize [that] the bulimia comes with me. I can't leave it at home. (Michelle, 11/02/97 p. 28)
>
> That's something that I really learned in the COP program--is that this is a coping mechanism! It's not a big sin or an indulgence or anything else. It's like an addiction in a way. But it's [also] a coping mechanism that's allowing me to survive. ... I don't think it was until I was in the COP program that I was really able to see that, and see the proof in what my outreach worker said, "Well, we've got to get you out, you are so isolated. It's self-perpetuating. If it means going out, having a cup of coffee and something to eat—and getting rid of it—that's fine." The outreach worker said, "I don't care about that [i.e., purging], I'd rather have you do that than [isolate]..." That's when I began to get the message that, oh, this isn't

> just weakness and a character flaw on my part. There's a reason for it. (Michelle, 11/02/97 p. 25-26)
>
> That has definitely been a big focus out. That has been a lot that I have concentrated on anyway. It is what I do outside, away from my eating disorder, kind of things—socializing more. (Natalie, 18/26/96 p. 20)
>
> I don't think that the setting of a particular body fat [percentage] or the setting of a particular weight based on your size is particularly helpful. So I choose not to. If I am totally consumed by one thing than I can't do anything else. So the COP program allows you to do other things and also allows you to build your own program. (Sarah, 14/03/96 p. 13)

Clients reported that the acceptance of their eating disorder symptoms or behaviours was helpful. When nutritional and weight-based measures of change are not central to the program admission, involvement, or focus, the clients generated more interest in participating, increased their awareness and their understanding of their eating disorder, and generally became more involved in changing their quality of life. Using principles of harm reduction (i.e., tolerating the symptoms) allows the clients to make contact with the program and its workers and to look, paradoxically, at attending to other factors in their life (i.e., isolation and hopelessness) that contribute to their eating disorder behaviours.

Activation and a client-centred approach.

The third component of COP's philosophy of a paradoxical treatment approach was the use of activation strategies and a client-centred focus. One of the goals of COP was to "foster independent living and improve quality of life in the [client's] community; increase supportive human contact; [and assist the] client to become actively involved in her own care" (Geller, 1996, p. 3). This component of the COP philosophical paradigm used rehabilitative strategies of "activation" to assist clients in improving their quality of life by becoming more active in their community. Activation was the process of getting the client "active" in her life by encouraging the development of personal goals and having the team assist her in achieving them. Activation was realized in a number of ways, as reported in the Interim Outcome Assessment (Geller, 1996). For example, clients attended program appointments; met with their activation workers; one client moved from an unhealthy living situation to an independent apartment; some clients enrolled in courses or returned to school; some increased their contact and meal support by going to the residential facility for meals; and several pursued ongoing interests they had previously been unable to explore (Geller, 1996). The way in which activation would be accomplished was by having the client define the goals, and to then break these goals down into manageable tasks for the client. Staff addressed the topic of activation in their interviews. Their responses demonstrated that an activation approach was necessary for reconnecting the client with her community and life outside an eating disorder and reducing isolation. In the following quotes, Amber comments on the challenge of goal-setting, Deborah addresses the value of activation, and Christine remarks demonstrate the philosophy behind activation:

> What I've found in the program was when they've been given that freedom [to choose their goals], they're able to meet it. Because it's like they've got the reins a little bit more. (Amber, 20/01/97 p. 10)
>
> That's the biggest thing for people coming into the program—for clients and staff—is to break it down to these tiny, tiny, tiny little pieces and make a do-able task, then recognizing that those are realistic, not be overlooked (Amber, 20/01/97 p. 9)
>
> It's really an activation model—getting the person back into the work place, getting them back to the time when—before they lost everything! (Deborah 01/06/97 p. 12)
>
> [Some are] living with a sense that anorexia and bulimia control everything that they do. Being so binge/purge dominated that they had no time to do anything else. And so most people had to leave their jobs, or school, or whatever, and were living like that—maybe in an apartment alone, very socially isolated. (Christine, 01/06/97 p 14)

The clients' responses also indicated a need for an activation approach. Clients had lived so long with an eating disorder that they did know what to do without one. From the client comments, Michelle found herself lost when she was not consumed with bingeing and purging, Sarah was challenged to refocus herself to life without an eating disorder, and Natalie found her depleted quality of life an impetus to enter the program and make change for herself. By their remarks, it can be inferred that activation was helpful in having the women address and live a life without an eating disorder:

> [The dietician] is trying to support the idea that if I'm having 3 or 4 [Ensure, a liquid meal supplement] a day, I won't feel hungry. I'll feel full and that will reduce the desire to binge. And it does. But then I'm left with, "Well, I'm not hungry. [If] I don't have that drive to eat, what do I do? And I don't know what to do with myself. (Michelle, 11/02/97 p. 4)

> I'm just trying to refocus now. What am I doing? I want to have a life. I don't want to have an eating disorder. How can I refocus it so that I do what I want to do with my life—that doesn't have to do with my eating disorder? You can do that in the COP program where you can't do that when you're in the hospital. (Sarah, 13/03/97 p. 13)

> I just couldn't handle it anymore. It was really awful. My eating was just getting to me. My life seemed to be eating and purging (or bingeing and purging, I guess it was) and that was it. It just took all my energy to purge, and of course I couldn't do anything else. I was so miserable. So I finally said, "I've got to do something about this." (Natalie, 07/01/97 p. 16)

The principle of activation worked on changing the clients' focus and motivation to change their lives. Activation was a central component of the paradoxical approach. By having clients focus on developing and working toward changes other than weight goals, activation decreased their isolation and hopelessness and improved their quality of life.

The clients stated throughout the interviews the different types of goals they were working toward. Natalie described many of her goals and her comments exemplify the variety of goals clients could design in their program. Amber states how specific and narrow the goal of one of her clients was:

> I just sort of got steadily more involved over the year. I guess the move towards going to college is a major one for me. Yeah, just major! I am looking forward to it and it is finally—I am finally, I am going to do this. *[Participant laughs.]* It's

> been a goal that has been around for a long time. I think I've been saying it for ten years. (Natalie, 18/12/96 p. 22)
>
> I tend to bottle my anger inside me and tend to explode sometimes. I feel like some of it's inappropriate anger, anger that's just built up. I want to work on that. (Natalie, 29/04/97 p. 12)
>
> One thing I want to work on is to expand my circle of friends because most of my friends have eating disorders, except one. (Natalie, 29/04/97 p. 11)
>
> And there's been small goals along the way, like, I'm supposed to be practicing containment with her, at the moment, [of] that body image stuff. But I keep kind of putting that one off. We're trying containment strategies—mine is just basically, I don't want to think about it because it's like the body image stuff has been really big and getting in the way. (Natalie, 18/12/96 p. 14)
>
> Her goal that she first came into program [with] was just breaking the isolation a little bit. She actually was somebody who came into the program not wanting any kind of nutritional contact. I was the only person on the team who really had contact with her in an extensive period for several months. It was really about being in the community and getting her out for a coffee. (Amber, 01/29/97 p. 7-8)

Client goals, as noted by both Natalie and Amber's comments, were specific and various. Most importantly, the goals focused on the client's individual desires and needs and were constantly adjusted as the client's degree of skill and recovery changed.

The staff also stated that the role of the program was to assist someone who is "ready" for this type of work. Client "readiness" is important. As treatment in COP is invitational rather than enforced, access to treatment, as Christine states, must be open to clients when they are ready to accept treatment of the symptom and to focus on other quality of life issues the program addresses. However, the staff also note the program is not appropriate to everyone as the clients must have some demonstrable initiative:

> This is not *the* answer for everybody because they have to be in a place where they set some goals for themselves and have some level of commitment. Because this isn't a program that's going to hold your hand in a lot of ways—in a supportive way—so they've got to be at a certain "readiness" level. (Amber, 20/01/97 p. 27)
>
> You have to have a tolerance for the eating disorder symptoms, and provision of education for people, and access to treatment options. So the access to treatment is

> always an open thing—that people are ready [and] if they are ready they will take it. (Christine, 05/23/97 p. 18)

> We've got this huge waiting list and people hear about this [program] and hear "Oh, they're not going to force me to eat," "My own goals!" and, "I get to do what I want?" Well there's a flip side to that of course. It's that you've got to take responsibility. Nobody is going to tell you what the agenda is. (Amber 20/01/9 p. 19)

Natalie is the ideal candidate for the COP program as she was certainly ready to change her quality of life. She states how she was motivated to make change even prior to beginning the program. In fact, Natalie set her own goals and, in effect, enlisted the program to support her:

> I went and stayed with [my parents]. I thought I would stay with them until after Christmas. And I remember I really got into Christmas that year *(laughs)*. I decorated everywhere and did all different things, and really got into Christmas shopping, and all this. It just really seemed to spark something for me. Like I'd made it into a short-term goal, to give me something to look forward to. And then I made other goals after that. ... That's how we sort of turned it around [at Christmas]. I thought, "Okay, enough's enough!" I mean I knew I was fed up with the anorexic lifestyle. It has just been too long and too miserable. And, um, it kept on going pretty well after that. (Natalie, 07/01/97 p. 16)

> I finally decided I didn't want to do it [enter the regular hospital programs], I wanted to do it *on my own*, outside of any program. (Natalie, 18/12/96 p. 4)

Natalie's high degree of motivation and her determination to make change are qualities of 'readiness' the program valued. The staff felt strongly that the program was to be used by those who were highly motivated and 'ready' for change, although as Amber noticed hopelessness made any long-term goals difficult to achieve. Hopelessness was also a barrier to clients developing goals. However, client readiness becomes imperative to the client's and, therefore, the program's success. At some level it seems apparent that incongruency exists between the client's abilities and the program's acceptance of the eating disorder symptomology. The reality may be that the clients' abilities to be motivated and committed are hampered by the degree of hopelessness inherent to a longstanding, entrenched eating disorders. In fact, what Amber describes as "hand-holding" may be what is required for some clients.

Activation is a principle part of the COP philosophy and program. It is a strategy used by clients and staff alike to focus on issues aside from the client's eating disorder symptoms. It also promotes the reclaiming of the client's life before the eating disorder took hold, reduces client's isolation, and increases their connection and activity in their own community. Activation was achieved by developing goals with the client and breaking these into smaller, do-able pieces to encourage success. Finally, staff commented that activation was most effective when the client was highly motivated to make personal change.

A client-centred program was identified as important in the consultations done with patients and family in the Eating Disorders Working Group and from the research on treatment programs for those with serious mental illnesses (Niblock, 1995). A client-centred approach meant that the program would focus on each client's unique needs and goals. The goals were to be client-determined rather than program-determined. This meant that COP would vary greatly from the more rigid group-focused and program-structured goal setting of other programs. The client participants reported that this client-centred aspect of the COP program was something they responded well to:

> I think that's where the COP program really, really has its strength. They can fit themselves around *you*. You're not—well you do to some extent make the effort to fit into *their* program. You have to meet them, make goals. You make the appointments—they expect you to make the appointments—to do some work. But the work that you do isn't straining, and it's extremely flexible. (Michelle 11/02/97 p. 23)
>
> I wanted something that treated me as an individual. I don't want to be told that this is my diet, this is what you have to eat, you need to eat this at this meal, you need to cook this, and do this at this time, and go to this group, and you have to feel like this and—I want something that fits me. (Sarah, 14/03/97 p. 10)

> When I started the transition program [COP], I only wanted to see an intern [activation] worker once [a week] because I wanted someone to get me out of the house—because I wasn't doing anything. I was like, "I don't want food. I don't want help with my food." They were like "Okay." " I'm not going to talk to the dietician," I was like, "Forget it!" I'm like, "I'm not doing work with dieticians." (Sarah, 14/03/97 p. 11)

> I like the freedom. I like to be able to set the goals. That it's it my goals to start with. I like the set up about the team meetings and how often I see [the dietician]. Umm *(pause),* so that sense of freedom. That there's no mandate such as I have to gain [so much weight] *(pause).* [Although] I did go in with the goal of gaining weight. (Natalie, 18/12/96 p. 15)

In addition, clients and staff remarked on how the involvement of the client in her treatment planning and treatment decisions was novel and effective. Both Natalie and Amber provide an example of this:

> I think it's more been me getting back my voice. Going from that, oh I don't know if I can say it, but that sick "victim" kind of thing—"You're just kind of a coward" —to that sort of feeling the right that I—well I *do* have the right to say something. That it *is* my treatment. I do want to take an active role in the treatment. Which is very different from the way it was [in other programs]. (Natalie 18/12/96 p.19)

> The whole program is such a different way of being in program. That whole different shift of giving them responsibility: "How do you want to use us?" "We're here for you, how do you want to use us—within these guidelines?" Really that's such a shift. It forces the client to meet you at that shift! Here we're saying, "You know, you tell us!" So, for a while, in program, or even in families where they've never had a voice, it's really difficult for a lot of them. That, in itself, is probably the biggest shift in the program. (Amber 20/01/97 p. 26)

This client-centred approach was particularly effective in dealing with clients' needs for hospitalizations to maintain their medical and nutritional health. Whereas previous hospitalizations may have been forced committals to hospital, the COP program found that clients were more proactive and compliant with hospitalizations when they were included in the decision-making process:

> And one of the neat things was with the use of [the ethical decision-making model] –when we used it with the individual and her family present—was the individual's identification of decision-makers and personal limitations. And she actually said that when she gets to this point, then she wants us to take over—when it is okay for

> us to take over. And so kind of being proactive around what we can foresee happening, what she can foresee happening. So she was in a good space, at that point, making decisions for when she is not in a good space. (Christine, 05/23/97 p 24)

> The difference with these admissions is that, generally, they are engineered by the patient and the team. And the patient usually asks for the admission. (Christine, 01/06/97 p. 27)

> We are just seeing generally more—a stronger—willingness to comply with those kinds of requests [for hospitalization]. In the past I think we would have had to use more aggressive measures. Many people have required hospitalization—they have, brief however they might be. But they're hospitalizations never the less. And [people] have been generally much more approachable and it doesn't mean that everyone is happy with it, but much more approachable. And more willing to take part in that process and to make decisions. (Christine, 01/06/97 p. 44)

> There's been committals. But nobody to date has been either restrained chemically or physically. (Amber, 20/01/9 p. 15)

> We haven't had to certify too many people—although it has happened occasionally. For the most part we have been able to contract this hospitalization and kind of work it through using an empowering approach. The clients have generally felt better about it. (Christine, 05/23/97 p. 21)

Having a client-centred approach to goals and treatment is pre-emptive. As it includes the client proactively in emergency hospitalization and planning, the program does not have to be aggressive. The program creates an opportunity for the woman to make the decision for herself.

Despite the philosophy and intention of producing a client-centred program, however, there does appear to be some incongruity with this approach. For example, Christine begins to say it is a client-centred program then restates that it is a "patient/staff driven program." The issue of motivation or readiness is also re-addressed. Christine remarks that the program can work only with those who are motivated toward change, while at the same time acknowledging how difficult it is for this specific population to be motivated:

> What it has been about is they own the program, they have been doing the program, the patients are in the program and I mean it is a real, I think, a patient/staff driven program. It is. And they—it's a community program in the best sense. (Christine, 01/06/97 p. 48)

> The individual has to want to do something. I mean if they don't want us to be there, we aren't going to be of help. I think, well, it is pretty hard to be motivated when you are—when you have this illness. So, what does motivation mean? It becomes really problematic for me. (Christine, 01/06/97 p. 43)
>
> If they are not interested in anything, there is no point in somebody being in a program. (Christine, 1/06/97 p. 47)
>
> I think that's one of the more important issues that we'll have to deal with because initially we were thinking that everyone would fit into this model, but that hasn't really been the case. (Deborah, 5/13/97 p. 16)

At one level these remarks seem to assume that a woman who struggles with an eating disorder is able to articulate her needs and make those into goals. The program does not remain client-centred at this point, but is rather program-centred, in that they need to work only with those who can demonstrate they are motivated and willing to make change.

From the client responses, it is clear that motivation and readiness are problems the clients struggle with. Natalie states the program's insistence on goals is helpful in that it makes her make a decision, however, being able to ask for help prior to COP had been difficult. Sarah talks about how difficult it is to articulate her needs and translate these into goals. Where motivation, readiness, and client-determined goals prove to be particularly problematic is when clients are required to set goals around weight. Clients found this part of the program difficult to do. Natalie, Sarah and Michelle comment on their fear and resistance to weight gain, and Michelle, in particular, makes self-degrading comments. These responses outline how difficult goals—particularly weight goals—can be for these clients:

> [What's helpful is] actually getting forced to have to make a decision somehow. Because it had always been like that before. I wouldn't take the responsibility or I wouldn't go ask for help, you know? (Natalie, 07/01/97 p. 30)
>
> We just go out for coffee. But now, they are trying to get me setting goals. So they want me to set three-month goals and that's—I'm going to have trouble with that. And I have to talk to them about that. We've stopped for a month because I've been a little upset with that. (Sarah, 14/03/97 p. 14)

> When they say the goals, I'm trying to figure out, "Now what goals do I want to have—do I have any goals?" And "Can they help me with my goals?" Like they can't do my school for me. Or get a job. I can't get them to help me get a job. You know I can't have them cure my eating disorder. How much do I want them to help me with my eating, like do I want to go out with [my activation worker] and eat dinner every night? And do I want to go to a movie with her? (Sarah, 14/03/97 p. 20)

> Suddenly with [the new program coordinator] coming in, it seems to be that this [goal setting] suddenly becomes a big issue. It never... *(sentence is muffled on tape)* [was before]. I don't know if it has to do with [her] in particular, or if it is because they've now set new goals or they've rearranged the COP program. (Sarah, 14/03/97 p. 14)

> I guess it's not that clear cut when I come to my goals. At the beginning I was like, "Oh yeah, I'm gonna do this, this, and this!" Now I'm kind of like "Yeah yeah, I'll do whatever is going on." I'm really a bit waffle-y at the moment in that department because I don't really have any goals set. So the last couple of team meetings have been—the whole meeting has been—around my weight gain versus maintaining. (Only I'm losing [weight]). We've been talking a lot around that and my having to make decisions around that. And that was another thing that I kept kind of putting off too—making the decision about that. I just hate goals, and especially with that kind of thing around eating. (Natalie, 18/12/97 p. 16-17)

> My weight is just increasing slowly and steadily, and I want to be at least a steady weight. I'm just not dealing with it so well; some of it's the anorexia. But some of it's wanting to slow it down somewhat—basically maintain—so I have a chance to get used to how I am now. (Michelle, 11/02/97 p. 6)

> Setting specific goals, I don't know if it is so helpful and I'm not sure what I am going to do. Like what kind of goals do they want to set? Do they mean weight goals and am I willing to maintain my weight at a certain level—and I am, as long as I choose the level. (Sarah, 24/03/97 p. 24)

> I just feel like I'm back to being the PIG I was before I was able to lose weight. I can't even control myself. And I'm going to be the only person with an eating disorder that's going to have to go on a diet. I can just imagine the sniggers and the laughter. I mean this is my life re-visited again. Shit! (Michelle, 25/02/97 p.5)

A client-centred approach is deemed important to the client's success in the program. Clients report that they responded well to the program's individualized focus and its emphasis on the client's determination of goals. Staff and clients remark on how the client's involvement in treatment planning, especially with regard to hospitalizations, has resulted in reducing the number of hospitalizations and the number of forced committals. There seems to be some difficulty or incongruency with whether the program is solely client-centred or if it is staff-driven as well. Where this becomes an issue is with assessing the client's readiness and motivation by her ability to articulate her needs into goals—particularly goals around weight.

Both activation and a client-centred approach to treatment are significant components of the program. From this philosophy, activation and a client-centred focus assist the client in reconnection to her life's activities before the eating disorder, and to her community outside of the hospital. The development of personal goals is supported by the team and broken down into smaller, manageable, components so as to encourage success at meeting these goals—contrary to experiences of failure in previous programs.

Activation and client-centredness are one component of the paradoxical treatment approach the COP program attempted to create. Other components include reducing hopelessness and isolation, applying principles of harm reduction to encourage the acceptance of eating disorder symptoms, and assessing client-readiness. By paradoxically focusing on aspects of the client's identity and abilities aside from her eating disorder, the client's eating disorder symptoms are addressed. Improvement to the client's quality of life becomes the base from which change occurs with the eating disorder. The next section discusses the third part of the program philosophy—length of treatment—that seems to impact the success of the client in her recovery and the program's success in providing treatment.

Length of treatment.

The length of treatment of the COP program was identified as being problematic to both clients and staff alike. In implementing a client-centred approach to treatment, one would assume that the length of treatment would be decided by what the client determines she needs or requires. Given the fiscal restraints to health services, however, time restrictions for treatment of the COP program were required and were implemented as interviews with participants were being conducted. Both client and staff responses comment on how disruptive the new time limitations were and how they impacted the client' and staff functioning.

As this particular sub-group of patients in the COP pilot program had continuously cycled in and out of existing programs, an open-ended treatment program may have been feasible and fiscally-responsible given the inherent costs in their ongoing, lengthy, and repeated treatment admissions. The original proposal for funding noted that the COP "model of service delivery is much less costly than traditional residential or long-stay hospital programs and allows services to be delivered to a greater number of individuals over a longer period of time" (Niblock, 1995, p. 1). No set length of treatment time was specified in the original program, as outcomes from the six-week pilot project were awaited. Upon the conclusion of the pilot project, the proposal for expanded development of COP was designed, critiqued, redefined and eventually approved (an eight-month long process), and interim funding was continued. Neither pilot program participants nor staff and administrators knew how long the program would or should run, as there was no previous template for COP, therefore, no model for length of treatment. As the interviews were conducted with participants, a time limit was newly established for the program. Newcomers to the program received handouts stating clearly that program time was limited:

> The COP offers support for up to one year. Three-month extensions can be requested if you have a specific goal with which you wish to receive further assistance. A maximum of two extensions can be requested. (Handout for COP Participants, Autumn 1996)

Participants interviewed for this research had been pilot program participants and, therefore, were now being considered for discharge from the program because their anniversary entry dates were drawing near. This caused much concern. The program was pressured by the funder to be cost-effective and to meet the ever-increasing demand for services identified by wait-lists. Simultaneously, staff recognized the precariousness of the relationships that had been established between the clients and the program. They also recognized that important changes, subtle yet significant, had taken place with clients. Much of what staff had noticed with client change was not measurable by scales and inventories, nor reduced hospitalzations, nor other costs that the funder examined as outcome measures. For example, looking at significant symptom changes (i.e., with regard to food and eating) was not a valid measure of client success. What staff noticed were significant internal and interpersonal change. All staff commented on these:

> The third client I worked with suggested that we just meet for a coffee one day. [I] didn't realize that she basically hadn't eaten without the significant other in her life for years! So, again having to remind myself, "Wow, what are you asking this client to do?" Just realizing her going out and having a coffee or tea with [me] is like this huge, huge deal! (Amber, 20/01/97 p. 10)
>
> From an outside perspective you might look at that person and they haven't done anything with their eating, you know, in the six-month period that it took them to do all that. (Deborah, 13/05/97 p. 13)
>
> So something is happening inside of them. That's really neat to see. God only knows what is going to happen with the eating disorder, but in terms of quality of life—big improvement! (Christine, 01/06/97 p. 44)
>
> ... [My] having to really acknowledge the tiny, little things. That's the population [we're working with]. You're not going to see leaps and bounds—either nutritionally or psychologically. So to see the little tiny steps, both for myself and being able to share that experience with a client, and my experience of their changes.... (Amber, 20/01/97 p. 7)
>
> There is such variety from week to week. One time school is a real positive thing and the next week it might not be. But having—my role, again, bringing [the] focus back to them, "[This] is what I can see." In the moment it can be really difficult to see the gains and to step back and say, "Well, I hear what you're saying and in the present it is really hard, but I just want to share what it has been like for me having worked with you over this period, and what I see. This is a huge thing." Whether that be in connecting with the community or whether that be nutritional

> [things]. "You said you had your latte with two percent milk instead of skimmed milk, hold on—when's the last time you did that?" (Amber, 20/01/97 p. 8-9)
>
> It's easy to minimize—"Oh, you saw her for coffee?" "You went to a movie?" "Oh, gee, I wish I had that job!" For myself as well, it's easy to minimize it. It's beneficial to have conversations like this [i.e., the interview]. (Amber, 20/01/97 p.22)

Clients also identified in their responses the significant changes they made in the program:

> Last week [I did] something that I've never been able to do. We stopped early for a coffee and muffin at the bakery. We talked for quite while and we ended up talking about going down to another place that makes their own soups. She said, "Well show me this place 'cause you've mentioned it a couple of times." So I walked down with her and ended up having a bowl of soup...I've never been able to do that with an outreach worker. (Michelle, 25/02/97 p. 10)
>
> I find my dietician now is really good because I can tell her that "Well, I can try that but I don't know if I can do that". And she is not going to say "Well, okay, you have to have three proteins and two fats and you eat this at every meal and this is what you *have to have.*" It can be like, "Well, what would you like? What things do you like?" And, well, yeah, maybe it's an egg white. Well, okay—well it's better than nothing. Okay, I'll have an egg at dinner, you know. She does things quite well, so I find working with her quite good. That's just her style. We work quite well. (Sarah, 14/03/97 p. 11)

Staff responses also indicated the debate about length of treatment. Was length of treatment to be based on the client's need or on the funder's need? Was the program to treat chronic anorexia similarly to other chronic mental health populations that require and receive on-going, life-long assistance, and/or support? The staff gave a variety of responses to this issue that reflects their ambivalence about length of treatment. Christine struggles with whether or not COP's mandate is to provide specialized treatment for a chronically ill population or to have them connected with the community (and out of the program) as soon as possible:

> I have always been interested in the population with chronic illness. For me it really means an unrelenting form of illness that could possibly go on for the rest of someone's life. (Christine, 01/06/97 p. 12)
>
> We have a population who now we know the characteristics of. Who require intervention very early on with community. And that's the way it is. And they

> may not be able to leave in a year. May be [it's] two years, may be three years.... (Christine, 05/23/97 p. 5)
>
> We are going to be looking at issues around "recovery" versus "living with" anorexia nervosa. There will always be a philosophical debate that I think will always go on. We are going to be looking at prolonging discharge dates for some people and looking at some long term care, as well as how we need to get them connected with the community early on in a little different way. (Christine, 05/23/97 p. 25)
>
> If you are looking at [other] chronically, mentally ill populations, some of those patients will have a care worker for the rest of their lives. The same one or a couple of different ones. But they are maintained by that care team for years and years and years and years. They are followed by that care team. And those people become their—you know—they kind of become their constant support and companion. (Christine, 05/23/97 p. 2)
>
> We decided that we are not a palliation program—we are not—because we actually do believe that anybody can recover from an eating disorder, no matter how horrible, how long whatever. We still will hold out hope for them. (Christine, 01/06/97 p. 17)
>
> We are not willing to let somebody die! (Christine, 05/23/97 p. 4)

Christine sees long-term eating disorders as similar to other long-term mental health issues. She suggests that the issue must be one of on-going and possibly life-long support. She acknowledges that "recovery" for some clients may not be feasible and strongly asserts that recovery is a hope and that the program must maintain for all clients.

Deborah found it challenging to determine when is appropriate to terminate treatment. This is particularly troublesome when the program appears to have conflicting interests in ethically meeting the needs of the clients versus meeting the needs of the funder:

> Two of the women I'm seeing right now are in acute crisis. And so as a program, even though I'm in the process of terminating with them, nobody feels comfortable having them finish now. So we're just trying to balance the needs of pushing people through the program and getting them hooked up in the community, with being compassionate and not doing them a disservice by cutting out at a time that they actually need us the most. (Deborah, 05/13/97 p. 6)

> In just some very basic financial management issues that she couldn't touch sixteen months ago. Like that's how long it took to get her there. And now she's there and she's got space to start filling her life with other things and we're having to say *[interviewee waves goodbye]* and it hurts and it's really hard to do. (Deborah, 05/13/97 p. 16)
>
> I mean that's my biggest grief about the program, and it's no fault of anybody's—it's funding and the wait list issues and so on. But I think we could do fabulous work with almost everybody in the program if we could have five years. If I had my wish list and we had unending funding and didn't have wait list issues, or resource issues, it would be that the program would serve five years. (Deborah, 05/13/97 p. 16)
>
> One of the feedbacks that we got at the presentation on the program in London [at an international eating disorders conference] is that thinking that we're going to be able to really make meaningful change in a year is not realistic. And we didn't know that. And this international community was so clear about that, "What! These are people who have struggled with an eating disorder for 20 years and you're going to give the a one year dose of treatment and send them off?" You know a lot of people had things to say about that, and said—thought that the model was wonderful, [but] the time frame was small, was very short. (Deborah, 13/05/97 p. 6)

Amber's responses seem to contradict the function and purpose of the program to meet the client's need and to "increase supportive human contact:"

> We have [had] a tendency in the past to take on all the clients and get caught in the day-to-day, just providing services to them. And [we] forget the step of "*You* [the client] should really be stepping out there." I think that is something that more recently we have paid more attention to. Constantly reminding ourselves, "Okay, our job is not to take care of them." (Amber, 20/01/97 p. 13)

The responses of staff seem to run contrary to the knowledge they have of their clients' needs, i.e., that treatment may require a life-long provision of services, that one year of treatment is unrealistic for some clients and that other clients may require constant support and attention throughout their lives. The incongruency between the program's philosophy, the clients' needs, and the program's provision of service may stem from a conflict between the specific individual needs of this particular client group and the fiscal needs of the program:

> It's that abandonment kind of stuff that comes up for people. A lot of our population has been abused, so abandonment is a very major issue there. And I think we just have to do it more smartly and we have to be more sensitive to the fact that they require—some women—require either longer-term care. And I do think that's another possibility. We're going to be looking at some clients who may even need two or three years in a program. (Christine, 05/23/97 p. 2)

> The goal is that Deborah will be handing over this client to the community, so in her work with the client she is getting the client ready to take on a community therapist. That's a hope. Because we don't want to be the therapist for this client we want this client to be totally connected back to the community in a year or a year and a half. (Christine, 01/06/97 p. 22)

> One patient who is to be discharged, her date has been shifted so she doesn't really have a date right now. We've told her that we need to do transitioning and that the relationship [with COP] is contingent on her allowing the community therapist to come into the program. And that's okay. It may sound coercive, but that's okay. In some ways you have to force the issue of spreading your wings. (Christine, 05/23/97 p. 5)

There is a disparity between COP being a client-centred program and flexible in meeting the clients' needs and the need of the program funder. Despite knowing that their clients require more time in the program, they have not been able to create the one essential factor to enhancing recovery—adequate time in the program. Clients, particularly Michelle, noted their difficulty in adjusting to the time restriction and found length of treatment to be one of the factors perceived as inhibiting recovery:

> Now they can only give you so much time so that they can get more people moving through the program. My impression was that one of the goals in this program when it first started was that it should be open-ended for people, like me, who seem to fall through the cracks and have no practical support. All of a sudden, they've put a limit on it: some people get short-limits; others get longer limits. To me that's not the point. You've got tons of other programs that have limits on them. They need a program that is open-ended, because there are some people like me who just keep struggling and struggling and not getting anywhere [in the other programs]. (Michelle, 25/02/97 p. 13)

> I can see where they need to move you to an outside dietician, or make sure that you are very well connected with a good family. But keeping an outreach program going indefinitely maybe, for some people, is what it' s going to take. (Michelle, 11/02/97 p. 29)

> I was just getting to the point where I was beginning to feel like—ah, I'm settling in now. I'm ready to get on with things. And ready to take some steps. And then, WHOA! You know I'm being told that my time is limited. Of course all those issues [I was working on] just go right out the window. And [now] we're focusing on kind of preparing for wrapping up. (Michelle, 11/02/97 p. 29)

> Five months seems like—on the one hand it seems like a lot—but when you're trying to deal with all the bureaucracy, [finding a] new house, and setting up support, and that sort of thing, five months goes by in no time at all. (Michelle, 11/02/97 p. 7)

> Within the COP Program they've kind of come to a point where they're saying that "We're now going to look at the time frame," or, "We now have a time frame for people going through the program." We've just started talking about that and I'm finding it's really knocked me sideways because I didn't realize how dependent I'd become on the program. Not just dependent, but how much I need the program for practical issues, to help me with the isolation, just someone to talk to. (Michelle, 11/02/97 p. 3)

Given her discontent with the time limit of the existing program, Michelle was asked what an ideal program would encompass. She responded:

> I think a program that doesn't have limits as far as the people it serves—particularly those who aren't suited to other programs. Or if they've tried other programs and they haven't worked. People who financially can't handle or can't find therapists yet are still interested in working on the problem. Lots of support around meals if that's what you're looking for. Or just doing small things, like with me it's a muffin and a cup of coffee. *(Pause)* And lots of time for talking. (Michelle, 25/02/97 p. 15-16)

Natalie talked about how time limits to the program affected her thoughts about the legitimacy of her own needs. She seems to rationalize why she *should* leave the program, thus reassuring herself that she no longer requires it:

> ...It's more of having that—"I'm going to have to leave soon." There is a time limit of some sort. *(pauses)* I guess I'll always have that guilt too that I am in the program, 'cause I guess I am doing better than some people in the program and it's like, "Well maybe I don't need this program." There's people, other people, that need this more than I do. This is a feeling I have had every time I have been in a program. And I think everyone else has too. I think it is pretty common. Someone always needs it more than you do. (Natalie, 18/12/96 p. 23)

Clients did not respond well to their upcoming discharges from the program. From the staff responses, it appears that the program was pressured to adapt to the limited fiscal resources. Therefore, the program was required to shape the program to fit the funder's requirements rather than the clients' needs. The staff commented:

> I think we were unrealistic about the one-year mark. I don't seem to think we ever believed it would be one year, to be quite honest with you, because when we first started we talked about eighteen months. And we said "Well, we'll do it one year," and I think we set that up, if you want to know the truth, more about funder saying "Three years? Four years? How are you ever going to see people?" But if you were going to have one year—and there are lots of people who will work through the program in a year, lot's of them—then we know that we want to start right away with getting them connected in [the community]. (Christine, 23/05/97 p. 3)
>
> One of the ideas that's being batted around that people are quite interested in is that people would leave, but then they would come back for shorter term bursts of therapy. So that we would have a higher case load than we have and a greater number of people at any one time, but we would be seeing them less intensively over a longer period of time. So we're looking at that moving to that kind of a model. (Deborah, 05/13/97 p. 6)
>
> And it is also hard for the program—programmatically—because the demands they [the funder] want to see. Because those aren't the things that always translate into black and white. (Amber, 20/01/97 p. 9)
>
> Estelle and Deborah were sitting down to look at [rate of hospitalizations]—and quite nervously. *Have* the hospitalizations decreased? Because [that is] what the program is about. That's pretty hard stuff for these clients to do. We have seen some clients actually increase hospitalizations. They are doing hard work and challenging hard stuff. So they are starting to get more quality of life, but that's scary. That's scary. That's something—as [a] program—we are looking at with a very conscious knowledge, that our funding comes [with] this pressure of decreasing hospitalization. (Amber, 20/01/97 p. 23)

It seems as though the program staff try to make the best out of a bad situation by accommodating the funder's requirements to push more people through the program. This requirement takes priority despite the staff's knowledge and increasing awareness that this is not helpful to recovery for many clients. The pressure from the funder is noticed by clients as well as revealed in Natalie's and Michele's remarks:

> It's a good program, apart from the team meetings. I only go once every three weeks. I was going every week, and then I'm like, "I can't do this! I don't like this!" I guess it's just—it's bureaucratical and—I don't know what it is. It just *(pause)* I hate them, I just hate them. They're just too program-y. It's also a time when they record how many times you see each person and that kind of stuff. I guess they need to do that for their funding right? (Natalie, 18/102/96 p. 11-12)

> I believe it [the program] definitely needs a lot of attention when it comes to funding. Funding kind of pulls one way instead of this way—serving all the people at a broader level instead of serving all those who need more intense [support]. It's frustrating. All the changes they've made—they've made a lot of changes since I first started the program—and it has steadily gotten worse and worse and worse and worse. Every change they make it ultimately ends up in less time for the person who needs the help. They're losing out! (Michelle, 25/02/97 p. 12)

Clients overtly or covertly stated their awareness of the funder's need to reduce the wait list and decrease costs. The funder's needs, however, were often in contrast to the client's need for maintained contact with and support from the program on a longer-termed basis.

Length of treatment was significant to client's success in COP. Both clients and staff commented repeatedly on the problem of time restrictions for treatment and identified the impact on clients' emotional and physical well-being. It addition, the needs of the funder seem to directly contradict with the program's philosophy of treating clients according to their unique and individual needs. While termination is congruent with the program philosophy and mandate requiring moving clients out of the program and into the community as soon as possible, it does not attend to the needs of the clients, according to the client responses. The staff responses also addressed ethical and moral concerns regarding ending treatment prior to the client's readiness for termination. Finally, as these particular clients had repeatedly cycled through several eating disorder programs prior to COP, insinuating that termination is required for fiscal reasons is short-sighted—and at the expense of the clients' possibilities for recovery.

In this section, the qualities of the COP program—specifically its philosophy and approach to treatment—have been described. The research participants' responses indicate that the program setting, the use of a paradoxical treatment approach and the length of treatment greatly influenced the clients' and staff's perceptions of client success in the program. The program model, the second part of qualities of the program—will now be discussed.

Program Model

The program model can be understood as the way in which the program's philosophies are executed into action. Two important features of the COP program model were its flexibility in delivering highly individualized services to the client and the availability of the program and staff. A third feature of the program model was the types of skills and strategies employed in carrying out the program's philosophy to the clients. Clients and staff identified that flexibility and availability of the program and the skills and strategies used in the model were beneficial to improving quality of life or enhancing recovery. All the research participants commented on these qualities of the program model.

COP differed from previous eating disorder programs in its flexibility and availability. It provided an individual format rather than a group format, operated outside the hospital, and outside of regular hospital hours. It attempted to be available to clients in ways previous programs had not, i.e., being available several times a week for the client rather than a once-a-week appointment, providing outreach in the evenings, and having outreach services comprise of any variety of events the client required (going for coffee, movies, studying, meal support). COP prided itself in being open to the variety of situations and goals the clients would bring to the program. The programs four activities—activation, nutritional counselling, medical supervisions, and psychotherapy—could be interchanged according to the emotional and physical status of the client. When flexibility and availability were attuned to the needs of the client, it was found to improve quality of life. When unattuned or absent, the clients were quick to express anger with the program.

Flexibility.

A review of the program's documents addressed the issue of flexibility. The program proposal and the program handouts to prospective clients noted the program's awareness of the need for flexibility. Here are some of the policies the program planned to implement according to the program documents:

> Care plans will be highly flexible and based on the needs and goals of the client at any given time. Care levels will vary between clients according to their needs. (COP Proposal, Niblock, 1995, p. 2)
>
> This care plan will be highly flexible, its structure dictated by the particular needs and goals of the specific client at any given time. (COP Proposal, Niblock, 1995, p. 10)
>
> COP is a flexible program and goals are adaptable to change and revisions. Goals can change and so can we! Our goal is your success. ("What You Need to Know About the Community Outreach Program," COP Participant Agreement to Participate, p. 1)

In their responses and speaking from their experiences with their clients, the staff highlighted the need to be flexible and to change program protocols as required:

> Some of them have not been interested in the activation work, but they have been interested in the therapy piece. And we've been really struggling with what do we do with that small subgroup of people who, in some ways, just don't seem ready to do the activation work but they're very engaged in wanting to do the therapy. And that's an issue that we're trying to resolve still. (Deborah, 13/05/97 p. 6)
>
> We are going to have to run this program probably—oh, I'd say three or four years before we really know anything. Because we are changing all the time and we are evolving as our client's tell us about what is satisfying, what isn't satisfying, what is working and what isn't working. We are shifting. And we are hoping that the program is really like that. (Christine, 06/01/97 p. 7)
>
> Do we need to think of the program as having different prongs, or something, where the majority will go into the full-blown program where they have contact

> with lots of people, or those who go for something else? (Deborah, 05/143/97 p. 15)

Given that the COP was an innovative program, without a model to base itself on, the program was required to be flexible as it developed in conjunction with the increased awareness of the clients' needs.

Clients also spoke of the value of program flexibility. Previous programs had rigid mandates and exclusionary policies. Michelle supports Deborah's statement. Michelle found the rigidity of previous program mandates, protocols, and restrictions to be of little benefit, especially when the needs of the client are not kept central:

> It just makes sense to me that instead of dividing everybody into these separate channels. You're in this program; you're in this program. The person that's in that program can't take advantage of things that are going in this program—they keep them so separate. To me it seems so artificial. It's a one-off thing! It's all in one place! After all, the goal is kind of the same! I think there should be a little bit more flexibility in what you're able to partake in. (Michelle, 25/02/97 p. 26)

Michelle's previous experiences of being moved from program to program with differing protocols and restrictions resulted in an opinion that programs needed to be more flexible to meet the needs of a variety of clients. She felt it necessary to be able to move between programs and to utilize the various components that worked for each individual client.

Clients remarked on how the flexibility and changeability enhanced their experience in the program. When the program can interchange its components, the clients find the flexibility useful and encouraging. Michelle likes the fact that she can use the dietician and the therapist when she feels best able to work with each. She also wants the time with her outreach worker to be modified so she can see her more often rather than for a longer period of time. Natalie is doing well in meeting other goals (school, socializing) although a weight goal was not being met. The program continues to work with her (rather than discharging her) and adjusts goals in order to be supportive of her:

> Being flexible around the therapist and dietician timing. You go through a period where you just are not into doing therapy and kind of tired. But you still need the connection to keep you going and to keep you from being isolated. To help keep you out of depression...kind of help you to keep things on an even keel and in contact with the program—but allow you to step back and take your breaks when you need to do that. (Michelle, 25/02/97 p. 16)

> We meet sometimes an hour, hour and a half, sometimes two. Sometimes it's almost too much. It'd be better to meet instead of 2 hours on one day, to meet an hour on two days. [A program that is] flexible in duration but definitely more frequency. (Michelle, 25/02/97 p. 20)

> My goals are adjusted around the weight gain. It's like right now I just don't feel like I can deal with gaining weight so I'm sort of maintaining where I am. Well supposedly—I mean [the team] did sort of question that one and challenge me around that one a lot. (Natalie, 18/12/96 p. 16)

The team is also flexible around the individual needs of each client and attempts to adjust themselves accordingly. The program does not become locked into a "cookie-cutter" approach but, instead, acknowledges individual differences. For example, whereas Sarah wanted nothing to do with the dietician upon entering the program, Michelle regards her time with the dietician as one of the advantages of the program:

> [When I started the program] I was like, I don't want food. I don't want help with my food. They were like, "Okay." "I'm not going to talk to the dietician, "I was like, "Forget it!" I was like I'm not doing work with dieticians. (Sarah, 14/03/97 p. 10-11)

> That's one thing that is really good is that you get a proper amount of time with the dietician. Versus being in some of the other programs [where] there's no real talk about issues about food, any questions you might have about nutrition. [They] don't have time to talk about, to have that back and forth between you and the dietician. (Michelle, 11/02/97 p. 3)

Thus flexibility of the program is an important factor in the clients' perceptions of what benefits recovery. Where the program fits their individual needs, clients remain engaged with the program and their goals. When flexibility lessens, clients become discouraged and angered.

Availability.

Availability is also an important aspect to participants and the availability of the outreach worker, in particular, was significant. When and how often the worker was available had a powerful affect on the clients. Natalie's relationship with her outreach worker was positive, as the outreach worker was flexible and could accommodate Natalie's needs:

> Once I went into the program, I was still having a difficult time at night. I tend to really hibernate and just close myself away at night. They [evenings] were more of a problem. I found that I was really obsessed with food. Not obsessed—but my focus was very much on food. I was really fortunate that [my outreach worker] could meet me in the evenings, so that really got me socializing at night (Natalie, 07/01/97 p. 29)
>
> I've suggested that [Trisha] carry on seeing me once a week, because I'm going to college and because things are changing. (Natalie, 07/01/97 p. 3)

Natalie also speaks to the importance of the program's availability in exceptional circumstances. The COP staff made themselves available to provide support to clients after the suicide of one of the pilot program participants:

> I think that if the Clinic hadn't made themselves available, I think there might have been more disastrous sort of occurrences. ... I see the program as being really beneficial for so many people that it would be more disastrous if they had decided, "Well you know this isn't going to work" [and ended the program]. (Natalie, 07/01/97 p. 23-24)

Christine also recounts an incident regarding the importance of availability in exceptional circumstances. The fact that the client's outreach worker, someone she had an established relationship with, was available on Christmas Eve resulted in a favourable, and possibly life-saving, outcome:

> On Christmas Eve, everybody mobilized. And the activation worker—(and I thought that this is where it really worked well)—was also on pager. She called the client in the hospital and they had a conversation. She talked [the client] into staying. They worked out an agreement. Everything was fine. *(Pause)* I mean she wasn't happy to be in the hospital at Christmas, but she was glad she stayed. And as it worked out, she was very, very ill. But I think it was the relationship with the activation worker that maybe made a difference in this case. In talking with the

> patient I got a sense that that had been important to her. ... She had a lot of trust with this person and this client feels very good about her and their relationship. ... I have known this woman for many years and I think she just felt safe and that it was okay. With this particular individual in the past this would have been a rage situation and she would have just left against medical advice, the police probably would have had to go to her house and pick her up because she was at that high risk. (Christine, 06/01/97 p. 28-29)

Having an outreach worker, someone with whom the client had established a significant relationship, available at a time of crisis was a significant change for this client. To have such a person available during Christmas Eve, a time when staff are not traditionally available was important to achieving an more positive outcome in this situation.

Sarah and Michelle had different experiences than the one Christine relates. In their interviews, they outlined the importance of availability. When their outreach workers were unavailable, Sarah and Michelle were disappointed, frustrated, and angry. Each of the women recounts their feelings and the impact of staff unavailability—Sarah with her activation worker moving; Michelle with the lack of time available to work with her worker. Sarah' s outreach worker had once lived closer to both Sarah and the program at the beginning of their relationship. But since her outreach worker moved, Sarah had found it difficult to maintain contact with her. For Sarah, her outreach worker's lack of availability also came at a time of great transition. As Sarah states three different times throughout the one hour interview, she had no control over the fact that her activation worker moved but it caused her hardship nonetheless. Sarah seems to use the busy-ness of her life to rationalize why she doesn't bother to get a new activation worker. It's as if Sarah rejects her outreach worker rather than feeling rejected because of a situation she is helpless to control:

> I had the problem that my [outreach worker] is restricted with movement so that I have to go see her rather than her come here. She was closer before she got married. She used to be right beside the hospital and now she is in [a suburb] and I can't change that. I can't change the fact that she works part-time elsewhere so I can't even see her on certain days. (Sarah, 14/03/97 p. 24)

> My outreach worker also works in another place so she has limited capacity as well. I would have to see someone else as well if I want more time...and I don't think I want to. I have a good relationship with [my outreach worker]; I like her. (Sarah, 14/03/97 p. 15)
>
> My outreach worker got married and moved [across the city] and I find that really hard. Because meeting her now is like a problem. It's been a problem. I don't feel like I can meet her. I have a problem going downtown, because I don't like being in the middle of nowhere and I don't like rush hour (and she doesn't really like rush hour either). And she doesn't want to have to come through both bridges, so we meet once a week—we *only* meet once a week. We could meet more if I really wanted to. I am not pressed at this point because I have also gone back to school and it has been like, "Oh!" And I have had to find a new therapist. So I have been going through a lot of transitions as well. (Sarah, 14/03/97 p. 6)

Michelle's responses reveal her disappointment and anger that she was not able to see her outreach worker as much as she would have liked. She was quite negative about this aspect of the program availability. She talked about how an "ideal" program would be in terms of flexibility and availability:

> She's really helpful but I hardly get to see her. It's the way my schedule works and the way her schedule works. I virtually don't have an outreach worker. It looks good on paper but when it comes right down to it *[shakes head side to side]* —practical getting-together-kind-of-things. It's really frustrating. I see her once a week. (Michelle, 25/02/97 p. 7)
>
> It's certainly not as big a deal as they [the program] make it sound. They really make it sound like there's someone around seven days a week to try to go out for coffee with or get meal support with. And it's not! (Michelle, 25/02/97 p. 11)
>
> It would be nice if we could meet once a day, every day. [And] on the weekends—because sometimes weekends are when you're the most unstable. And especially, *especially*, [having] workers available around holidays and long weekends. They are just nightmares when you're by yourself. Unfortunately the eating disorder is a 24-hour-a-day, 7-day-a-week thing. (Michelle, 25/02/97 p. 17)
>
> I've thought about short-term [support]. For times when you're having a lot of problems, or you've kind of got an emergency that's come up, or you just feel very out of control. Having access to beds—that aren't necessarily hospital beds—but a way for getting out of an area where you're isolated. ... If someone's looking at a birthday or a significant day and it's going to be rough—it's a long weekend (the worse case scenario is this one)—it would be nice if you had that back up if you knew trouble was coming. (Michelle, 25/02/97 p. 18-19)

> I'm the one who is falling behind. Other women are out there needing these outreach programs and outreach workers [and] that's what the program is developed for—that's what they're being paid for. And they [outreach workers] spend half their time on taking their days off, and then they spend a lot of time taking time out because they're doing education, meetings, or they're doing rounds or something else has come up. Or it's a holiday. And then you have to try to fit your time in with everybody else's time. So you really get ripped off! This happened with my first outreach worker too. I just don't like that one thing is written on paper but reality is something else. (Michelle, 25/02/97 p. 11)

The attachment that forms for clients to their activation workers cannot be under-estimated. The clients demonstrated their frustration when their outreach worker and, by extension the program, was unavailable, and thus, could not meet their needs. Michelle identified that availability outside of regular hours was important to dealing with the extent to which eating disorders are present in the clients' lives. Sarah talked about her frustration when her outreach worker became less available and her reluctance to see someone else in order to have that increased contact. Natalie asserted that the availability of her outreach worker in the evenings coincided with her ability to loosen the grip on her isolation and return to college. The needs of the clients were clearly articulated, however the program was often incapable of meeting those needs as the clients saw as necessary. Christine noted change in the extraordinary circumstance when a client was brought to hospital during the Christmas holidays. The availability of the outreach worker and the connection the client had with her prevented the hospitalization from becoming a power struggle. The needs of the clients to have available to them the people they had created significant relationships with is evidently important to attend to. Availability was significant according to the client and staff remarks. Where people were unavailable, the clients stated it was an impediment to their growth and recovery.

Flexibility and availability were two important components of the program model. The program intended to be flexible and available in its establishment. Where the program was successful in providing flexibility and availability, clients stated it enhanced their experience in the program. Where the program failed to meet the mark the clients or the program model set for flexibility and availability, the program was less beneficial. Inflexibility and unavailability engendered disappointment, frustration and anger in the clients.

Skills and strategies of program model.

Skills and strategies describe the techniques activation workers and other program staff used to assist the clients with their goals and to support healthy behaviour. The only source of documentation for skills and strategies to be employed was found in the job description of the activation worker position, attached to the COP proposal for funding (Niblock, 1995). The outreach worker position required the "key tasks" of:

> …implementing a structured program by providing organizational assistance to the client to perform tasks of daily living as independently as possible. The areas of focus may include: meal support and meal preparation, household management, "breaking the isolation" of anorexia using activation strategies; liaison with appropriate community resources and further development of coping strategies… (p. 7).

While skills and strategies were not outlined in detail, the clients' responses indicated that certain strategies were successful in helping improve their quality of life. These strategies pertained to issues such as initiating contact by meeting for coffee, maintaining conversation, articulating coping strategies for the client to remember at a time of crisis, assistance with studying, getting the client out of her home and into public, and having "fun." Although these seem like relatively simple things to accomplish, the achievement of these events was significant given the degree of isolation to which these clients were accustomed. Thus, both clients and staff positively acknowledged activation strategies:

> Trisha has a way of getting the conversation going. I remember the first time I met her; we were like this *(moves hands in a gesture that suggests quick-paced talking)* —the whole time just chatting away. And it was because she got it going and I just felt comfortable. We just kept chatting and it was like "Whoa, this is a bit different!" I have seen some of the fill-in workers and it hasn't been quite the same and I am not sure why that is. (Natalie, 07/01/97 p. 5)

> If we're just meeting for a coffee and it's something I've run into the previous day and if it's still bugging me, we have a full hour to try and discuss certain issues. They try and help me get it into perspective or encourage me to do something about it. If it's still bugging me and I think it's wrong, [they] just support me in whatever options I take. (Michelle, 11/02/97 p. 22)

> She [the activation worker] has been so supportive with me going back to college. She really, really helped me. She has an English degree and she really helped me study for the English exams and stuff... I don't think I would have done it. She really helped me out with that. Even getting to the exam the day I wrote—she picked me up, we went out for breakfast, and I went! So yeah she's been really terrific. Like someone there to hold your hand. (Natalie, 07/01/97 p. 8)

> I was very specific. I certainly wasn't going to ignore that she had a bad day—but I wasn't going to get into her issues with her. I would do meal support and then we would talk about if she'd had a rough time. But I would be more of a reminder of "Okay, what can you do now? What are your support systems? Who can you call? How are you going to make it through the next twenty four hours?" More just crisis kind of interventions. But it was meal support (Amber, 20/01/97 p. 10)

The clients spoke of the inherent personal qualities of their activation workers and how these impacted whether an interpersonal connection was made. When such connections were made, recovery was enhanced. When the client and staff members did not connect, recovery was greatly inhibited. Natalie provides an example of her enthusiasm with Trisha, her second activation worker, and then her lack of commitment to her goals with her third and newest activation worker:

> [Trisha] is just so easy going and she's funny. Sometimes we can be really silly together. We sort of joke with each other and sometimes take the mickey out of each other. *(Participant and interviewer laugh.)* We seem to come from fairly similar places. I don't mean like geographically or anything like that nature but more mindset—our belief system. Plus she's so friendly. I don't think Trisha could *not* get along with someone. She is just one of those people. She is very non-judgmental. (Natalie, 07/01/97 p. 4)

> It can be quite funny. Sometimes I'll say something and I'll know it sounds really stupid what I have just said. And then she'll start joking at me—she makes it into a joke—like "Oh, yeah right!" She'll sort of turn it around and I *always* end up laughing. And it *really* seems stupid after that *(laughter)*. But yeah, I am going to miss her. Every time I've always gone to meet her, I've really looked forward to it. (Natalie, 07/01/97 p. 9)

> It just felt like a chore. The meetings were just go, go, go. [My new activation worker] wanted me to do lots of goals, which was not what I wanted to do. I mean I wanted to have fun—something I really lacked in my life. And Trisha and I would have fun. (Natalie, 29/04/97 p. 10)

Trisha's non-judgementalness, her playfulness, and her ability to challenge Natalie's negative or self-punitive thoughts were instrumental in Natalie's growth in the program. The inability of Natalie's third activation worker to engender that with Natalie seemed to affect Natalie's enthusiasm for the program

Another example of this type of skill set was found in Sarah's experience with the nutritionist, Sandi. It also provides an example of the effectiveness of meeting the client at her level of readiness. Sandi was present at team meetings, but not insistent about Sarah's eating. Sandi made herself available to Sarah, but was not intrusive. Her presence and respect of Sarah's defensiveness about food created a slow-developing trust in Sarah that, eventually, permitted her to work with Sandi as her time in COP progressed. Sarah recounts a prior history with a nutritionist and Amber describes the process she witnessed between Sarah and Sandi:

> There was another dietician I was going to work with and I ended up walking out on her because she kept telling me, "This is what you have to eat" and I was like, "I can't." And she'd be "You have to." It would be a joke. I was like, "I'm not going to play games with you guys" ...I get too tired to do that. (Sarah, 14/03/97 p. 11)

> Sandi wasn't imposing on [Sarah] any kind of weight she had to get to. I know it was a real struggle for Sandi too, to say, "Well if you're stable." As long as you're stable, use Sandi however you want. [Sandi had] always been there and always offered support. [Sarah] just slowly started to have more and more discussions with Sandi. We'd talk and have a little more feedback. And that trust that if [Sarah] might see someone individually, she had to be safe. (Amber, 20/01/97 p. 25-26)

Meeting the client at her level of readiness was imperative to this relationship in order for Sarah to do well in the program. This patience and focus on the client's current level of abilities created safety for Sarah and permitted her to take part more fully in an area she, historically, had much difficulty with.

Another important skill of the program staff was to be able to model a healthy interpersonal relationship. Having the ability to resolve conflict in a productive and healthy manner was also important. Amber identifies this in her interview and Natalie acknowledges how Trisha's frankness, care, and consideration were important to their relationship:

> I see one of the biggest goals for activation workers is to model a relationship. Being there. Especially a long-term relationship. Especially one that doesn't disappear at the first sign of conflict. Able to provide some modeling [as] to what "chit chat" would look like. But also not to slip into a dependent kind of situation where they think you [the activation worker] are their best friend. (Amber, 20/01/97 p. 11)
>
> We'd chat. It's just one of those situations where you start learning about each other. You know things come up in conversations and we might have a discussion about that. And we have had discussions where we don't agree too. She is one of those people who if she's got something, she's not going to change her mind on it. And I'll say "Well, whatever, Trisha! That's not what I think!" *(Laughs)*. But um, yeah, we just had—I don't know! It's just, I guess I've just found it—right away, I was really comfortable with her. Communication was really free and easy. (Natalie, 07/01/97 p. 5)
>
> [Trisha] certainly comes from [an] empowering [approach]. We might go through some problems or reframe things—like the way I am thinking about something. She'll question some of the things that I am saying. She's pretty point blank and she'll say, "Oh come on now Natalie, that's really [whatever]." It's like, "What are you talking about?" And I like that, I like that kind of approach. (Natalie, 07/01/97 p. 7)

Trisha's ability to be consistent and honest and to allow room for Natalie's differing point of view created a sense of safety and empowerment for Natalie. Natalie recounts one particular incident where Trisha's ability to be present with Natalie during strong emotions of frustration, anger, and self-denigration, as well as Trisha's ability to reframe the problem, were very significant for Natalie:

> At one point I had written an essay or something. I showed it to her to see what she thought. There were a few mistakes in it. Not really drastically many, there were a few grammatical things. But I got so mad and so pissed off that (I look back on it and it's really embarrassing, really, about how I reacted to it) that I would never be able to write again, that I would never be able to go to college, or write this exam, or do English! It was just this whole catastrophizing. I thought, "Well I'll just be a cleaner for the rest of my life" *(laughs)*. *(Long pause)*. But, you know it was really serious. And it is so stupid and pathetic now, but it was just very—I got very angry that night. And we talked through it a lot...*(pause)*. When I left, later I sort of mulled over what we had talked about and what she had said to me. "Well yeah, I do have choices and I can learn to improve" sort of thing. That's what I finally came away with. Rather [than] saying, "Well, fuck it all," which has been usually one of my things *(laughs)*. (Natalie, 07/01/97 p. 8)

The relationship skills that Trisha employed created change for Natalie, from a self-defeating behaviour to a self-forgiving and more self-empowered position.

Skills and strategies were the techniques that staff used to implement the program's philosophy. Some skills and strategies were congruent with the activation workers' personalities, i.e., being consistent in the relationship, being honest and non-judgemental when there was a difference of opinion, and the ability to be encouraging and comforting. Other skills and strategies were directly employed to decrease the client's isolation and increase the client's trust in the program or in the personnel, such as the relationship between Sarah and the nutritionist, and the one between Michelle and her activation worker. Skills, such as the ability to initiate and maintain conversation and connection and the ability to provide information and support during a crisis, were also important. According to the client and staff reports, when the client connected with others, decreased her isolation, was supported in her activities, or seemed to have "fun," her quality of life seemed to improve and her feelings of hopelessness were less entrenched. Thus, according to the research participants, the skills and strategies the staff used to successfully relate or connect with the clients was vital to the program goals of increasing quality of life for clients and decreasing their hospitalizations.

This section has detailed the components of the Outreach program's model that helped to deliver the program's philosophy to its clients. The program model included the ability of the program and its participants to be flexible and available to the needs of the clients, and to provide highly individualized services to its participants. In addition, this discussion of the program model has also looked at the skills and strategies that program staff employed while working with the clients.

The program model and the program philosophy are bound together by the common intention of having the women improve their quality of life and to encourage and support their physical, psychological, social, and emotional well-being. The program philosophy included locating treatment in the client's community rather than the hospital setting, using a paradoxical approach that insists on having a client-centred treatment focus, and providing the treatment necessary to improving health of this particular population of women. The program model incorporates flexibility and availability of services and the skills and strategies that staff provided to clients. The clients and staff indicated that what enhanced recovery were these aspects of the program. Where recovery was inhibited was when the length of treatment was set according to the needs of the funder rather than to the needs of the client and when staff were unavailable to work with the clients as the client required. The next section of this chapter discusses the qualities of interactions between the staff, the clients and the program that enhanced quality of life and recovery for these women.

Qualities of Interactions

The qualities of interactions that occurred between the program, the staff, and the clients were also found to inhibit or enhance quality of life for participants and/or decrease their hospitalizations. These qualities of interactions included interpersonal interactions (i.e., interactions occurring between people or between people and the program) or intrapersonal (i.e., interactions occurring within the person— e.g., a personal change in attitude or behaviours). Participants reported that both interpersonal and intrapersonal qualities were beneficial to their well-being. These qualities include consistency and reliability, connection, trust, and self-awareness. These qualities of interactions will be discussed to illuminate what the research participants found to be beneficial to recovery.

Consistency and Reliability

Consistency, in this discussion, is used to describe the ability to maintain the same stance or course of action in a relationship. Reliability is demonstrated by the belief that a person can be safely trusted and counted on to do or be what is expected, wanted, or needed and that one can be completely confident in the good judgement or honesty in the other person. The degree of consistency and reliability in the relationships clients established with the program and staff was associated with greater satisfaction and successful outcomes.

Natalie speaks of the way in which getting to know someone, over a period of time, enhances her ability to connect with that person. She remarks on how her relationship with her activation worker, Trisha, was different than with previous care providers, such as nurses or therapists. Natalie gets to 'know' Trisha personally—i.e., as a person—more so than with other previous care providers. This creates an opportunity for Natalie to connect with Trisha and permits a deeper interpersonal involvement and interaction with Trisha:

> I haven't worked with someone this long before [eight or nine months]. Like in this context. I mean, I'm not talking about like with a therapist—because she's not a therapist. Some of the nurses on the ward [during previous long-term hospitalizations] I used to get along with really well because we could laugh and joke. But it was not quite the same because it's a completely different relationship. It's really different because I have come to know Trisha a lot more personally than I would have done a nurse. You don't really have the opportunity or the setting or the time with it if it's with the nurse. (Natalie, 07/01/97 p. 5)

Natalie also notes how she experienced the consistent presence of the program and staff as helpful with her range of emotions through a variety of situations. In fact, Natalie credits the program with her ability to return to college and to regulate her emotions:

> Support with going back to school and stuff and being really encouraged. I don't think I would have made it unless I had been in the program in that way. And getting through a couple of tough spots too, where my mood just kind of went down again and I think it probably, well, might have got worse or [I] might have crashed a bit without the program. (Natalie, 07/01/97 p. 29)

Natalie acknowledges the way in which Trisha and the program were consistent and reliable in their presence and how this was encouraging and supportive in her recovery.

Amber also addresses the issue of consistency and reliability. She feels that her role of activation worker requires her to be reliably present with the client, despite the circumstances the client is in. It is in the consistency of her presence and her reliability in not "disappearing" when conflict arises in the relationship that the client is best supported in her personal growth. In addition, hospitalizations are viewed as a part of a process of recovery and not a "failure" to recover:

> I hear about it [conflict] through some of the other members of the team because talking directly to me—direct conflict resolution—is really scary [for clients]. For me it is just about consistently being there. And just being consistent—that I don't disappear. (Amber, 20/01/97 p. 12)
>
> It's that consistency of being with them whether they're in hospital, or in community. We just assume we will follow them wherever they go. I think that's helped a lot of them see their hospitalizations differently. It's not as isolating. They're not on hold for the rest of their life. It's on a continuum, as far as recovery, with their lives—it's not this separate piece. (Amber, 20/01/9 p. 25)

Amber also finds that consistency and reliability allow her to take advantage of opportune moments to connect with the client. These are moments that happen over time in a relationship and cannot be designed into the program agenda. Like in the field of education when a teacher finds a 'teachable moment' opening up in the classroom dynamic, Amber speaks of what could be called a 'connectable moment' that arises from being in relationship with the client:

> For a lot of them, certainly the trust issue. They all have a lot of trust issues. But I think it's about catching them at the right moments. If you do, they might feel positive and think it's the best thing they've ever done. The next week, it's in that hopeless place—and what was the point. I think it's just catching them when they're in the right place. (Amber, 20/01/97 p. 27)

Being a consistent and reliable presence is important to this group because of their issues and concerns about trust.

Amber's remarks bring attention to another finding regarding connection, i.e. that this client group does not manage change easily. The clients interviewed had had numerous changes in their histories of treatment. The comments by both staff and clients demonstrate how change, when clients do not feel ready for it, can have a negative impact on them. Amber remarks how clients have had "ups and downs" as a result of the numerous program changes; Michelle states that in her "ideal program" she would have lots of notice about change; and Sarah has had several changes in psychiatrists, therapists, and program staff in previous programs and in COP and finds herself having to "step out" due to a disagreement:

> I feel a lot more secure and better. [New clients to COP are] getting a more coherent picture in what they can expect versus clients whom started with us [earlier]. They learned as we did as we went along and there are some real ups and downs of things changing for them (Amber, 20/01/97 p. 6)
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> [There needs to be] lots of warning when there's going to be program changes. (Michelle, 25/02/97 p. 17)
>
> I have made five, six, seven—I think I've gotten seven therapists, cause I saw one lady for three months and it was like "I'm paying a lot of money to say one word for one hour." I don't talk very well with her and it took me a long time to trust

> myself that this wasn't working, and say, "I'll look for someone else." (Sarah, 14/03/97 p. 7)
>
> We aren't doing anything for a month. That has to do with the fact that they have a new team coordinator, and my team coordinator right now has a very powerful personality. I have trouble dealing with that. So, I think I am having a problem with her rather than the rest of my team.... I've had like four different coordinators so and they've all of them done things differently. Some of them have been really involved and some of them haven't been involved at all. (Sarah, 14/03/97 p. 14-15)

Consistency and reliability were qualities of interactions that both clients and staff reported as beneficial to change. Change was not viewed or experienced as beneficial by clients unless accompanied by the presence of a reliable connection with the program staff. Therefore, as an interpersonal interaction, consistency and reliability seemed to enhance client well-being, according to the remarks made by clients and staff during their time in the program.

Connection

Christine's earlier quote indicated that the importance of hospitals cannot be underestimated with this client group. From the comments of the research participants, the importance of connection also can not be underestimated. Connection is a term used to describe the closeness, validation and attachments felt for another person. What seems to foster connection are the qualities of acceptance, non-judgementalness, consistent contact, a congruency between what is said and what is carried into action or behaviours. The issue of hospitalization brings attention to the need for connection that is felt by those so isolated. When desperately disconnected, it appears that the program clientele formed unexpected attachments to the hospital. Christine notes how the hospital becomes a place of connection and indicates the degree of isolation and disconnection some of the clients have lived with:

> If you were to ask some of these people who they're most connected to in their lives, some of them would even say St. Paul's. I mean, hey, that's the way it's been. I don't mean to sound arrogant in any manner...I hope that doesn't sound you know, but I think that's what patients say. (Christine, 05/23/97 p. 2)

When connection is made, it is precious and healing. Natalie notes how her relationships with her two activation workers helped her to heal a negative belief about herself.

> I guess where it really helped me, especially last year, was getting to know Trisha and Jane [first case manager]. Making that connection with them and seeing that I did get along with them. Breaking that idea in my head that no one likes me. (Natalie, 29/04/97 p. 31)

The value Michelle places on her connection with her activation worker is that it is as essential a relationship as her connection to a therapist:

> Activation workers are—well, the same thing as therapists almost. I got lucky with my first activation worker. She was just fabulous! She was the one who really began to help me take the stigma away of the bulimia. By calling a spade, a spade. [By] her acceptance of what other people would find fault in. We were talking about drug abuse one day and she said, "You know, pain is pain..." that was one of the things that came up. I can remember her saying that, "...and their drug abuse is their way of surviving." (Michelle, 11/02/97 p. 30)

For Michelle, the stigma she has attached to her eating disorder has been a driving force in her isolation. Her connection with her activation worker and her trust in the activation worker's belief about pain, begin a process whereby Michelle could slowly move out of her isolation and connect with others. The activation worker made it clear to Michelle that she could accept Michelle despite her bulimic behaviours. This, according to Michelle was a major breakthrough for her and enhanced her self-acceptance.

Amber reveals how a client's primary connection with activation worker provides a secure base from which the client can try other components of the program. This demonstrates how connection is effective in a paradoxical approach:

> Breaking that isolation—I saw her [the client] as a little different against the individuality of the program, where a lot of the goals for the activation workers [were] to help clients get connected with their community. Whereas I saw my role

> was providing a "holding environment." She was quite good at connecting with her community herself, but she just needed a consistent holding environment so she could feel safe enough to try little bits and pieces [of the program]. Her being in COP was a big reason why she was able to connect with the therapist, which was one of the issues she was struggling with all of the time (Amber, 20/01/97 p. 8)

For Amber, her position as a temporary "holding" place allows the client to connect with other team members—and in particular, with a therapist. This is similar to allowing Sarah to make the connection with Sandi during team meetings was an important change and a successful interaction versus Sarah's previous negative experiences with nutritionists.

Deborah claims that one of the important understandings she has come to in her work with COP clients is the challenge in establishing connections:

> [What I learned from my work is] it was all about developing a therapeutic alliance with people who haven't generally developed strong alliances with therapists in the past. (Deborah, 13/05/97 p. 7)

This difficulty with developing therapeutic alliances likely results in a reluctance for these clients to work with therapists and for therapists work with these clients, thus making it difficult for these women to attain the therapeutic support they need.

A rupturing of connection is an inhibiting interaction for the clients in the program. Sometimes, connections are severed by chance and the disconnection becomes progressively worse. Other times, the rupture has a negative effect simply because the connection to someone was an important part of the client's life. Michelle details how her isolation progressed because of her loss of connection to others and how bulimia began to fill the time created by this disconnection:

> I was working nights too. There wasn't even anybody else on the shift, so I was by myself. My day consisted of sleeping during the day, getting up in the afternoon, eating until it was time to go to work, going to work, not having anything to eat at work and other than Emerge calling or the wards calling for blood work, I never saw anybody. It was very, very isolating. I didn't have that chance during the day to get out and meet anybody. (Michelle, 11/02/97 p. 13-14)

> No contact with people and no opportunity to make connections—like many shift workers. As time went on I got more and more—I would spend more and more time with the bulimic cycle, eating and getting rid of it, eating and getting rid of it. Making sure that I was getting rid of enough so that I could keep losing weight. Then eventually I increased the amount of time spent doing this to the point where I no longer had time for a social life. I was feeling guilty and depressed too because I was getting more and more isolated. Eventually, work was the only thing I had outside of the bulimia. (Michelle, 11/02/97 p. 9)

Natalie notes how she has become disconnected from things that used to bring her laughter:

> I just met with a rec [recreation] therapist (which is part of COP) to hopefully sort of work on having fun. Which is one of the reasons I'm staying in [the program] because I need to work on my leisure time and entertainment. I've really noticed, particularly in the last while, that I rarely laugh. It's horrible. I don't have much fun. And I really miss that. I'm intense too much. (Natalie, 29/04/97 p. 10)

Sarah remarks on how great an impact losing her therapist had on her, given that she has endured several changes in programs, psychiatrists, and other personnel prior to this. When she finally connects with the hospital psychiatrist, only to have this connection abrupted too, Sarah is affected:

> I saw her [the therapist] in hospital and it ended up that I was allowed to keep seeing her. So I saw her for quite a while and then I had to stop seeing her and that was devastating. (Sarah, 14/03/97 p. 6)

Natalie echoes Sarah's sentiments and demonstrates further the impact a rupture of connection has. By the second interview, Natalie had been informed that Trisha, her activation worker, would be leaving the program in one month. Natalie expressed disappointment and began to talk about leaving the program herself:

> I think that when I eventually do leave the program—well not eventually, when I *do* leave the program—I think that's going to be really difficult. More than anything. It's just that the rapport that we've had and the fact that I've enjoyed spending the time [with Trisha]. It's not so much the program, or anything about leaving the program, or anything like that. It might have been that in the past. But that I think I will really miss her. *(Pauses)* I like my new activation worker. She seems nice enough but I don't have the same connection as I did with Trisha. I'm sure she's great at her job, but it's not—and I try not to compare them, as she has a completely different personality. As obviously they're not the same people. It's just one of those kind of things. *(Pauses)* At one point I said that I was thinking

> about quitting. I felt it was a big chore meeting with my worker. It's not something I look forward to like I used to. I don't think it's any fault of the program. I mean how can you hand-pick a worker for each person, right? I don't know. It might have been different if I'd never had Trisha, right? (Natalie, 29/04/97 p. 8-9)

Michelle demonstrates a more extreme reaction to disconnection. Her reaction to the information that she is required to leave the program in the upcoming months has an element of self-destructiveness to it because it seems to reinforce, or preserve, her bulimia:

> I've caught myself thinking the last couple of weeks—with everything that's been going on and I'm looking at the end of my stay in the COP program—thank God I've at least got this eating problem because it, at least, I can hang on to. It may be the only thing that keeps me going. I figure it makes me feel half-decent. Otherwise there would be nothing. (Michelle, 25/02/97 p. 25)

By their responses, Sarah and Natalie demonstrate how precious and therapeutic the bond of attachment can be, once made, and Michelle displays how ruinous detachment can be to someone who uses an eating disorder to cope with feelings of isolation, loneliness, and rejection.

Although the clients may need to form a close attachment with at least one person, as Natalie did with Trisha and Sarah did with Amber, before being able to connect with others, the program seems to be at odds with this need for attachment. Clients and staff expressed in their interview responses how time must be given to establish close connection. Unfortunately, the needs of the funder and the paradigms' objective of reducing hospitalizations and containing costs by off-loading these clients into the community run contrary to the clients' needs to establish a consistent, trusting relationship over time. Again, length of treatment has a vital impact and a part of the program's philosophy seems to short-change the prerequisites necessary to move clients into the community in a meaningful way. In a few of the staff responses, the issue of clients' "dependency" was discussed in a negative manner:

> Deborah is doing one-to-one; she is not doing it with everybody. In her one-to-one she is connecting, but she is also disconnecting. She is trying to get the person ready to leave. And that's hard. I mean *especially* with this group of people who do need in a major way to connect (Christine, 01/06/97 p. 23).
>
> The difficult part will be in disengaging. (Christine, 01/06/97 p. 29)
>
> As I said, I don't think that they're going to be the really big goodbye. I think that we'll continue to see them in some way. (Deborah, 05/13/97 p. 16)

The way in which this can be viewed as a negative attitude to connection is that disengaging from clients ought not to be difficult if the client is ready and in an appropriate emotional space for discharge, transition, or "weaning" from the program to occur. The timing, however, must come from the client. Furthermore, there may be incongruency between the therapist's skill, the program's strategies and objectives, and the client's needs that make disengaging from "dependency" necessary. It is possible that connection is seen as "dependency" when the client is not ready to disconnect but the program needs to have her detach.

The program's administrative changes seem to emphasize decreasing clients' contact with activation workers, and therefore not allowing them to attach:

> The activation workers would only want to do meal support in the context of planning some community activity [rather than] meal support in itself. What they would like to do is move towards getting other people in the person's life to do those things so they [activation workers] don't become the only person that the client can eat with. They want to *decrease* dependency and [have] whatever they're doing be happening with other people. And keeping the focus of their contact with the client on things that only [activation workers] can do. (Deborah, 05/13/97 p. 15)

However, perhaps it is important to attend to the possibility that an activation worker may be the only person the client feels safe with. It seems unfortunate that before the client can depend on, attach to, or connect with someone, it is taken away.

Several of the client participants spoke of the difficulty of transitions and discharge dates. With her comments, Michelle states powerfully how the major transition of discharge dates negatively impacts her. She recognizes that she is, in fact, dependent on the program. The strength of this connection is symbolized in her belief in the safety and "sacredness" of the meal supplements she receives from the program. Furthermore, she speaks to the need to have a consistent bridging of the people and places she is currently feeling connected to and the areas and people she must eventually begin to move toward in her life outside the program:

> Within the COP Program they've kind of come to a point where they're saying that we're now going to look at the time frame. Or we now have a time frame for people going through the program. We've just started talking about that and I'm finding it's really knocked me sideways because I didn't realize how *dependent* I'd become on the program. *(Pause).* Not just dependent but how much I *need* the program for practical issues, to help me with the isolation, just someone to talk to. (Michelle, 11/02/97 p. 3)
>
> Ensure is something I won't purge 'cause it comes from the hospital. It's sacred—because they're supplying it and I won't waste it. I refuse to waste it. I will not have it rather than waste it. It's my bottom-line *safe* food. (Michelle, 11/02/97 p. 6)
>
> Before leaving, even if it's like a bridge to get you out and resettled into another place to live. Making sure that everything is followed up on, that you've gotten a therapist. That you're settled with that therapist, that you're settled with your doctor, and your meds are in order. Where that might only take a few weeks or a couple of months, and *then* [you] won't need the COP team. (Michelle, 25/02/97 p. 26)

Michelle's statements summarize the importance of connection for program participants particularly as transition is made. The connection is, essentially, first and last in the relationship because it reduces isolation and facilitates transition. For this client group, transition or change of any nature is safely mediated by connection. Connection is the second quality of interaction that has an impact on client well-being and clients' abilities to recover from the debilitating effects of their eating disorders.

Trust

Trust in the relationship is a third quality of interactions that enhances client quality of life, while mistrust inhibits it. Trust is engendered by connection, consistency, and reliability. Mistrust arises from previous negative experiences where people and programs were not congruent with stated goals or interactions. The clients and staff provided many examples of how trust factored into their interpersonal relationships. Sarah speaks to her trust with the nutritionist. As she begins to trust the nutritionist as a person, she can therefore feel safer in the relationship because Sandi stays consistent over time and doesn't become forceful with Sarah:

> I can ask her questions and I don't feel like I am putting myself in that—in a trap. And that is why I like the COP program, because it is not so trapped a feeling. (Sarah, 14/03/97 p. 11)

Conversely, Natalie feels defensive and distrustful. Her mistrust has roots in her historical experiences of the program and her personal worldview. She talks about this with regard to the team meetings and how her mistrust has changed through her experiences with COP:

> This whole thing around team meetings...I just can't stand it. It's hard for me to pinpoint what about it that I don't like. And then what to replace it with? I don't know. I don't know if it has to do with three people so I sort of feel sometimes like it's three against one. Even though I know it's not, I've always had that problem in the programs. (Natalie, 18/12/96 p. 18)
>
> [In other programs] if I felt something was unjust or I didn't agree with something I would tell them. When I was pissed off I would tell them. I think it's almost like that rebellion against that kind of authority. I don't feel like that there's that within this [COP] program—that authority kind of thing. I don't feel that...it *is* more of a team. I think that's partly too where I am in recovery 'cause I don't see it so much as a "Them" and "Us" anymore, like I might have done a long time ago. (Natalie, 18/12/96 p. 19)

Natalie also has reason not to trust the proceedings of team meetings as she is aware that the meetings are not held in her best interest but often are conducted in the interest of the funder:

> I can't really put my finger on what I dislike [about the team meetings]. In a sense because it does feel like I'm the patient. And then you've got all these workers and you're the focus and they're asking all these questions, what goals do you have, la-

> la-la-la. Trisha noticed that I just carry myself, in that situation, I almost get defensive. I know there needs to be a certain amount of questions for the program—I know they need that stuff for funding. (Natalie, 29/04/97 p. 15)

Michelle also addresses the issue of trust. Again the funder's need takes precedence over her need for consistent contact. As she is being told she will be terminated from the program, she finds the process of doing work with a therapist pointless:

> The goal is to split our time now. So the minority of [therapy session] time is spent looking at future issues—getting a place if I want a place, the logistics of how to do that. Getting set up with a new therapist. Easing out of the COP program. The bulk of the work is going to be focused on what the issues are and still working on them. But because it seems like the last couple of weeks—it's been all about this future stuff, you know, what's the point of going into therapy if you're only talking about ending it. (Michelle 25/02/97 p. 33)

From that staff perspective, Christine also draws attention to the fact that the thought of terminating is distressing for many of these clients as it disrupts the connection and trust they have placed in the program and the staff. Christine describes how trust is an issue with this client group and the difficulty they have expressing their need for connection and the sense of betrayal they feel. She may also provide a clue as to why previous treatment programs have failed with these women:

> They say, "I can't imagine what am I going to do? I know you now. I trust you!" It's very, very scary [for them]. And some people can't even say that. What they do is they cut off all communication with us as soon as the discharge starts to approach so that they can kind of reject us before we reject them. It's that abandonment kind of stuff that comes up for people. (Christine, 05/23/97 p. 2)

Trust that develops in the therapeutic relationships over time has profound intrapersonal impacts as well. Natalie discovers many things about herself during her time in COP. In the consistency of the relationships she develops with Trisha and other members of the COP team, Natalie finds that she can trust that she is a good and worthy person to be in relationship with:

> I've always seen it as I was the patient so they kind of had to like me. In COP, it was a slightly different relationship. I was seen as a person and not as a patient. They generally enjoyed the time that we spent together. (Natalie, 29/04/97 p. 31)

Trust, therefore, is an important quality of the relationships established between clients and staff in the COP program. When trust is created, a therapeutic relationship is also created; when trust is shaken or disrupted, there are several dramatic reactions that affect clients interpersonally and intrapersonally. Trust demonstrates a commitment made by the staff and the program to clients' care and well-being and, thus, is vital to recovery.

Self-awareness

Self–awareness was the fourth quality of interactions that research participants spoke of impacting client's recovery and quality of life. Self-awareness was an intrapersonal interaction wherein the person, client or staff, had more positive insight into their attitudes, beliefs, and interactions with others. This category is been divided into two sections, the first dealing with the increased self-awareness of the clients, the second the increased self-awareness of the staff.

Client self-awareness was evident in the way in which participants spoke of their learning about themselves during their time in the program. Many of these learnings arose as a result of the interactions the clients had with others and the way in which they began to see themselves as a result of these interactions. All three client participants spoke of how the personal relationships they developed with the team members in COP increased their self-awareness and self-acceptance. The clients' responses indicate an increased compassion for themselves and their struggles with their eating disorders. Natalie discusses her realization that she can allow herself to be affected by another person without it being a sign of "weakness":

> I'm not sure...(long pause)...it's sort of like it's one of those *(whispers)* "Oh, I'm tough. I can deal with that!" *(mock tears and bravery)*. It's also about—even for the longest time—being able to admit that something might actually *affect* me. Because I guess it's growing up with that kind of like "I can't let anyone know I'm hurt" kinda thing. I still have that in me. It's like somewhat of an embarrassment—or I'm ashamed to admit it. To admit that I might be sad, or something like that. And that that would be some kind of a weakness. It's just the

> way I grew up. You don't say that kinda stuff. (Natalie, 07/01/97 p. 10)

> I felt like it was more than they had to put up with me. I talked to Trisha about it. I always had felt like a number. I always had this image, and it's starting to break now, I used to feel that everyone hated me at the hospital—I've had a few wild times, I have to admit. But I know [now] that most of it was really low self-confidence. It was more the case of I was there as a patient and they had to treat me. That old voice saying, "Oh, Natalie, they're just tolerating you. I was always making comments like, "Oh, I don't want to take up your time," or, "You shouldn't be doing this; you've probably got better things to do." And its still very much there. And it was very much there at school. You know, *everyone* hates me! That kind of stuff. (Natalie, 29/04/97 p. 32)

Michelle states she has a new curiousity about the meaning of her bulimia and is less self-condemning about it:

> It's been a subtle change that's taken time but I'm coming to view it [the eating disorder] a little bit more objectively. And not to be quite so hard on myself. I still don't accept it [entirely]. There's better ways of handling a situation. And financially I'm cutting my throat every time to do this. There's a cost in being bulimic. I forgot all that I had lost. On the other hand it's served a purpose and I'm trying to find out what the purpose was—is. To try and sort that out because this behaviour is just not acceptable. (Michelle, 11/02/97 p. 26-27)

Sarah begins to more accurately and honestly articulate her relationship with food:

> When I say that I can't eat it it's not like that I can't eat it. It's that I don't want to—I'm *afraid* to eat it. And if I purged it, I can't say that I didn't do it. I did. (Sarah, 14/03/97 p. 12)

The staff also show increased self-awareness. This was found in their comments regarding their understanding of the client's situation, their increased respect for the clients, and their own awareness of the impact they have on the client. Staff's increased self-awareness manifests in greater respect for the client and in more understanding and compassion. For example, Deborah realizes that she must be "genuine" in her interaction with clients rather than simply embodying a clinical therapeutic stance that her training has taught her. With reference to her new approach of "radical genuineness," Deborah recounts:

> I learned this from the women in the program. Because they used their voices loud and clear with me when I screwed up by not being genuine and saying all the things that therapists are taught they're supposed to say—understanding, empathic kind of stuff. But only [to say] validating things that are absolutely 100% felt within me as being true. And that required a lot of work on my part to be able to do that. (Deborah, 05/13/97 p8)
>
> This group has been burned too many times. They don't have the same resilience to moments of un-genuineness. 'Cause they're not going to tell you about it. They're either not going to tell you about it *at all* or it's going to be *in your face*! (Deborah, 05/13/97 p.12)

Deborah learns a more respectful interaction in her work with these women. They need genuineness in the relationship, otherwise trust and connection cannot be attained.

Christine's recollection of an issue that arose in the program also reveals a problem of respectful interactions. Christine seems to frame the issues of exercise and enmeshment as a problem created by the client with which the staff must deal:

> Walking, for most of our clients has to do with purging. It has a mission attached to it. If someone is very emaciated, are you aiding and abetting [the anorexia]? How do you help the client, um, and at the same time tolerate the symptomology? ... One of the people [program staff] is just deathly afraid that one of her clients is just going to drop dead. (Christine, 05/23/97 p 20)
>
> We have some clients right now who are really interesting. Where there is a real issue of enmeshment. (Christine, 01/06/97 p.44)

Perhaps it is possible that both of these issues have to do with connection in the relationship. Is Christine's assumption that walking is a form of purging and enmeshment is problematic condescending? Is it possible that walking may also be an opportunity for "connectable moments" between the client and the activation worker? Is walking a coping mechanism similar to Michelle's understanding of purging? Is identifying enmeshment as a negative issue demonstrating a lack of insight and empathy for clients' abilities to articulate their needs? There does not appear to be an apparent development of a mechanism for facilitating the staff's understanding from the client's perspective. The interaction is less respectful as it assumes the client's mal-intent, refuses to accept the symptom, and does not look to see what other possible dynamics or interactions may be happening with this circumstance.

Christine and Amber also speak of the self-awareness they develop in their experiences of the program. For example, Christine grappled with the philosophical question of what is the orientation and understanding of the program when ideal is put into action:

> The other day, we were trying to decide, whether this patient really wanted to die or not. Was this a death wish for this particular individual? That was really hard for people. It is really hard to think "Well, are we actually providing a palliation program or is this really a quality of life program aimed at, or with the underlying hope that there might be recovery one day?" (Christine, 01/06 p. 16)

Amber recognizes the impact that her interactions with clients has on her own well-being and peace of mind and the practices she must implement in order to ensure her own self-care:

> But also hopelessness too, being prepared, and taking it home with me all weekend. I'd be concerned about that person's safety or something like that. There's a certain piece in my gut anytime if someone's feeling really suicidal [given the deaths in the program]. There is a piece of me that reacts and still reacts to that. I am sure that it will take some time. So, just constantly checking out my own boundaries with that, getting support when I need it.... (Amber, 20/01/97 p. 21)

One example of lack of self-awareness arises in Deborah's statements. It does not appear that she is aware of the incongruity of her words and actions. In particular, Deborah has described a current part of her research where she and the nutritionist have begun to document in detail the clinical and nutritional interventions made with clients:

> We're really just at the beginning now [to record data] so we're just going to be completely descriptive because we don't even know how to ask questions, we don't even know what the big questions are going to be. We really just tried to be overly inclusive and look at everything in sight. Hopefully we can share the information with other people. (Deborah, 05/13/97 p.5)

> The ones for who it's more subtle are the ones where I think a lot of the work is happening inside their heads and their hearts; and who are just not ready to touch the eating. (Deborah, 05/13/97 p.13)

The attempt to quantify the effect of interventions with clients is contrary to the fact that many of the successful interactions are not quantifiable but are, rather, qualitative in nature. Deborah acknowledges, on one hand, that for this client group quality of life scores were below a recordable or quantifiable level. She also acknowledges that for the some of the clients, recording information on eating behaviours will not begin to verify the changes that occur internally. However, Deborah continues to try to measure and quantify the effect of the nutritional interventions. This lack of self-awareness may, once again, be linked to the issue of the funder's need for measurable, statistical outcomes that, in effect, negate the qualitative changes occurring on a more descriptive level.

Self-awareness is an important component for delineating and describing some of the positive outcomes of successful interactions between program clients and staff. As indicated from staff and client responses, self-awareness increases respectful interactions, self-acceptance, and compassion. A lack of self-awareness, particularly when awareness is necessary to developing a more comprehensive understanding of eating disorders and recovery, is a hindrance. The lack of self-awareness may in fact result in "red herring" outcomes where what does not encompass what is happening in the arena of human interactions. Self-awareness is, then, an important component of intrapersonal and interpersonal interactions that research participants demonstrated as having an influence program outcomes.

The qualities of interactions that seemed to enhance client outcomes are found on both the interpersonal and intrapersonal level. These qualities include consistency and reliability, connection, trust and self-awareness. Both staff and clients reported that when these qualities were apparent in interactions between clients, staff and the program, the outcomes were positive and therapeutic. Where these interactions were missing, outcomes were less favourable and recovery was inhibited.

Summary of Research Findings

The responses from the research participants were various and the findings are summarized here and in Table 3.3 to facilitate further discussion in Chapter Five. With regard to the qualities of the program—its philosophy and model—clients and staff commented on COP's emphasis on an out-of-hospital setting, a paradoxical approach to treatment, and the length of treatment. Treatment set outside of the hospital was viewed as beneficial, particularly given clients' previous experiences in programs that included forced feeding, involuntary committals for treatment, and emphasized a focus on weight gain. Clients saw in-hospital treatment as negative because of the program restrictions on bingeing and purging behaviours and the hopelessness of repeatedly witnessing others continuing to struggle with an eating disorder. When treatment was placed outside of the hospital setting, clients stated they had increased motivation and enhanced attitude to taking part in the program. In addition, they felt the setting was more relaxed and more realistic. Finally, clients stated that as their treatment moved into the community, they began to see themselves as more than just an eating disorder.

Staff speculated that hospitalizations were experienced as dehumanizing and created more upheaval and isolation in the clients' lives. Moving the treatment setting into the community, therefore, may be significant to the decreased hospitalizations seen in the preliminary outcome reports. An out-of-hospital treatment setting required change in staff roles to those of community consultants. Activation workers were seen as the core workers who would provide consistent contact with the client as she connected with community care providers. Activation workers were seen as providing essential support through transitions. The shift to a community setting also assisted with administrative concerns regarding reducing wait lists for services and increasing cost containment for the Eating Disorders Clinic. One surprising finding was that, for some clients who's isolation was severe, hospital provided an important therapeutic function of reconnection and increasing human contact.

Findings regarding the paradoxical approach to treatment focused on three aspects: reducing clients' hopelessness and isolation, using harm reduction techniques, and providing a client-centred focus and activation strategies. Preliminary scores for client's perception of quality of life were so low as to be immeasurable by the Quality of Life Scale. Hopelessness was exacerbated by clients' isolation and seen as a barrier to recovery for staff and clients alike. According to staff reports, hope and isolation shifted as clients spent more time in the program and that their eating disorder behaviours were reduced.

The use of harm reduction techniques, particularly the emphasis on accepting the eating disorder symptoms while still maintaining contact with the clients, was helpful to breaking isolation. Clients reported that an acceptance of the symptoms increased their self-awareness and self-compassion with regard to their eating disorders, and increased their enthusiasm and involvement with the staff and program. Acceptance also permitted clients to examine their quality of life aside from their activities with anorexia and bulimia and they reported a challenge in identifying their wants and needs when not preoccupied with food and weight-related behaviours. Treatment was more invitational and the client could take part in treatment without necessarily surrendering her eating disorder.

An activation and client-centred approach was implemented to have clients actively reclaim aspects of their life that they took part in before their eating disorder became so predominant. Staff reported that clients became more active in community pursuits and increased their quality of life as they developed highly individualized and personal goals. Staff found that when clients were given the freedom to be part of the decision-making process around their treatment they were more likely to meet their goals. When clients were proactively included in decision-making around their medical care, there was an increased client compliance with hospitalization and all admissions during the pilot project were voluntary. Staff also stated that breaking down the client's self-determined goals into small, manageable, pieces was essential to encouraging clients' success. The staff noted that significant changes were occurring with clients (although these changes may not have been measurable using standard outcome measures) and their attention to these changes was important to motivate the client to further change. Finally, with regard to activation, staff noted that the clients needed to have some level of motivation, initiative, or "readiness," with which to ensure a greater level of successful outcome. This statement was made despite contradictory knowledge that, with this client group, hopelessness makes motivation difficult.

The client-centred approach meant that the treatment focus was highly individualized rather than a group format or focus. Clients reported they felt empowered by this approach as it permitted a shift away from a "victim" perspective to allowing them to reclaim their voice around their treatment and life direction. Clients did report difficulty in articulating goals and stating their needs, particularly when these pertained to weight goals.

Length of treatment was a controversial component of the program philosophy. In some aspects it contradicted the program philosophy of a client-centred approach as treatment was not based on what the client needed or required, but rather on what the funder required. Restrictions around length of treatment were determined by the funder's need to put people through the program and to reduce the wait lists for eating disorder services. However, what the administrators and staff knew (and what was supported by opinions from an international field of care providers) was that 12-18 months of treatment was an unrealistic program objective given the burden of illness with some of these clients. In addition, some clients may require life-long support given the chronic nature of their eating disorders.

Hastening treatment had negative impacts on the clients. As trust and abandonment was an issue for this group of patients, terminating their treatment just as they were seeing some progress was devastating. Clients found the newly placed time limits to be a difficult transition to make and also stated how these restrictions had devastating impacts on their treatment. This included feelings of rejection, increased self-loathing, and renewed hopelessness. Given that even subtle change was difficult for this client group, staff felt that it was often unethical to be terminating treatment when clients were beginning to do well in the program. Length of treatment was an issue that was viewed negatively by staff and clients alike.

Interview responses regarding the program model focused on flexibility and availability of the program and the skills and strategies employed to deliver the program philosophy. Clients found the program's flexibility in shaping itself to the clients' changing needs, skills, and goals and the employment of a highly-individualized, rather than "cookie-cutter," approach beneficial in comparison to existent programs. Flexibility was seen as essential to meeting the client at her present level of ability to work on goals, and to employ program components as she was ready for them. Availability was also an important quality of the program model. Where the staff and the program were available to the client, the client had greater satisfaction and more successful outcomes. Unavailability was experienced negatively by clients and they expressed anger and disappointment. In some circumstances, clients seemed to reject the program and to deny their own need for the program rather than experience the distress of the program or staff not being available. Clients found that when outreach workers were available outside regular office hours, their quality of life improved. Clients identified that having staff available for evenings and weekends was beneficial, however, more availability would be better—particularly on weekends and holidays as an eating disorder is a "24 hour per day" problem. Skills and strategies staff employed that were identified by clients as beneficial had to do with initiating contact, maintaining conversation, providing coping strategies, modelling healthy relationship dynamics, and being a person who can generate fun and laughter.

Qualities of interactions that facilitated recovery and increased quality of life for participants were both interpersonal and intrapersonal in nature. The research respondents commented on qualities of interactions such as consistency and reliability, connection, trust, and self-awareness. Both clients and staff made statements that indicated the degree to which these qualities were beneficial to well-being, quality of life, and recovery.

The greater the degree of consistency and reliability in the relationships between clients and the program staff, the greater the degree of client satisfaction. Clients remarked that consistency was established by getting to know someone more personally over a period of time and that increased consistency resulted in an increased sense of reliability. Consistency was fostered by the client's sense of the staff's staying with the client through a variety of situations and range of emotions. Changes to the program were not beneficial without the consistent and reliable contact with the program staff. In fact, staff members'—especially outreach workers'—consistency was beneficial to the client's ability to manage change or transition.

Connection was an important quality of interpersonal relationships with the research respondents. Clients identified that connection was made when there was a climate of acceptance, non-judgementalness, reliable contact, and congruency with team members. Connection was healing particularly given that connections have not been easily made with this client group given their histories of ruptures in relationships. Connection provided a secure base from which clients could try other program components and facilitated transition to community living. Connection seemed to increase the client's self-awareness and self-acceptance. The program, however, seemed at odds with clients' need to connect and form attachments and referred to this as "dependency." For some of the clients, dependency is a reality in that the clients do form dependent attachments to the program. The program staff spoke of needing to have the clients detach. It seems, however, more beneficial to have the detachment initiated by the client.

Trust was engendered by qualities of consistency, reliability, and connection. Mistrust was a remnant of negative experiences and incongruencies in previous programs and relationships. The development of trust in the interpersonal interactions between staff and clients had profound impacts that included increased understanding of the self and the eating disorder behaviours, compassion, and the sense that the relationship was more honest and genuine. Within a trusting relationship, clients remarked that they found a more profound understanding of themselves.

Self-awareness was defined as a positive insight toward the self and greater self-awareness resulted, again, in greater understanding and self-compassion. When staff reported increased self-awareness, their interactions with clients became more respectful and genuine. One instance of a negative self-awareness, or a less respectful interaction, was found when Deborah attempts to measure the quantifiable effects of interventions and negates the degree to which change in clients is personal, qualitative, and inherent to the qualities of relationships within which the changes have occurred.

Summary

This chapter has presented the profiles of the research participants and the anecdotal data from the study. Participants responded to the basic research interview question of what they found to be qualities of the program that enhanced their experiences in COP, enhanced their quality of life, or assisted in successfully treating their eating disorder. These findings were presented in two categories (a) the qualities of the program philosophy and model and (b) the qualities of the interactions between staff, clients, and the program. The themes that emerged in each category were discussed and supported using the words of research participants (both clients and staff) and, where appropriate or available, triangulated with written documents from the program.

The qualities of the program that the research respondents addressed in their interviews centred on the program philosophy and program model. Participants identified qualities of the program philosophy as the program's setting outside of hospital, the use of a paradoxical approach emphasizing decreasing hopelessness and isolation, acceptance of the symptoms, providing activation and a client-centred focus, and the program's length of treatment. According to the participants, these qualities of the program philosophy and model enhanced recovery and quality of life, and decreased hospitalizations. Identified qualities of the program model pertained to flexibility and availability of the program and its staff, and the skills and strategies that staff employed. Qualities of interactions that participants identified as enhancing recovery and quality of life and/or decreasing hospitalization included interpersonal and intrapersonal interactions of consistency and reliability, connection, trust, and self-awareness. The chapter concludes with a summary of the findings. The discussion and implications of the findings, the limitations of the study, and suggestions for further research are addressed in Chapter Five.

Table 3

Summary of the Research Findings

A) Qualities of Program Philosophy and Model		
Philosophy		
	• Setting outside of hospital • Use of a paradoxical approach	
		- Focus on decreasing hopelessness and isolation - Acceptance of symptoms - Providing activation and client-centred approach
	• Length of treatment	
Model		
	• Flexibility and availability of program staff • Skills and strategies	
B) Qualities of Interactions Between Staff, Clients, and Program		
Interpersonal		
	• Consistency and reliability • Connection • Trust • Self-awareness	
Intrapersonal		
	• Self-awareness	

CHAPTER FIVE

Implications of the Findings

Introduction

This study was designed to examine participants' perspectives on the success of the Community Outreach Program. Three clients of the program and three members of the interdisciplinary staff were interviewed. The results of the interviews were presented in the previous chapter and summarized. In this chapter, I present the significance of the findings by addressing the initial research questions and the *a priori* knowledge or hypotheses upon beginning this work. First, I apply my critiques of the literature review to the findings and look at the implications of the literature on chronicity and iatrogenesis. I also examine the roles of biomedical, psychogenic, and the trauma-based theories in light of the study's findings. The second part of this chapter discusses the implication of the findings with regard to developing responsive treatment for eating disorders, in particular, what the findings suggest about the therapeutic relationships. In this section I bring in relevant literature on object relations (self-in-relation) and attachment theory. Finally, I look at the issue of the continued mis-identification of the problem and the pursuant difficulties in addressing the issue of eating disorders effectively. I suggest how this is further perpetuated by a false economics. This chapter thus presents a process of "theory-building" that has arisen from the confluence of *a priori* knowledge, the fieldwork, and the findings.

Significance of the Findings

In this initial section of the chapter, I reflect on the previous critiques of the literature review of Chapter Two and how they pertain to the findings from the study. I begin with the literature on chronicity and iatrogenesis, continue with biomedical and psychogenic models, and conclude with the trauma-based theories. The findings from the study are compared and contrasted with the findings from the literature review.

Chronicity

The literature on chronicity did not identify what "causes" an eating disorder to become chronic, but rather was more descriptive of what qualities and circumstances are correlated to chronicity. The literature showed that most studies have been short-term in duration and have tended to focus on weight restoration and mortality. Estimates that one in five eating disorders is likely to become intransigent are difficult to assess given the lack of long-term follow-up studies. Most follow-up studies have been attempts to measure the efficacy of treatments (of a usually brief nature) rather than to monitor the long-term course of eating disorders and the long-term effects of treatment.

My thoughts from conducting this research are that clinicians, researchers, and theorists must examine evidence that eating disorders are likely to be long-term illnesses—and often longer than currently anticipated in treatment programs. In fact, the language used to describe eating disorders (Theander, 1992) reflects a growing awareness that eating disorders are long–term issues, i.e, "protracted" eating disorders (15 years or less duration) versus "chronic" eating disorders (continuous for more than 15 years). Thus, treatment programs that are a few months in duration are unlikely to provide the on-going support necessary to make "recovery" meaningful or effective.

The lack of awareness of the long-term nature of the disorders seems to be inherent to the issue of treatment design. Most treatment programs have been of a relatively short duration or selectively focus on weight restoration and symptom management. (Certainly this had been the case with clients interviewed from the COP program.) The literature on chronicity is showing that good outcomes are expected in only 50% of patients with, 30% having intermediate outcomes, and 20% becoming chronic or intractable. Thus, it is necessary for treatment programs to be designed to address all degrees of transigency in order to promote effective recovery for all clients. Russell (1992) supports this, stating his belief that variability in outcomes may be due to a lack of knowledge regarding the natural long-term course of the illness in an eating disorder.

The client participants in this study had histories of hospitalizations and treatments that failed to address the problems of their eating disorder despite having had extensive care provided within the private and public health care system and (for Sarah) out of province treatment. Their illnesses fit with Theander's (1992) criteria for "protracted" eating disorders as all had a duration of less than 15 years, however, all three were at risk of mortality from the effects of their prolonged illnesses. While the Community Outreach Program was originally designed to address their specific and individual treatment issues, the program was unable to provide the length of treatment all three women felt was necessary to their recovery. I believe a prime concern that must be seriously addressed in the treatment of eating disorders is the expectation that service provision can be short-term, i.e., less than two years, for the most serious degree of affliction. Russell (1992) advocates not only for more long-term follow-up studies for clinicians but for more ongoing support for patients. Tolstrup (1992) states that treatment design must be cognizant of the fact that clients who do not recover in the short-term will require long-term support to prevent the feelings of failure that promote chronicity.

Therefore, a more realistic timeframe for treatment must be adopted within the Community Outreach Program and all eating disorder treatment programs.

A second consideration that arises from the literature on chronicity is the issue of relapse. Relapses must be expected and mechanisms should be built-in to treatment programs to assist clients with relapses. The literature shows that relapses occur when there is crisis or disruption in the client's life (Theander, 1992). Relapses were certainly evident in the allopathic-based treatment models that clients had encountered in previous programs in the province: symptoms were attended to but the underlying issues were not; women were repeatedly returned to their homes, families, workplaces, and communities once *symptoms* subsided but without treatment of the *problem*; and subsequently, relapses occurred. Relapses cannot be viewed as failures on the client's part but an expected part of the recovery process. Relapses must be anticipated, planned for in treatment design and delivery, and not viewed as the "institutionalization" of clients but a part of the process of attachment and separation from the program and staff.

COP was meant to stop the revolving door of treatment that resulted from this past approach, however, it is uncertain whether the issue of relapse could be accounted for within a proposed 18-month treatment plan with so few community resources available to these clients. Certainly, Michelle's distress about being discharged from the program could not have been conducive to recovery, and was likely to promote relapse. In particular with protracted and chronic eating disorders, it seems reasonable that support must be provided *throughout* the recovery process—not just during treatment—in order to appropriately manage and possibly prevent relapse. Most importantly, relapse prevention and management would likely prevent eating disorders from becoming more entrenched because of repeated "failures" upon discharge and the emotional toll that this places on clients and families.

Therefore, the literature on chronicity and relapse was supported by the findings from the interviews. The intent of COP was to stop the revolving door of treatment—the institutionalization of clients—for both fiscal and compassionate reasons. However, length of treatment was unrealistic given the literature on course of illness, degree of transigency, and relapse. Thus, an 18-month length of treatment is unreasonable for clients with protracted or chronic eating disorders. Instead, treatment may require a life-long provision of attention, support, and services throughout the course of illness.

Iatrogenesis

Garner (1985) found that iatrogenesis was a common phenomenon rather than an isolated event in eating disorder treatment, a result of lack of knowledge and misguided assumptions about eating disorders, and the negative emotional reactions that eating disorder patients elicited in the care providers. Goldner et al. (1997) found that iatrogenesis was also a result of pessimism. Thus, there is a strong need to educate and support the persons providing services regarding the nature of the illness, what the course of treatment will look like, and the effect providing services has on caregivers themselves.

When analyzing the findings from the study of the Community Outreach program participants, questions regarding iatrogenesis occur. For example, Sarah is asked to "step out" of the program when she has difficulty setting goals, despite the program knowing that Sarah had infrequent and inconsistent contact with caregivers, has required a considerable amount of time to form relationships with staff in COP. Sarah also had great difficulty with weight gain (one of the goals she is asked to set) and a horrific history with weight restoration which included having her requests not to be tube-fed overridden. . Although I was not privy to either Sarah's understanding of, nor the COP team's reasons for, her being asked to "step out," it seems counterproductive to have Sarah stepping away from a program that has provided some initial safety and support for her and in which a positive connection with her activation worker and a nutritionist was finally formed. Michelle, on the other hand, is working hard to meet her goals and seems to benefit from the program on many levels: decreasing her isolation; increasing her self-awareness, knowledge, and self-compassion; decreasing her shame about her bingeing and purging; voluntarily admitting herself to hospital for medical stabilization; and developing a trusting relationship with the psychologist. However, Michelle is being discharged from the program before she feels she is ready to do so which causes her much anxiety, anger, and desperation. Thus she clings to her eating disorder with even more vehemence. Her bulimia seems to provide psychological reassurance and security while her world is being drastically changed—"at least I still have my eating disorder." Decisions about terminating treatment seem to be based on an interpersonal conflict (e.g., Sarah's dismay with her case manager) and/or concern for the growing need for services (e.g., the waitlist). Although it is difficult to assess the effect of these treatment decisions for Sarah, such decisions are deleterious and iatrogenic in Michelle's case.

Is it possible that pessimism regarding client's recovery or outcome also influences such treatment decisions? For Sarah and Michelle, decisions to have them step out of treatment occur at a time when more short-term clients are entering the program. Amber talked of short-term clients being less onerous than long-term, and the decision to include them in the program was to give "a break" to activation workers. Decisions to bring in short-term clients appear to be based on COP's need to accommodate the wait list for services, the funder's need to decrease costs, and the needs of activation workers rather than on the needs of current clients (for whom the program was initially designed). I think the program's lack of awareness to the current clients' needs, the lack of attunement and commitment to their subsequent distress, and the unrealistic expectations on length of treatment create a negative and iatrogenic impact because they are based on "misguided assumptions" about course of treatment. For example, Sesan (1994, p. 262) comments about inpatient treatment, claiming that "women who continue to be symptomatic…are often expressing longing for or fears of connection with others. When symptom expression is prevented, these women may not be able to share themselves with others." Sesan advocates that instead of imposing greater isolation or *disconnection* on the patient, opportunities for *enhancing* connection should be made. Thus, I suggest that when Sarah continues to be "symptomatic" by failing to establish weight goals, the team's job is to enquire as to what the significance of this resistance may mean to Sarah rather than seeing her as treatment resistant and asking her to "step-out." Furthermore, removing Michelle from the program because of an arbitrary decision on length of treatment only serves to disrupt her progress and disconnect her from the relationships that assisted in reducing her symptoms.

An additional concern regarding the introduction of short-tem clients to the program comes from Amber's explanation that short-term clients were to provide relief for activation workers from the burden of working with more chronic clients. The issue of caregiver burden is important for as Garner (1985) states, lack of self-awareness, misguided assumptions, lack of information, and caregiver frustration contribute to iatrogenic treatment. Michelle and Sarah talked about the decreased service they perceived themselves receiving from their activation workers as the program progressed. Both Sarah and Michelle viewed this as a negative aspect of the program's popularity and a hindrance to their recovery. They felt that they did not get an adequate amount of time to spend with their activation workers and spoke of the difficulties and challenges activation workers had in travelling to meet with them. Furthermore, Amber's description of her 17.5-hour work week only emphasized the logistical challenges for activation workers.

Transition also played an iatrogenic role in client's recovery. Natalie spoke of the difficulty of adjusting to three different activation workers in her nine months in the program and Sarah of the disappointment of having a new case manager make changes to her program. After connecting with Trisha, Natalie is required to adjust to another activation worker when she leaves the program; Sarah attributes her difficulties in the program (and her subsequent "stepping out") to the interpersonal difficulties with the new case manager. All of these challenges and hindrances can be attributed to changes the program makes and not to any actions on the part of clients. The fact that the program was in constant transition—for both clients and staff alike—contributes to the negative outcomes as reported by the clients. While there is likely to be transitions in any on-going program, COP did not prepare for the emotional fall-out for clients as a result of these transitions. Instead, clients are asked to prepare to step-out of the program. In addition, none of the clients I spoke to had been able to make successful connections with healthcare providers in the community. While staff participants also spoke of the need to make connections with community providers, it was likely that such community connections would also take time to develop. This had not occurred when Michelle was being prepared for discharge.

With regard to caregiver burden, it is important to see how the work the activation workers provided was valued, undervalued, or devalued. This was done either by the workers themselves, by the program's outcome measures, or by the funder's decisions. Amber spoke of the need to constantly remind herself that her job, in essence, required her to pay attention to the subtle but significant changes clients demonstrated. As she stated, it was easy to minimize what clients were doing around food, isolation, and assertiveness, and thus easy to minimize her own work and its value.

The program itself devalued the work that seemed to go on in the relationships between activation workers and clients. Deborah's research focus continues to measure the "measurable" by tracking nutritional interventions. What is not recorded are the subtle, less measurable, relational interactions between worker and client that proved so instrumental to supporting change—for example, Trisha helping Natalie study before an exam, taking Natalie to breakfast and waiting until the exam is finished, and basically "holding [her] hand." While Deborah's research work may be legitimate given the dearth of such research studies in this area, what seems incongruent is the valuing of one paradigm (quantitative) over another (qualitative). This is evident in the funding decisions to support such use of the psychologist's time when concerns about cost containment is the rationale for reducing services to the current clients. Another example of value bias is evident in the fact that the activation workers were the lowest paid positions in the program after secretarial and administrative support staff yet seemed to have the most instrumental role in assisting with client recovery. Sarah reports being concerned about the activities she can take part in with her activation worker because she is unsure of how much money Amber is allowed to spend on such pursuits. Also, according to Sarah and Michelle, the (funder's) decision to bring in additional, short-term clients compromised the existing quality of relationships with long-term clients.

Neither does the program appear to be designed with concerns for the exhaustive work for activation workers in servicing this population of clients—as Amber's description of her 17.5 hour week reveals. The staff comment on the degree of difficulty encountered in working with these clients given their high degree of social isolation or impairment and their requirements for longer-term, securely-attached relationships with COP staff. Both Sarah and Michelle spoke of the difficulty in meeting with their activation workers and the disappointment and anger they felt about time together being compromised. Thus when caregivers are compromised in terms of support, access, financial compensation, and energy, client well-being is also compromised. Such decisions and actions can be viewed as iatrogenic.

Chronicity and iatrogenesis are inextricably linked in treatment planning, design and delivery for the clients in the COP program. While the original program design and execution was conducive to recovery, the decisions around funding and length of treatment were based on a narrow view of what eating disorder recovery involves, and thus proved to be iatrogenic. The next section fo this chapter examines the findings from the study and compares these with the findings on the biomedical, psychogenic, and trauma-based models of causality.

Biomedical Model

The histories of the client participants in this study demonstrated the shortcomings of the biomedical model of treatment as participants had been through all treatment programs this model had to offer in the province in their collective 31 years of treatment. Sarah in particular demonstrated this when she attended the "specialized" treatment program in the U.S., failed to meet their protocols, and was returned home early. As stated in the literature review chapter, I feel strongly that the biomedical perspective, while adept at *managing* the symptoms of clients' eating disorders, should no be viewed as *treatment* for an eating disorder—particularly for clients who have intractable anorexia and bulimia. For such clients, the biomedical model has failed to address the complex underlying emotional and social problems that bring them to the point of requiring medical treatment. Medical treatment must be seen as an adjunct to other forms of therapies that address the issue of how an eating disorder works on the client's behalf and which attempt to contextualize the personal and sociopolitical meanings of symptoms (Moore, 1998).

What is disheartening about the COP program is the continued determination to make a link between dietary behaviours and eating disorders as evidenced in Deborah's focus on developing a database with the nutritionist to examine the correlation between dietary interventions and client well-being. In the meantime, clients talked about the importance of relationships they are establishing (or failing to establish in the case of community connections) yet this goes "unmeasured" and devalued. While weight and food are important issues to address for these clients in terms of health, all three clients were reluctant and hampered by continued efforts to make and meet weight goals. I am reminded of Michelle's enthusiasm that the COP program was not going to reduce her to a "register of body values" such as previous programs had, while the irony is that "body values" continue to play an important role in the psychologist and nutritionist's time. Is this perhaps because such values are easier to measure than examining, describing, and qualifying the nature of human relationships? My concern is that the continued habit and practice of working a the biomedical perspective prevents careproviders from looking elsewhere to expand the understanding of eating disorders and to, therefore, develop effective treatments. Is the nutritional interventions database not simply "putting old wine in new bottles" while what may be really influencing recovery and creating change goes unacknowledged, unrecorded and unrecognized?

I had hypothesized that the focus on restoring "health' based from a biomedical perspective of weight restoration and other symptom reduction had led to what had been labelled as "client failure" in previous treatment programs and, thus, increased chronicity. It would appear that the continued biomedical focus of the COP program (despite the stated intention to move beyond this and to implement social rehabilitation strategies) continues to influence treatment outcomes because treatment efficacy is still measured by weight goals, hospital usage, and client improvement after relatively short-term interventions.

My observation is that the problem continues to be defined through a bio-medical lens rather than through a concern for the relational nature of both the development of and recovery from an eating disorder. Despite spoken agreement and discussion from all interview participants that the interpersonal relational nature of COP service providers and clients seemed to be making a significant difference in the client's recovery, treatment decisions seemed to "fly in the face" of such collective knowledge. Wooley (1994a and 1994b) speaks of a tendency for women's common knowledge to be lost or ignored in scientific formulation—particularly in the field of eating disorders: "Women's lifelong marginal status positions them to perceive, if not always to articulate easily, aspects of female experience not captured by our current science"(1994a, p. 196). She also states that psychology's "blind faith in empiricism is misplaced and implies that knowledge, a product of transactions, is as rich or as impoverished as the breadth of participation in the discourse." Certainly the voices of women with eating disorders has not often been included in treatment design nor in theorizing in the bio-medical perspective. COP's use of the findings from the patient focus group set the program on the right course—as evident in the unique treatment design for this eating disorders program. Peters and Fallon, (1994) state that "studies of eating-disordered women have been primarily studies of treatment outcome that employ behavioural parameters; they focus on what the person does rather than what she feels or who she is" (p. 546). Streigel-Moore (1994) states that an interactive stance with research participants expands knowledge of the phenomena under study and allows for more "textured analysis" of the problem, and I add, a more contextualized understanding of what is required in treatment. Peters and Fallon (1994) found that women they interviewed who had recovered from an eating disorders stated that recovery was a multi-dimensional process that "involves a progression of changes in relationships to self, body, family and culture" (p. 352) and that reciprocity between individuals both within and outside of therapy resulted in women feeling *connected* and that this connection was the foundation for personal development and recovery. Therefore, the current biomedical theoretical orientation and treatment model does not promote recovery because it refuses to acknowledge the relational nature of recovery from an eating disorder.

Sesan (1994) and Belenky et al. (1988) note the need for interactive teaching in education and therapy with women. "Connected teaching" is a model in which students gain knowledge within "the context of a relationship" (Sesan, 1994, p. 264) and where education is a "dialogue in assisting the students in giving birth to their own ideas, in making their knowledge explicit and elaborating on it" (Belenky et al. p. 264). Steiner-Adair (1994) suggests that therapy needs to be "a dialogue, a two-way interactive process" rather than a mirroring because a connected teaching model helps to demystify the therapy relationship and helps clients to learn important information about themselves while remaining connected. In addition, a connected teaching model helps clients by modelling a "real-self" as opposed to "false-self" relationships (Sesan, 1994). The COP clients remarked on such "connected teachings" and interactions with COP staff. For example, Sarah, Michelle, and Natalie all spoke of the ways in which they increased self-awareness of their disordered eating and its meanings in their lives while dialoguing with their activation workers.

A fast footing in a biomedical perspective may have hindered not only client's recovery in COP, but also COP's success in effectively treating clients. As Peters and Fallon (1994) suggest, the voices of eating disordered women must be "amplified" and allowed to teach service providers what is (and *must*) be involved in the process of recovery. In this case, client's voices were important in designing the program, however they were lost in the delivery of services as the need for "results" and cost containment dominated the process of recovery.

Psychogenic Model

The advantage of the psychogenic model is that it moves beyond the individual's physicality and presents a more wholistic approach to viewing the person as a human being with individual characteristics and family and social connections. Certainly the client participants' responses were conducive to an understanding of eating disorders from a psychogenic perspective. For example, Natalie spoke of her perfectionist tendencies with regard to her college entrance essay. Michelle and Natalie spoke of their negative self-regard and Sarah spoke of her difficulties with interpersonal conflict. All three COP clients spoke of their concerns about themselves in relationship to others. In addition, the participants did provide some information regarding their family situations (Michelle spoke of teasing and stigmatization as a child with an obese parent, Natalie told of physical abuse) but these were limited in detail. My length of and infrequent contact with participants did not promote more analysis of other psychogenic factors that may have contributed to the development of their eating disorders. Staff participants spoke in general of the COP client group and had more contact with participants and greater access to client files. Staff participants alluded to abuse backgrounds and "abandonment" issues with the COP population.

The psychogenic model is useful for understanding the impact of the relationships a person has with the world. As mentioned in the literature review, feminist critiques of the model centre on the tendency for the model to be individually- and family-focused without regard for the systemic influences that shape these relationships. Larger systemic pressures that impact women in general, such as violence, harassment, teasing, sexual abuse, were likely to have been a part of these clients' lives—but, I attained limited information on these. The literature does show a high correlation between abuse and eating disorders, however, it would be interesting to examine more closely the correlation of abuse of women with more intransigent eating disorders (Wooley, 1994a). Wooley (1994a) discusses the "concealed debate" regarding sexual abuse and eating disorders, noting the field's curious and historical reluctance to listen to and address the extent of sexual abuse reported by clients in the formulation of eating disorder etiological theory and treatment. She states that failure to do so by clinicians and researchers will force women to "eventually abandon treatments that don't meet their needs" (p. 200) and suggests that abuse histories are likely to be associated with "treatment failure, especially (but not solely) when abuse has not been addressed" (p. 192).

In terms of findings from the interviews, the activation workers and other staff in COP were developing on-going relationships with clients and getting to know varying aspects of their personal lives. For example, Amber talked about realizing that the client she was having coffee with had never eaten without her partner for years. Natalie spoke about having Trisha stay emotionally and physically connected with her through her college entrance work and the overwhelming negativity she felt about herself. Michelle talked about realizing how much she had come to rely on the program for simply talking to someone and her profound awareness that her eating disorder was a coping mechanism for dealing with emotional pain. In all these circumstances, activation workers were present in the places and ways that clients lived with their eating disorders. Information that may never be presented in a clinical situation is not only known and understood but also witnessed by activation workers and integrated into further treatment because of team meetings. Certainly, this type of contact would present information to staff not otherwise available regarding the psychogenic factors and influences that contribute to the development and maintenance of an eating disorder. Therefore, the unique setting of COP and the consistent contact the program provided promoted greater recognition and understanding of the psychogenic (and relational) factors—the places the women *lived* and *had lived*—and the contributions to the development and recovery from their eating disorders.

Trauma-based Theories

The literature on trauma indicates that clients may not recognize, remember, or reveal trauma until a strong therapeutic alliance is established and weight is restored (Wooley, 1994a). In addition, Larkin et al. (1996) suggest that women experience trauma in a variety of everyday occurrences that centre on their female bodies. An eating disorder, according to trauma-based theories, is a mechanism by which women have learned to cope with distress. Michelle exemplifies this when she states her belief it is a good thing she still has her eating disorder intact when she is being discharged from the program because "otherwise I'd have nothing."

Trauma is often kept "secret" because of the shame and isolation traumatized individuals experience and/or because they may have been ignored when trying to tell someone about their experiences (Herman, 1992). Given my limited contact with client participants, I did not encounter direct information that revealed further accounts of trauma than mentioned above. However, I believe that there were likely many traumas in the women's lives although I may not have been invited to share this information regarding their experiences. I also suspect that what I was seeing in my brief contact with clients was the *aftermath* of trauma. For example, it may be possible that the degree of social isolation the women described was indicative of historical experiences of trauma (Herman, 1992). In terms of the COP program, the long-term relationships and close attachments the clients form with the staff may help to illuminate clients' histories of trauma and begin to create "the fundamentals of recovery...establishing safety, reconstructing the trauma story, and restoring the connection between survivors and their community" (p. 3).

Trauma-based theories describe the way in which women use an eating disorder to cope with the resultant emotions, memories, and sensations of trauma. If women have experienced trauma, we need to examine what is significant about trauma to the development of eating disorders on both a psychological (Herman, 1992; Schwartz & Cohn, 1996; Wooley, 1994a) and physiological basis (Wooley, 1994; Levine, 1997). It is likely that the degree to which women experience a variety of disordered eating relationships to food and their bodies corresponds to the varied ways in which they experience trauma—perhaps daily—throughout their lives. In addition, it is important to understand the issue of resiliency and its connection to more chronic forms of eating disorders.

Herman (1992), Masson (1996), and Wooley (1994a, 1994b) recount the historical reluctance of the field of psychology to examine abuse and trauma. Herman states that late 19th century studies on hysteria, led by Freud, Janet, and Breuer, foundered on the question of sexual trauma and childhood exploitation and promulgated with Freud's recantation of his theory of the etiology of hysteria because of the social, professional, and political pressures of his time. As Herman states, "Freud glimpsed this truth and retreated in horror" (p.28). Early 20th century studies regarding trauma focused on men in combat returning from World War I and II, but this too lost scientific zeal as the world settled into Cold War "peace" time. While the Vietnam war renewed interest in trauma and post-traumatic stress, Herman claims it wasn't until the feminist movement of the 1970's that it was recognized that "the most common post-traumatic disorders are those not of men in war but of women in civilian life" (p. 28.).

I found Herman's (1992) account of the "therapeutic" interactions with between Breuer, Janet, Freud and their patients to be of considerable interest in my review of the research findings:

> ...Rivalry was particularly intense between Janet and Freud. Each wanted to be the first to make the great discovery. In pursuit of their goal, these investigators found that it was not sufficient to observe and classify hysterics. *It was necessary to talk with them.* For a brief decade, men of science listened to women with devotion and respect unparalleled before or since. Daily meetings with hysterical patients, often lasting for hours, were not uncommon. The case studies of this period read almost like collaborations between doctor and patient. ... The collaborations between

> doctor and patient took on the quality of a quest, in which the solution to the mystery of hysteria could be found in the painstaking reconstruction of the patient's past. Janet, describing his work with one patient noted that as treatment proceeded, the uncovering of recent traumas gave way to the exploration of earlier events....Breuer, describing his work with Anna O, spoke of "following back the thread of memory." (p. 11-12 [emphasis added])

Herman continues:

> By the turn of the century, the political impulse that had given birth to the heroic age of hysteria had dissipated.... The study of hysteria...had required them [Freud, Charcot, and Breuer] to listen to women far more than they had ever expected to listen, and to find out much more about women's lives than they had ever wanted to know. Certainly they had never intended to investigate the sexual traumas in the lives of women. ... The backlash began even before Charcot's death in 1893...As Charcot retreated from the world of hypnosis and hysteria, Breuer retreated from the world of women's emotional attachments. The first "talking cure" ended with Breuer's precipitate flight from Anna O... Abruptly he discontinued a course of treatment which had involved prolonged, almost daily. meetings with his patient over a period of two years. The sudden termination provoked a crisis not only for the patient, who had to be hospitalized, but apparently also for the doctor, who was appalled at the realization that his patient had become passionately attached to him. He left his final session with Anna O in a "cold sweat" (p.17-18).

I find these passages analogous to the interaction within the Community Outreach Program. It was "in pursuit" of finding specialized services for clients who had been failed by previous programs and were demanding treatment, and because of the growing pressure from grass-roots consumers and feminist practitioners insisting that treatment and research move beyond the biomedical inclination for classification and nosology, the "working group" was established. This working group invited and listened extensively to what clients had to say with "devotion and respect unparalleled before." The Community Outreach Program philosophy and design arose from these conversations. In accordance with this, clients received almost daily contact with the program via team meetings, appointments with clinical staff, and contact in their communities with activation workers. "Collaborations" between clients and the team were found in the "client-centred" approach and development of individualized goals. Like Breuer following back the "thread of memory," COP staff were privy and witness to the clients histories and experiences. But can COP staff, program administrators, and funding bodies bear to listen, long and hard, to what participants have to say? Can participants tell their stories that overtly or covertly indicate the degree of their need and still be heard? Participants spoke of needing companionship, financial and physical security, fun, and acceptance. Herman (1992) details the conscious and unconscious reluctance and denial often conveyed toward listening to what women have to say— particularly about trauma. Wooley (1994a) states that women will not be able to speak the "unspeakable" until the needs they currently present are met. Wooley (1994a and 1994b) also remarks on the reluctance of the research and theory to integrate common knowledge about sexual abuse and other traumas into the popular research literature. Historically (and again with COP), programs have not been designed to adequately provide time and conditions for women to develop the therapeutic relationships that will ensure their testimonies *can* be told and heard. My view is that neither the funders nor the public are prepared to examine how prevalent disordered eating and trauma is in the lives of females.

This first section of the chapter has looked back to the findings of the literature review and examined these within the context of the findings from the participant interviews. In the next section, I look at the original questions, hypotheses, and assumptions that I brought to the research to suggest what would make treatment responsive and what is at the heart of a therapeutic relationship.

What is Responsive Treatment with Eating Disorders?

In this second section, I look at two outcomes from the findings that address the issue of developing responsive treatment for eating disorders. The first is listening to what participants have to say about their needs. The second is to theorizing what contributes to developing a therapeutic relationship. Both outcomes answer some of the initial questions and hypotheses I brought to this work.

Listening to What Women Say They Need

Streigel-Moore (1994) and Wooley (1994a) state that in the field of eating disorders the repertoire of treatment theories must be expanded in order to identify and implement more appropriate treatment and prevention initiatives. To do so, we must first and more increasingly listen to what clients say they want and need. Therefore, according to the research findings from this study, basic needs such as safe and secure housing, and financial and physical security must be fundamental to any treatment program. Clients cannot do well if they are not able to take basic care of themselves. While COP attempted to address these fundamental needs, physical and financial security are ongoing issues in the lives of women and were certainly so for the COP participants. On a less primary, but nonetheless important level, companionship was also a fundamental need the program attempted to address and, given their isolation, something that the participants needed in significant amounts. Clients indicated, however, that while this component of the program was instrumental to their success, it was met less consistently as COP progressed. This was largely a result of increasing the ratio of clients to staff in the program and implementing a time limit on length of treatment.

Decisions to do so were based on "economics"—i.e., the waitlist for services and pressures to provide treatment to more women who heard about COP from other programs. At some level, COP was a victim of its own success. As women who were considered to be treatment resistant began to do better, other women, who were at less critical levels of illness also wanted access to the program.

I would consider the decision to limit the original clients' time in the program as a decision based on "false economics." Not permitting participants to complete the program as they needed to and removing them before they felt ready only served to increase anxiety and trigger more eating disordered behaviour. The decision to not provide treatment on an on-going basis increases the likelihood that clients would be returning for treatment in future when they relapse. If, however, eating disorder programs built-in relapse support—which I see as a part of on-going recovery—the likelihood that someone would return to the program in serious medical condition would be lessened. In essence, the decision to pull people out of treatment before they are ready only replicates the revolving door of treatment of previous programs (and which are still prevalent throughout the province). I believe that the program should have stayed with supporting the six original participants and followed them through until the women decided they no longer needed the services. I hypothesize that clients' need for COP will decrease when they are reliably, consistently, and thoroughly addressed in the first place.

A second criticism of the length of treatment is that without adequate services developed in the community, clients do not have the opportunity to be supported outside of the program and will remain dependent on COP. Community "outreach" was not, in my opinion, established and thus, clients were at greater risk of relapse. What are community linkages and how are they made meaningful if no time nor money is invested in the development of such services? If current program limitations are necessary for balancing the budget for the provincial eating disorders program, then moving clients into community before there are sufficient services are established is simply "off-loading" the problem into other healthcare department budgets. If the underlying aim is to get people out of hospital and, thus, reduce costs by reducing dependency, then other services must be made available in the community before clients are "de-institutionalized." Off-setting costs to other areas (mental health, paramedics) is really nothing more than a "shell game"—where costs are moved from one area, to another, to another—and, in effect, decontextualized.

A third criticism of decisions based on "false economic" is the still greater costs inherent to women being chronically incapacitated and/or dying after many years of on-again/off-again treatment. I believe, however, that women with eating disorders do not likely "cost" much to the system because, given the nature of eating disorders, they will not likely to call attention to themselves if they become disenfranchised. Women with eating disorders are similar to many women—well-socialized to curtail their activities and themselves and to conform to the "tyranny of niceness" (Steiner-Adair, 1994). Women with eating disorders tend to conduct themselves in ways that come at great personal cost in order to avoid inconveniencing others and create increasingly smaller worlds of social isolation. Women who are discharged from treatment in an already overburdened public health system and who can't afford private clinicians are likely to simply die. These costs are not calculated when operating from a perspective informed by false economics. Who will be accountable for the types of decisions that effect women's lives in this way? What is the impact of cost-cutting measures? If there is more need than available services it is imperative that we endeavour to create services that work and create plenty of them. In other words, we need to "turn off the tap instead of stepping on the hose" (PEDSC, 1999). This also implies that as a society and culture—we must carefully examine the role, meaning, and value of early intervention and prevention. Wolf (1991) feels that the lack of response to women and girls struggling with eating disorders/disordered eating in indicative of the devaluing of females in general:

> How would America react to the mass self-immolation by hunger of its favourite sons? How would Western Europe absorb the export of such a disease? One would expect an emergency response: crisis task forces convened in congressional hearing rooms, unscheduled alumni meetings, the best experts money can hire, cover stories in newsmagazines, a flurry of editorials, blame and

> counterblame, bulletins, warning, symptoms, updates; an epidemic blazoned in boldface red. The sons of privilege *are* the future; the future is committing suicide. Of course, this is actually happening right now, only with a gender difference. The institutions that help shelter and promote these diseases are hibernating. The public conscience is fast asleep. Young women are dying from institutional catatonia....The world is not coming to an end because the cherished child in five who "chooses" to die slowly is a girl (p. 180-181).

What contributes to the problem of false economics is the persistent definition of the problem. If the medical model continues to dominate theory and treatment and views the issue as simply anorexia and bulimia (rather than a widespread continuum of disordered eating), our solutions will continue to be myopic. We will always be at risk for relapse and revolving door treatments if we refuse to address the true scope of the problem. To better understand the problem we must continue to listen to what women say, and in order to do that, we must position ourselves in relationships that support women telling their stories.

Theory-building: What Did Participants Say was Therapeutic?

The participants stated that what made a difference was the quality of relationship and support of the program. But how does this relate to an understanding of providing responsive treatment? First, we must make treatment fit with what the client's stated needs are. The Community Outreach Program attempted to do so. Where is was successful, I believe, is when it encouraged the formation of attachments; where it failed was when client's need for attachment were thought to be too overwhelming for program's abilities and protocols. At this point, clients were labelled as "dependent" and dependency was seen as problematic and reacted to negatively. What constituted a therapeutic relationships were qualities of contact that provided consistency, reliability, trust, connection, concern, and self-awareness. Clients, as reported in Chapter 4, stated they found benefit when they were being supported and encouraged, and when spending time together with their activation workers. Support cannot be underestimated and should be central to any program providing therapeutic treatment to individuals with eating disorders. Support is not secondary to any other treatment modality—but is an integral, adjuvant, component.

> According to some researchers, an intimate, loving relationship as an adult can offset many of the harmful effects of childhood adversity and parental deprivation. Whom you choose to be with in a relationship—and how you relate to that person—can either help overcome adverse childhood experiences or reinforce them (Ornish, 1998, p. 40).

Programs also must value the benefit of support by providing this to the workers (i.e., education, supervision, reimbursement) to reflect the value and therapeutic impacts of their work.

My *a priori* theory about eating disorders hypothesized that it was the contact with the activation workers in the community setting that made a difference for clients. What became more clear to me in analyzing the findings is that eating disorders are about attachment and separation in relationships (Belenky et al., 1986; Larkin et al., 1996; Peters and Fallon, 1994; Rice, 1996; Steiner-Adair, 1991, 1994; Wooley, 1991, 1994a) —clients are hurt in relationship, and clients are healed in relationship. The issue of treatment, then, is more complex and dynamic than current funder/stakeholders are prepared to address. Treatment programs, then, must provide education on the nature of eating disorders to funders in order to develop strong philosophical ties—to have them "buy in" to the solution—and combat the impact of false economics and limit the human costs (iatrogenesis) of failing to provide adequate services. This approach to treatment and the theory behind it are discussed in the following section using the object relations, self-psychology, or self-in-relation theory.

Reflection/Discussion

"No single model is comprehensive enough
to explain all facets of human experience" (Corey, 1996, p. 3)

I believe, like Corey, that any approach to therapy is likely to be more beneficial when various models, techniques, and theories are arranged to best attune interventions to the needs of the client. In the area of eating disorders, this is of special importance given the lack of a comprehensive understanding of what causes an eating disorder in any particular individual. Given Corey's statement and with an acknowledgement of the limitations inherent to any theory-building, I have found the work of developmental psychologists to present the best way to interpret what the interviews revealed and to explain the significance of the findings. In doing so, the most poignant and fitting examples I found were in Heinz Kohut's (1959, 1971, 1977), Carl Rogers' (1957, 1961, 1977), and D. W. Winnicott's (1958, 1960a, 1960b; 1965; 1971) descriptions of child development. In fact, as the participants spoke, I often heard words similar to those with which they summarized human development. I will describe the parallels between the research findings and the developmental theories of the self.

Kohut's (1977) self psychology and Rogers' (1961) person-centred theory have largely shaped my approach to the findings because of their positive and optimistic views of human nature. Kohut claims that the "self" gets formed *in relationship*. Winnicott (1960a) suggests that the individual grows, *through dependence on another*, to a personal way of being and that early environment makes this possible. Rogers proposes that the underlying motivational force in human nature is the "*actualizing tendency*"—a growth-directed process that pushes us toward reaching our full potential. I agree with these thoughts and suggest that maladaptive, self-limiting, or self-destructive behaviours are not irrational, but can be understood as self-survival and, therefore, amazing adaptations to less than ideal conditions.

The Community Outreach Program promotes similar ideas in its treatment approach to eating disorders. They see an eating disorder as providing a significant coping function for the client—and if a therapeutic relationship (*dependence on another*) is established, perhaps the pathogenic secret (Beaumont, Russell, and Touyz, 1995) behind the self-destructive behaviour will be revealed. However, the illness is not the sole focus of treatment in COP, contrary to previous programs the clients attended. In COP, the client is seen as a whole individual rather than a "register" of illness symptoms. The COP philosophy echoes the idea of a "growth-directed process" in that when treatment focuses on the whole person (her interests and values outside of food, weight, or body-related concerns), the client is motivated to develop the skills necessary to achieving social, vocational, recreational goals (Dobney, Lauritzen, and Zaitsoff, 2000)—in other words, the *self-actualizing tendency*. COP also recognizes that client change occurs *in relationship*, i.e., "readiness to change is not a client trait, but a fluctuating product of interpersonal interactions" (Dobney, Lauritzen, and Zaitsoff, 2000).

Winnicott (1960a) stated that the most fundamental need for individuals is the need for relationship. Growth is an on-going task of psychosomatic integration. Winnicott stressed the need for a continuity of care (which he called "good-enough mothering") to sustain the "life-line" of the infant at the earliest stages of its life. He regarded illness as the inhibition of the potential spontaneity that characterized a person's aliveness. Winnicott claimed that psychopathology originated in the *breaks in continuity* of relationship. Such breaks were the result of the distractions in a person's early development, i.e., gaps caused by the intrusions and deprivations and natural catastrophes of childhood which he saw, mostly, as the result of failures in parental provision.

Kohut (1959) saw psychological problems as a result of unfavourable conditions for growth that created "chronic empathic failures" or traumatic events in the individual's history.

Faulty personality development was the result of *injuries* or *empathic failures* and, more severely, *derailments* at different developmental stages throughout life. Kohut talked about three different stages of development—mirroring, idealizing, and twinship—which fostered an integrated self that permitted interdependence, self-direction, and the freedom to make informed choices. When there were deficits at these stages of development, one's ability to reach one's potential was hindered by compensatory character structures, such as an eating disorder.

Rogers (1961) saw pathological personality development arising as a result of incongruency between an individual's *ideal* self and the *real* self. Such incongruency is formed by *conditional positive regard*, as a child learns early on to deny or disown authentic parts of the self in order to live up to *conditions of worth* that allow it to remain in emotional connection with caregivers. Rogers believed not only were early caretakers influential in the development of incongruency, but that social forces and social values were problematic when people sacrificed inherent self-actualizing tendencies in order to maintain connections with the social world. Rogers stated that in doing so, people lost touch with their inner growth process, learned to distrust their feelings, and disturbed the natural *organismic valuing process* (Corey, 1986). Rogers emphasized that significant personality change does not occur *except* in relationship (1967).

The Community Outreach program, or any treatment program or care provider, is a "holding environment," a "safe place," a "mother" on which (or who) the eating disordered person can depend while they simultaneously grow. This is precarious, however, because programs and therapists are not dealing with an infant but an adult woman. The program is working with a woman who is presumed and appears to be capable of growth or change, when she may, in fact, be least capable of helping herself. Sarah is a good example of this situation. She appears to be highly motivated for change, however, has great difficulty making a connection with program staff on whom she is reliant for care. In fact, her inability to attach is of serious consequence and she is asked to step out of the program to better discern what *are* her goals in the program. Amber states the program is not for everyone because "[the client] needs to be in a place where she can set some goals for themselves and have some level of commitment. Because this isn't a program that's going to hold your hand in a lot of ways...". Amber's statement seems to suggest the frustration that occurs by this seeming appearance of capability and, yet, the refusal of care. The professional finds it difficult to hold the reality of the client, precisely because of that appearance of capability. This is also mitigated by the fact that the client's "reality" is mutable—transforming within hours, days, and weeks—depending on how stable the clients "self" is at that moment.

In Winnicott's theory (1971) of human development, it is the mother as the first environment (like the activation worker), who "actively adapts" to the needs of her infant. In Winnicott's terms, the child has the natural right, initially, to use the mother "ruthlessly" for the recognition and gratification he requires to develop: "Without someone specifically oriented to *his* needs, the infant cannot find a working relation to external reality" (1958, p. 58). But if the mother is unable to adapt to the child's needs, due to some reasons in her own personal development and is, instead, intrusive or demanding the child must become falsely compliant in order to maintain the maternal connection. Kohut identified this interaction as the development of the false self.

Client growth or recovery is dependent on an experience of "good-enough mothering" wherein the program, or caregiver, provides a continuity of care attuned to the needs of the client. This would require patience, consistency, skills, and the ability to tolerate being needed by the client for as long as the client perceives attention is necessary. Continuity of care means not pushing the fledgling out of the nest before it can fly. Natalie provides a good example of how difficult this is to do. First, the program needs to provide services to the province—as waitlists lengthen and the demand for services increases. As Christine reveals, "In some ways you have to force the issue of spreading your wings". Second, the appearance of capability and the compliance of the false self complicate this. Natalie's suggests that others may need the program more than she does, because she is doing well. Fortunately, Natalie has care providers who recognize the "false self" statements, and are attuned to Natalie's needs for support while she returns to school. Natalie continues with the program for another six months.

Attunement is a quality inherent in COP's use of the harm-reduction model and the activation model. Harm-reduction honoured the client's need for restricting, bingeing and/or purging and did not try to take away a function that she was not ready to give up, nor that treatment had offered an adequate replacement for. Staying focused on enhancing her quality of life rather than on stopping the symptoms of the eating disorder was like the mother attuning to the needs of the child in a compassionate and self-esteeming way. Additionally, focusing on the client's strengths and successes by breaking self-determined goals into easily achievable steps creates an environment where the client is not overwhelmed by the demands of the social world. COP "actively adapts" to establish conditions for a "the working relation to external reality" for the client.

The failure of the program to attune or to be flexible to the needs of the participants thwarts the potential for growth and recovery. Failure on the part of the program equates with the chronic empathic failures or breaks in continuity that lead to pathology. Garner (1985) and Goldner et al., (1997) recognized the iatrogenic nature of these empathic failures of attunement in previous treatment regimes. Sarah and Michelle talk about the breaks in continuity and the deleterious effects and anxiety caused by activation workers becoming less available. Michelle has a major break in continuity when she is told she must leave the program. Although

Deborah, Amber, and Christine all speak about the negative impacts of the program's time limits, the waitlist pressures, and the constraints and expectations of the funder create a *derailment* tantamount to the failures of parental provision that result in pathology.

Failures can occur at the level of the support system and negatively influence growth and recovery. Inadequate housing, lack of money for food and leisure activities with clients, the lack of weekend and holiday support, as Michelle suggests, are all growth-inhibiting. Another example is to examine such failures at the systemic level—is there adequate provision for staff training, adequate time for meeting clients, supervision and support for activation workers, validation, recognition and financial compensation for the services being provided. Finally, trauma-based theories of eating disorders document the myriad ways in which there is a societal failure to provide basic necessities such as physical and emotional security and human dignity to women.

If the program is unable for a variety of reasons to adapt to the client's needs and was "intrusively demanding"—i.e., as Christine states:

> "I'll help her connect with those people (in the community). And I want that to happen now, because I want her to establish a relationship with this person...She needs to be moving in her life and that needs to be putting St. Paul's a bit behind her...or a lot behind her.

—a precocious compliance is fostered in the client in order to meet the demands of the Community Outreach Program. Clients may get good, but not better, such as was indicative of Natalie's response.

Compliance is a crucial issue for Winnicott (1960b) because of the fact of dependence—the infant needs the mother to survive, as the clients need the program—there is no other treatment available at this point. In Winnicott's view, the infant relies on the mother's firm attentiveness for survival, similarly (and particularly given the chronicity of these clients) as the clients need COP for survival. For example, Michelle's speaks about how the food supplements are her one "safe" food, how much she has come to depend on the program, and how much she "needs the program for practical issues, to help me with loneliness, just someone to talk to". Ultimately her death illuminates the true survival relationship some clients will have with the program. But Winnicott also acknowledges the mother's need to rely and depend upon the people around her that will enable her to be available to attune so well to the child. The program also needs this type of support—from colleagues in the community, collegial relations with each other, the funders, the hospital, the families, the social support agencies. Covington (2000) states that for treatment programs to have integrity, all decision-makers must "buy in" to fully support the program. If the program lacks integrity, then the clients cannot re-establish integrity. The support of the larger social context is identified as pertinent to growth and recovery.

Rogers' research (1957) found that the most significant element in determining the effectiveness of counselling is the *client's perception* of the quality of the relationship with the therapist. Kohut (1984, p. 213) echoes the importance of this stance, "The patient, as I finally grasped, insisted—and had a right to insist—that I learn to see things exclusively in his way, and not at all in my way." Duncan & Miller (2000*)* state that client perceptions of relationship factors such as empathy, warmth, respect, and genuineness account for 30 percent of successful outcomes. They cite research demonstrating that client perceptions of the relationship are the *most consistent predictor* of improvement and call the client's perception as the "trump card" of therapy outcome, "second only to the winning hand of the client's strengths" (p.72). Orlinsky et al. (1994) concluded in their extensive review of the literature on therapeutic alliances between clients and caregivers that:

> The quality of the patient's participation in therapy stands out as the most important determination of outcome....The therapist contribution toward helping the patient achieve a favourable outcome is made mainly through empathic, affirmative, collaborative, and self-congruent engagement with the patient....These consistent process-outcome relations, based on literally hundreds of empirical findings, can be considered *facts* established by forty-plus years of research on psychotherapy (p. 36i, italics in original).

I would suggest that the Community Outreach Program continue to focus on the attachments/alliances clients form. Furthermore, the "success" of COP is directly related to the clients' perceptions of the therapeutic relationships.

To "successfully sponsor the development of another person," Rogers (1967, p. 73) claims, requires a strong alliance with the client, the client's own experiences of safety and acceptance, and the therapist's empathic understanding. Both Natalie and Michelle provide examples of Rogers' theories at work. When Natalie and Michelle experienced acceptance, non-judgementalness, and empathy with their activation workers, profound self-acceptance happened. When Natalie experiences Trisha's acceptance of her, she begins to believe she is a lovable person; however, when Michelle perceives first her activation worker is rejecting her, then the program, her self-disgust is rampant.

Rogers (1967) was also a proponent of establishing a collaborative relationship with the client taking an active stance in assuming responsibility for the direction of therapy. His intent was to foster an *alliance*, not a *reliance*—although he thought that initially the client may need to experience a temporary reliance on the therapist because the therapeutic relationship may be the first place the client feels heard and understood, seen and validated for their "real self." The COP program adopted a similar stance, noting that previous program failures reported "doing more work than the client," taking on too much responsibility for the client's medical severity (forced hospitalizations, decisions to tube-feed), and establishing "expert/recipient" roles between care providers and the client (Dobney et al., 2000). Instead, COP looked to establish more "partnerships" with both the client and the community service providers; incorporated the ethical decision-making model, and had a client-centred approach.

Duncan and Miller (2000) suggest that it is clients who determine "theory" for therapeutic change. They state:

> Because all approaches are equivalent with respect to outcome, and technique pales in comparison to client and relationship factors, an evolving story cast the client as not only the star of the therapeutic stage, but also the director of the change process... We now consider clients' worldviews, their maps of the territory, as the determining "theory" for therapy, directing both the destination desired and the routes of restoration (p. 78).

Thus, listening to clients is essential to the understanding of etiology and direction of treatment.

In this section of the chapter, I have drawn parallels between the developmental theories on human development and the establishment of a psychological self and the philosophies, practices, and experiences in the Community Outreach Program. The next section looks at the original research question: was COP successful from the perspectives of participants and why?

Conclusions

> What is most meaningful often cannot be measured. What is verifiable may not necessarily be what is most important. As the British scientist Denis Burkitt once wrote, "Not everything that counts can be counted." (Ornish, 1998, p.4).

Was COP successful?

Initially, participants in the Community Outreach Program were asked whether they felt COP was successful. The question was never answered directly and from the findings I find that the question of "outcome" is perhaps not answerable. It is difficult to ascertain "success" because of the limited amount of time spent with participants. The data on chronicity and recovery indicates that "success" needs to be evaluated over a longer duration that could extend for decades. It seems unfair to pronounce whether COP was successful from the perspectives of the research participants given these limitations.

However, there were indicators of success in the program. As reported in the preliminary report and by the participants, clients' hospitalizations, acute care and emergency room admissions had decreased. Two of the clients I spoke with reported returning to school or being more active in the community. All three clients spoke of decreased hopelessness and isolation and increased contact with staff members (however, it is possible that this was only a temporary state for Michelle and Sarah). Both clients and staff indicated that clients expressed less hostility and anger about treatment, were more proactive in treatment, and had met some of the goals they had set out for themselves.

Indicators that the program may have been less successful were the number of relapses clients struggled with, one client's need to "step out" of the program, and of course Michelle's subsequent death. However, unfortunate as these factors were, given Russell's (1992) findings on the course of chronic eating disorders and issues of relapse it is unfair to consider these as treatment failures.

One of my criticisms of the program pertains to the program's philosophy of client-centred care and social rehabilitation when this conflicts with the program's ability to deliver services to the clients on an as-needs basis. The question that continued to reoccur when I examined this aspect of the program was whose need is being attended to—the funder's or the client's? Who is truly at the centre of the program's focus? This incongruency was consistent with my *a priori* knowledge that there is a confounding variable of false economics with the program's success. The main impetus for the development of COP was a funding concern—the need for cost containment and demand for services from this unique client population. Requests for out-of-province treatment were becoming more frequent and current programs were becoming a costly series of repeated admissions for the Ministry of Health. The program's aim was to reduce hospitalizations and *impact* the outcomes of the "hard to treat" patients who were absorbing so much of the limited funding of eating disorder programs. It appeared to me that the program was greatly compromised by the continued pressure to reduce costs rather than to truly provide the type, scope, and length of services required to address the issues these chronic clients were bringing to treatment. For example, the addition of short-term clients to the program was likely a decision to reduce the wait lists and appease the funder as to reduce the burden to program staff. The need to discharge people from the program had more to do with the wait list pressures than on the well-being of the clients. The anguish, pain, and frustration that Michelle expressed upon hearing she was needing to detach, her dropping out of the interviews immediately after the announcement, and her subsequent death are difficult to overlook. Unfortunately, significant changes that the women were making did not necessarily translate to the funder's ledger of credits and debits.

A second hypothesis that was supported by the findings was that the role of the activation workers was therapeutic and seemed to make a difference to these women's lives. The connections and attachments that all three of the clients had made with their activation workers brought about profound personal change. What was significant was the fact that the clients had someone who was consistently available to meet with them in their communities and to spend time with. It was in the daily interactions—skim milk lattes; having a bowl of soup; talking about a movie; studying with someone and being reassured about personal competence; laughing and crying in the company of a warm, caring, and compassionate person; being picked up and taken for breakfast before an important exam—and the conversations that occurred during these interactions that was therapeutic. Again, these are events—connectable moments—that are not easily quantified.

A third hypothesis was that focusing away from weight would be a more helpful approach to treatment. My experience in the support groups taught me that the women were "more than just their eating disorder." The program's purposive focus on quality of life was invitational to clients, solicited a higher participation, and fostered trust. The program's flexibility was crucial to meeting clients at their level of ability and maintaining and deepening that trust.

What Qualities of Interactions Facilitated Change?

A second question that initiated this research was to determine what may have altered the "revolving door of treatment" for these clients. The findings indicate that it was the program philosophy and model that made a difference. However, I also find the literature on attachment useful for explaining the interpersonal phenomena that seemed to make this occur. A distressed infant is comforted by the sight, sound, and touch of its caretaker. The infant wants its caretaker and wants to be sure the caretaker is always there. As the child grows and develops, it ventures further away from the caretaker, gaining courage for increasingly more distant expeditions and explorations of the world. But the child can only attain ultimate independence when assured that there is a secure home base to return to when the child experiences unmanageable threats or challenges. The caretaker is seen as the fuelling station for the adventures and a safe harbour for refuge and to gain reassurance and encouragement to venture out again (Hendrix, 1992).

Separation from the caretaker evokes distress. As children get older they become increasingly secure in the knowledge that the mother will be there when needed; they can rely on this and therefore tolerate increasingly longer separations. According to some psychologists, this emotional knowledge provides a basic trust which then serves as the foundation for further attachments and allows the child to become independent and a well-adjusted adult (Erikson, 1963).

The program staff, and particularly the activation workers provided often daily contact and support to women who were extremely isolated and hopeless. The program created a transitional holding space—the safe harbour and fuelling station—that allows the client to explore the world. The program's consistent and longer-term contact with clients, and the personal nature and relaxed locations of interactions between activation workers and clients, permitted the program to recognize the incredible complexity of these clients' lives. Trisha helping Natalie study for the exam, reviewed her college application, made sure she had a ride, and waited while she completed the exam, thus creating safety for Natalie to venture further in the world of college and move toward greater independence.[1]

It may be that the therapeutic benefit of consistent support is so valuable to growth and recovery in women with chronic eating disorders that it should be *central* to treatment rather than an adjunct to treatment. This has implications for the further development of support services in the community and the ability to teach and learn what supportive relationships look like and are manifested. As Ornish (1998) reports:

> When people state that they have others who really care for them, with whom they feel close to, who love them, in whom they can confide, and who want to help them, their risk of premature death and disease from *all* causes was three to five times lower than those who reported they didn't have this support. Social support is defined as information leading the subject to believe that she is cared for and loved, esteemed and a member of a network of mutual obligations (p. 28-29).

In summary of this section on the significance of the findings, participants were able to delineate what constituted a therapeutic relationship. These were the ability to foster attachments via interpersonal qualities of consistency and reliability, connection, trust, self-awareness and humour. In addition, attunement to the needs of the clients and their present

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[1] Of note, Natalie has completed her college training, found full-time employment, and is involved in a long-term, intimate relationship.

level of readiness was imperative. This required a program and staff who were flexible and available, and who believed in the client as a whole human being with strengths and abilities.

Summary

This chapter has provided a discussion of the significance and implication of the research findings. The use of developmental models on self psychology by Kohut, Rogers, and Winnicott were used to describe the interactions and experiences that research participants found enhanced their growth and recovery. The two initial research questions were answered: was COP successful from the participants perspectives and what aspects of the program seemed to alter the revolving door of treatment these clients appeared to have been trapped in. The qualities of a therapeutic relationship and recommendations for eating disorder program development were provided in a discussion on developing responsive treatment programs. Finally, a contextualizing of the data was provided by revisiting the literature review and juxtaposing the findings with the critiques on chronicity, iatrogenesis, the bio-medical and psychogenic models, as well as looking at the trauma-based theories of eating disorders.

APPENDIX A

Provincial Framework of Eating Disorder Services

Primary Services

Provincial and local grassroots organizations

Self-help support Groups, Facilitated Support groups, Family physicians

(E.g., ANAD, B.C. Eating Disorders Association,

Eating Disorders Resource Centre of B.C , B.C. Coalition to End Disordered Eating.)

Secondary Services

Diagnostic Assessments, Psychoeducation, Nutritional Counselling,

Monitoring clients released from tertiary care

Psychotherapy (group and individual formats),

Public Health Units, Mental Health Units, Private Practitioners,

Tertiary Services

Acute Care Hospitalization, Specialized In-patient treatment,

Day treatment program, Residential facilities

- St. Paul's Hospital (Adult Care-8 Beds for Province)
- B.C. Children's Hospital (Child and Adolescent Care- 3 Beds for Province)
- Vista Residential Facility (Adult)
- Hudson House Residential Facility (Child and Adolescent)

<u>Quaternary Care</u>

Specialized Intensive Care

Re-feeding, Acute Psychiatric Unit, Family Medical Units

Community Outreach Program

APPENDIX B

Definition of Terms

The following terms are defined as they were used in the context of this thesis:

Activation: A process of providing opportunities to clients to participate as fully as possible in their return to health and well-being through increased activity in defining goals and decision-making, through active engagement with others, and with supported experiences in the community.

Attachment: To bind by affection. A process of learning to intimately connect with others based on the perception of trustworthiness and reliability in the relationship, over time. Bowlby (1973) views the ability to form bonds with others as critical to optimal personality development and mental health.

Client-centred approach: An approach to treatment which recommends services be designed so they are responsive and adaptable to the client's individual needs as the client defines them (Moxley & Freddolino, 1990).

Chronicity: An unrelenting form of illness that continues for an extended length of time, possibly for rest of one's life.

Congruency: Authentic communication reflecting consistency or agreement between expressed intentions, thoughts, and philosophies and actual behaviours and actions. Another term, which refers to this, is "genuineness" wherein the person presents as what s/he seems to be (Kitchener, 1992).

Consistency: Maintaining the same stance, quality, principles, or course of action in a relationship that contributes to the texture of the relationship.

Empathy: The ability to recognize, sense, and accurately perceive and communicate understanding and acceptance of another's behavioural and verbal expressions of feelings with sufficient detachment to avoid becoming directly involved in those feelings (Kitchener, 1992). In psychology, the process of entering fully, through the imagination, into another's feelings or motives.

Empowerment: The promotion or attainment of autonomy and freedom of choice for individuals or groups. Non-controlling, non-possessive, non-judgmental behaviour on the part of the person "in power" that creates a safe atmosphere and gives decision-making power to others, resulting in a perceived sense of enhanced abilities necessary to successfully influence one's environment (Kitchener, 1992).

Ethical decision-making model: A verbal and written process whereby a course of action to be taken by care providers, on behalf of a client, is determined. During the process, the client and others involved in her care identify the decision-makers and the client's personal limitations, generate alternatives, assess feasibility, and develop ongoing planning.

Forced Committal: When a person is legally certified under the Mental Health Act as incompetent around self-care decisions, and/or poses a threat of violence or harm to herself or others. Upon certification, she can be legally forced to hospital for treatment against her consent.

Harm-reduction approach: Adopted from policy work in the field of drug and alcohol treatment. In eating disorders, an approach to treatment which attempts to decrease the negative consequences of eating disorder behaviours by tolerating the symptoms rather than insisting on abstinence, educating clients, and permitting access to various treatment options. The aim is to reduce the need for disordered eating behaviours by identifying their usefulness to the client and establishing other mechanisms for coping.

Interactions: The exchanging of messages or actions on each other, transmitted physically, verbally or non-verbally, that occurs among people involved in the communication process. (Kitchener, 1992)

Occupational therapy: A model of rehabilitative practices which works with the client to define, establish and meet self-defined goals. The emphasis is on assessing the client's current skill and abilities level and breaking the goal down into manageable steps. This approach is used to encourage success and motivate the client to continue to strive toward the goal.

Paradoxical approach: An approach that places emphasis on addressing interpersonal issues and less focus on addressing the client's nutritional status and eating behaviours. The paradox is that in treating the interpersonal issues, changes in the nutritional and eating behaviours are observed.

Psychosocial Rehabilitation Model: A program model where services are designed and delivered in a manner that enhances clients' control over their own lives via a commitment to client self-determination, client involvement in evaluation, and the empowerment of clients as advocates (Moxley & Freddolino, 1990).

Quality of Life: The perception of areas of importance and satisfaction in one's life, as defined by the client, and including but not limited to satisfaction with health, self-esteem, goals and values, finances, occupation, recreation, education, creative and leisure pursuits, friendships, family, intimate relationships, sense of community, residence.

Recovery: A process of coming back to health or normal condition, or recouping that which was lost, taken away, or stolen. The act of locating, repossessing, or reclaiming one's position of mental, physical, emotional, and social health.

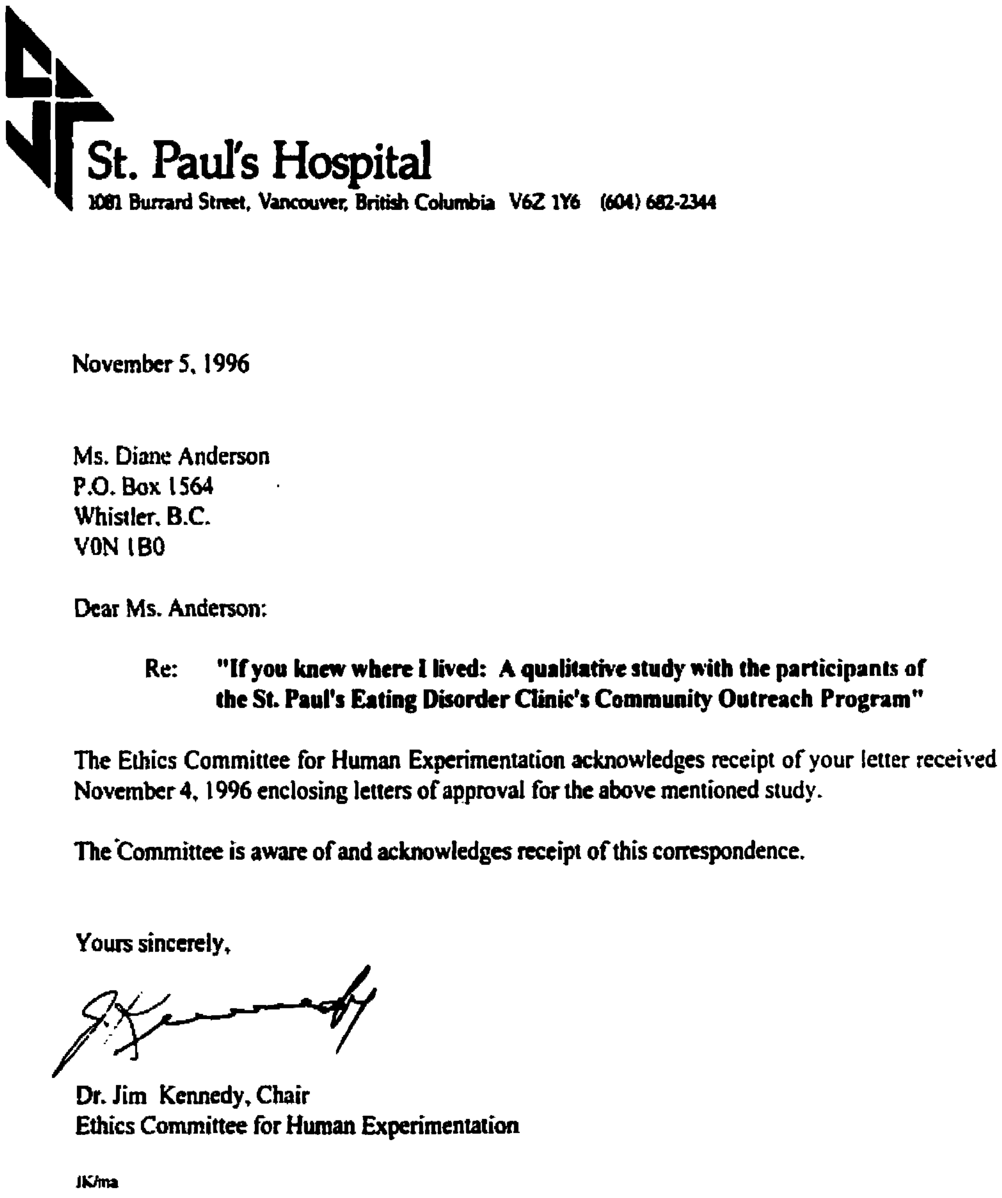
Reliability: The quality of being reliable, trustworthy, and dependable. In a relationship, the perception and belief that a person can safely be trusted and counted on to do or be what is expected, wanted or needed. Also the perception of complete confidence in the truthfulness, honesty, good judgement, justice, etc. in the other person.

Support: The attuned provision of contact with another. The contact may be verbal or non-verbal and given in the form of acknowledgement, validation, empathy, encouragement, information, and strength (whether this be moral support or the teaching of skills and abilities) to prevent another from falling down emotionally, mentally, physically, or spiritually.

Trust: A firm belief in the honesty, truthfulness, justice, or power of a person or thing; a confident expectation or hope. The faith that one can depend on, or leave something with another without misgivings or fear of consequences. A belief in a commitment made by another to one's care and well-being. In addition, trust is the obligation or responsibility imposed in one in whom confidence or authority is placed.

APPENDIX C

St. Paul's Hospital Ethics Review Committee Approval



St. Paul's Hospital
1081 Burrard Street, Vancouver, British Columbia V6Z 1Y6 (604) 682-2344

November 5, 1996

Ms. Diane Anderson
P.O. Box 1564
Whistler, B.C.
V0N 1B0

Dear Ms. Anderson:

Re: **"If you knew where I lived: A qualitative study with the participants of the St. Paul's Eating Disorder Clinic's Community Outreach Program"**

The Ethics Committee for Human Experimentation acknowledges receipt of your letter received November 4, 1996 enclosing letters of approval for the above mentioned study.

The Committee is aware of and acknowledges receipt of this correspondence.

Yours sincerely,

Dr. Jim Kennedy, Chair
Ethics Committee for Human Experimentation

JK/ma

ST. PAUL'S HOSPITAL
CERTIFICATE OF APPROVAL
FOR
CLINICAL RESEARCH AND OTHER
STUDIES INVOLVING HUMAN SUBJECTS

Project Title:	"If you knew where I lived: A qualitative study with the participants of the St. Paul's Eating Disorders Clinic's Community Outreach Program"	**Date Submitted:**	June 7, 1996
Investigator:	Diane Anderson	**Date Approved:**	August 19, 1996
Department:	Eating Disorders Clinic		
Comments:			

The members of the St. Paul's Hospital Ethics Committee for Human Experimentation identified below consider the experimental procedures outlined by the investigators to be acceptable on ethical grounds.

Name:
Dr. J. Kennedy, Chair
Ms. F. Bouthillette
Dr. A. Eisen
Dr. D. MacDonald
Ms. C. Molley
Mr. I. Woodcock

J. Kennedy

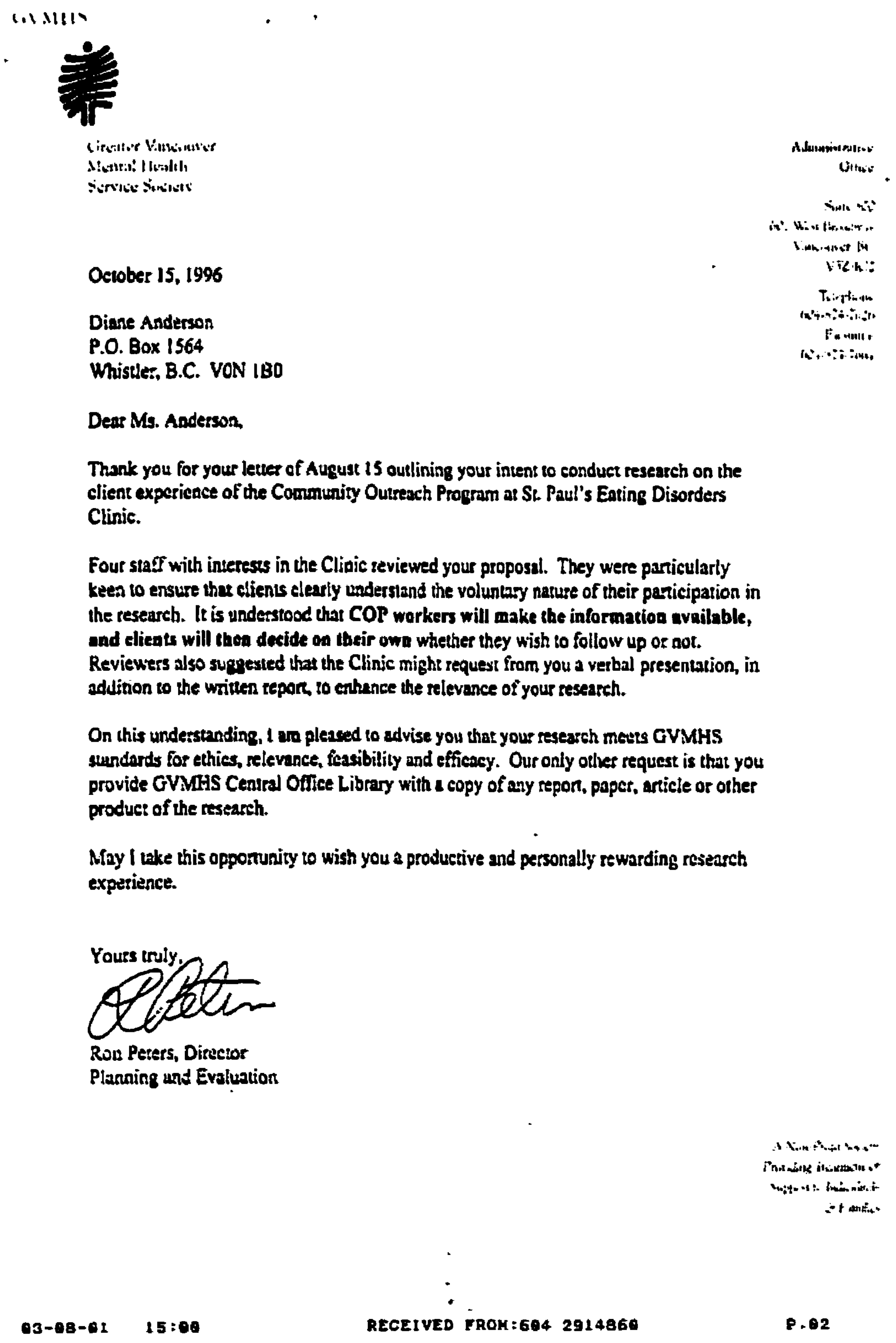
J. Kennedy, Chair
St. Paul's Hospital Ethics Committee for Human Experimentation

Date: Aug. 19, 1996

This certificate of approval is valid for three years from the date of approval. Any changes to the protocol must be submitted to the Ethics Committee for Human Experimentation for the continuation of approval.

APPENDIX D

Greater Vancouver Mental Health Services Society Approval



GVMHS

Greater Vancouver
Mental Health
Service Society

Administrative
Office

Suite [illegible]
[illegible] West Broadway
Vancouver BC
[illegible]

Telephone
[illegible]
Facsimile
[illegible]

October 15, 1996

Diane Anderson
P.O. Box 1564
Whistler, B.C. V0N 1B0

Dear Ms. Anderson,

Thank you for your letter of August 15 outlining your intent to conduct research on the client experience of the Community Outreach Program at St. Paul's Eating Disorders Clinic.

Four staff with interests in the Clinic reviewed your proposal. They were particularly keen to ensure that clients clearly understand the voluntary nature of their participation in the research. It is understood that **COP workers will make the information available, and clients will then decide on their own** whether they wish to follow up or not. Reviewers also suggested that the Clinic might request from you a verbal presentation, in addition to the written report, to enhance the relevance of your research.

On this understanding, I am pleased to advise you that your research meets GVMHS standards for ethics, relevance, feasibility and efficacy. Our only other request is that you provide GVMHS Central Office Library with a copy of any report, paper, article or other product of the research.

May I take this opportunity to wish you a productive and personally rewarding research experience.

Yours truly,

Ron Peters, Director
Planning and Evaluation

03-08-01 15:00 RECEIVED FROM:604 2914860 P.02

APPENDIX E

Simon Fraser University Ethics and Review Committee Approval

SIMON FRASER UNIVERSITY

VICE-PRESIDENT, RESEARCH

BURNABY, BRITISH COLUMBIA
CANADA V5A 1S6
Telephone: (604) 291-4152
FAX: (604) 291-4860

August 22, 1996

Ms. Diane Anderson
Graduate Student
Education
Simon Fraser University
c/o P.O. Box 1564
Whistler, B.C. V0N 1B0

Dear Ms. Anderson:

Re: **"If You Knew Where I Lived ...": A Qualitative Study with the Participants of the St. Paul's Eating Disorder Clinic's Community Outreach Program**

I am pleased to inform you on behalf of the University Research Ethics Review Committee that the above referenced Request for Ethical Approval of Research has been approved contingent upon this office receiving a letter of acknowledgment and approval from St. Paul's Hospital authorizing your research to be conducted. Once this letter has been received by this office, you may proceed with your research.

This approval is in effect for twenty-four months from the above date. Any changes in the procedures affecting interaction with human subjects should be reported to the University Research Ethics Review Committee. Significant changes will require the submission of a revised Request for Ethical Approval of Research. This approval is in effect only while you are a registered SFU student.

Once received, please forward a copy of the St. Paul's Hospital letter of ethical approval to this office. Best wishes for success in this research.

Sincerely,

Barb Ralph

Bruce P. Clayman, Chair
University Research Ethics Review Committee

c: C. Haig Brown, Supervisor
P. Winne

BR/hme

APPENDIX F

Letter of Invitation

St. Paul's Hospital
1081 Burrard Street, Vancouver, British Columbia V6Z 1Y6 (604) 682-2344

An Invitation to Take Part in a Research Project:

"If You Knew Where I Lived: A Qualitative Study with the Participants of the St.Paul's Eating Disorder Clinic's Community Outreach Program"

Who am I?

I am a graduate student in the Faculty of Education at Simon Fraser University. I am interested in doing a research project on what the participants of the Community Outreach program have to say about their experience of it.

I am a therapist who has started a private practice in Whistler. I am being supervised in my practice while I complete my Master's degree. My practice consists mainly of women who are struggling with disordered eating. I have also facilitated a support group for women with disordered eating for the past three years, and I present education and workshops on disordered eating within my community. I am a member of the board of ANAD (Cdn. Association of Anorexia Nervosa and Associated Disorders), an organization that provides support groups for people with disordered eating and their family and friends, and provides education and outreach to the province of B.C. I represent ANAD on the Provincial Eating Disorders Steering Committee, which is composed of medical, governmental, and consumer groups. ANAD was invited to represent a voice of people using/ needing eating disorder services in B.C.

I am thirty five years old. I had a four year history of bulimia which was preceded by eleven years of compulsive dieting and exercise. This experience grounds me to this work in a very personal way.

What is the Research Project About?

The Community Outreach Program has had some success as defined by the administrators and staff of the program. I would be interested in what you, the participants, have to say about the program. Do you see any indications of the program being successful for you ? If so, how or why was it successful in your opinion? What was effective in the Community Outreach program that you hadn't received in other interventions or programs? What do you think could be done differently, or wish was not a part of the program? I am interested in all aspects of this program from your perspective. What do you have to say?

Why is this Project Different?

I am approaching this research from a qualitative perspective. I am not interested in measuring or quantifying--I believe that "talk is serious" and that what you have to say about the *qualitative* differences in this program (i.e., how the program has made a difference to you) is extremely important and needs to be heard. My intention is to document and describe what you have to say in a way that is respectful and honors your participation. This type of work is called "research by invitation" because I am asking to be invited to work with you, not "for" you.

Working with you means that you have a lot of input into this project. You have control over what gets said about you, where it goes, how it is interpreted. You can have as little or as much input as you'd like, but I would be welcoming your input at all levels of the research. I encourage and invite you to take part in the design and outcome of this project as much as possible, for example, by providing feedback on this proposal, during the preliminary analyses, in the final report, and in the decision-making process throughout the project.

This research is approved by, but independent of, St.Paul's Hospital, St.Paul's Eating Disorder Clinic, and the Community Outreach program. Your participation will not affect funding, continuation, nor admission to the program. You are free to refuse to participate or to withdraw from this study at any time without any consequence to your continuing medical care.

What's Involved?

First, you can decide if you are interested in taking part in this study. Whether you decide to participate of not, please complete the bottom of this form, seal the envelope provided and return to me as soon as possible. You can return it to a COP team member or to the receptionists at the Eating Disorder Clinic who will forward it to me. Or you may send it to me directly--whichever is more convenient and feels safest to you. Just make sure the envelope is sealed; in this way your COP team members don't know who is or isn't participating, and it will hopefully allow participants to feel more freedom of expression.

Once I know you are interested, I will contact you and answer any questions you may have about me, the study, and what's involved. We will also arrange a place and time to meet. During this first meeting, I will answer any questions you have regarding the study and your participation and, if you would still like to participate, will have you sign informed consent forms for both SFU's and St.Paul's Ethics Review committees.

Once your "invitation" and permission to do this work are received, the study proceeds as such:

1. **Background:** I will be reading everything I can about the Community Outreach program and getting as much historical information about it as possible. I would be talking to the staff, administrators and the activation workers to help me obtain a context for my work. I will be documenting this information in a field journal and audiotaping interviews. I anticipate that this will occur during November and December, 1996. (You should know that at this stage it may be possible that I may obtain information about participants from a third party.)

2. **Interviews:** I would be asking for you to do interviews with me (audiotaped with your permission). I anticipate that there will be from three to six interviews, approximately 30-60 minutes long (at your discrimination). We will meet at sites to be determined by you and I. Although I anticipate that most of those meetings will occur outside of the clinical setting, we will meet wherever you are most comfortable.

The interview will be open-ended and conversational. The interviews are less structured in format because I am interested in what you have to say--your perspective--rather than responses to my preset questions which would reflect my perspective. My initial question to you would be, "What was your experience of the Community Outreach program?" My previous work has indicated that we will always find lots to talk about. However, I can give you a list of questions that I could ask if you would like.

The interviews will begin as soon as possible after receiving your consent. I anticipate that the interviews will be scheduled between December 1996 and March 1997, although you may decide how frequently you would like to meet during this time.

3. **Documentation:** The first interview will help us to get to know each other. The subsequent interviews will continue our discussions from the first, and to build upon the themes that have emerged. I will return transcripts and initial analyses of interviews to you throughout our meetings. I will ask you to indicate which parts of the transcripts you specifically do not want me to use in the construction of a final report and to "check" with you that transcripts are accurate and my analyses accurately reflect your perspective. In the final interview, I will ask your permission for the actual quotes which will be used in the construction of the final report. This report will be given to the Community Outreach program and participants at the end of April, 1997. (Again, you will be reminded that your identity may be able to be deduced and that you should consider which portions of the transcript you are comfortable in having produced in document that could be seen by doctors, COP staff, and other COP participants.)

4. **Confidentiality:** After the transcription of the interviews, all audiotapes will be returned to you. Anonymity will be maintained in the study with the use of pseudonyms; you will not

be identified by the use of names or initials. Confidentiality will be maintained throughout the project by not revealing the contents of the interviews without your permission and then, only in a way that you cannot be identified. (Other than myself, only my faculty supervisor and/or a professional transcriber may have access to the inteview materials.) Again, your participation is invitational and you may choose to withdraw at anytime.

5. **Publication**: This research is my thesis work for the completion of my Master's degree. It will be published and become the conjoint property of myself and Simon Fraser University. A copy of the final report will be made available to the Community Outreach program for their files. Each participant will receive a copy of the final report. It is undetermined whether there would be further interest in my research at this time. A copy of the thesis will be made available upon request to the researcher upon completion in September, 1997.

Reciprocity:

The issue of reciprocity is central to the work of "research by invitation." I believe that all researchers should be giving something back to the people with whom we do research. I would appreciate your thoughts on some ways I could reciprocate you for what you are generously giving to me with the opportunity to do this work.

Thank you for your time in considering this proposal.
If you have any questions regarding participation in this study please contact me (collect):
Diane Anderson (604) 938-1006.

You may contact my Senior Supervisor for further discussion about this project:
Dr. Celia Haig-Brown,
Faculty of Education, Simon Fraser University,
(416) 736-5002 (extension 88786)

- -

Please indicate if you are interested in participating in this study:

________ **Yes, I am interested in participating.** ________ **No, I am not interested.**

Name:____

Address: (optional) ______________________________________

____

Phone Number (Home/Work): ______________________________

Okay to call the above number(s) (yes/no): ______________________

Okay to leave message (yes/no):______________________________
If not okay to leave message, please indicate when it is best to contact you (mornings, afternoons, evenings): ______________________________

Please return this bottom portion in the envelope provided whether you choose to participate or not. Seal the envelope, and return it to your COP team member or to the receptionists at the Eating Disorder Clinic, or mail it to me.

Thank you.

APPENDIX G

St. Paul's Hospital Letter of Informed Consent

INFORMED CONSENT

St. Paul's Hospital
1081 Burrard Street, Vancouver, British Columbia V6Z 1Y6 (604) 682-2344

Title: "If You Knew Where I Lived: A Qualitative Study With the Participants of the St.Paul's Eating Disorder Clinic's Community Outreach Program

Investigator: Diane Anderson, BA, MA (Candidate)
Faculty of Education, Simon Fraser University
(604) 938-1006

Contact Person:

St.Paul's Eating Disorder Clinic

Josie Geller	(604) 631-2344
Vicki Smye	(604) 631-5582
Elliot Goldner	(604) 631-5347

Simon Fraser University, Faculty of Education

Celia Haig-Brown	(416) 736-5002	Faculty Supervisor
Robin Barrow	(604) 291-3203	Dean of Education

You have been asked to participate in a research study. I am interested in finding out what you, the participants in the St.Paul's Eating Disorder Clinic's Community Outreach Program (COP), have to say about your experiences of this program in a detailed and dialogic way. Participation in this study is entirely voluntary. Although this research project has been approved by St.Paul's Ethics Review Committee, it is an independent project from St.Paul's Hospital, the Eating Disorder Clinic, and the Community Outreach Program. Your are free to refuse to participate or to withdraw at any time without any consequence to your continuing medical care.

Purpose:

The Community Outreach Program has been deemed successful at some level by the program's administrators and staff. I am interested in what the participants of the program have to say and will use audiotaped conversational interviews in an attempt to do so. The purpose of the study is to record and interpret the perspectives of the Community Outreach Program participants in a way that is respectful and honors your participation.

Procedures:

If you decide to take part in this study, you will be asked to determine the extent to which you wish to participate, and you may limit your participation, or may withdraw from the study at any time. You will be asked to sign two informed consent forms and will be given a subject feedback form which you may decide to fill out during or upon completion of the study.

You will be asked to participate in 3-6 interviews, approximately 30-60 minutes in length each (at your discretion). These interviews will be open-ended and conversational in format; I will ask you one question, "What was your experience of the Community Outreach Program?" The interview will continue naturally from there. These interviews will be audiotaped (with your permission). I anticipate that the interviews will occur outside of the clinical setting, but we will meet wherever you are most comfortable.

The first interview will help us to get to know each other. The remaining interviews will be to continue our discussions from the first, and to build upon the themes that have emerged. I will return transcripts of previous interview and any initial analyses to you with each subsequent meeting. I will ask you to decide which portion of the interviews you do not want used in the report. I will check with you that what I've recorded is accurate, and to verify that my analyses accurately reflect your perspective. At the final meeting, I will ask your permission to use specific quotes in the construction of the final report. The interviews will occur over 12 weeks from December 1996 to March 1997.

Please note that a detailed review of your medical records and consults with your attending physician may be required. I will ask for your permission before requesting such information.

Confidentiality:

After the transcription of the interviews, the audiotapes will be returned to you. Anonymity will be maintained in the study with the use of pseudonyms; you will not be identified by the use of names or initials. Confidentiality will be maintained throughout the project by not revealing the contents of the interviews without your permission and then, only in a way that you cannot be identified. Only myself, my faculty supervisor, and a professional transcriber will have access to the interview materials. No outside agency will have access to this data.

This research is my thesis work for the completion of my Master's degree. It will be published and become the conjoint property of myself and Simon Fraser University. You will receive a copy of the final report that should be completed in April 1997. A copy of the final report will also be made available to the Community Outreach program for their files. It is undetermined whether there would be further interest in the research at this time.

You will be reminded that with a copy of the report going to the Community Outreach program and to other participants, your identity may be able to be deduced by someone other than myself (i.e., doctors, clinicians, other COP participants, etc.). I will ask you to consider the extent to which to wish to protect your identity when you are approving the transcripts and the final quotes.

I will be doing a contextual research on the Community Outreach program's development. During this time (November/December 1996) I will be interviewing staff of the program. Please note that there is the possibility that I may obtain information about participants from a third party during this process.

Risks and Benefits:

There are no known risks or side effects to participating in this study. You may feel uncomfortable responding to questions about your experiences, however, you are not obliged to answer any questions you do not wish to. My previous usage of these interviewing techniques with women with disordered eating indicated that talking to an interested researcher was a positive experience.

\- - - - - - - - - - - - -

If you have any questions or concerns at any time during the study, you may contact myself, Diane Anderson at (604) 938-1006, or SFU's Education Faculty, Dr. Celia Haig-Brown or Dr. Robin Barrow; or the St. Paul's contacts, Dr. Josie Geller, Vicki Smye, or Dr. Elliot Goldner, at the numbers given above. You will be informed of any changes to the procedures and any information pertaining to your safety immediately.

\- - - - - - - - - - - - - -

I have read the above information and I have had an opportunity to ask questions to help me understand what my participation would involve. I freely consent to participate in the study and acknowledge receipt of a copy of the consent form.

\---   ____________________

Signature of Participant   **Date**

\---

Signature of Witness

APPENDIX H

Simon Fraser University Letter of Informed Consent

SIMON FRASER UNIVERSITY
INFORMED CONSENT BY SUBJECTS TO PARTICIPATE IN A RESEARCH PROJECT OR EXPERIMENT

The University and those conducting this project subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of subjects. This form and the information it contains are given to you for your own protection and full understanding of the procedures, **risks (as specifiied on the "Informed Consent Form" for St.Paul's Hospital and on the "Invitation to take Part in a Research Project" Notice to Participants)** of the proposed research. Your signature on this form will signify that you have received a document which describes the procedures, possible risks, and benefits of this research project, that you have received an adequate opportunity to consider the information in the document, and that you voluntarily agree to participate in the project.

Having been asked by **DIANE ANDERSON** of the **EDUCATION FACULTY** of Simon Fraser University to participate in a research project experiment, I have read the procedures specified in the document.

I understand the procedures to be used in this experiment and the personal risks **(as specifiied on the "Informed Consent Form" for St.Paul's Hospital and the "Invitation to take Part in a Research Project" Notice to Participants)** to me taking part.

I understand that I may withdraw my participation in this experiment at any time.

I also understand that I may register any complaint I might have about the experiment with the chief researcher named above or with **Dr. Robin Barrow**, Dean of Education, Simon Fraser University.

I will obtain a copy of the results of this study, upon its completion, from the principal investigator, **DIANE ANDERSON**, and I may obtain additional copies by contacting her at: **P.O. Box 1564, Whistler B.C., V0N 1B0 (604) 938-1006**.

I have been informed that the research will be held confident by the principal investigator where possible, and I have been notified as to when that confidentiality will be at risk.

I agree to participate by
1. being interviewed 3-6 times, for approx.30-60 minutes each time.(at my discretion);
2. indicating on interview transcripts what portions I do not want used in the report;
3. approving actual quotes to be used in the final report. as described in the documents referred to above, during the period: **December 1996-March 1997 (over twelve weeks as decided by myself and the principal investigator)** at **locations to determined by myself and the prinicpal investigator.**

NAME (please print): ____________________
ADDRESS: ____________________

SIGNATURE: ____________ **WITNESS:** ____________

DATE: ____________

ONCE SIGNED, A COPY OF THIS CONSENT FORM AND A SUBJECT FEEDBACK FORM SHOULD BE PROVIDED TO YOU

APPENDIX 1

Simon Fraser University Subject Feedback Form

SIMON FRASER UNIVERSITY
UNIVERSITY RESEARCH ETHICS REVIEW COMMITTEE

SUBJECT FEEDBACK FORM

Completion of this form is OPTIONAL, and is not a rquirement of participation in the project. However, if you have served as a subject in a project and would care to comment on the procedures involved, you may complete the following form and send it to the Chair, University Research Ethic's Review Committee. All information ireceived will be treated in a strictly confidential manner.

Name of Principal Investigator: Diane Anderson

Title of Project:
"If You Knew Where I Lived: A Qualitative Study with the Participants of St. Paul's Eating Disorder Clinic's Community Outreach Program"

Dept./ School/ Faculty: Faculty of Education

Did you sign and Informed Consent Form before participating in this project? ______

Were there significant deviations from the originally stated procedures? ________

I wish to comment in my involvement in the above project which took place:

____

(Date) (Place) (Time)

Comments: ____

____

____

____

____

____

Completion of this section is optional

Your name: ______________________________________
Address: ____
Telephone: (w) ________________ (h) ________________

This form should be sent to the chair, University Ethics Reveiw Committee,
c/O Vice-President, Research, Simon Fraser University, Burnaby, B.C. V5A 1S6

APPENDIX J

Authorization to Record Interviews

Authorization to Record Interviews

For the purposes of accurately recording and transcribing the content of our interviews, I am asking for your permission to audiotape these sessions. You may withdraw your permission to record at any time by informing me verbally and then by changing this form. If you request copies of the tapes to be destroyed at any time, I will promptly do so. The tapes in my possession will be used only in a professional manner for the purposes of this research study and will be kept in a secure location. Copies of transcripts and recordings will be returned to you throughout and upon completion of this study.

I would appreciate your consent to record these interviews.

______ I give permission for audio recordings of interviews between Diane Anderson and myself for the purposes of the research study "If You Knew Where I Lived: A Qualitative Study with Participants of the St. Paul's Eating Disorder Clinic's Community Outreach Program."

Any restrictions:____

______ I refuse permission for recording at this time.

Signature of Participant: ________________________________

Signature of Researcher:_________________________________

Date: ____

APPENDIX K

Interview Schedule

(Appendix 5)

Research Instrument

Questionnaire*

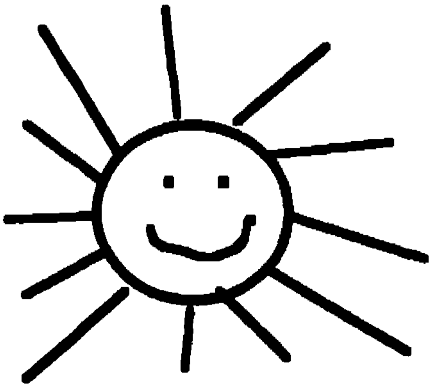
"If You Knew Where I Lived: A Qualitative Study with the Participants of the St.Paul's Eating Disorder Clinic's Community Outreach Program"

*** *Given the evolving nature of qualitative work, these questions are guidelines only.***

1. What is your experience of the Community Outreach program?
2. Do you think the program had, or is having, a positive outcome in you struggle with anorexia?
3. If so, how and why is this program successful?
4. What was effective in the Community Outreach program that you had not received in previous interventions?
5. What could be done differently to make the program more effective?
6. What did you like most about the program?
7. What did you like the least about the program?
8. How long have you had your anorexia?
9. What do you think you would need to let go of your anorexia?
10. If you could imagine that you could be taken care of in exactly the way you wanted, what would that be like?
11. Were there things you saw or heard happening with staff, administrators or activation workers that you didn't like or that you wondered about?
12. Were there things you saw or heard happening with other participants in the program that you didn't like or that you wondered about?

APPENDIX L

General Reminder Notice



Community Outreach Program Participants

January 5th, 1997

I am still looking for Community Outreach Program participants to take part in a qualitative research study to talk about what is or isn't working for you in the program. A research package was sent out to you through your COP team in November, however I haven't heard back from everyone yet. Please contact me in Whistler (collect) 938-1006 or in Vancouver (Tuesday/ Wednesday 9am-5pm) at 665-3441.If you:

* **did not receive the package**
* **would like another package**
* **would like more information before deciding to participate**
* **are interested in participating**

Your participation is confidential and involves simply talking about your experience(s) in the program, through a series of conversational interviews. The COP activation workers, administrators, and staff are not aware of who is or isn't participating unless <u>you</u> choose to inform them.

I appreciate any feedback you could provide and I thank you for your time.

Sincerely,

Diane

Diane Anderson,
Researcher, "If You Knew Where I Lived: A Qualitative Study with the Participants of St.Paul's Eating Disorder Clinic's Community Outreach Program"

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