

UNIVERSITY OF MANITOBA

GROUP THERAPY AS A MEANS OF ENHANCING
PATIENT COMPLIANCE WITH TREATMENT REGIMENS AND IMPROVING
SELF ESTEEM AMONG INSULIN DEPENDENT ADULT DIABETICS

A PRACTICUM REPORT SUBMITTED TO
THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF SOCIAL WORK

FACULTY OF SOCIAL WORK

BY

MARLENE A. CLAY

FEBRUARY, 1992

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BY

MARLENE A. CLAY

A Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba
in partial fulfillment of the requirements for the degree of

MASTER OF SOCIAL WORK

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The purpose of this Practicum Report involves developing a good understanding of coping mechanisms associated with chronic illness, specifically diabetes, as well as compliance issues related to chronic illness. In addition, group therapy for persons with chronic illness is examined.

This practicum investigates group therapy as a means of enhancing compliance with therapeutic regimens and improving self-esteem among insulin dependent adult diabetics. The practicum sessions are discussed according to content and process of each group meeting.

The major findings of this practicum include the following:

1. It is difficult to mobilize persons with a chronic illness to change in a short time.
2. It is difficult to measure compliance behaviour directly.
3. Group therapy can be an effective means of providing social support for persons with a chronic illness.
4. Short-term group therapy can be beneficial for diabetics.
5. There are inherent problems to deal with to be successful in using group therapy.
6. Effective group leadership adds much to group process.

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While the names are too numerous to mention, I wish to extend my deep appreciation to all of my dear friends for their support during the process of the completion of this practicum.

DEDICATION

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My interest in diabetes as a chronic condition was sparked by my relationship with my husband, Leigh, who has struggled with the daily challenges of living with diabetes for the past 25 years. This practicum is, therefore, dedicated to my husband, Leigh Everett James Clay.

A heartfelt thank you for sharing with me your inner self. You have taught me so much by your continued support and belief in my dreams. I am grateful you are a part of my life.

I would also like to dedicate this practicum to Darel, who passed away suddenly on January 24, 1992.

Darel was a faithful participant in this diabetes support group. He faced many challenges in his 38-year battle with diabetes and I always appreciated his efforts to make lifestyle changes.

I am saddened by his passing.

"Chronic diseases are long-lasting; they affect and even disrupt the lives of the afflicted individual and those around her. Caused by non-reversible pathological alterations in the body chronic diseases generally require long periods of supervision, observation, care, and rehabilitation. Most are characterized by periods of recurrence and remission. Because there are rarely cures, the goal of treatment for these illnesses becomes control of the progression of the disease, which means its tendency to involve and damage increasing amounts of body tissue. Chronic illness is often marked by a loss of physical or mental ability, which curtails a person's capacity to look after her needs. Each disease disables differently, so much of the impact a chronic illness has on the life of an individual and her family members is inextricably bound to the facts of the particular disease."

(Kerson & Kerson, 1985, p.1)

INTRODUCTION TO PRACTICUM

Purpose

This practicum involved group therapy as an intervention with noncompliant insulin-dependent adult diabetics. The long term span of chronic disease means that the interaction between psychological factors and the disease can be even more complex than in acute conditions. Failure of patients to comply with medical advice may be exacerbated in patients with chronic illness (Johnston, 1984).

Strauss (1975) states that chronic illness can cause multiple problems of daily living. One of these problems is adhering to prescribed regimens and the management of problems in carrying out these regimens. Diabetes Mellitus is a chronic metabolic disorder characterized as permanent and progressive. It is the complex interrelationship of time control, food control, and daily monitoring to prevent physiological crises that cause the ordinary and usual events of daily living to assume uncommon proportions.

The major purposes for which this group was formulated include the following:

1. To provide peer support in relieving the stresses felt by long-term diabetics in facing and dealing with the chronic disease.
2. To help patients to change or improve in some aspects of their psychosocial functioning that interfere with their daily coping with diabetes.
3. To provide a forum for problem-solving issues related to diabetes control.
4. To enhance feelings of self-esteem.

5. To facilitate the development of social skills that will empower clients to take more personal control of their lives.
6. To help diabetics improve their control.

Social support acts to encourage patients with chronic illness to take the first steps toward self-care (Caplan, 1976). Interventions directed towards enabling patients to seek help from and give help to other people with the same condition will result in improved self-care. (Cole et al, 1979).

CHAPTER I

AN INTRODUCTION TO CHRONIC ILLNESS

Incidence and prevalence

Chronic illness is the greatest health problem in the United States (Mayo, 1956; Anderson & Bauwens, 1981). An umbrella term encompassing many long-lasting diseases, chronic illness implies some degree of disability.

A number of formal definitions of chronic illness exist; that developed in 1956 by the Commission on Chronic Illness (Mayo, 1956, p.9) is still in use:

All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care.

Accurate statistics on the chronic illness incidence and prevalence in the United States are difficult to obtain. A survey carried out in the United States substantiated the prevalence of long-term illness as the major health problem indicating that approximately 50% of the civilian population (23.3 million people) had one or more chronic conditions (U.S. Department of Health, Education and Welfare, 1971b; Strauss, 1975; Epiopoulos, 1981). The survey cited the following incidences (in percentage of the population) of major chronic illnesses: heart conditions, 16.4%; arthritis and rheumatism, 14.8%; impairment of back and spine,

8.2%; mental and nervous conditions, 7.8%; impairment of lower extremities and hips, 6.1%; visual impairments, 5.6%; and hypertension without cardiac involvement, 5.4% (U.S. Department of Health, Education and Welfare, 1971b; Strauss, 1975; Epiopoulos, 1981).

Hanson (1987) indicates that the leading health problems in the United States today are heart disease, stroke and cancer, all of which largely affect adults. Arteriosclerosis and related conditions occur in one of every four adults and are the greatest cause of chronic illness and death. The incidence of cancer is rising, striking one of every four people; it has become the number two cause of mortality. Arthritis, the leading reason for immobility, affects one of every ten individuals.

Appendix I illustrates the prevalence of top chronic conditions in persons 45-64 years and 65 plus.

Anderson and Bury (1988) point out that prevalence studies produce highly variable results due to problems of both definition and measurement, and to real variations associated with, for example, geography, or the age of the population.

Anderson and Bury (1988) also indicate that the realities of living with chronic illness have generally failed to receive focused attention from social scientists, despite their importance. The many detailed studies of doctor-patient relationships, use of services, and even the patients' perspective on, or satisfaction with, health care have seldom been presented in the context of specific illnesses.

Common Themes in Chronic Illness

"Illness for the chronically ill means a lifetime of days upon days filled with ongoing fluctuating health problems that have no easy solutions or quick answers."

(Lewis, 1985, p.4)

Chronic illness presents a series of challenges at several levels as Turk (1979) describes:

Despite the range of conditions and disabilities encompassed by the category, a number of common features are concomitants of each illness. All chronic illnesses represent assaults on multiple areas of functioning, not just the body. Patients with various chronic illnesses may face separation from family, friends, and other sources of gratification; loss of key roles; disruption of plans for the future; assault on self-image and self-esteem; uncertain and unpredictable futures; distressing emotions such as anxiety, depression, resentment and helplessness; as well as such illness related factors as permanent changes in physical appearance or in bodily functioning. (Turk, 1979, p.29)

Kerson & Kerson (1985) discuss common themes in chronic illness. First, they all do some unalterable physical damage that must be dealt with, or the results will be increasingly disabling even when the disease process is in remission. Second, most of the illnesses share continuous cycles of recurrence, followed by remission, followed by recurrence, which remain unpredictable as to timing, duration, and extent of severity. All the illnesses involve fatigue, unseen by others but an added drain on the ill person. The degree to which symptoms are visible also differs according to the kind and severity of the disease. Nonetheless, visibility is a common theme.

In diagnosis and treatment there are also commonalities. Along with the labelling process of diagnosis comes prognosis, with its concomitant fears and panic reactions.

Common, too, in most of these diseases is the place of the regimen in the life of the ill person and family, whether it be medicine or diet, radiation or exercise. Once the diagnosis is made and treatment is prescribed, self-management becomes most important, and anticipating, observing, preventing, and treating become themes in the life of anyone who is chronically ill. Closely aligned with this theme is the idea that one can make the best of resources and minimize limitations through good self-management, but the illness may progress despite the best adherence to regimen.

Because many of these illnesses offer little or no chance of cure, ill people and their families often become desperate. When conventional and sometimes experimental treatments do not work, some people resort to unfounded promises of cure, following diets, or even taking medicines that have to be obtained illegally, at great expense, or out of the country.

Chronic illness can be accompanied by an increased dependence on others to do not only what one has previously been able to do for oneself, but what society expects. Families and friends often contribute to the increasing confinement and isolation.

There is also the stigma of the disease. The degree of stigma is related to the ways in which society judges each illness. For example, it is less stigmatizing to have heart disease than cancer.

With a chronic illness, society sees you as a less-than-perfect-person (Kerson & Kerson, 1985).

Family members are affected by chronic illness. The family must also grieve about the losses the illness has created for them. The burden of the care falls to family members, and the burden is not just physical and social, but financial as well. If the person is severely disabled, family members can become completely responsible.

Many family members feel that in some way they have caused the illness. Sometimes family members develop their own cycle of psychological adjustment. Feeling guilt, refusing to look after themselves, followed by anger and resentment that this has happened to them, followed again by guilt for having these thoughts. Another cycle that sometimes befalls family members is an alteration of over-protection and rejection, stifling the ill member, then pushing him away, then pulling him too close again.

Life outside the family also makes things difficult for family members. Many chronic illnesses are stigmatizing to families as well. People abandon families, are afraid that illnesses are contagious or that they will not know how to behave or what to say.

When the illness is in crisis, work and social responsibilities are curtailed. The presence of the illness also makes the future less certain. Since chronic illnesses are of long duration, there is rarely a sense of completion. Generally, neither cure nor death is imminent. When the illness is in remission, one waits for a crisis. When the illness is in crisis,

one looks for signs of remission (Kerson & Kerson, 1985).

Pain control is another common theme among the chronically ill. The experience of pain is associated with a large number of chronic diseases. Hence, pain control is an area of concern for almost all chronically ill patients. The experience of chronic pain may result from diverse causes such as diabetes mellitus, rheumatoid arthritis, coronary heart disease, spinal cord injuries, and various cancers (Burish & Bradley, 1983). In addition, the experience of chronic benign pain (i.e. long-term pain that is not the result of a malignant process) may itself become a disease characterized by drug misuse, decreases in physical activity, depression and disability (Brena, 1978; Fordyce, 1976). It is also important to note that pain is affected by psychological factors such as attention, suggestion, anxiety, modelling, and conditioning (Weisenberg, 1980). Hence, the ability of many chronically ill patients to withstand pain and reduce its influence on their lifestyles depends upon their psychological coping abilities.

Lewis (1985) indicates that pain is an individual, pervasive experience. The amount of pain experienced is clearly affected by the circumstances in which it occurs. The meaning of the pain may also be important and one might expect that angina pain might be experienced as more painful because of the threat involved. The quality and intensity of pain is influenced by one's unique past experience, and by the state of mind at the moment the pain is experienced. Lewis (1985) further explains that much pain behaviour is learned in the family unit and the culture in which a

person was raised. Response to pain seems more favourable when the pain is predictable and within the person's control.

"Chronic pain, which still remains somewhat of a mystery and, in considerable measure, impervious to treatment, exacts a heavy toll from the chronic pain patient, as well as the patient's family members. Psychological and social costs of chronic pain are substantial." (Roy, p. vii, 1989).

Loss is another commonality for many chronically ill persons. Loss of control is a significant and universal feeling for those with a chronic illness (Kerson & Kerson, 1985). It often begins at the time of diagnosis, when there is a pervasive feeling of powerlessness. Even with long remissions, one can never again be free of the spectre of illness or disability. The knowledge of the presence of disease can alter one's aspirations. There is a lack of predictability. One cannot pretend to know, negatively or positively, what lies ahead.

There is the loss of one's health, certain kinds of ability, a positive self-image, self-esteem, loss of attractiveness, aspects of sexuality, and many adult roles (Kerson & Kerson, 1985). These losses can range from mild to severe, but for people to adjust to their illness there must be an acknowledgement of loss and appropriate grieving.

Chronically ill people commonly experience feelings of isolation. If the illness becomes severely disabling, one's isolation is compounded with fear of abandonment.

Psychological Reactions to Chronic Illness

The diagnosis of a chronic illness and the life changes it produces often create psychological reactions in patients. Miller (1983) and Strain (1974) discuss patient manifestations of and reactions to chronic illness. First, chronic illness impairs function in more than one system and may interfere with many normal activities and routines. Second, the medical regimen is limited in its effectiveness and often contributes substantially to the disruption of usual life patterns. Third, patients may experience numerous psychological reactions:

- : Perceived threat due to the loss of mastery over their own bodies
- : Fear that their illness and dependence will cause significant others to withdraw love and approval
- : Fear that loss of control over bodily functions or parts will increase dependence on others
- : Anxiety about separation from supportive, protective loved ones and environments
- : Fear of pain
- : Fear of strangers who must provide intimate care

Presenting Symptoms

For some chronic illnesses the presenting symptoms are psychological, eg. neurological diseases. Some patients may present with changes in mood or motivation. The observation of changes in patients' behaviour, thinking style, and emotional state are clearly important in the diagnostic process (Johnston, 1984).

According to Johnston (1984) chronic illness may bring problems of pain and discomfort; unpleasant medical procedures and

treatments; admissions to hospitals and the associated separation from home, family and friends; restrictions in the individual's choices of occupation, hobbies, leisure activities, social contacts, changes in appearance and functioning of the body; changes in the reactions of others; threats of future loss of functioning or even life, all of which demands some degree of adjustment and may evoke anxiety, depression, irritability, anger, etc.

Denial

Taylor (1986) indicates that the diagnosis of a chronic illness often comes as a shock to a patient. Within a few minutes everything suddenly changes. The initial diagnosis may be so disorienting and uprooting that it is impossible for the patient to fathom immediately the depth of change that will be required.

Denial is a defense mechanism by which people avoid the implications of an illness. They may act as if the illness were not severe, that it will shortly go away or that it will have few long-term implications. Denial is the subconscious blocking out of the full realization of the reality and implications of the disorder.

Denial is a common reaction to chronic illness that has been observed among heart patients (Krantz & Deckel, 1983), stroke patients (Diller, 1976), and cancer patients (Katz et al, 1970; Levine & Zigler, 1975; Meyerowitz, 1983).

Depression

Depressive reactions are more common in all types of physically disabled groups when compared with healthy individuals and they are particularly likely at acute stages such as the onset of the illness, the time of a relapse or sudden deterioration or an acute episode requiring hospitalization or extra care. These reactions can be considered in terms of "learned helplessness" (Johnston, 1984).

The clinical manifestations of the depressive reactions include not only the mood of sadness, hopelessness, and self-deprecation, but also reduced activity and social interaction, insomnia, changes in appetite and weight, lack of libido, increased somatic complaints, etc. There is some evidence of increased suicide rates and increased incidence of self-destructive behaviours in patients with various orthopaedic difficulties, diabetes and heart disease, compared with the rates for the general population.

Johnston (1984) further postulates that the development of depressive symptoms is not necessarily related to the severity of the condition. For example, patients with both mild and severe heart disease are likely to become depressed. However, if the heart disease is mild, the depression is likely to be of shorter duration than if it is severe.

Taylor (1986) points out that depression may occur later in the adjustment process. Depression may be a delayed reaction to chronic illness because it often takes time for patients to

understand the full implications of their condition. Once the acute phase of chronic illness is over, the attention they received from family members and friends may decline and it may be time for them to resume their usual activities with the weight of the chronic illness and its restrictions firmly imposed. Restrictions due to treatment may now also become fully evident.

Taylor (1986) also says that depression among chronically ill patients can be extreme and pervasive involving dependency, helplessness, and unnecessary restriction of activities.

Fear

Taylor (1986) indicates that immediately after the diagnosis of a chronic illness, fear is also a common presenting symptom. Many patients become overwhelmed by the spectre of potential changes in their lives and by the prospect of death. Fear may also arise intermittently throughout the disease process. There can be fears about future complications, loss of control, the experience of pain and fears about the abandonment by close family and friends.

Anger

Another presenting symptom for those with chronic illnesses is anger. Anger is an immobilizing reaction, triggered when any expectation is not met. It is the result of wishing the world and people in it were different (Dyer, 1976, p. 210).

Lewis (1985) points out that chronic illness is certainly not what one expects to happen. With chronic illness, a person's expectations of what his or her life was to be like may be totally

shattered and replaced by something that he or she would never have dreamed of. The expectations of significant others are also blown apart, creating anger in all involved in one's life. As chronic illness invades one's life, the things that trigger one's anger may change and multiply. Delay in diagnosis may initiate anger due to the frustrations of looking for answers and not finding them.

Furthermore, according to Lewis (1985), anger may be stirred when medical health professionals can not offer assurances that everything will be all right; when they do not have all the answers; when there may be no remedy to relieve every ache and pain; when there may be no known cause, treatment, cure, or prognosis for an illness; or when medical bills mount up as the illness continues on a daily basis.

Fear of losing the support of significant others and ability to function may generate anger. A sense of hopelessness, helplessness, fear, and/or betrayal by the body adds yet additional logs to fuel the flames of anger. Limitations enforced by illness produce frustrations and anger when they interfere with desired activities, and necessitate dependency on others for many things.

Anger may be directed toward God, institutions, friends, family and self. Furthermore, anger is a common response to separation and loss. Initially, dysfunctional anger often accompanies physical illness or disability since there is a sense of disbelief that the losses of the self and others are permanent. As permanence becomes a reality, anger is an attempt to signal the return of what is lost.

Lewis (1985) says that the person in the early phase of chronic illness frequently questions his own worth. "He wants people to be close and reassure him that they still like him and need him, even if he is sick. But the anger, whose aim is to signal the lost part of function to return, works against the formation or continuation of essential human relationships" (Werner-Beland, 1980).

According to Taylor (1986) anger may be delayed in the early stages following diagnosis of a chronic illness. Patients may be too fearful to feel any anger or their denial may block out any hostile reactions. However, as the full implications of the chronic disease set in, the patient may begin to wonder, "Why me?"

Lewis (1985) also discusses various expressions of anger. Anger can be expressed in many ways, both verbally and non-verbally. Anger may be seen in passive resistance to treatments and measures to improve health, i.e. not following medication, diet, rest or exercise regimen. Chronic complaining may spring from hidden hostility. Constant criticism of others reflects anger. Chronic pain may elicit aggressive, hostile behaviours. Constant depression may be a cover for anger or the result of anger. A well-ingrained pattern of forgetfulness, preoccupation, half-hearted efforts, blaming, verbal outbursts, intimidation of others can be a subtle expression of anger that prevents the honest communication of feelings.

Anxiety

Many people diagnosed with a chronic illness present with symptoms of anxiety which include shakiness, fatigue, muscle aches, sweating, palpitations, fearful anticipation. A phobic reaction may result where the patient becomes unduly fearful of symptoms or situations associated with symptoms and learns to avoid any situation which might elicit symptoms, at the same time developing protective behaviours (Johnston, 1984).

The source of anxiety among those with chronic illness may be related to fears for the future or worries about complications of the illness, such as disfigurement that might result. Those who have lost their job as a result of the chronic illness may become anxious and depressed.

Anxiety can result in the hospital as nervousness over the results of tests or surgery can produce insomnia, terrifying nightmares, and a general inability to concentrate (Taylor, 1986). When people are anxious, their learning can be impaired. Anxiety makes it difficult to concentrate attention and process incoming information. Anxiety is one of the most commonly observed responses for the terminally ill patient (Hinton, 1967; Schulz & Aderman, 1974). Often, however, anxiety is less tied to dying itself than to the symptoms experienced during terminal illness. What patients fear most is not being able to control pain; they may welcome or even seek death to avoid it (Hinton, 1967). Other symptoms such as difficulty breathing or uncontrollable vomiting,

likewise produce anxiety, which may exacerbate the patient's already deteriorating physical and mental condition.

Anxiety may also occur as a result of changed body image following the diagnosis of a chronic illness. Problems or conflicts can arise when an individual's body image is threatened by a chronic illness (Lubkin, 1986). One of the problems that may arise from a chronic illness is physical disfigurement. The individual must cope not only with personal feelings about the disfigurement, but with the responses of others also. This can result in feelings of anxiety.

In his study carried out in the late 1970's in Greater Manchester, Bury (1988) looked at the experience of arthritis. Twenty-five women and five men with rheumatoid arthritis were interviewed using an interview schedule covering the experience of the onset and development of the illness, its impact on work and home life, and the processes of seeking medical help. All of the respondents were facing an altered future, were experiencing symptoms at the time of the interviews, and were struggling with the meaning and implications of events, both for themselves and for others.

Twenty-three of the thirty individuals were married, three were separated, and four of the women had been widowed. The research reported was designed to be exploratory in character, in an attempt to build up a picture of the illness and its consequences. The data presented reinforced the general observation that the onset and development of arthritis is

simultaneously an assault on the body and a disruption of social life. The study also showed that the meaning of chronic illness only emerges over time as specific aspects of the condition make themselves felt.

Furthermore, the experience of rheumatoid arthritis is characterized by anxiety. The experience of arthritis most certainly involves pain and discomfort, and even disfigurement, and effective treatment for these will obviously be a major priority for patients. But patients must also live with what the illness means; with its consequences for daily life and an altered future.

Psychological reactions to chronic illness may vary with age, cultural values, race, and ethnicity (Anderson & Bauwens, 1981). Even when diseases are not age-specific, different age groups react differently to the experience. As well, each person's cultural background and personality affects reactions to illness, pain, and impairment. Each culture has beliefs and values about health and illness and how people should respond. Race and ethnicity also affect the occurrence of and response to chronic health problems. Certainly some chronic problems are more prevalent among specific races; the occurrence of hypertension and diabetes in non-white populations, for example (Hanson, 1987).

The probability, nature and severity of psychological reactions to chronic disease are likely to be affected not so much by the presence of the disease, but by the individual's perception of his or her disease. Largely, an individual's perception of his

or her disease is derived from social, ethnic, familial, religious and intrapsychic variables (Johnston, 1984).

Social Consequences of Chronic Illness

Those with a chronic illness are not only affected psychologically, but their social life can change as well.

Financial considerations

D.W. Millard (1984) outlines three areas that should be considered when looking at finances and those affected by chronic illness:

1. The social norm is that income is received in exchange for work done, but the disabled have restricted access to the employment market.
2. State social security benefits are generally inadequate, inequitably distributed and too difficult to obtain.
3. The expenditure of people with disabilities are necessarily higher than those of comparable members of the population.

Walker (1981b) indicates that even when in work, there is evidence that the disabled are more likely than the non-disabled to be in low-paid occupations. Part of the explanation for this is that many disabled people have a diminished capacity for work. This factor is likely to be more significant when impairments are multiple; a single impairment may be coped with or compensated for by the person concerned and his family; but two impairments seem more than twice as difficult to all concerned.

Employment

Taylor (1986) indicates that many chronic illnesses create problems for individuals' vocational activities and work status. Some people may need to restrict or change their work activities.

Some of these changes will require vocational retraining. For example, spinal cord injured persons who previously held positions requiring physical activity will need to acquire skills that will let them work from a seated position.

Many chronically ill patients, such as heart patients and cancer patients, face job discrimination (e.g. Davidson, (1983). When these persons return to their jobs, they may be moved to less demanding positions and they may be promoted less quickly because the organization believes that they have a poor prognosis and are not worth the investment of time and resources required to train them for more advanced work (Taylor, 1986).

Warnock (1978) considers the psychological importance of work:

...it gives people a sense of purpose and competence, it makes them feel needed; it provides a change of environment so that they may appreciate their home better when they return to it in the evening, it brings them into contact with a different range of people from their friends at home and may lead to further interests and social activities...

The ability to secure suitable employment depends largely on the type of occupation desired and the degree of disability. Many employers have the mistaken perception that individuals with a chronic illness are unable to function in the workplace and are unwilling to consider certain structural adaptations in the workplace to employ a qualified individual, for example, ramps, special washroom facilities, special aids or modifications to tools, electric typewriters, telephone attachments, etc. To a great extent, people must suit their work to their physical capacities. This becomes difficult when suitable work is not

available. In this society, great value is placed on being self-supporting and the issues around work are much more than financial. Self-esteem, sense of purpose, and status come from one's work (Kerson & Kerson, 1985).

Family Issues

Disability is a family affair. Any family is affected by the onset of a disabling condition in one of its members, and the entire family usually begins a struggle to retain its equilibrium and to adapt to the given situation (Power, Dell Orto, & Blechar Gibbons, 1988). Family factors also directly influence the mental and emotional functioning of the disabled individual. Power & Dell Orto (1980) state that the disabled person's reaction to treatment and performance in rehabilitation efforts is a function of both the person and the family environment.

Chronic illness affects the family system as normal patterns of interaction are disrupted, and there are often reassignments in tasks and roles assumed by particular family members (Biegel, Sales, & Schulz, 1991). Leventhal et al (1985) note that chronic illness alters the relationships not only of family members to the person who is ill, but to one another as well.

Changes in relationships can occur around problem-focused activities such as work, household tasks, or provision of family income, or in interpersonal areas such as solidarity and belonging, sexuality, and love. These role changes may lead an ill family member to become "sicker," or "well" family members might become "sick" to gain attention (Bruhn, 1977).

Strauss et al (1984) identify eight social and psychological problems that patients and families face in coping with chronic illness:

1. The prevention of medical crises and their management once they occur
2. The control of symptoms
3. The carrying out of prescribed regimens and the management of problems attendant on carrying out the regimens
4. The prevention of, or living with, social isolation caused by lessened contact with others
5. The adjustment to changes in the course of the disease, whether it moves downward or has remissions
6. The attempts at normalizing both interaction with others and style of life
7. Funding - finding the necessary money - to pay for treatments or to survive despite partial or complete loss of employment
8. Confronting attendant psychological, marital, and familial problems (p. 16)

Family caregivers often shoulder the principal responsibility for maintaining the ill member at home. Goldetz, as cited by Lubkin (1986), makes clear the wide ranging responsibilities of family caregivers. The roles family caregivers may have to provide for their ill family member include the following: cook, maid, janitor, launderer, nursing assistant, transportation provider, mobility supervisor, overseer/administrator of medications, supervisor of special medical equipment, and provider of personal hygiene, such as toileting and incontinence care, as well as manager of transfers, exercises, feeding and washing.

At some point in the disease process almost all of those dealing with a chronic illness are confronted with the redefinition of roles, especially in terms of work, family responsibilities and self-care.

Chronic illness can be incapacitating due to problems of cognition (Alzheimer's disease), reality disturbance and social stigma (chronic mental illness), movement (stroke), reduced energy levels (cancer, heart disease), or the demands of the treatment regimens (cancer) (Biegel, Sales, & Schulz, 1991). These authors further state that different incapacitation patterns may result in differential impacts on patients and family. For example, diseases with both cognitive and motor deficits require greater role changes within the family than diseases with only one of these deficits. Incapacitation and onset also combine to produce different effects in families. Incapacitation with stroke, for example, is greatest at time of onset, whereas with Alzheimer's disease incapacitation increases over time, giving families more time for adjustment and planning (Rolland, 1988).

The emotional impact of an illness is never limited to the person who has the illness. Every member of the family will in some way be touched by the problem and will experience some sort of emotional upheaval because of it (Maurer & Strasberg, 1989). Most often, feelings will be those of sadness and discouragement. This may be considered a form of depression and is an emotional response that is appropriate and common in the setting of chronic illness or disability. Maurer & Strasberg (1989) further state that sadness,

loss of appetite, crying, anger, and sleeplessness after a serious chronic illness, terminal illness, or physical disability are appropriate, normal responses to a major life stress. Family members, as well as the ill or disabled person may find themselves crying and feeling sad and discouraged. This is, in fact, grieving, according to Maurer & Strasberg (1989). These authors also point out that grieving is a common response to many types of loss. Included are those losses associated with chronic illness and disability, which can be pervasive and shattering. In fact, families may notice that when an ill person dies, they are not as sad as they were often before the person's death. Family members sometimes even feel relieved. That is because family members have already mourned, long before the person's death, the losses of roles, dreams, plans, and life changes that the illness caused.

Maurer and Strasberg (1989) also explain that grief is episodic for people with progressively debilitating illnesses that do not stabilize or stabilize only temporarily. During periods of stability, family members become more optimistic; but when things worsen, anger, disappointment, and sadness return. This sort of emotional roller coaster is particularly difficult, but becomes a fact of life for the family dealing with a progressively impairing illness or disability.

When illness is serious and debilitating, the traditional roles of breadwinner, nurturer, and chief decision-maker, among others, are often shifted to other members of the family. The extra burden on the other family members can be stressful for all

concerned. Such role changes reverberate throughout the family and can disrupt its very fabric, as well as its usual social activities and place in the community (Maurer & Strasberg, 1989).

Schott & Badura (1988) conducted a longitudinal study of 1000 men with a myocardial infarction. They investigated problems of the spouses of the heart patients and how they cope with being a main source of support for the patients. The following two questions were addressed: How stressful is the life-event, a heart attack, for the patient's wife?; and, What conditions alleviate or aggravate the 'stress of caring?'

The patients were identified through notifications from 213 hospitals selected to be representative of all acute hospitals in West Germany. The first phase of the study was completed in May 1983. One year after the infarction, questionnaires were sent to the wives of the patients and almost 70% returned a completed questionnaire.

The results of the study indicated that 83% of the wives described the first few days following the heart attack as the period of very severe stress and 90%, twelve months after the infarction, described themselves as often worried about their spouses' health. More than half of the wives reported that they shouldered more of the responsibility within the family after the heart attack.

An important implication of the research is that the wife of the heart patient suffers stress and the support of the patient's wife is essential both to help her reduce her own uncertainties,

fears and worries, and to help her in her role as the most important social resource of the heart patient.

Power (1988) has identified the following family strengths as important areas to consider in working with families with a chronically disabled member:

1. The ability of the family to listen
2. Shared, common perceptions of reality within the family
3. The ability of family members to take responsibility for disability-related problems
4. The ability of family members to use negotiation in family problem-solving
5. The family's ability to focus on the present, rather than on past events or disappointments
6. Family members' willingness to take good care of themselves
7. The ability of family members to provide reinforcements to each other
8. The ability of the family members to discuss their concerns
9. The ability of family members to provide an atmosphere of belonging
10. Family members' capacities to use everyday experiences as resources
11. The family's willingness to have hope and to appreciate that a change is possible

Stigma

Webster (1974) defined stigma as a "mark of shame or discredit." Those with a chronic illness are often stigmatized. Stigma is a universal phenomenon. Every society stigmatizes certain conditions (Becker, 1981).

Lubkin (1986) proposes that American values contribute greatly to the perception of chronic disease as a stigmatizing condition.

The dominant culture emphasizes qualities of youth, attractiveness, and personal accomplishment. Lubkin (1986) further states that a stigmatizing condition has a profound impact on both the affected individual and on normal persons. The stigmatized individual is often unsure about the attitudes of others and, therefore, may feel a constant need to make a good impression. At the same time, normal individuals may worry about whether to acknowledge the deficiency; they may be concerned about making unrealistic demands (Goffman, 1963).

The way an individual deals with the reactions caused by a stigma varies depending on the length and nature of the condition, as well as the individual's personal characteristics. Dudley (1983) eloquently identifies how the stigmatized often feel when he states:

A depreciating remark, cold stare, wilful disregard of a person's viewpoint hurts in unimaginable ways. The pain derives not only from each stigma-producing incident, but also from the cumulative effect of numerous previous incidents, with the latest one serving as a further reminder of their inferior status (p. 64).

Stigmatized individuals respond to this pain in a variety of ways. A person's first response to a stigmatizing reaction may be disregard. Individuals may choose not to reflect on or discuss the painful incidents. Well-adjusted individuals who feel comfortable with their identity, have dealt with stigma for a long time, and choose not to invest much effort in responding to the reaction may disregard it (Dudley, 1983).

Other individuals may respond to stigmatizing reactions with isolation, i.e. staying within one's own group. This is often easier and requires less effort for those with chronic conditions. Staying with others who are similar is a source of support.

Dudley (1983) points out that another response to a stigmatizing situation is resistance. Individuals may speak out and challenge rules and protocol if their needs are not met. Anger often serves as a catalyst for those seeking change.

Due to the potential threat and anxiety-producing nature of disclosure of a stigmatizing defect, many people de-emphasize their differentness. This response, called covering, is an attempt to make the defect seem smaller or less significant than it really is (Goffman, 1963).

Macdonald (1988) studied patients with rectal cancer to yield information on perceived stigma. A cross-sectional survey was conducted because interviewing patients only once would minimize inconvenience to families and to patients who might be very ill. This was a population-based study and provided a representative sample of rectal cancer patients. Each patient was interviewed at home by one of a team of twenty-eight specially trained health visitors who used a semi-structured questionnaire.

The study was also designed to yield information on quality of life - physical, emotional and social health - as perceived by the patient and assessed by both the general practitioner and the health visitor.

The Leeds scale for the self-assessment of anxiety and depression (Snaith et al, 1976) was also used. Level of perceived stigma was included in the definition of quality of life. A stigma self-rating measure was devised, consisting of statements about avoidance of others, avoidance by others, feelings of self-consciousness, of unattractiveness, and of being different from other people. A total of 420 interviews were successfully completed; 210 were with men and 210 were with women.

Results of this study showed that those who felt stigmatized were much more likely to have perceived their emotional health as poor and to have scored as clinically depressed or anxious. Feelings of stigma and poor physical health were also correlated. As well, feeling stigmatized was correlated with the presence of specific medical problems. Finally, those who felt stigmatized were much more likely to isolate themselves from recreational activities outside the home, as well as participate less in informal community life.

The author also suggested that a large fraction of patients with rectal cancer suffer from a poor quality of life because of their experience of stigma of cancer and colostomy.

Summary

Chronic illness can affect every aspect of a person's life, including psychological functioning, social activities, employment and family relationships. Chronic illnesses are permanent and progressive. There are commonalities among chronic diseases; they all cause unalterable physical damage and most share continuous cycles of recurrence; chronic illness sufferers can become dependant on others and most conditions bring pain and discomfort.

There are many emotional reactions that accompany the diagnosis of a chronic illness. Depression is common among individuals with a chronic illness. Moods of sadness, hopelessness, apathy and emotional lability can occur. Very often, depression occurs later in the adjustment process when the full reality of the condition becomes evident. There are many fears for chronically ill persons. Fears of loss of control, abandonment by family and friends and future complications can arise. Anger is a presenting symptom for many chronically ill persons and can be expressed in many ways, including chronic complaining or constant criticism of others. Persons with a chronic illness can experience periods of anxiety producing insomnia, fatigue, and difficulty in concentration and focusing attention.

Age, cultural values, race, and ethnicity affect reactions to illness and pain. The social consequences of chronic illness include financial considerations, access to employment, family issues and the stigma of the disease. Persons with a chronic illness tend to be in lower-paid occupations and have a diminished

capacity for work. Suitable work may not be available for chronically ill individuals. Chronic illness affects family systems. Families are often confronted with redefinition of roles and changes in relationships. Every family member will experience the emotional impact of the illness and may also find themselves grieving the losses associated with chronic illness and disability. Stigma is also a consequence of chronic illness and can have a profound impact on both the affected individual and normal persons. Individuals deal with reactions caused by stigmatization in different ways including disregard, isolation, resistance and covering.

CHAPTER II

COPING WITH CHRONIC ILLNESS

Definition of coping

Lazarus and Launier (1978) define coping as:

"efforts, both action-oriented and intra-psyhic to manage (i.e. master, tolerate, reduce, minimize) environmental and internal demands, and conflicts among them, which tax or exceed a person's resources" (p. 311)

People have different coping styles (Walker & Lattanzi, 1982) and adjust at different individual rates appropriate to them. Previous and current coping mechanisms are aspects of an individual's personality that affect the manner in which adaptation occurs. In most instances, a person's coping with the present situation depends on the success with which the individual has handled other life stresses (O'Brien, 1980).

Patients' beliefs about chronic illness

Taylor (1986) states that if patients are to adjust to chronic illness satisfactorily, they must somehow integrate their illness into their lives. Most chronic illnesses require some alteration in activities and some degree of management. Developing a realistic sense of one's illness, the restrictions it imposes, and the regimen that is required is an important process of coping with chronic illness.

A number of researchers have suggested that patients form an organized, cognitive representation of their illness that influences these adjustments (e.g. Garrity, 1973, 1975; Nerenz &

Leventhal, 1983; Lau & Hartman, 1983). This representation includes such factors as the identity, cause, duration, and consequences of the disease (Nerenz & Leventhal, 1983).

According to Taylor (1986), of the many beliefs that patients hold about their illness, two may be particularly important in predicting adjustment: perceptions of the cause of their illness and beliefs about whether or not the illness can be controlled.

Taylor (1986) further states that self-blame for chronic illness is widespread. Patients frequently perceive themselves as having brought on their illnesses through their own actions. In some cases, Taylor says these perceptions are to some extent correct as faulty health habits like smoking, improper diet, or lack of exercise can be risk factors in the development of diseases such as heart disease and diabetes.

Self-blaming individuals may be poorly adjusted to their illness because they focus on things they could have or should have done to prevent it.

Self-blame may be adaptive for some. One study (Bulman & Wortman, 1977) found that patients with spinal cord injuries (paraplegics and quadriplegics) who took responsibility for the circumstances that produced their injuries were better adjusted. Perceiving the cause as self-generated may represent an effort to assume control over the disorder; such feelings can be adaptive in coping with and coming to terms with the disorder (Bulman & Wortman, 1977).

Individuals develop a number of control-related beliefs with respect to chronic illness. They may believe, as do many cancer patients, that they can prevent a recurrence of the disease through good health habits or even sheer force of will (Taylor, 1986). They may also believe that by complying with treatments and physicians' recommendations, they achieve vicarious control over their illness. They may believe that they personally have direct control over the illness through self-administration of a treatment regimen.

Feelings of psychological control may be essential for good mental functioning. Individuals who feel they have at least some control over their lives may be better adjusted than those who feel they have no control in their lives. For example, cancer patients who believed that they had control over their illness were better adjusted to their cancer than patients without such beliefs (Taylor, Lichtman, & Wood, 1984). Several studies that have attempted to enhance feelings of control in cardiac patients also suggest beneficial effects (Klein et al, 1968; Cromwell et al, 1977; see also Krantz & Schulz, 1980).

Personal responsibility for health

Chronic disease patients face problems associated with the issue of personal responsibility for their state of health. Every individual has a great deal of responsibility for maintaining - or losing - his or her health. Knowles (1977) poignantly summarized

the situation:

"Over 99 percent of us are born healthy and suffer premature death and disability only as a result of personal misbehaviour and environmental conditions....The individual has the power - indeed, the moral responsibility - to maintain his own health by the observance of simple, prudent rules of behaviour relating to sleep, exercise, diet and weight, alcohol, and smoking....He should be aware of the dangers of stress and the need for precautionary measures during periods of sudden change" (p. 79-80)

A key to success with the complex, life-long diabetes therapeutic regimen is responsible self-care. Maintaining tight control and compliance with the health care regimen is an integral part of maintaining optimal health and delaying or preventing the complications of diabetes (Danowski et al, 1980).

People can take concrete steps to preserve their health and avoid disease, especially chronic disease. However, the constant reminder of responsibility for one's own health frequently causes considerable guilt in victims of chronic disease. Many chronically ill patients bear not only the suffering caused to themselves by their disease and treatment, but also the suffering imposed upon their loved ones. The burden can be tremendous. Low self-esteem, anxiety, depression, increased sensitivity to rejection, and reduced attempts to engage in the usual activities of daily living often result, posing major but common coping problems (Burish & Bradley, 1983).

Social Support

Social support - by significant others - or support networks - helps individuals cope with chronic illness and reinforces

compliant behaviour (Lubkin, 1986).

Family and friends often do not realize how important they can be in helping the patient adapt to chronic illness, and often they are not properly informed about how they can aid in the rehabilitation process. For example, family and friends can cause considerable damage by being overly protective or indulgent, by abruptly reducing intimate contact, or by socially excluding the patient (see Lavigne & Burns, 1981). Family members and friends may have personal difficulties in coping with the patient's chronic illness, and these problems may have to be dealt with before they can concentrate on helping the patient.

Mechanic (1977) has provided a pertinent summary of the situation:

Families often have their own problems in coping with the sick or disabled family member and may require information and assistance from the clinical team. Moreover, family members can become a very effective extension of the clinical team by providing support for active coping, encouraging conformity with medical instructions, and facilitating through joint participation those patterns of behaviour most consistent with minimizing the patient's disability....The fact is that many family members feel excluded from the care process, have difficulty obtaining needed information, and rarely receive adequate instruction as to what they might do and how to do it. (p. 83)

One of the major problems that usually requires considerable preparation and change by the family is the increased dependency caused by chronic diseases. The chronically ill person in many cases must depend on others for financial assistance and for such

things as helping with personal care, meeting new dietary requirements, and assuming some of their responsibilities. In some cases, the roles of the husband or wife, father or mother, must be largely taken over by others, which reduces many of the pleasures and increases the guilt of the patient.

Unless both the patient and the family are prepared for such changes, they may present obstacles to effective coping (Burish & Bradley, 1983).

Anderson (1988) studied stroke patients and their supporters. The patients, aged 60 and over, were registered with a general practitioner from the Greenwich health district in London, England and had suffered a stroke between April and December 1983. Altogether 176 patients were identified. There was a small majority of women (55 percent) and a high proportion of people aged 75 or over (58 percent).

The patients' main supporters were asked about the support they were then giving. The aim was to focus on the reality of caring and consider the experience of stroke from the carer's perspective.

Anderson (1988) reported that in comparison with life before the stroke, nearly half the carers, 45 percent, said they were now spending 'much more' time helping with practical jobs - bathing, shopping, and doing housework. Other difficulties that supporters related to giving more practical help included being 'on call' all the time, feeling worried or depressed about how the patient was

coping with practical tasks, and having too little time for other people.

The results of the study suggest that some patients and carers find adjustment more difficult - for example, carers who live with the patients and, especially, those who were less happy in their relationships before the stroke. Nearly a quarter of all carers described social isolation or restriction as the most distressing problem, and the greater significance of social life over practical tasks as a cause of stress has also been reported in a large study of carers in South Wales (Jones & Vetter, 1985).

The suffering of carers has been obvious for many years, as an editorial in the British Medical Journal more than a decade ago illustrates:

A sense of isolation is felt as much, or more, by the relatives than by the patient in many households; only those who have experienced it fully appreciate the despair which sometimes overcomes a wife or husband who, without warning or training, has to assume for months or years, a responsibility combining the skills of a nurse, remedial therapist, psychologist, and speech therapist. This role which calls for unfailing optimism, resilience, and the patience of Job, also calls for a measure of sympathetic understanding and support from community services and society which is seldom forthcoming.

(1974, p.122)

The evidence to support these observations has become increasingly emphatic in the years since that editorial. A high proportion of people who support the survivors of a stroke identify

deleterious effects of caring on their health and emotional well-being (Brocklehurst et al, 1981). Isaacs and colleagues (1976) point out that the stroke patient's increased dependency upon contacts with close family and relatives may contribute to increasing conflict and hostility at home. For carers, the loss of the patient as an active social partner and the demands of patients which reduce the time or energy available for social activities, may be an important cause of problems and distress. Among the spouses of younger stroke patients, the loss of companionship and interference with social and leisure activities were described as the major reasons for a loss of enjoyment in life (Coughlan & Humphrey, 1982).

Individual coping mechanisms

Defense mechanisms are said to prevent unconscious material from intruding into consciousness where it would cause unmanageable anxiety. Denial is the defense mechanism most often attributed to ill or disabled people. The use of denial is common in chronic disease. Denial has been reported in a wide variety of conditions and there are many examples of blatant denial e.g. a wheelchair patient describing herself as having been dancing the previous week (Johnston, 1984).

Kerson & Kerson (1985) propose that each illness is accorded some part in the identity of the individual. Some people make the illness one part of themselves. Some deny that they are ill. Others may describe their illness as trivial, denying the more major or threatening aspects of their illness or they may recognize

the illness but attribute it to some benign cause. In each case, the anxiety-provoking aspects are denied allowing the patient to cope with some less threatening, more manageable condition. Some have their lives revolve around their illness and, in fact, almost become the illness.

However, there are points at which the disease must be acknowledged so that the person's health will not be endangered. There is a difference between denying the presence of the disease and denying the limitations the disease presents. Denial of the disease can be destructive; denial of some limitations may be helpful.

In coping with chronic illness, the psychological response usually evolves over time. There is usually depression at the time of diagnosis and prognosis, hope and sometimes euphoria at the first remission, great despair at the first recurrence, then somewhat of a flattening of the highs and lows as the cycles continue. The work of Moos (1976) can be drawn upon to understand coping behaviour with chronic illness.

Adaptive behaviour involves the simultaneous management of at least three things: securing adequate information, maintaining satisfactory internal conditions, and keeping up some degree of autonomy (Moos, 1976).

Several factors influence the quality of a person's coping response, i.e. the environment may offer practical and emotional resources, such as social agencies and support from family and friends. The environment also sets limits, in the form of cultural

norms and expectations within which the individual must operate.

Specific coping strategies differ in appropriateness according to the particular combination of situation and personality factors involved. Coping refers to two distinct but related tasks. One must respond to the requirements of the external situation and also to one's own feelings about that situation. These tasks are not always dealt with at the same time since the coping response is unique to each person and the demands of the situation as well as strategies of the individual can change over time.

The overall pattern tends to fall into two phases: an acute phase in which energy is directed at minimizing the impact of stress, and a reorganization phase in which the new reality is faced and accepted. In the acute phase, feelings may be denied while attention is directed at practical matters. This allows people to ration out their limited physical and emotional energy while giving them time to adjust to the change in their lives. The reorganization phase involves the gradual return to normal functioning and to the achievement of a new equilibrium in which changed circumstances are integrated into the individual's life and self-image (Moos, 1976).

Life crises, such as the diagnosis of a chronic illness, can present an unusual opportunity to positively influence coping ability for those people who resolve the crises in a healthy way. The successful mastery of life crises can constitute an important growth experience (Kalis, 1970).

Grief in chronic illness

Loss and change are normally a part of life. They may not be noticed much and are naturally absorbed into the lifestyle. Chronic illness may accelerate the losses and label them in an undeniable way (Lewis, 1985).

The big or small losses accumulated along the way in chronic illness result in a long-term grieving process that is influenced by the way the initial grief is handled. Among the things that may be lost by the chronically ill are health, fantasies of immortality, privacy, control, role identity, independence, means of productivity or self-fulfilment, self-image, dreams or goals for the future, relationships, old ways of sexual expression, feeling good, undisturbed sleep, play or recreational activities, and energy, plus many other losses that serve as an expression of the self (Lewis, 1985).

Purtillo (1976, p. 281) postulates that, of these losses, privacy, body image, and relationships are the most important. "The tapering off of supportive relationships often is the most difficult reality the person has to face in either chronic or terminal illness" (p. 281-282).

Grieving the losses in chronic illness has its own peculiar difficulties. "Perhaps one of the major differences between grief associated with long-term illness and disability and grief associated with the loss of a significant other is that the person is there to mourn his own loss" (Werner-Beland, 1980, p.42).

Physiologic changes due to chronic illness, depression, and the grief process all, individually and together, have the potential of producing emotional responses that would perpetuate grief into a cycle if they were not resolved.

There is a need to work through the "grief so that one can get the past in perspective and find meaning in the present" (Cox-Gedmark, 1980, p.21). This also requires coping strategies to help make the most of what is in the now. "Grieving the loss entails a progression from the initial reaction of numbness or disbelief to a growing awareness of pain, sorrow and often anger and preoccupation with the lost object, and gradually reorientation in which the loss is accepted and equilibrium restored" (Moos, 1977, p.18).

Lewis (1985, p.38) emphasizes that "grieving is painful and difficult, however, there may be certain benefits to grieving. New strengths may develop as by-products of coping with chronic illness. The gift of life, without conditions, may be more deeply treasured and celebrated. Joy can replace sorrow, laughter can push aside the tears, peace can pervade turmoil, and involvement with life can appear in place of loneliness, as grief serves as a bridge between life in the past and life in the 'now'."

Keys to grieving

Lewis (1985, p. 39-41) discusses ten important keys to grieving:

Key 1: You have to stay with the pain and experience it in order to work through it.

- Key 2: Experience the pain and then let it go. You must let the tears flow to cleanse the wounds of grief, thereby allowing healing.
- Key 3: Learn to laugh, try to see humour in your situation, and celebrate life.
- Key 4: Keep the lines of communication open.
- Key 5: Times of solitude and times of fellowship need to be alternated.
- Key 6: You need to utilize your special support persons and seek counselling to help find the way.
- Key 7: Take responsibility for yourself and realize that you do play a role in your illness.
- Key 8: Faith gives hope and courage to reach beyond where you are and venture into the unknown.
- Key 9: In some ways, dying is the easy part - fully living presents the greater challenge. Death is merely a breathing out of the spirit, requiring no effort or energy, but only a release.
- Key 10: Our uniqueness comes in our living, not in our dying.

Self-management skills

Tobin et al (1986) discuss self-management in chronic disease. Environmental and social resources may have a strong relationship to self-management success. For example, disorganized or dysfunctional family process can undermine self-management efforts (Gurman, 1981).

Client motivation is often considered the most important predictor of success for all forms of psychological or medical healing that require the active involvement of the patient (e.g. Frank, 1974).

Coping skills in self-management

Self-monitoring refers to a patient's observation and recording of factors that influence the particular health problem that they are attempting to change.

Self-instruction refers to instructions patients provide to themselves to direct, increase, maintain, or decrease certain aspects of their responding. Self-instruction aids in the rehearsal and performance of behaviours that reduce risk factors or alleviate symptoms. As in self-monitoring, self-instruction can be used to facilitate responses that target any or all of the interacting components in a patients' disease process.

Self-induced stimulus change involves any attempt to change environmental conditions that can impact some aspect of a patient's illness. This can involve making environmental changes that affect a patient's illness directly.

Self-induced response change refers to a patient changing certain aspects of behaviour to reinforce or punish responses that affect health (Thoreson & Mahoney, 1974). This may involve self-contracting, self-reward, or self-punishment strategies that encourage adaptive response sequences or inhibit maladaptive ones.

Relaxation provides a means of controlling physiological processes that precipitate symptoms (e.g. reducing muscle tension that causes headaches).

Lastly, Tobin et al (1986) indicate that Decision-making is an important part of all self-management intervention. Patients must choose among alternative courses of action in everyday self-

management activities. The most important decisions in self-management programs include prediction of illness episodes or illness exacerbation and of what to do in such an event. The patient with chronic illness also encounters important decisions when faced with circumstances likely to promote relapse.

Summary

Coping with chronic illness is a complex process. Patients' beliefs about chronic illness are important to consider. Cognitively, patients need to form an understanding of the meaning of illness in their lives. Perceptions of the cause of their illness and beliefs about whether or not the illness can be controlled are important in predicting adjustment.

Self-blame for chronic illness is common as patients perceive that they are to blame for the development of the illness through their own actions.

Those who are chronically ill have a great deal of responsibility for maintaining their health. The burden of constant self-responsibility can be tremendous. Feelings of anxiety, depression, isolation, and rejection often result, posing major coping problems.

Social support helps individuals cope with chronic illness. Families may have their own coping problems as well. Increased dependency by the chronically ill person can place many demands on family members. Restricted involvement in social activities is a common problem for family members as they find themselves spending much more time in helping the ill person with practical tasks.

Defense mechanisms are commonly used by chronically ill persons as they adjust to a new diagnosis. Denial is reported as the defense mechanism most often attributed to ill or disabled people.

Coping with chronic disease involves a response to the requirements of the external situation and a response to one's own feelings about the situation.

One must grieve the losses that chronic illness brings, including the loss of independence, privacy, self-image, control and relationships. One must work through the grief associated with these losses to successfully adapt to chronic illness.

Self-management skills are important in chronic illness. These include self-monitoring, self-instruction, self-induced stimulus change, self-induced response change, relaxation and decision-making.

CHAPTER III

DIABETES

What is diabetes?

According to Edelwich & Brodsky (1986), diabetes is caused by the body's inability to produce sufficient insulin or to use effectively the insulin supply it has. Insulin is a protein hormone which is produced by beta cells in the pancreas, a large gland situated behind the stomach, and from there secreted into the blood. There it has two major functions. One is to transfer glucose (a form of sugar into which most carbohydrates and some proteins are converted) from the blood to the body cells, where it is "burned" as energy. Insulin's other function is to convert excess glucose to glycogen, which is stored in the liver and muscles as an energy reserve.

When insulin is lacking or cannot be used properly, the body loses its ability to process glucose. As a result, glucose accumulates in the blood - a condition known as hyperglycemia (high blood sugar).

There are two types of diabetes. In Type I, insulin-dependent diabetes, the pancreas produces little or no insulin. In Type II non-insulin dependent diabetes, the amount of insulin produced varies and may even be normal, but the body cannot make efficient use of it.

Diabetes is a disease which affects people of all age groups and often compels them to make drastic alterations in their way of life. Its etiology is unknown. Genetic factors, patterns of

nutrition and possibly some viral infection may be involved. There are also indications that a period of emotional stress could operate as a precipitating factor.

Since the disease is due to a disturbance in the regulation of the metabolism prompted by an insufficient production of insulin, its treatment is aimed at the restoration of equilibrium between the uptake of food and the amount of insulin required for its metabolism.

Coping with diabetes

There is no other chronic illness in which health behaviour must be as continuously and rigidly controlled as diabetes. The demands of diabetes are constant.

According to Armstrong (1987), coping with diabetes is a full-time job, 7 days a week, 52 weeks a year. One cannot take a vacation from diabetes without risking at least temporary health impairment. Armstrong (1987) also says that adherence to diabetes management behaviours places considerable psychologic stress on the afflicted person and calls for numerous adaptation and coping processes.

The diagnosis of diabetes presents a crisis for most people. A crisis is an overwhelming, threatening event. The response to a crisis may include feelings of anxiety, confusion and helplessness. Other reactions may be shock, disbelief, fear, anger, denial, panic, guilt, depression (Aloia, Donohue-Porter, & Schlusel, 1984).

Aloia et al (1984) further postulate that diabetics may use a variety of defense mechanisms to help control anxiety and reduce the stress that results from a crisis. Defense mechanisms allow a person to cope temporarily with a crisis until he can adjust. Adjustment to diabetes involves a coping process. "Coping" is defined as struggling with something, usually with a certain degree of success. Defense mechanisms are used by everyone in varying degrees. They allow you to distort reality so that you are not overwhelmed. However, they are only temporarily useful. Overuse of defense mechanisms eventually slows adjustment. If one continues to use defense mechanisms in response to diabetes, one may not obtain emotional control.

Many people, following initial diagnosis, attempt to cope with diabetes by using denial, disregarding the existence of diabetes in daily life. Denial may be manifested by neglecting to take insulin injections or not following a diet. Some diseases are more difficult to deny than others. Diabetes is easy to deny because its physical effects may not be experienced on a daily basis. Denial of diabetes is an involuntary, unconscious, psychiatric defense that is particularly impervious and unresponsive to confrontation (Rynearson, 1988).

Diabetics commonly fail to assimilate the reality of their disease for days or weeks after their diagnosis. It takes time to develop the concept that diabetes is and will continue to be a part of their lives. Psychologic responses of numbness, shock, and

incredulity are the rule in the beginning, later replaced by more constructive adaptations (Rynearson, 1988).

According to Aloia, Donohue-Porter, & Schlusel (1984), anger may develop in response to diabetes. "Why me?" "What have I done to deserve this?" Anger directed at the physician may lead to "doctor shopping" in hopes of receiving a more favourable diagnosis or prognosis. Problems may arise when anger remains and interferes with self-management. If anger is held inward and not expressed, a person may become depressed and unable to cope with the demands of diabetes self-management. These authors further discuss:

DEFENSE MECHANISMS COMMONLY SEEN IN DIABETES

Denial	Blocking out aspects of reality that cause pain or fear
Rationalization	A false explanation of behaviour that you do not wish to acknowledge; it prevents guilt
Displacement	Placing emotions or feelings upon a person other than the one to which the feelings belong
Regression	Unconsciously returning to an earlier level of emotional adjustment

Tattersall & Jackson (1982) indicate that the newly diagnosed diabetic is confronted by a new vocabulary, a need to learn food values previously ignored, a new responsibility for administering his own treatment, the frightening immediate or remote possibility of self-injection and anxiety about the possibility of hypoglycemia, and future medical complications. His ability to meet these challenges will depend to some extent on his previous

knowledge of the disease. Diet tends to pose the greatest challenge for diabetics.

A common anxiety for diabetics is the need to be responsible for their own treatment. Self-monitoring provides a constant reminder to the patient of his success or failure in controlling his own disability.

Kelleher (1988) studied diabetics living in London, England to examine coping strategies with diabetes. The people in the sample were thirty diabetics all aged 17 years and over. Twenty of them were randomly selected from a register of 217 patients with diabetes which had been set up by the GP's of three practices with the help of the local hospital. Of the others, five were newly diagnosed diabetics recruited at their first appointment at a hospital clinic and another five were diabetics who had recently been hospitalized. The study was intended to be an exploratory one and it included both insulin-dependent and non insulin-dependent diabetics in the sample.

The respondents were interviewed once in their homes (except for three individuals). The interviews were semi-structured and tape-recorded.

Three themes emerged from the data; the theme of being normal, of the claim to be a normal healthy person; the theme of control, whether there was a sense of being in control of the diabetes or a feeling that it did not dominate daily life; and thirdly, the theme of how much of life had to be considered and tailored to fit with diabetes.

Kelleher (1988) found that those who coped with their diabetes were in a minority, being characterized by having a basic knowledge of how treatment works and the determination to apply that knowledge. They were prepared to alter their treatment regimen rather than reduce their social roles, their engagement with others in the social world. The role of being a diabetic was for them a less salient role in their identity rather than being a husband, a wife, a worker, or a mother; they did not deny the reality of their diabetes but, by trying out alterations in their medication and exploring the boundaries of their own reactions, they achieved a sense of control.

For those who coped in this study their diabetes remained a practical problem for them but it was not a disruptive problem at the cognitive level, as they had arrived at a relatively stable meaning for it. For those people who constantly worry or agonize about their diabetes, it achieves a dominant place in their identity and remains a problem at both the practical and cognitive level.

The author also points out that whether people view themselves as healthy (whatever that means to them) or not, is a centrally important question which influences how they fit the diabetes into their lives and which may influence their identity and the way they engage with everyday life. Whether or not they see themselves as healthy also influences how they manage their diabetes. Tattersall

& Jackson (1982, p. 271) state:

For most the crucial factors determining the level of control (of blood sugar level) actually achieved are the patient's own motivation and enthusiasm, which in turn depend largely on his emotional response and the way he adapts to the diabetes. Therefore, the identification and prevention of social-emotional problems are arguably of more importance in preventing complications than new methods of insulin delivery.

The analysis in this study suggests that it is not so much the search for and identification of social-emotional problems which is important, but understanding the meaning given to diabetes by people experiencing it in their everyday lives. Such meanings, it is suggested, incorporate the individual's perception of the problems related to being a diabetic and the ways actively used to cope with or adapt to the problems.

Diabetes is a physical, not a psychosomatic, disorder and patients react with the personality resources available to them (Tattersall & Jackson, 1982). These will include age of onset, and socio-economic status as well as level of education and intelligence. The extent to which the diagnosis of diabetes affects an individual depends largely on the psychological implication of illness to him.

Basic personality traits such as independence, perseverance and strong emotional ties to others may help a person to meet the demands of diabetes. Jay Skyler, MD (1979) has identified the following potential adverse coping patterns in those with diabetes:

Seclusiveness

Aggressiveness

Bravado (boastfulness, devil-may-care attitude)

Shame, leading to concealment of feelings

Guilt feelings, depression

Open resentment, rebellion, subversiveness (eg. faking urine tests, omitting insulin, disregarding diet)

Meticulousness, conscientiousness, perfectionism and other obsessive-compulsive reactions

Submissiveness (especially in those who developed diabetes early in childhood)

The particular coping strategies that are chosen are especially important because the decisions, values and beliefs that characterize the coping strategies adopted in times of crisis, such as the initial diagnosis, will very likely shape later coping styles and influence important outcomes in the future (Galatzer et al, 1982).

Aloia et al, (1984) discuss: STRATEGIES THAT AID IN COPING WITH DIABETES

The most important strategy is to seek information. Education allows a person to feel better about him/herself and his ability to control diabetes. If a person knows little about diabetes, he will feel that he cannot cope. He will feel insecure in recognizing signs and symptoms of impending problems. Thus, education is an important tool in psychological adjustment.

Another coping strategy is taking positive action to improve health. Health-related behaviours such as scheduling doctor's visits, attending a diabetes education centre and establishing a regular exercise program are examples of such actions. Other

coping efforts may be directed at controlling emotional distress through stress-reducing exercises.

Lastly, Aloia et al (1984) indicate that the establishment of a self-management program is another coping behaviour. Along with this is the development of individual problem-solving skills. Problem-solving skills involve individuals actively finding solutions to their own problems. In order to solve problems successfully, one must first be able to identify the problems. Next, priorities must be established. Then consider which problems need immediate attention. Set goals and see what is available to help meet these goals. Be realistic about the scope and time involved in the solution of such problems. Finally, evaluate whether or not meeting the goals helped to solve the problem.

Summary

Diabetes is a chronic health condition characterized by partial or complete failure of the pancreas to produce insulin. Diabetes affects people of all ages and often means that individuals have to make lifestyle changes.

Coping with the demands of diabetes can be a constant struggle. Many diabetics use a variety of defense mechanisms to help control the anxiety and fears surrounding the diagnosis, including denial. Anger may also develop in response to diabetes. Self-monitoring provides a constant reminder of the success or failure in controlling the disease.

The meaning that people give to their diabetes is important to consider as such meanings incorporate the individual's perception of the problems related to being a diabetic and how they will cope with these problems.

The extent to which the diagnosis of diabetes affects an individual can depend on the perception of illness to him. Personality traits such as independence, perseverance and strong emotional ties to others may help a person cope better with diabetes.

Seeking information, taking positive actions to improve health and the establishment of a self-management program are all strategies that aid in coping with diabetes.

CHAPTER IV

COMPLIANCE WITH THERAPEUTIC REGIMENS

"Failure to comply with prescribed regimens is a problem of enormous dimension for all health-care providers. The problem is grossly understated by patients. Noncompliance carries a multibillion-dollar price tag and heavy toll of human suffering. It has been extensively analyzed and yet remains poorly understood. A fresh perspective on issues of compliance emerges when the problem is viewed in its multilevel context. When one considers all the systems that interplay in any individual's life - biochemical, cellular, neurological, familial, societal - and all the factors that influence a physician's diagnosis and treatment plan, it is less surprising that traditional methods of achieving patient compliance prove inadequate. A systems view suggests new approaches that have the potential to cut the human and economic cost of noncompliance. The people who pay for health care - individuals, insurance companies, HMO's, the federal government - and the people who provide health care - doctors, nurses, pharmacists, therapists, - all share a substantial interest in solving the compliance problem."

(Rissman and Rissman, 1987, p. 446)

Characteristics of noncompliance

Patient's lack of compliance with prescribed treatment is a major problem in primary health care. The magnitude of patient compliance with medical treatment is possibly one of the most crucial issues facing health care providers today.

Haynes (1979) has defined compliance as "the extent to which a person's behaviour (in terms of taking medications, following diets, or exercising life style changes) coincides with medical or health advice."

Compliance can be viewed as both an attitude and a behaviour. Compliance as an attitude consists of a willingness or intention to follow health prescriptions, whereas behaviour relates to the actual carrying out of prescriptions (Davis, 1968). Noncompliance behaviour could then include reluctance, reactance, and recidivism characterized by disinterest, refusal to comply, or the lack of sustained effort to follow health recommendations (Arakelian, 1980). There are specific physician factors that need to be considered as well. (These will be reviewed later on in this chapter).

Compliance is a major issue in virtually every area that brings people to seek medical attention. The most common medical problem investigated is hypertension, "the silent killer," where following a prescribed drug regimen has been proven to lower blood pressure and reduce the risk of stroke, heart attack, and kidney disease (Petersen & MacLean, 1982).

Noncompliance impedes preventive medicine when patients fail to follow home regimens. Noncompliance inhibits patients from achieving desired lifestyle changes such as improved nutrition, adherence to prescribed diets and exercise programs, cessation of smoking, and control of alcohol and drug intake.

Patient noncompliance may be manifested in a variety of behaviour patterns including: delay in seeking care, nonparticipation in community health programs such as immunization or screening, failure to keep follow-up appointments and failure to follow physician's instructions.

The incidence of poor compliance is alarmingly high. A review article by Robbins (1980) determined that approximately one half of patients instructed to follow a specific regimen do not do so.

Haynes (1976) indicates that when all of the "determinants" of compliance are considered, it is apparent that there is no single or simple explanation for non-compliant behaviour. There are, however, a small number of factors that are of undoubted and considerable importance. These "confirmed" factors, according to Haynes, are summarized in Appendix II.

Patients may be noncompliant because they do not have sufficient knowledge about their illness and because the prescribed medical regimen has not been sufficiently explained. Noncompliance has also been attributed to the patient's fear of medication or the adverse side effects of the medication. If the prescribed regimen causes painful, frightening, or unusual body reactions, then patients may be reluctant to comply with the regimen.

There is always a basic problem in the validity of the data that is collected on compliance behaviour, since rarely can health behaviour be directly observed, particularly for ambulatory regimens. Even when the health behaviour can be directly observed, it is biased by the observation.

Psychological Factors

According to Strain (1978), the psychological conditions that may find expression in noncompliance include depression, psychotic states, phobic conditions, and obsessional preoccupations. Strain, (1978) also says that noncompliance may be a manifestation of apathy, inertia, helplessness and hopelessness, or a suicidal wish (all of which are classic symptoms of depression).

Psychological stress

Strain (1978) states that non-compliant behaviour may arise as a consequence of the stresses related to the medical illness. Noncompliance may also provide a vehicle for the denial of illness. The patient attempts to deny the existence of the illness, and this illusion is strengthened by his avoidance of the medical regimen.

Intrapsychic factors

Searight and Noce (1988) indicate that there are several intrapsychic factors that contribute to recognition and interpretation of symptoms as well as presentation for treatment. These include cognitively-held attributions and attitudes, as well as emotional responses to illness.

A common precursor to beliefs about controllability of disease is a search for some personal meaning in the illness or disability.

By creating a cause for the illness, an explanation of its significance can be generated and then one can develop a strategy to control it. This appears to be especially true for serious physical illnesses. In a study of women with different forms of cancer, Taylor (1983) found that the patients provided a wide range of explanations for the disease.

The most frequently cited reasons was some form of stress - this often took the form of ongoing marital discord or a recent divorce. Other frequent explanations included a poor diet or the occurrence of a physical blow to the region of the body in which cancer appeared.

These personally constructed explanations have been found to be predictive of treatment utilized by patients (Gray, 1983). Among the women with cancer, a common belief was that a "positive mental attitude" would prevent reoccurrence (Taylor, 1983).

Individual patients interpret and treat their health problems on the basis of internal schemas consisting of needs, values and affective states which may lead them to engage in health care practices that are at variance from medical knowledge (Cerkoney & Hart, 1980).

In general, an individual's belief system is derived from social, ethnic, religious, familial and intrapsychic variables. Together, these factors are combined to create an internalized blueprint of the world (Sluzki, 1983) which organizes "raw reality." These blueprints serve as the basis for perception, meaning and action. Behaviour, in the form of overt action, as

well as verbalizations, provides the external observer with access to the blueprint (Sluzki, 1983).

Health Belief Model

Marshall H. Becker (1979) discusses the development of the Health Belief Model. He indicates that during the 1950's a group of social psychologists (Hochbaum, Kegeles, Leventhal, and Rosenthal) developed a theoretical framework for explaining the likelihood of an individual undertaking a recommended preventative health action.

Usually termed the Health Belief Model (HBM), this theory, as illustrated in Appendix III, is based on the decision-making concepts of:

1. attractiveness of the goal to the individual and
2. the personal estimate of likelihood of goal attainment.

The theory argues that whether or not an individual will undertake a recommended health action is dependent upon that individual's perceptions of:

1. level of personal susceptibility to the particular illness or condition.
2. degree of severity of the consequences (organic and/or social) which might result from contracting the condition.
3. the health action's potential benefits or efficacy in preventing or reducing susceptibility and/or severity.
4. physical, psychological, financial or other barriers or costs related to initiating or continuing the advocated behaviour.

The HBM also suggests that a cue to action must occur to trigger the appropriate behaviour by making the individual consciously aware of his feelings about the health threat. Such cues can be either internal (perception of symptoms) or external (mass media campaigns, interpersonal interactions (Becker & Rosenstock, 1977)).

Another factor that determines the patient's ability to comply is the regimen itself. Therapeutic regimens often involve a number of components, some of which dictate changes in lifestyle (modifying eating, drinking, or activity levels) whereas others entail the taking of medications.

Some reviewers (Kasl & Cobb, 1966; Rosenstock, 1966) conclude that the HBM provides a satisfactory explanation for the majority of findings in the area of preventive health behaviour.

Becker (1976) outlines the components of the HBM as follows:

1. Evaluation of the health condition

- i. Perceived susceptibility

This includes:

1. Examining the individual's estimate of (or belief in) the accuracy of the diagnosis. Where the disease is very threatening, where there is lack of confidence in the physician or diagnostic procedure, or where erroneous health knowledge exists, the patient may reject the clinician's conclusions and thus maintain a distorted view of

personal susceptibility to the disease (Becker, Drachtman & Kirscht, 1972).

2. Measuring the individual's subjective feelings of vulnerability to various other diseases, or to illness in general.

Perceived susceptibility has demonstrable explanatory and predictive value and should be a fundamental part of a psychosocial compliance model.

ii) Perceived severity

The HBM asserts that even when an individual recognizes personal susceptibility, action will not occur unless he or she believes that becoming ill will bring serious organic and/or social consequences. Again, this refers to the person's subjective perceptions. The role played by perceived severity in determining compliance with prescribed therapies is quite similar to that demonstrated for perceived susceptibility.

2. Evaluation of the Advocated Health Behaviour

i) Perceived benefits

Perception of the benefits of an advocated health behaviour has also been shown to be related to compliance. In studies of sick-role behaviours, Donabedian & Rosenfeld (1964) identified "doubt about the recommended procedure" as a reason for elderly patients not following physician's instructions relevant to their chronic illnesses.

ii) Perceived costs or barriers

Fear of pain or discomfort and of the monetary expense associated with obtaining dental care is inversely associated with compliance (Kegeles, 1963; Tash; O'Shea, & Cohen, 1969; Antonovsky & Kats, 1970) as are such "negative" aspects of prescribed therapeutic regimens as cost (Alpert, 1964; Donabedian & Rosenfeld, 1964; Antonovsky & Kats, 1970); duration (Bergman & Werner, 1963; Charney et al, 1967) and side effects (Caldwell et al, 1970; Weintraub, Au, & Lasagna, 1973).

iii) Cues to action or motivation

Suchman (1967) and Becker et al (1974), looking at preventive and sick role behaviour reported that compliers were more likely to seek formal medical care (as opposed to self-treatment) in the presence of symptoms.

iv) Modifying factors

Many additional variables have been looked at in compliance-related research, but only a few have been predictive with sufficient consistency to be included in the model.

These include:

1. Patient-practitioner relationship

Davis (1968) found that "patterns of communication which deviate from the normative doctor-patient relationship will be associated with patients'

failure to comply with doctors' advice" including situations where the clinician is formal, rejecting, controlling, disagrees completely with the patient, or interviews the patient without giving information.

2. Physician continuity

Patients are more likely to comply if they have continued to see the same physician over time.

3. Demographic and personality variables

Only "extremes of age" are significant to be used in a sociobehavioural model of compliance.

Becker (1976) presents a hypothetical model explaining and predicting compliance with health and medical care recommendations. This sociobehavioural model of compliance is shown in Appendix IV.

Patient-practitioner relationship

Previous efforts to understand the problem of non-compliance have focused increasingly on the interaction between the physician or other health care provider and the patient (DiMatteo & DiNicola, 1982; Kasl, 1975; Stone, 1979; Svarstad, 1976).

Pendleton (1983) suggests that outcomes of the interaction can be immediate, intermediate or long-term. One immediate outcome that has been studied extensively is patient satisfaction with medical care. In spite of some methodological and theoretical problems in this literature (Locker & Dunt, 1978), one consistent finding is that the major source of patient dissatisfaction concerns the patient-physician relationship.

Pendleton (1983) summarizes the findings by saying:

...satisfaction of the patient is more likely when the doctor discovers and deals with the patient's concerns and expectations; when the doctor's manner communicates warmth, interest and concern about the patient; when the doctor volunteers a lot of information and explains things to the patient in terms that are understood (p. 39)

Another important immediate outcome of the interaction is the patient's memory of the physician's instructions. Closely related to these outcomes is compliance, the major immediate outcome variable mentioned by Pendleton (1983). Dissatisfaction with the interaction, communication problems, and failure to remember or to understand what they have been told are major sources of patient noncompliance with treatment recommendations.

Communication of information

An essential part of the patient-physician interaction is communication of information. It is important that patients give an accurate account of their symptoms in order to assist the physician in making a correct diagnosis. The physician then must convey information to the patient regarding the results of diagnostic procedures, diagnosis, prognosis, and the treatment regimen.

Haney and Colson (1980) argue that the greater responsibility in this interchange lies with the physician and that it is the physician's ethical responsibility to learn the necessary communication skills to appropriately convey information to the patient. Such communication skills involve more than just giving verbal information. Attention must also be paid to nonverbal

aspects of communication, as well as understanding the psychological, social, cultural, and situational variables that either facilitate or impede the communication process.

A number of factors have been identified which may contribute to physician-patient communication problems. These factors include: physician variables, patient variables and interactional variables.

Physician variables

The amount of time a physician spends in conveying information to the patient is important to consider. Geertsen, Gray, and Ward (1973) found that the patient's perception of the amount of time spent with physicians was more important than the absolute amount of time. That is, patients who felt that their physicians spent an inadequate amount of time with them were less likely to comply.

Another important issue is the degree to which the physician conveys information in comprehensive terms to the patient. Although patients may be impressed by their physician's use of medical jargon, they can hardly be expected to comply if they fail to understand what they are expected to do. Ley (1982) found that many patients report that they did not understand the information presented to them. One of his studies found that 43% of patients did not understand information regarding their treatment regimen.

Patient variables

Cassata (1978) summarized the physician-patient communication research as it relates to patient recall of information. The major

conclusions are as follows:

1. Patients forget much of what the doctor tells them.
2. Instruction and advice are more likely to be forgotten than other types of information.
3. The more a patient is told, the greater the portion he or she will forget.
4. Patients will remember (a) what they are told first, and (b) what they consider most important.
5. Intelligent patients do not remember more than less intelligent patients.
6. Older patients remember just as much as younger ones.
7. Moderately anxious patients recall more of what they are told than highly anxious patients or patients who are not anxious.
8. The more medical knowledge a patient has, the more he or she will recall.
9. If the patient writes down what the doctor says, he or she will remember it just as well as if he or she merely hears it.

For the patient, noncompliance may be caused not only by negligence or unwillingness to cooperate with the doctor. In the patient's perception, medical advice may be ineffective, needless or even noxious (Stimson, 1974).

Hayes-Bautista (1976), on the basis of empirical study, found that the patients' willingness to change medical regimens was a consequence of belief that the original treatment was in some way inadequate. These changes did not always involve nonfulfillment of doctor's instructions. It may also mean increasing the frequency

or intensity of prescribed behaviour or introducing additional means; taking extra pills, using home remedies, etc. Sometimes the patient tries to consult the doctor regarding such changes, sometimes he or she decides to act on his or her own and the doctor does not suspect that his directions are not exactly executed.

Interactional variables

Baekeland and Lundwall (1975) reviewed six studies, all of which found that discrepant therapist-patient treatment expectations were associated with dropping out of treatment. Although these studies focused on individual psychotherapy, the authors suggested that poorly informed patients who either fail to understand or disagree with the rationale are likely to drop out of other forms of treatment as well.

The nature of the physician-patient interaction may significantly affect the communication process. For example, physicians who tend to be more formal and authoritarian may intimidate passive, unassertive patients and prevent these patients from asking for additional or clarifying information.

Communication of Information in Chronic Conditions

Much of the communication literature showing that patients often forget or misunderstand the information given by their physicians is based on patients' first visits for a certain illness or on visits for acute conditions. Thus, it could be hypothesized that retention and understanding of information improves with repeated physician contacts as needed by many chronic conditions.

An even more significant issue related to chronic conditions is whether the patient remains in treatment. Baekeland and Lundwall (1975) provide a comprehensive review of the factors associated with dropping out of treatment. With regard to chronic medical conditions (such as hypertension) one factor associated with drop-out is poor instruction regarding the possible dangers of the condition, as well as the importance of remaining in treatment. Another important factor is the degree of congruence between the provider and patient's ideas about the goals and methods of treatment.

Content of Information

In addition to examining the communication of information to patients, it is important to consider what types of information are most related to subsequent compliance.

Although ideally the patient should be given information regarding the disease itself (e.g. diagnosis, etiology, severity, or prognosis), evidence regarding the relationship between such knowledge and compliance is equivocal (Haynes, 1976). For example, Gordis, Markowitz, and Lillenfield (1969), Vincent (1971), and Weintraub, Au, and Lasagna (1973), and Bergman and Werner (1963) found no relationship between such knowledge and compliance. Furthermore, attempts to improve compliance by providing more information about the disease have occasionally met with failure (Sackett et al, 1975; Tagliacozzo, Luskin, Lashof, & Irma, 1974).

In addition to information about the disease itself, the other significant type of information concerns the treatment regimen, the

specific health behaviour required, and the possible consequences of failure to follow the regimen. Some of the studies mentioned above failed to find a relationship between knowledge of the treatment rationale and compliance (e.g. Weintraub, et al, 1973).

These findings should not be interpreted as indications that information about the disease itself and the rationale for treatment is not important. Rather, knowledge of the illness and reasons for treatment may not be as important as the patient's subjective interpretation and evaluation of such knowledge and rationale. As Leventhal (1982) points out, a physician's presentation of information regarding illness or treatment rationale may not be as important in itself as the degree to which such information corresponds with the patient's own theories about the illness and what should be done about it.

The Physician's Influence on Patient Compliance

Physicians should take responsibility for assessing compliance in their patients and reasons for noncompliance. Although assessing whether or not a given patient is compliant is an essential part of medical care, it is unfortunately often neglected by many physicians.

It is important for the physician to determine the extent to which a patient is actually following a given treatment in order to assess the utility of the treatment.

In addition to the failure of many physicians to directly assess patient compliance, it has been noted that patients often fail to report spontaneously their noncompliance and some may even

deliberately distort the truth (DiMatteo & DiNicola, 1982).

The success of a thorough compliance assessment requires a physician-patient relationship that allows and encourages open discussions of compliance issues.

Further, it has been suggested that the actual process of undertaking such an assessment can contribute to the forming of a good relationship, which in turn can facilitate improved compliance (Matthews & Hingson, 1977). The assessment process can communicate to the patient that the physician is genuinely interested in the patient's own perception of the treatment regimen and also appreciates the difficulties that may be involved in following it.

Szasz and Hollender (1956) present a physician-patient relationship model. In this model, called mutual-participation, the physician and patient share equal power and work together in a collaborative manner.

The development of a treatment program is a negotiated process where both the physician and patient are actively involved. Another aspect of the mutual participation process is the awareness that patients have the right to refuse any treatment they believe is not in their best interest. Physicians also have the right to refuse any suggestions by patients that are judged to result in more harm than good. Brody (1980) also suggested that this process requires flexibility in the physician in considering alternative courses of action. Such flexibility can be enhanced by physicians' attempts to understand the patients' internal belief system

regarding the nature of the disease, its seriousness, and expected consequences of various courses of action.

A mutual participation relationship has several advantages in promoting patient compliance. By allowing patients to participate in the treatment planning process, they will be more likely to continue in treatment (Eisenthal, Emery, Lazare, & Udin, 1979) and many problems in following the treatment program can be avoided. Also, this type of relationship facilitates the recognition and understanding of compliance problems which may develop when the patient tries to follow the program.

How Society Contributes to Noncompliance

Cummings and Nehemkis (1986) review those factors associated with society's contribution to noncompliance.

Medical noncompliance takes many forms, from failure to seek health care to fraudulent and self-inflicted injuries. The costs of noncompliance are enormous. They include all the forms of compensation paid for illnesses and disabilities that are caused by noncompliance, as well as lost productivity and the perpetuation of preventable diseases and chronic disorders.

There are other results of noncompliance which cannot be seen in dollars, but may be just as costly to society in the long run. Cummings and Nehemkis (1986) pose this question: What are the intangible consequences to the larger community when increasing numbers of its members are willing to accept a non-productive role by remaining unnecessarily disabled?

The Role of the Clinician

Patients are sometimes caught in a system that makes noncompliance seem the most reasonable choice. Labelling the patient as "uncooperative" or "resistant" is just a variation of "blaming the victim."

Health care providers must become aware of the pressures on patients so that they do not take an unwitting role in an arrangement that is not therapeutic. For example, clinicians should not begin a long, demanding, and expensive program of treatment if a patient's motivation is restricted by legal advice or monetary self-interest. A physician or other health care worker can be most helpful by clarifying the issues with a patient in a supportive manner.

It is also important to avoid getting into an adversary relationship with a non-compliant patient. The clinician can help the patient to realize that it is always better to be strong and healthy no matter what the incentives to maintain invalidism.

Another question Cummings and Nehemkis (1986) ask is: What can the clinician do when noncompliance is caused by societal factors?

Strategies for Improving Compliance

The improvement of compliance rates has been a major treatment concern in the field of health psychology. A variety of behavioural techniques have been used with limited success. Among these methods are cueing, stimulus control techniques, self-monitoring methods (Johnson, Taylor, Sackett, Dunnet, & Shinizu,

1978), and reinforcement of medication use and symptom reduction (Haynes, 1976).

Other treatment approaches have stressed informational/educational interventions. Such methods have not, generally, improved compliance rates (Kirscht & Rosenstock, 1979).

Interventions aimed at improving patient-practitioner relationships have been identified as holding significant promise for future interventions (Stone, 1979). Here, improving effective communication skills of medical professionals would be the major treatment focus.

The reviews of compliance literature (Epstein & Cluss, 1982; Kirscht & Rosenstock, 1979; Mazur, 1981; Stone, 1979) generally conclude that compliance rates are the result of complex interactions of many differing factors. The awareness of this view of compliance as multifaceted has not always brought effective treatment protocols.

Haynes (1982) discusses interventions that have been shown to work in improving compliance with treatment programs.

Self-monitoring works well in combination with other methods. This has been used successfully for blood pressure management in conjunction with positive reinforcement for improvements in compliance and blood pressure control (Haynes, Sackett, Gibson, Taylor, Hackett, Roberts, & Johnson, 1976).

A strategy that has received only limited testing but that appears to hold promise, at least when combined with other methods,

is soliciting and encouraging family support for the patient (Levine et al, 1979).

Group discussions provide another method for enhancing compliance in combination with other methods (Levine et al, 1979; Nessman et al, 1980).

Home visits to patients have been found worthwhile in promoting adherence to hypertension, as well as reminders and reinforcement of compliance (Wilbur & Barrow, 1969).

Fink (1974) discusses strategies that attempt a negotiated regimen or management plan by health provider and patient.

The most fundamental concepts and assumptions of tailoring the consensual regimen include:

- A. Regimens must be individually negotiated. There is no such thing as a standard regimen for a standard patient.
- B. Health decisions and behaviour are carried out in the context of the total life setting. The impact of such factors as family and social stress and sociocultural aspects of illness will directly affect compliant and non-compliant behaviour.
- C. The universe of health problems of a particular individual is always changing and contains those components that require provider assistance and those that do not.
- D. In the vast majority of instances, the provider-patient relationship is most appropriate and effective as a relationship of "mutual participation," such as described by Szasz & Hollender (1956).

E. The goal of compliant behaviour is to achieve objectives that are client-focused, as well as provider-focused.

In Appendix V, Robie (1987) presents his methods of treating noncompliance. He says that the physician should adopt a positive role in preventing noncompliance since preventing noncompliance is more effective than correcting it.

The following case examples show the problem of noncompliance with health care practices.

A 67-year-old diabetic male presents with persistent sugar in the urine, high blood-glucose levels, and frequent chest pain. His wife calls before his next appointment and says he continues to eat cookies and candy and refuses to quit smoking.

A 44-year-old school teacher has just been switched to her fifth blood-pressure medication. The medical work-up proves negative, but her hypertension is still out of control. The doctor now suspects that she is not taking her pills.

A 52-year-old housewife has been evaluated and re-evaluated for chronic neck and back pain, insomnia, and irritable bowel syndrome. The doctor astutely realizes that there are multiple stresses in the home environment. He has, on three occasions, set up appointments for family counselling. The appointments have been cancelled three times.

Rissman & Rissman (1987, p. 447-448)

In each of the above cases, failure of the patient to comply with the prescribed therapeutic regimen is the major obstacle in the delivery of health care.

Summary

Patients' non-compliance with treatment is a major issue for health professionals. Patients' lack of knowledge about their illness, as well as fear of medication can lead to non-compliance. Non-compliance may occur as a result of the stresses related to the medical illness.

The Health Belief Model was developed as a framework for explaining the likelihood of whether an individual will follow the recommended treatment regime. The Health Belief Model asserts that whether or not an individual will follow a prescribed regimen is dependent upon several factors including:

1. the level of susceptibility to the particular illness
2. degree of severity of the consequences which might result from contracting the condition
3. the health action's potential benefits or efficacy in preventing or reducing susceptibility and/or severity
4. physical, psychological, financial barriers or costs related to initiating or continuing the advocated behaviour

The patient-practitioner relationship is an important component in whether or not an individual will follow recommended treatment regimens. How information is communicated to the patient can make a difference in compliance with treatment. Physicians need to convey information to patients in terms they can understand. Physicians also need to communicate with patients in a non-authoritarian manner so that patients do not feel threatened by asking for additional or clarifying information.

Physicians have the responsibility to assess compliance in their patients and reasons for non-compliance behaviour.

Physicians should determine the extent to which patients are following a prescribed treatment plan in order to assess the effectiveness of the treatment.

When the patient participates in the treatment planning process with the physician, he or she is more likely to follow the treatment program.

Society contributes to non-compliance when health care providers label the patient as 'uncooperative' or 'resistant.' For these patients, non-compliance may seem the most reasonable choice. Health care professionals need to be sensitive to the client's issues and promote compliance with health care recommendations.

Strategies that aid in improving compliance include self-monitoring with positive reinforcement; encouraging family support for the patient; group discussions; and negotiating a management plan between health provider and patient.

CHAPTER V

GROUP THERAPY

Group therapy for patients with chronic illness

Group participation can be a valuable experience for people trying to cope with similar health problems. Realistic adjustment and increased responsibility are encouraged by support from others. Several studies (Lewin, 1947; Lewin 1958; and Groen & Pelsler, 1979) have shown that new ideas, attitudes, and values are more easily accepted by people who identify themselves as members of a group dedicated to those principles.

Zrebiec (1988) indicates that all psychotherapy groups share the principle that talking about feelings, ideas, and experiences in a safe, respectful atmosphere increases self-esteem, deepens self-understanding, and helps a person get along better with others.

Cole, O'Conner and Bennet (1979) point out that self-help groups for patients with chronic diseases such as hypertension, diabetes, arthritis, cerebrovascular and cardiovascular disease represent a valuable adjunct to continuing medical care, and can promote better understanding, as well as better compliance with medical regimens.

Yalom (1975) has listed 11 factors that he believes to be curative in traditional group therapy. Yalom's nine curative factors are listed with examples of their relevance to therapy groups for medical patients: (Cunningham, Strassberg & Roback, 1978)

Instillation of hope - In groups that attempt to aid the patient in management of any chronic disease, the presence of group members who have been successful in dealing with the problem and who are not currently in debilitating distress greatly enhances the hopeful feelings of new members.

Universality - The therapeutic value of universality lies in an individual's sense of relief in recognizing that he is not alone in his misery. Members of a group for cancer patients (Parsell & Tagliereni, 1974) believed that since other members shared their medical problems, they would be understanding and helpful listeners.

Imparting of information - Symptoms and treatments are frequently confusing and distressing to the patient and his family. Often, factual information removes misconceptions and relieves anxieties. Such information can come from the group leaders, as well as from other group members.

Altruism - Patients with major medical problems seldom have much reason or opportunity to help others. However, a chance to be of help can do a great deal to relieve feelings of hopelessness and uselessness. A therapy group composed of patients with similar medical problems often provides many group members with the perfect opportunity to provide aid, insight, and comfort to each other (Asch & Calhoun, 1966).

Development of socializing techniques - Traditionally, therapy groups have served as a setting in which individuals could learn and practice new ways of dealing with other people in an atmosphere of understanding and support. Therapy groups provide an opportunity for many types of medical patients to learn new social skills necessitated by the nature of their physical condition.

Imitative behaviour - Patients in therapy groups are often able to benefit from the therapeutic experiences of other group members. This can be particularly important for those patients whose psychologic defenses make it difficult for them to recognize maladaptive patterns in their own lives. For example, Reid (1962) found that chronic, disabled asthma patients could safely learn the relationship between their own symptoms and stresses in their lives when they saw such relationships in other group members.

Interpersonal learning - Perhaps the most significant advantage of group therapy over individual therapy is the opportunity it provides for patients to receive feedback as to how others perceive them.

Group cohesiveness - Cohesiveness refers to the group members' feelings that their group is important and worth their participation. Group cohesiveness has been shown to decrease the social isolation experienced by Parkinson's disease patients as a result of their own and others's embarrassment at their symptoms (Chafetz, Bernstein & Sharpe, 1955).

Catharsis - Authors mention catharsis and ventilation most often as important curative factors in their groups. Cancer patients (Parsell & Tagliereni, 1974) found relief in expressing themselves freely concerning their own deaths and the process of dying in their group; they had previously repressed these feelings because they feared it would upset their families.

Patients with chronic illness often feel inferior and experience themselves as helpless victims of a disease process out of their control (Strauss, 1975). Demoralized, they become less able to cope with life's problems, and isolate themselves from sources of social support (Goffman, 1963). They then fail to comply with their prescribed regimens of diet, exercise, and medication. This behaviour pattern often leads to more severe symptomatology, more frequent flare-ups of the acute phase, and greater utilization of the emergency room, out-patient clinics and hospital beds. For the rest of their lives, many people with chronic illness can only look forward to persistent disability, unemployment, and long periods of hospitalization (Donabedian & Rosenfeld, 1964). In this situation, the mobilization of family and peer-group support could provide the crucial leverage to assure closer cooperation of patients with health professionals.

"....social support can protect people in crisis from a wide variety of pathological states (and may even) reduce the amount of medication required and accelerate recovery and improve compliance with prescribed regimens..." (Cobb, 1976).

On the other hand, people who are socially isolated, with minimal primary group or work-related social ties, have a "heightened vulnerability to a variety of chronic diseases" (Rabkin & Struening, 1976).

Dougherty (1982) states that groups provide unique opportunities to members. They open the door of discovery and enable clients to see that others have similar problems. While retaining one's uniqueness, there can be a sharing of difficulties from which all can learn.

The client senses group support and is thereby encouraged to address his own dilemmas, to be more active in his own behalf. Since the group "represents a microcasm of social reality for members" (Capuzzi, et al, 1979), it affords them an opportunity to test behaviour in this relatively safe environment. It enables them to experiment with changes in thinking and lifestyle.

The members have an opportunity to increase their understanding of mutuality as they "learn to give, as well as receive" (Capuzzi, et al, 1979). They learn how others solve problems.

Northen (1990) indicates that group experiences can be helpful in meeting the psycho-social needs of patients and their relatives in many ways. All people need to develop and sustain satisfying connections with other people; human relatedness is the key to healthy development and functioning.

A medical illness or disability upsets the patient's steady state, disrupting interpersonal relationships, and changing

patterns of role functioning. The illness of one person requires shifts in the attitudes, role expectations, and behaviour of all concerned; it requires complementary adaptations by other family members, colleagues, friends and others. These other people may support or sabotage realistic adaptation to the medical situation. The stress created by the illness is aggravated when other problems exist in the family, in friendships or at work or school. Groups have special values in helping clients and their families to cope with the emotional distress and changes in living as a result of the illness.

Group therapy with diabetics

According to Zrebiec (1988), living with diabetes means adjusting to the complex interplay between family relations, personality, emotions, and blood sugar control. The group setting gives each member a chance to see how others react to their feelings about diabetes and observe how they incorporate diabetes into family, work, and play.

Zrebiec (1988) indicates that group therapy has specific advantages for people with diabetes. It can help individuals:

: Learn that they are not alone. In group therapy, many people find, often for the first time, that they do not feel different because of their diabetes. They feel truly accepted and have a sense of belonging that leads to something quite special; a growing sense of importance, status, and self-esteem. With it, people are often able to confront problems with their diabetes that they would not have been able to do otherwise.

: Discuss deeper feelings, worries, and concerns that they may never have dreamed of mentioning elsewhere. Group members intuitively understand because of their shared experiences. There is no need to explain the intricacies of insulin adjustment, for example, or the demands of dieting and testing.

: Discover new approaches to old problems. Members learn from others who have already dealt with similar problems. By listening and sharing experiences, group members gain new hope and motivation. Because the group itself represents a social context and a setting analogous to the family, each member has an opportunity to test new ways of behaving in a realistic situation.

: Explore self-image. As a group member, one can identify other members' traits, styles, and attitudes that are more attractive or effective than one's own. Discovering parts of oneself in other people is crucial to the group process. In this way, long-held attitudes about diabetes can be replayed in the group, recognized by the members, and then changed.

: Reduce stress which may lead to more stable blood sugars. A strong support system combined with emotional stability is linked to more responsible self-care. In addition, groups may help anticipate stressful events and pitfalls to motivation, improving coping skills rather than creating helplessness and demoralization. Because diabetes care primarily has to do with motivation, it makes sense that a central group task is to examine the influence of other groups, like family, friends, and colleagues, on one's motivation.

Group therapy as a means of enhancing patient compliance with diabetic regimens has been proposed by several authors (Tattersall et al, 1985; Oehler-Giarratana & Fitzgerald, 1980; Rabin et al, 1986; Marrero et al, 1982; Warren-Boulton et al, 1981; Pelser et al, 1979).

Tattersall et al (1985) propose that group therapy may be one way of helping patients to express their feelings directly and effectively rather than through poor control and other diabetes upsets.

Pelser and colleagues (1979) studied the use of group discussions in the management of diabetes in Holland. Their object was to find out whether group discussions could improve understanding and management and also give patients more insight into the problems of life that they had to face. Participants were

invited by an advertisement in the journal of the Dutch Diabetes Association to partake in group discussions, "to offer diabetic people the opportunity to meet to discuss under expert guidance the difficulties associated with their conditions, as well as the general problems of life."

Forty patients, both insulin and non-insulin dependent, volunteered and were divided into three groups, two led by internists and one by a psychologist. The attendance rate was high and members clearly found the experience worthwhile. The important conclusions were that: 1. doctors often neglect the emotional needs of their diabetic patients: 2. emotional stability is probably one of the most important factors in maintaining diabetes control: and 3. formal teaching may not be the best method of education: "cooperative communication: or a "negotiated therapeutic alliance" seems to give better results.

Oehler-Giarratana and Fitzgerald (1980) used a short-term therapy group with four insulin-dependent diabetic patients to explore their reactions to blindness and examine the potential of group therapy for rehabilitation. The four participants were 19 to 36 years of age. There were two men and two women. None were married. The diabetes was severe, long-standing, and complicated. There were seven consecutive weekly two-hour group sessions. Many issues other than blindness were discussed. The authors concluded that short-term group therapy proved extremely effective in assisting adult diabetics to adapt to deteriorating vision and to accept rehabilitation. These authors also point out that there is

"a pressing need for patients to air their feelings about diabetic complications, as well as a need to have their misconceptions in this area corrected." By virtue of such qualities as universality, support and inspiration, groups like this can help the patient in adjusting to blindness and facing the future with optimism.

Rabin et al (1986) propose a group training program designed to increase compliance and self-confidence in diabetic group members. The type of group training used in the program was based on the model of group work presented by Rose and others in the area of behavioural group training (Rose, 1977; Paul and Shannon, 1966). This kind of group work stresses structured group sessions with pre-determined learning content; role-playing and practice as a major therapeutic tool; specific individual goals as a means of creating a task-oriented atmosphere; assignments based on these goals; and the use of questionnaires and other assessment tools as a way of stimulating discussion and evaluation of outcomes.

The group work carried out in the program included 12 weekly meetings lasting three hours each. Nine females attended the sessions. Their ages ranged from 20 to 36 years, and four out of nine were married.

The authors concluded that the group became centrally important for its members. The group was originally designed to increase compliance with medical regimens. From the self-reports given by the members, the group was considered a success in that six out of nine group members went on a diet during the course of

the group and also reported better blood sugar results in home testing.

Marrero et al (1982) conducted a pilot study of a long-term outpatient support group for diabetic adolescents. Twenty-three were thought to need psychosocial support, but not individual psychotherapy. The authors found that clear trends indicated a reduction in depression and an increase in self-esteem. The group was valued by participants who reported that it was "the only place where they could share and explore their problems in adapting to their illness."

Warren-Boulton et al (1981) discuss a group approach to the management of diabetes in adolescents and young adults. An interdisciplinary team of health professionals developed a model treatment program to improve adherence, self-management and metabolic control for five inner-city black, young adult, diabetic women. Following an initial in-hospital evaluation, the staff met with the patients as a group once a month for 18 months. The women were between the ages of 17 and 23 years.

Analysis of clinical findings showed a significant improvement in plasma glucose, hemoglobin A_{1c} and cholesterol levels. The authors concluded that although the sample size was small and no control group was available, it is not unreasonable to suggest that without intervention, the level of metabolic control in the patient group would not have improved significantly and may have worsened over time and that a significant improvement in diabetes control

for adolescents and young adults is technically possible in an intensive group setting.

Group therapy implies the use of the group process to alleviate illness or distress (Ryle, 1976). This requires the regular meeting of small, face-to-face groups with a leader where free discussion and interaction is encouraged. The aim is to create an atmosphere in which members can get to know themselves better, feel sufficiently confident to disclose their worries and improve the way in which they cope with their disabilities and lives in general.

Summary

Group support can be extremely beneficial for those trying to cope with chronic illness. Factors such as instillation of hope, universality, altruism, catharsis, and development of socializing techniques can be of therapeutic value for those with chronic illness who participate in support groups.

Groups provide a relatively safe environment where members can discuss experiences, share feelings and learn how others solve problems. Groups have special values in helping the chronically ill to cope with the emotional distress and changes in living as a result of the illness.

Group therapy provides unique opportunities for diabetics to discover new approaches to old problems, discuss deeper feelings and concerns and explore self-image. Several authors detail the positive outcomes of support groups. In all cases, participation in a support group was worthwhile and became centrally important for members. The groups were valued by participants and led to improvements in the way in which individuals adapted to diabetes in their lives.

CHAPTER VI

PRACTICUM

Setting

The setting for the practicum was at the Canadian Diabetes Association (Calgary Branch Office). Referrals were made by community physicians to the group. Letters were sent to community physicians describing the purpose of the group and criteria for participation in the group. See Appendix VI for a copy of the letter sent to physicians. The group began on October 1st, 1990 with the last session held on December 17th, 1990. A total of 10 sessions were held with one meeting each week for a duration of 2 hours.

Clients

This practicum involved four insulin dependent adult diabetics in the group. The diabetics for participation in the group were insulin-dependent; duration of diabetes ranged from 22 to 36 years; group members were between the ages of 24 to 43 years old; they all had experienced diabetes-related compliance problems (according to the referring physician); all members demonstrated the intellectual capacity to understand the goals of the group and the motivation to participate in the group process; all members were able to understand and speak English. Each group member was screened individually by the therapist involved to determine specific compliance problems (i.e. not following diet plan, exercise regimen or blood-testing methods) and discuss group purpose and client

expectations. See Appendix VII for individual profiles of each group member.

Personnel

The Advisory Committee involved with the practicum was comprised of Professor Ranjan Roy (Chair); Addie Penner (Faculty); Janet L. Townsend, M.S.W. (Out of Faculty Representative). The supervision for the practicum was provided by Janet L. Townsend who has extensive group therapy experience. Regular weekly supervision sessions were held with Mrs. Townsend. Ranjan Roy and Addie Penner were consulted as needed throughout the practicum.

Procedures

Once referred, each individual was seen by the therapist prior to the commencement of the group. When the individuals were selected, the pre-interventive measures were taken to determine the pre-test values. These measures included:

1. A direct medical measure of compliance, a hemoglobin A_{1c} which was taken at the physicians office (Hemoglobin A_{1c} is a direct measure of diabetes control over a 2 - 3 month period).
2. The Index of Self-Esteem and the Generalized Contentment Scale (Hudson, 1977) were administered. See Appendix VIII. These standardized measures are self-reports that are easy to use. The Index of Self-Esteem (SE) is designed to measure the degree or magnitude of a problem the client has with his or her self-esteem; how the client sees himself. The Generalized Contentment Scale (GCS) is a measure of the degree or magnitude of non-psychotic depression; the degree of

contentment that a person feels about his life and surroundings. Each of these scales are short (25 items each). The scales are reported to have high reliability and high face, concurrent and constructive validity.

3. In order to measure the effectiveness of group therapy in enhancing compliance, members were asked to list the three most important goals they wish to work on during therapy. These goals were rated on a five-point scale from Least Favourable Outcome to Most Favourable Outcome. See Appendix IX. Adapted from Kiresuk and Sherman's (1968) Goal Attainment Scaling technique, this was utilized in an effort to construct an individualized outcome measure as a way of determining effectiveness of treatment as measured solely by the degree to which individual pre-determined goals have ultimately been reached.

Following the administration of the pre-test measures, the clients began group treatment. Upon completion of group treatment, the measures package was re-administered to the clients to obtain the post-test values and make recommendations on the intervention's efficacy.

During treatment, clients were asked to keep a daily diary to monitor daily control. See Appendix X.

Since the focus of this practicum was to utilize group therapy as a means of improving self-esteem and enhancing compliance with diabetes control, measures of social support or social skills were not undertaken. Compliance was measured by directly observing

blood glucose prior to the commencement of the group and at the termination of the group.

Intervention

The modality of group therapy that was utilized for this practicum closely resembled behavioural group therapy. The main goal of this type of group therapy is to promote change in a patient's maladaptive behaviour and the group usually involves structured sessions, is closed in membership and time-limited in duration. According to Rose (1983), behaviour group therapy combines the advantages of: 1. behaviour therapy, i.e. social skills training with: 2. cognitive therapy, especially cognitive restructuring and problem-solving and: 3. group therapy, especially the development of cohesion and universality.

Furthermore, cognitive restructuring helps clients replace any negative thoughts about themselves and their lives with positive, healthy thoughts. By using this technique, clients may begin to raise their self-esteem.

During group sessions, members had the opportunity for social skills training and a chance to develop problem-solving techniques as they began to resolve specific issues related to diabetes control.

Yalom's (1970) therapeutic factors operated as mechanisms of change in this group. In the early stages, the group was concerned with establishing boundaries and maintaining membership. Factors such as instillation of hope, guidance and universality dominated. Altruism and group cohesiveness were salient factors in the group

throughout the duration of therapy. The nature and role of cohesiveness in the group changed over time. Initially, the group cohesiveness was reflected in group support and acceptance. Later it facilitated self-disclosure.

Patients' needs and goals change during the course of therapy and so do the therapeutic factors which are most helpful to them since each group member has his or her own needs, personality style, level of functioning and psychopathology.

Recording

Each group session was audiotaped for supervisory purposes and as a way of monitoring group progress and planning for ongoing sessions. Members signed a consent for audiotaping purposes. Brief notes were kept following each session outlining process and content of each session and reviewed at each supervision session.

CHAPTER VII

PRACTICUM SESSIONS

This practicum involved a closed group that met for a predetermined number of sessions (10) with a fixed number of participants (4) and sessions were structured in nature.

Despite the number of letters sent to community family physicians in the Calgary region (25 in all), the response was dismal. The persons that were referred who did not participate in the group had either other personal commitments and could not attend or were not intellectually able to understand the goals of the group. The five people selected for participation in the group were appropriate individuals based on the criteria outlined in the practicum proposal. Although the original proposal mentioned eight members for participation in the group, this was not possible based on the lack of referrals by physicians.

Several authors indicate that smaller groups are more cohesive than larger groups (Dimock, 1983; Gitterman, 1982; Yalom & Vinogradov, 1989). In a small group (5 - 13 members), there is more interaction among members which, in turn, increases attraction for the group. And, the increased participation possible in a small group for each member also promotes satisfaction (Dimock, 1983).

Smaller groups offer greater opportunity for individualization, providing each member with sufficient time and accessibility to peers and the worker. Members in crises, for example, often need the attention afforded by small groups. The

optimal group size that allows members to share experiences with one another ranges from a minimum of four or five to a maximum of twelve (Yalom & Vinogradov, 1989)

Gitterman (1982) states that small groups (3 - 5 members), however, do make greater demands for participation, involvement, and intimacy.

In this group there was a high level of involvement and participation by all members, although when one member was absent, it was felt by the other group members. The group began with five members and terminated with four members.

Descriptions of Group Members

Darel is a 42-year-old man who has had diabetes since the age of 6 years. He is single and has a high school education. Darel has had diabetes-related compliance problems for many years. He has difficulty maintaining diabetic control as he has a tendency to miss meals which would result in erratic blood sugar levels. Darel sometimes slept late in the morning, missing his morning injection of insulin. Feelings of depression, isolation, loneliness and inadequacy interfered with his ability to control his diabetes. He had a lot of difficulty sustaining interpersonal relationships. He tended to withdraw from new relationships and situations with others due to negative feelings and fears of rejection and failure.

Dianne is a 39-year-old married woman with two teenage daughters. Dianne has had diabetes since the age of 17 years. She did not always follow her meal plan and did not take any particular interest in maintaining her diabetes control. Dianne often felt

alone with her diabetes and became anxious during visits to her physician. Dianne had difficulty adhering to an exercise regime and had been feeling chronically tired, which her physician suspected was largely due to poor diabetic control.

Robin is a 28-year-old man who has had diabetes since the age of 7 years. Robin's diabetes had been under variable control through the years. Robin tended to feel alone with his diabetes and did not always eat regularly or follow his diet to incorporate the number of calories needed each day. Robin also did not exercise on a regular basis. He struggled with low self-esteem as well and had difficulty talking about feelings related to his diabetes.

Rick is a 24-year-old single man who has had diabetes since the age of 11 years and epilepsy for several years. Rick has had multiple hospital admissions for glucose control. He has difficulty accepting his diabetes and has struggled with diabetes related psycho-social issues for many years. His lack of motivation to maintain diabetes control led to major difficulties with adherence to a regular meal plan; maintaining proper insulin adjustments; and irregular blood glucose testing. As a result, his blood sugars became erratic and frequent hypoglycemic reactions occurred. Rick also presented with a depressed mood and low self-esteem.

Darlene is a 33-year-old married woman with a 6-year-old daughter. Darlene was diagnosed with diabetes at the age of 22 years. Darlene had difficulties adhering to her diabetes regime.

She did not always follow her meal plan and did not pay close attention to maintaining good blood sugar levels. Darlene had a history of depression which interfered with her control.

Session 1 - October 1, 1990

Group members present: Darel, Dianne, Rick, Robin, Darlene

Content: The first group meeting began with the group leader outlining a format for the session. Members were asked to participate in an introduction of group members exercise. Group rules were discussed and agreed on by all members including the leader.

The rest of the session was devoted to the establishment of individual and group goals that would be the focus for the next nine sessions. Four members were able to outline individual goals and the members identified group goals.

Corey & Corey (1987) state that one of the major tasks of the initial stage is to establish both group and individual goals. It is essential that these group goals be explicitly stated, understood, and accepted by the members early in the group. Corey & Corey (1987) have identified general goals for group members and goals for disabled people. See Appendix XI.

This group was able to identify the following as goals for the group:

- To be able to share personal experiences.
- To feel support and encouragement.
- To learn techniques to cope better with stress and stressful situations.

- To learn new ways of handling situations by sharing with others.
- To be able to cope better with diabetes and long term effects.
- To develop more awareness of how we affect other people.
- Honest interaction.
- To learn to be assertive with others.
- To learn how to stop being hard on yourself.

The session ended with a homework assignment of completing the individual goal sheet based on goal attainment scaling and begin to use a daily diary.

Process: During the first session, it was evident that members were uncertain about group norms and expectations. There were moments of silence and awkwardness. One group member appeared rather resistant to participating in the introduction exercise and completing the homework assignment.

Session 2 - October 15, 1990

Group members present: Dianne, Darel, Robin, Darlene

Content: The second session began by giving each member an opportunity to share any afterthoughts they had about the previous session. All members reported that the group helped them to realize that they are not alone in their struggles with diabetes as other members shared information about themselves.

Homework assignments were reviewed. How members completed the individual goal sheets and daily diaries was discussed.

The session ended with a look at a homework assignment for the following week. Members were asked to begin to think about the

issues they wished to see addressed in the coming sessions. Issues that were related to diabetes within five areas: interrelational, self-control, emotional, medical and social.

Process: Universality was becoming apparent during this session as members shared a sense of relief in recognizing that they are not alone in their difficulties with diabetes control; a realization that their problems are universal and are shared by other group members. During this session, Darlene was extremely verbal in sharing her feelings and past experiences. She tended to monopolize the session by her own catharsis, focusing on how she had dealt with severe depression and hopelessness. Her self-disclosure was very personal and surprising at this early stage of the group. Although Darlene essentially took control in this session, it was evident that there was Instillation of hope for other members. The presence of Darlene, who had been successful in dealing with her depression and who seemed to be in no acute distress, tended to enhance the hopeful feelings of other group members.

While Darlene essentially gave a self-dissertation with her own solutions to problems, she tended to monopolize the discussion at the exclusion of other members. The other group members did appear involved and accepting of Darlene's catharsis, although not yet ready to trust or self-disclose as openly about themselves.

The imparting of information as members began to talk about solutions to problematic situations was evident in this session also.

Several goals that members outlined last session began to develop. There was sharing of experiences, a feeling of support and encouragement and honest interaction was emerging.

In this session, the therapist needed to facilitate more active involvement of other group members, instead of allowing Darlene to monopolize the session and take as much control as she did.

Session 3 - October 22, 1990

Group members present: Dianne, Darel, Robin, Rick

Content: The therapist opened the session by asking each member to review their week and share any thoughts or experiences they wished with other group members.

This opening exercise was followed by a request for members to share any thoughts about the previous session. In this session, discussion mainly focused on issues about interrelationships with others and the difficulties involved in these relationships as a diabetic.

Process: Darlene did not return to this group after the last session. The permanent group members became Dianne, Darel, Rick and Robin. The therapist suspects that Darlene may not have returned because she didn't think her own individual needs could be met in this group. She seemed to be more comfortable with a high degree of self-disclosure which leads one to hypothesize about a previous involvement with a support group. When the therapist asked about her reason for not returning to the group, she indicated that she had too many personal responsibilities at that

time and could not commit to once a week group therapy.

During the session, the atmosphere was very different from the previous week, as each member was given an opportunity to share with others. There was no sense of monopolizing of discussion by one member. Honest interaction, as well as support and encouragement of other members was evident.

During this session, Rick seemed withdrawn and depressed. Although he listened to other members experiences, he participated only minimally. He did begin to share more about personal experiences near the end of this session.

Members shared opinions with each other about ways of handling situations and began to affirm each other's thoughts and feelings.

The therapist was better able to facilitate equal discussion among members without the presence of a monopolizing group member.

One question this session did pose for the therapist was how to facilitate involvement of a silent member.

Session 4 - November 05, 1990

Group members present: Dianne, Robin, Darel

Content: In the fourth session of the group, theoretical material focused on self-esteem. The previous session centred around discussion on issues about interrelationships and the need to be more assertive. A positive sense of self will aid in becoming more assertive in appropriate situations. The idea is that before we can improve our relationships with others, we first need to improve our relationship to ourselves. The focus of this session was to provide information to the group members to enhance understanding

of self-esteem and how it develops from childhood.

Material presented was taken from Dorothy Corkille-Briggs' (1977) book "Celebrate Yourself: Enhancing Your Own Self-Esteem." Corkille-Briggs discusses three types of people:

SELF-HATER: Feels unlovable, strongly self-critical, easily discouraged, tend to be isolated, highly sensitive to criticism.

SELF-DOUBTER: Tend to be conformists, dependent on social acceptance, unsure.

SELF-AFFIRMER: Feel self-confident, can take criticism, tolerate frustration, not threatened by failure. Tend to be physically healthy, enjoy life and have a positive outlook.

Corkille-Briggs further discusses parts of the inner self:

Parent (taught) records external events	nurturing critical
--	-----------------------

Adult
(thought)

Child (felt) (records internal events)	Not-ok natural
---	-------------------

Natural child - spontaneity, playfulness, intuitiveness, creativity, impulsive
The part that houses your emotions and intuition

Parent
Your impressions of your parents' attitudes toward you, themselves, others, the world and life-in-general
Your "taught" tape

Nurturing parent - when they:
were appreciative, supportive, kept requests in line with what you could handle
Showed that you counted even though your behaviour needed changing
Saw what was right and positive about you

Believed in and increasingly supported your own power to control yourself
Met your needs with friendly co-operation and without unreasonable delays

Process: This session focused mainly on material presented by the therapist so there was not a lot of process to attend to. The group members continued to share honestly and opening with each other and be supportive of one another.

Session 5 - November 12, 1990

Group members present: Dianne, Darel, Robin and Rick

Content: The fourth session essentially focused on self-esteem and negative thoughts. The theoretical material presented in the fourth session was reviewed and a discussion on negative thinking and how it impacts on behaviour was the major focus of this session. More content was offered on how problems can arise for individuals when negative thinking about oneself as a self-doubter or self-hater emerges and affects one's ability to take control of one's life situation.

The material presented was taken from Lou Coffey-Lewis' book "Be Restored to Health" (1982). She discusses the power in thoughts. Thoughts greatly influence our lives. Self-responsibility for your thoughts is not easy. Choosing your own thoughts and not being dominated by incorrect ideas is important. Coffey-Lewis (1982) suggests: use your own power of thought to affirm your desires and needs and somehow they will be fulfilled. Words and thoughts of healing, of laughter, of joy will bring those things to you in your life. Continual thoughts of disease and stress will bring those things into your life. Coffey-Lewis (1982)

indicates that one has to become aware of what one is thinking about most of the time. Once this awareness takes place, the next technique to practice in using thoughts for healing is to learn to substitute positive, healthy thoughts for negative, diseased thoughts. By substituting positive thoughts for negative ones, you will soon find yourself becoming the thoughts you have substituted. If you substitute healing and happiness in your thoughts and behaviour for long enough and ignore and give no thought to disease, you will find yourself being healthy, happy, and whole (Coffey-Lewis, 1982).

The homework assignment given included the recording of individual thought patterns. Members were asked to record the following:

What are the first thoughts you generally have every morning when you first wake?

Are there themes in your daily conversations that are repeated over and over?

Who do you enjoy talking to each day? What do you talk about?

Identify your most common negative thoughts.

(Taken from Coffey-Lewis, 1982, p.55).

The purpose of this assignment was to help individuals become aware of and analyze their thoughts.

Process: It was evident in this session that this small group of four permanent members was cohesive, as all members responded to each other positively and affirmed each other's thoughts and feelings. Members were able to offer each other aid and insight and provide comfort to each other - altruism.

Session 6 - November 19, 1990

Group members present: Rick, Darel, Robin, Dianne

Content: In the sixth session, a review of the homework assignment on recording of negative thoughts lead to more discussion of how negative thoughts impact on daily life. Negative thoughts that group members identified included:

Having diabetes is an injustice
It's not fair
Why me?
How come I have to get this?
How come I don't get the results I want?
I'm so stupid
Why can't I do anything right?
I have to be perfect
I'm being too hard on myself
I'm fighting a battle
I'm tired (of having this)
I'm an emotional cripple (losing control of emotions)

The homework assignment for the next week involved the practice of using affirmations to replace negative thinking. Affirmations are positive thought statements that can be used to help heal yourself and improve your life. Appendix XII (Taken from Coffey-Lewis, 1982) shows a list of positive affirmations group members were asked to practice.

Process: The development of socializing techniques began to emerge in this session as members shared their experiences on new ways of dealing with situations. Group members began to share their thoughts on how they would begin to use the positive self-statements in their daily lives.

In this session, Rick did a lot more sharing about his feelings and difficulties with diabetes than in previous sessions.

Although a depressed mood was still evident, he felt supported by other group members and validated as a member of the group. Other group members shared opinions with Rick about handling personal situations. It appeared that Rick was able to benefit from therapeutic experiences of other group members - imitative behaviour.

Session 7 - November 26, 1990

Group members present: Robin, Dianne, Rick

Content: This session began with a review of the homework assignment on positive self-statements. In discussing the assignment, group members indicated that they do try to replace negative thinking with positive thoughts in daily life. The session focused on individual members' experiences with negative thinking and how positive thinking is vital to healthy, happy life -- how to replace negative thoughts with positive self-statements.

Process: It was apparent that members were beginning to develop new social skills and problem-solving techniques in resolving issues related to diabetes control. The cohesiveness of the group certainly facilitated self-disclosure, particularly for Rick.

Session 8 - December 03, 1990

Group members present: Darel, Rick, Robin

Content: This session began with some discussion on long-term complications and one member's difficult decision regarding treatment for a specific problem. The rest of the session focused on a discussion about "Quality of life with diabetes." According

to group members, quality of life with diabetes means:

Feeling good about yourself
Doing what you want to do
Making your own decisions about your life with diabetes
Freedom to choose without guilt
Assertiveness in finding accurate information
Control over your life
Rewards

The following ideas were generated through the discussion:

Choices are up to each individual. Quality of life means not feeling guilty when you "pig out" for example.

A lot of denial exists for diabetics as they begin to realize that answers are not always available when they attend a support group. People are hoping (looking for) answers to problems that are not always there and so do not attend anymore.

Diabetics need to do their own work in terms of making changes - if a person is concerned about their own life with diabetes, they will mobilize themselves to change.

If you get support, it encourages you to talk more about your diabetes.

You need to keep your mind open to other alternatives and not focus on one aspect of a problem.

Positive affirmations are important.

Do not give up. Get as much information as possible.

When you are complying with everyone else's expectations and your life is so structured and regimented, it is not realistic to follow this regimen every day of your life.

Process: Group members were supportive of the self-disclosure of one member's difficult problem and struggle with decision-making.

This session was very powerful and generated some intimate discussion on "quality of life" issues. The level of intimacy could not have occurred without the cohesion of the group and the level of trust between group members.

Session 9 - December 10, 1990

Group members present: Darel, Rick, Robin

Content: In the ninth session, a major focus centred on goals and the importance of making one's own decisions in reaching these goals.

The goals of the group were reviewed and members were asked to share their thoughts on whether the group was successful in reaching its goals.

In considering the goals originally established in the initial session, it would appear that most of the goals were reached:

- members were able to share personal experiences and feel support and encouragement.
- some discussion in the nine weeks centred around stressful situations and how to handle them.
- individual coping strategies were identified and discussed.
- members did gain more of an awareness of how they affect each other.
- the discussion on interrelationships and self-esteem allowed some ideas on how to be assertive and not so hard on yourself.

Members also expressed that quality of life also included reaching individual goals and being successful. Facing one's fears is important as a step in overcoming fears along with changing attitudes and positive thinking which are necessary in making changes in one's life. Setting future goals is vital as well.

Generally, members felt very positive about their experience in the group and the issues that were discussed.

Process: Again, a high level of intimacy and trust was evident. The supportive atmosphere, predominant throughout the group, yielded high levels of participation, involvement, and intimacy.

Session 10 - December 17, 1990

Group members present: Rick, Darel, Dianne, Robin

Content: The final session included discussion on termination of the group, a review of the pre-session tests, and overall group experience for members.

Three group members did not keep a daily diary or journal as requested by the leader at the outset of the group. (Members said they had individual preferences for daily record keeping). Two group members did not complete a goal sheet. All members completed the standardized measures which were re-administered at this final session. An evaluation form was given to each member to complete for the leader's benefit. See Appendix XIII.

Process: This group had difficulty with termination. They felt that the group had been worthwhile and met their needs, however, did not want to completely terminate with each other. The ongoing support that the group offered was something they wanted to continue in their life. Members were encouraged to express their reactions to the group's termination. It was evident that all members were saddened by the prospect of the group's ending. The group members may have felt that the trust they now feel in the group will not be replicated outside.

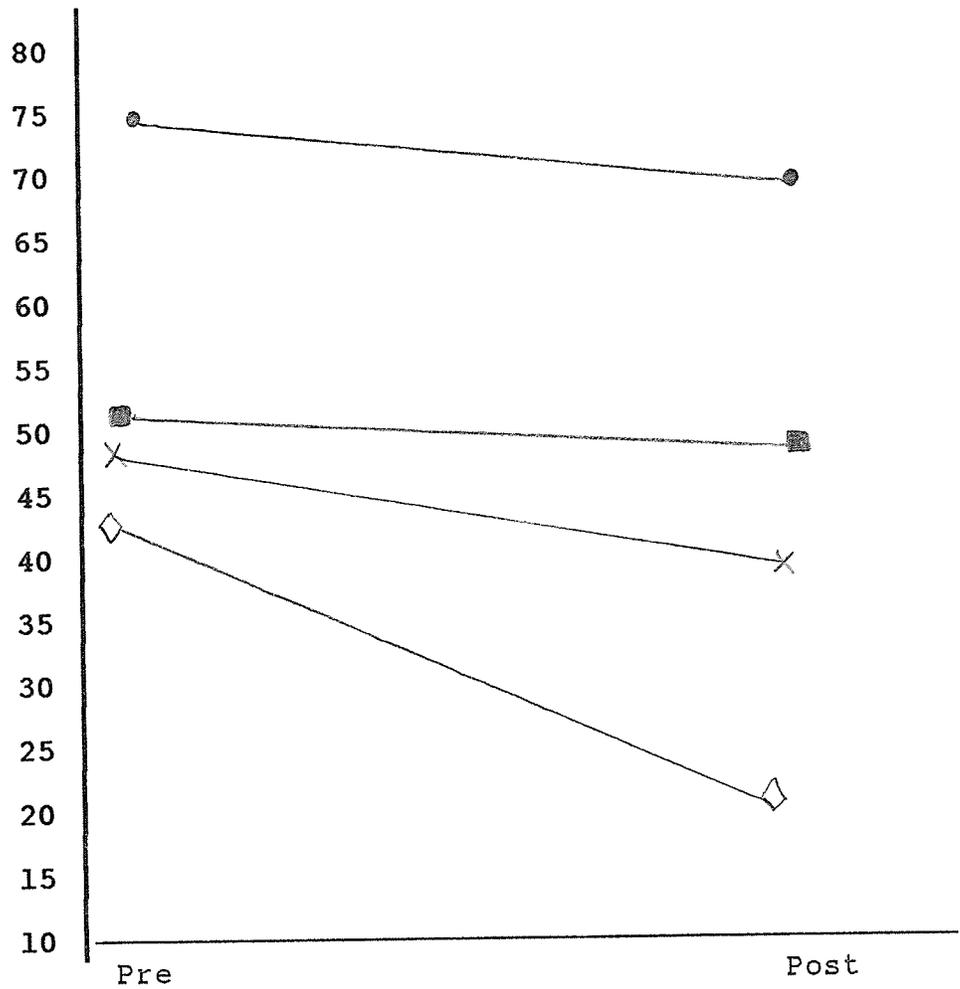
It was a mutual decision between group members and the leader that the group would continue meeting once a month and new members would be encouraged to join.

CHAPTER VIII**FINDINGS**

The standardized measures that were administered at the pre- and post-test included Hudson's (1977) Index of Self-Esteem and Generalized Contentment Scale. Hudson (1977) indicates that on all scales, the higher the score the greater the magnitude of the problem. Each of the scales has been designed to have a "clinical cutting score" of 30. The idea here is that people who score over 30 generally have been found to have problems in the area being measured. While these scales are intended to be used to measure the severity, intensity, degree, or magnitude of a problem, they are not intended to be used to determine source, focus, or origin of the client's problem. As a very rough guide, changes in a score of more than five points in either direction probably reflect real changes in the client's problem or situation.

The following shows the results of this group as displayed on a graph.

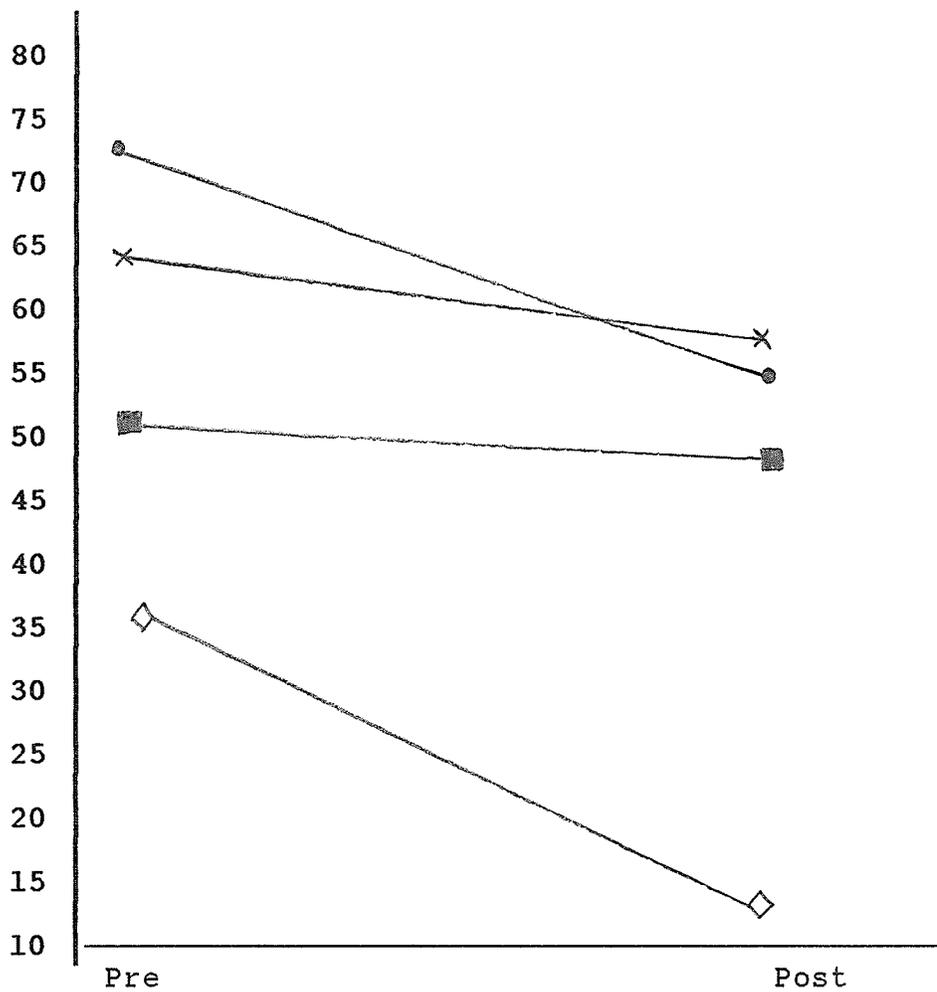
INDEX OF SELF-ESTEEM



	<u>Pre</u>	<u>Post</u>
Rick ●	76	70
Darel X	48	40
Dianne ■	52	50
Robin ◇	44	21

↓ Shows increase in Self-Esteem

**GENERALIZED
CONTENTMENT
SCALE**



Rick ●
Darel ×
Dianne ■
Robin ◇

<u>Pre</u>	<u>Post</u>
75	56
66	60
53	50
39	16

↓ Shows improvement
in General Content-
ment

Rick's score of 76 on the Index of Self-Esteem at pre-test obviously showed an intense lack of self-esteem. At post-test, Rick's score of 70 showed nominal improvement in self-esteem over the 10 week period, but the magnitude of the problem still remains.

Rick's score on the Generalized Contentment Scale of 75 at pre-test showed a high degree of discontent with life and an intense level of non-psychotic depression. The score of 56 at post-test showed marked improvement in general contentment, but obviously the problem in this area was still evident.

Darel's score of 48 at pre-test indicated some problem with self-esteem and at post-test, a score of 40 showed again a problem, however, some improvement was evident. A score of 66 on the Generalized Contentment Scale at pre-test indicated a fairly high level of non-psychotic depression and the score of 60 at post-test showed nominal improvement in this area.

Dianne's score of 52 at pre-test and 50 at post-test on the Index of Self-Esteem indicated no real change in her level of self-esteem over the 10 week period. She obviously still had a problem in this area. The score of 53 at pre-test and 50 at post-test on the Generalized Contentment Scale again indicated no change for Dianne in her level of non-psychotic depression, still a problem area.

Robin's score of 44 at pre-test on the Index of Self-Esteem showed some problem in this area, however, at post-test a score of 21 indicated that his self-esteem over the 10 week period had markedly improved. Robin's score of 39 on the Generalized

Contentment Scale at pre-test and 16 at post-test again showed significant change in his perception of contentment with life.

The group members' self-esteem and general contentment with life generally appeared to be better at the outset of the group. Robin's significant improvement in self-esteem and general contentment over the 10 week period was a positive factor for other members as he shared individual experiences about solving problems related to diabetes control. Robin appeared to change the most in the course of this group in terms of level of self-esteem and general contentment with his life. Rick appeared to have the lowest level of self-esteem and the greater sense of discontent with life. A self-esteem score of 76 shows severe problems that will not be easily changed in 10 weeks and may require individual psychotherapy to facilitate improvements.

As a direct measure of diabetes control over the period of group therapy, a Hemoglobin A_{1c} (HbA_{1c}) or glycosolated hemoglobin was drawn on each group member at pre-test and post-test.

Gorman (1988) indicates that glycosolated hemoglobin testing has been introduced as a routine part of diabetes management over the last 15 years. The availability of this test had enabled doctors to assess the degree of diabetes control in patients, and to give them much better advice as to what treatment is necessary for their particular needs. The level of hemoglobin A_{1c} is related directly to the average blood glucose concentration during the 2 months prior to measurement. The best use of this test is to perform it before and several months after a therapeutic

intervention to establish the magnitude of the therapeutic effect. Hemoglobin A_{1c} can then be followed at 2 to 3 month intervals to see whether the therapeutic effect is sustained.

Gorman (1988) further states that the normal range is between 4.0% and 6.0%, or 0.04 - 0.06. Generally a value of less than 0.06 is considered excellent, less than 0.075 is considered good, between 0.085 and 0.075 is considered fair, and above 0.085 indicates the need for careful reassessment of the overall treatment programme. Many diabetics fall above the normal range of 0.04 - 0.06 most of the time.

The HbA_{1c} results for each group member were as follows:

Rick's HbA_{1c} at pre-test was 11.0%, or 0.11 and at post-test the result was 8.5%, or 0.085. This showed a big improvement in level of control.

Dianne's HbA_{1c} at pre-test was 6.8%, or 0.068 and at post-test the result was 7.2%, or 0.072. There was not a big change in the result (or level of control of blood glucose) for that period of time.

Robin's pre-test result was 6.2%, or 0.062 and at post-test the result was 7.6% or 0.076. Although the post-test result was higher, this is still considered relatively good. One might hypothesize that other variables may have played a part in the difference. Given Robin's level of increased self-esteem and general contentment from pre- and post-tests, the group support may have made a difference in these results.

Darel's HbAl_c prior to the commencement of the group was 7.0% or 0.07 and at post-test the result was 8.0% or 0.08. Darel's HbAl_c was not as good at post-test which indicated that the blood glucose level over this particular three-month period was not as good as in the previous three months. Again, there may have been extraneous variables involved which made a difference in the level of blood glucose control.

For three group members, these results show higher averages of blood glucose concentration for the three months during the group. It is difficult to predict why this was the case. Other factors in the lives of the group members may have been at work (illness, change in type or amount of insulin).

It is safe to say that the group was a success by virtue of the therapeutic factors that were evident throughout the course of group therapy. HbAl_c may not be the best predictor or measure of success for this type of intervention with long-term diabetics.

Only two group members completed the goal sheet and one member kept the daily diary. The members who did not keep a daily diary indicated that they had their own method of daily record-keeping and did not find it particularly helpful to use this type of daily diary. For the two members who completed the goal sheet, they indicated some improvement in reaching expected levels of success with the three goals listed at pre-test. See Appendix XIV.

Short-term group therapy can be effective for diabetics. The lack of significant improvement in compliance and self-esteem for this group may be due to several factors. The sample size is

really too small to draw definite conclusions on the success of the group based on the outcome measures used. Groups of four patients are generally below optimum size for good group process (Yalom, 1970), however, there are potential benefits for patients as the group becomes a source of support for long-term diabetics. See Appendix XV for narrative evaluations of the group experience.

Another factor that might explain the lack of improvement is the short duration of the group. All of the group members had a history of depression and low self-esteem which interfered with maintaining diabetes control and led to poor compliance with the diabetes regimen. Compliance habits and low self-esteem do not easily improve in a 10-week period.

It is difficult to measure compliance behaviour since rarely can health behaviour be directly observed. As a result, there is always a problem in the validity of the data that is collected on compliance behaviour. HbA_{1c} may not be the best predictor or measure of compliance for this type of intervention with long-term diabetics.

CHAPTER IX**CONCLUDING REMARKS**

One of the hardest populations to work with in a group are those individuals with a chronic illness. It is hard to mobilize those with a chronic illness to change and keep coming to a support group where all the focus is on their diabetes. To come together each week to talk about their diabetes is very difficult since it is a reminder of what they are struggling with every day.

There are problems that are unique to having a chronic illness. With diabetes, people do not have a lot of control. The loss of control can be significant in many areas of life with diabetes. A profound sense of loss of control means that changes are necessary to regain control in life. Along with loss of control comes poor self-esteem and depression. This was evident for all group members.

One of the questions this type of study raises is: What is the best method for a therapist to use to help people cope with their chronic illness?

Other questions one might pose are:

Do people need to get together once a year in a group to help them to continue to maintain their health regime?

Will this make a difference in how people cope with their diabetes?

What therapeutic process reaps the most benefits for these people?

or What therapeutic "recipe" works best for people with chronic illness?

There are always inherent problems to deal with to be successful in using group therapy. One problem that group leaders have to be concerned with is attrition. With a small group, such as the one discussed in this report, this is even more crucial as the absence of members makes a small group vulnerable to disintegration.

Another inherent problem in groups is group composition. According to Gitterman (1982), composition affects the nature of group development and its direction, i.e. whether the group will move toward mutual aid or disintegration. Groups composed of members with common backgrounds (i.e. age, sex, ethnic, social class) and common personality capacities and behaviour (i.e. ego functioning, role skills) tend to be stable and supportive, quickly developing a group identity. Similar life experiences, concerns, interest, and adaptive styles provide members with a sense of commonality and a collective stability.

Groups composed of members with diverse backgrounds and diverse personality styles and behaviours tend to be less stable and predictable. They may experience difficulty in developing a sense of group identity and cohesion.

Conflicts and struggles for control are problems for group leaders. These need to be dealt with effectively for continuing success of the group.

Experience with this group yielded information about compliance and diabetes. The group became centrally important for its members. Their need for continued support after the

termination of the practicum was evident in their desire to become a self-help group. The group leader agreed to continue to be a part of the group. One new member has since joined the group. Rick is now involved in a work training program and is hopeful about his future. His mood is brighter and he is animated during group sessions and more content with his life. He attributed much of this change to his involvement in the diabetes support group. The group was originally designed to achieve two types of outcomes: 1) to enhance self-esteem of group members, and 2) improve compliance with treatment regimes. Despite the small number of group members, the group could be considered beneficial for group members, as the self-evaluations of group members attest to.

In considering what was beneficial about this group, one might say that patients need to have support from others with similar problems to be assured that they are normal, and they need to know that their coping mechanisms are used by others. They need to learn concrete ways of coping with interpersonal conflicts so that they can begin to solve their problems with compliance issues.

Corey and Corey (1987) identify factors evident in a working group that were significant in this group:

Members trust other members and the leader. There is a willingness to take risks by sharing meaningful here-and-now reactions.

Goals are clear and specific and are determined jointly by the members and the leader. There is a willingness to direct in-group behaviour toward realizing these goals.

Most members feel a sense of inclusion, and excluded members are invited to become more active. Communication among members is open and involves accurate expression of what is being experienced.

There is a focus on the here-and-now, and participants talk directly to one another about what they are experiencing.

Cohesion is high; there is a close emotional bond among people, based on sharing of universal human experiences. Members identify with one another.

Members accept responsibility for deciding what action they will take to solve their problems.

Feedback is given freely and accepted without defensiveness. There is a willingness to seriously reflect on the accuracy of the feedback.

Members feel hopeful; they feel that constructive change is possible - that people can become what they want to become.

Confrontation occurs in such a way that the confronter shares his or her reactions to the person being confronted. Confrontation is accepted as a challenge to examine one's behaviour and not as an uncaring attack.

Communication is clear and direct.

Group members use one another as a resource and show interest in one another.

There is an emphasis on combining the feeling and thinking functions. Catharsis and expression of feeling occur, but so does thinking about the meaning of various emotional experiences.

Members feel powerful and share this power with one another.

In this group, members shared openly with each other about their experiences and struggles with diabetes. They began to trust each other very quickly. The goals of the group were mutually agreed upon by group members and the leader. All members felt a sense of inclusion and were able to talk directly to one another about their individual problems related to diabetes.

The group cohesion was high as members felt comfortable with each other and had difficulty with termination issues. They were all concerned about ending the group and wanted to continue meeting

each month to support each other and develop their own self-help group.

By listening to others discuss problem-solving methods, members became hopeful about their own future. Group members often used each other as a resource by sharing information on new books to read or techniques for blood-testing or insulin administration.

As a final point, there were educational benefits to this practicum. I had a chance to develop theoretical and practice understanding of the use of group therapy as a means of enhancing compliance with treatment regimens for diabetics. There was an opportunity to increase knowledge of behaviour and problem-solving techniques in a group therapy setting with diabetics. My knowledge and understanding of group dynamics and the importance of effective group leadership was also enhanced throughout the course of this practicum. I became more aware of the therapeutic factors that operate in groups over time. It was encouraging to see the group process develop from the initial stage where members were more anxious and reluctant to share feelings openly to a stage where all members were active participants. This was particularly true for Rick, who found a sense of hope in his life through participation in this group and his depressed mood lifted.

Effective group leadership adds much to group process. I was able to gain an understanding of the importance of honest, direct feedback and a non-threatening, caring response to group members.

I gained more personal awareness of the many problems that long-term diabetics have to face in their daily life. To be helpful is to understand the disease. I now have a greater understanding of what life is like for a person with diabetes and how important it is for health professionals to be sensitive to the issues that people with a chronic condition face.

The development of the self-help group as a result of this practicum experience is an exciting prospect. Self-help groups non-judgementally act as mirrors of understanding, reflecting back shared experiences and advice. Self-help groups become an important social outlet for people who are isolated and in crisis.

As Kathleen Lewis (1985, p.xiii) so aptly says:

There can be victory in defeat,

gain in loss,

living in dying,

wholeness in brokenness,

giving in receiving,

receiving in giving,

success in failure,

strength in weakness,

peace in turmoil,

joy in sorrow,

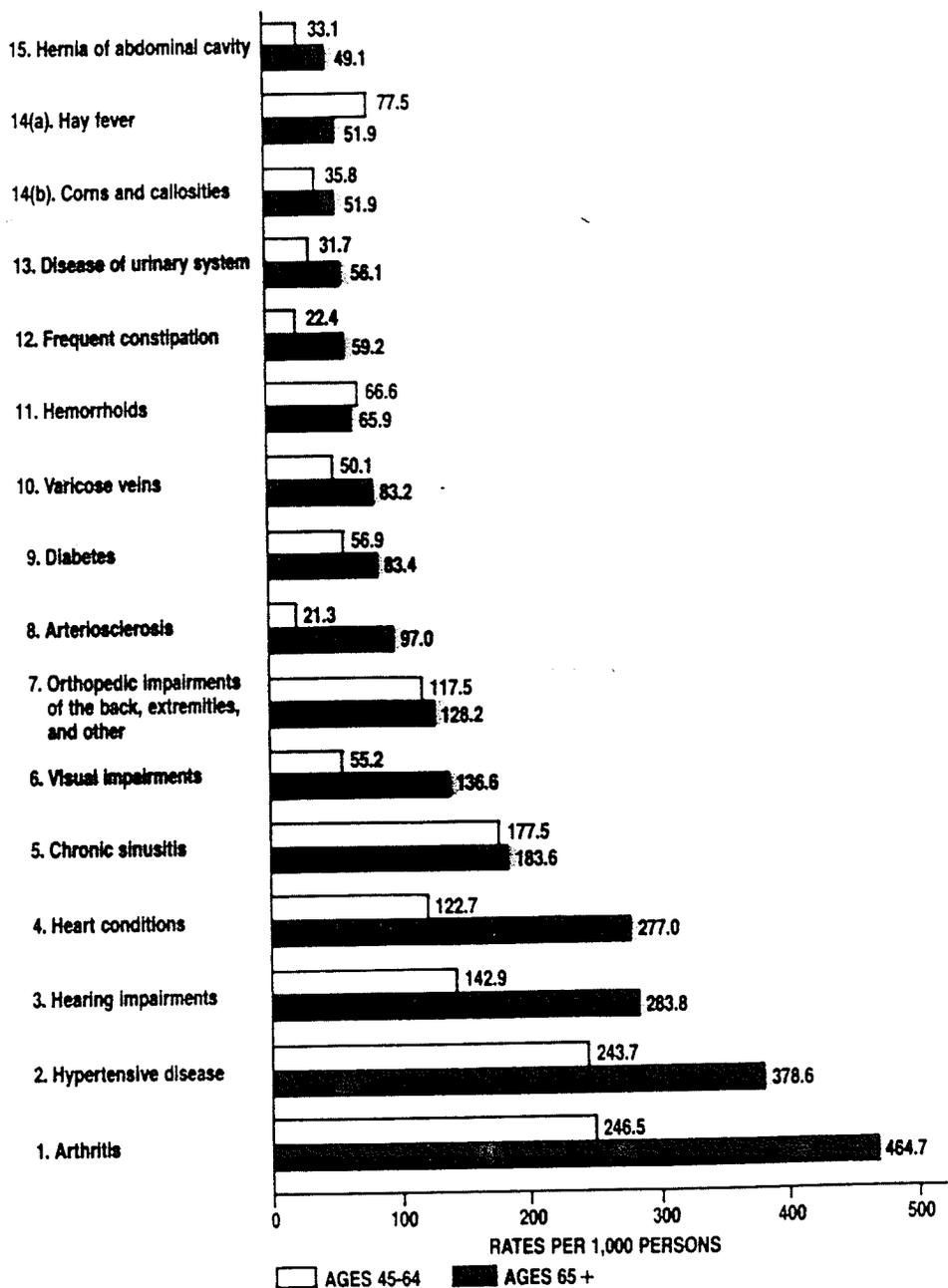
growth in pain, and

mental health in the midst of physical illness!

Lastly, my heart goes out to those who struggle with a chronic illness on a daily basis!

APPENDIX I

**Figure 1.2 Prevalence of Top Chronic Conditions
(in persons 45-64 years and 65 +)**



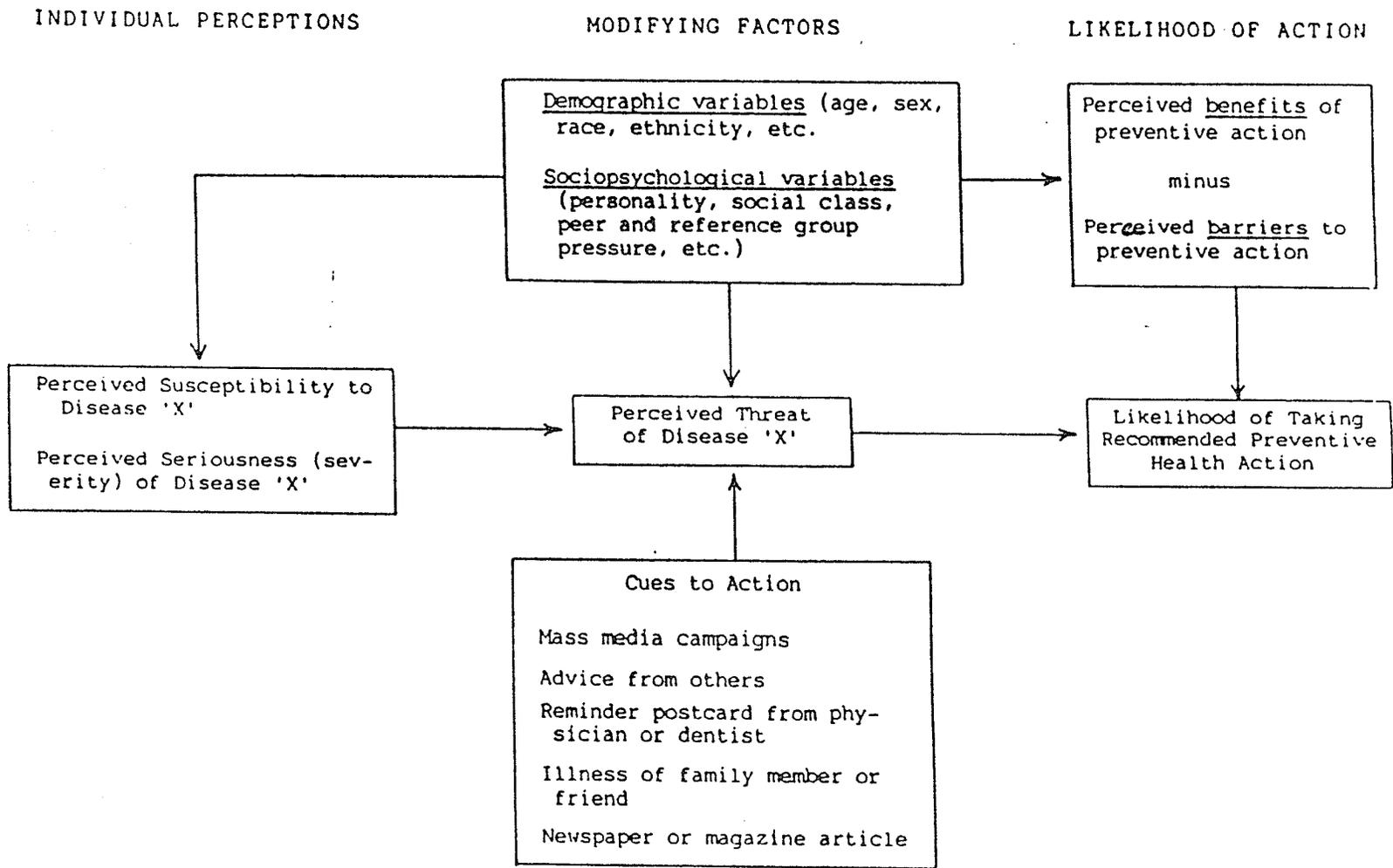
Source: *Aging America: Trends and Projections*. Washington, D.C.: American Association of Retired Persons, 1984.

APPENDIX II

"Confirmed" factors associated with noncompliance

Factor category	Specific factors associated with noncompliance
1. Disease	Psychiatric diagnosis
2. Regimen	Complexity Degree of behavioural change Duration
3. Therapeutic source	Inefficient and inconvenient clinics
4. Patient-therapist interaction	Inadequate supervision Patient dissatisfaction
5. Patient	Inappropriate health beliefs Previous or present noncompliance with other regimens Family instability

Reprinted from Haynes, 1976 (p. 39)



Original formulation of the health belief model.
 Reprinted from Becker, 1979 (p. 79).

READINESS TO UNDERTAKE
RECOMMENDED COMPLIANCE BEHAVIOUR

Motivations
Concern about (salience of) health matters in general
Willingness to seek and accept medical direction
Intention to comply
Positive health activities

Value of Illness Threat Reduction
Subjective estimates of:
Susceptibility or resusceptibility (incl. belief in diagnosis)
Vulnerability to illness in general
Extent of possible bodily harm
Extent of possible interference with social roles
Presence of (or experience with) symptoms

Probability that Compliant Behaviour Will Reduce the Threat
Subjective estimates of:
The proposed regimen's safety
The proposed regimen's efficacy to prevent, delay, or cure (incl. "faith in doctors and medical care" and "chance of recovery")

MODIFYING AND ENABLING
FACTORS

Demographic (very young or old)
Structural (cost, duration, complexity, side-effects, accessibility of regimen; need for new patterns of behaviour)
Attitudes (satisfaction with visit, physician, other staff, clinic procedures, and facilities)
Interaction (length, depth, continuity, mutuality of expectation, quality, and type or doctor-patient relationship; physician agreement with patient; feedback to patient)
Enabling (prior experience with action, illness or regimen; source of advice and referral [incl. social pressure])

COMPLIANT
BEHAVIOUR

Likelihood of:
Compliance with preventive health recommendations and prescribed regimens; e.g. screening, immunizations, prophylactic exams, drugs, diet, exercise, personal and work habits, follow-up tests, referrals, and follow-up appointments, entering or continuing a treatment program.

Hypothesized model for predicting and explaining compliance behaviour.

Reprinted from Becker, 1976 (p. 48).

APPENDIX V

Treating Noncompliance

In the Office

- Provide good patient education about the disease, the role of medicine, and the symptoms and frequency of common side effects.
- Schedule follow-up appointments to document disease improvement from prescribed medicines.
- Credit patients with controlling their diseases.
- Be available often enough for questions and problems.
- Further patient education through the services of nurses, dieticians, etc.
- Examine the physician-patient relationship for communication problems.

At home

- Have family members supervise administration of medication.
- Arrange for visiting home nurses to monitor compliance.
- Make referrals to social services agencies when poor finances affect the purchase of medication.

With the Pharmacist

- Simplify the regimen:
 - Reduce dosage to once or twice a day.
 - Use generic, low-cost medicines.
 - Avoid multiple-drug regimens.
 - Provide patient education.
-

Reprinted from Robie, 1987, (p.15).

July 04, 1990

135

Dr. Dennis Linden

Dear Dr. Linden:

I am a clinical social worker presently working on my Master of Social Work degree. As part of the requirements for the practicum component, in September I plan to start a support group for insulin dependent adult diabetics. The focus of this group will be to assist diabetics to enhance compliance with their treatment regime and improve self-esteem.

I am requesting your assistance in selecting appropriate clients from your practice who would be interested in participating in a diabetes support group. I am specifically looking for Type I diabetics between the ages of 21-41 years who have had diabetes for more than one year and have diabetes-related compliance problems. They must be able to understand and speak English.

Prior to commencing the group, and at termination of the group, each client will need a HBA1C taken as a direct measure of compliance with treatment. As it is often difficult to measure compliance directly, this is one way to determine change in compliance over time.

I would be most grateful if you could refer to me, at your earliest convenience, any clients who fit the above criteria.

Please direct all correspondence to:
Marlene A. Clay, B.S.W.

Sincerely,

ENCLOSURES

PERSONAL INFORMATION

NAME DAREL AGE 42 DATE OF BIRTH April 19, 1948
ADDRESS _____ PHONE _____ (h) MARITAL STATUS Single
_____ (b)
SIGNIFICANT OTHER _____ CHILDREN _____ AGES _____
EDUCATION high school OCCUPATION _____ HOBBIES _____

DIABETES HISTORY

DURATION 36 yrs. AGE OF DIAGNOSIS 6 yrs.
FAMILY PHYSICIAN Sosnowski DIABETES SPECIALIST _____
INSULIN Humulin UNITS R4N25 HOW OFTEN 1 daily

PERSONAL INFORMATION

NAME ROBIN

AGE 28

DATE OF BIRTH Oct. 23, 1961

ADDRESS _____

PHONE _____ (h)

MARITAL STATUS M

_____ (b)

SIGNIFICANT OTHER Shelley

CHILDREN - **AGES** -

EDUCATION college

OCCUPATION credit assistant

HOBBIES reading, drawing, music

DIABETES HISTORY

DURATION 22 yrs.

AGE OF DIAGNOSIS 7 yrs.

FAMILY PHYSICIAN Fundytus

DIABETES SPECIALIST Edwards

INSULIN Ultra-Lente
Novolin Toronto

UNITS varies
65 units

HOW OFTEN 4 times daily

APPENDIX VII continued

PERSONAL INFORMATION

NAME Rick **AGE** 24 **DATE OF BIRTH** June 13, 1966
ADDRESS _____ **PHONE** _____ (h) **MARITAL STATUS** _____
_____ (b)
SIGNIFICANT OTHER _____ **CHILDREN** _____ **AGES** _____
EDUCATION GED diploma **OCCUPATION** _____ **HOBBIES** _____

DIABETES HISTORY

DURATION 13 yrs. **AGE OF DIAGNOSIS** 11
FAMILY PHYSICIAN Vicha **DIABETES SPECIALIST** Linden
INSULIN Humulin N & R **UNITS** 55/day **HOW OFTEN** 2 injections

PERSONAL INFORMATION

NAME DIANNE AGE 39 DATE OF BIRTH May 30, 1951
ADDRESS _____ PHONE _____ (h) MARITAL STATUS M
_____ (b)
SIGNIFICANT OTHER Robert CHILDREN 2 girls AGES 16, 12
EDUCATION B. Ed. OCCUPATION _____ HOBBIES Arts & Crafts, courses,
reading

DIABETES HISTORY

DURATION 22 yrs. AGE OF DIAGNOSIS 17
FAMILY PHYSICIAN Ross DIABETES SPECIALIST Nelson
INSULIN Hum. NPH, Toronto UNITS 20 total HOW OFTEN 2
4 total

INDEX OF SELF ESTEEM (ISE)

Today's Date

NAME:

This questionnaire is designed to measure how you see yourself. It is not a test, so there are no right or wrong answers. Please answer each item as carefully and accurately as you can by placing a number by each one as follows:

- 1 Rarely or none of the time
- 2 A little of the time
- 3 Some of the time
- 4 A good part of the time
- 5 Most or all of the time

Please begin.

1. I feel that people would not like me if they really knew me well
2. I feel that others get along much better than I do
3. I feel that I am a beautiful person
4. When I am with other people I feel they are glad I am with them
5. I feel that people really like to talk with me
6. I feel that I am a very competent person
7. I think I make a good impression on others
8. I feel that I need more self-confidence
9. When I am with strangers I am very nervous
10. I think that I am a dull person
11. I feel ugly
12. I feel that others have more fun than I do
13. I feel that I bore people
14. I think my friends find me interesting
15. I think I have a good sense of humor
16. I feel very self-conscious when I am with strangers
17. I feel that if I could be more like other people I would have it made
18. I feel that people have a good time when they are with me
19. I feel like a wallflower when I go out
20. I feel I get pushed around more than others
21. I think I am a rather nice person
22. I feel that people really like me very much
23. I feel that I am a likeable person
24. I am afraid I will appear foolish to others
25. My friends think very highly of me

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GENERALIZED CONTENTMENT SCALE (GCS) Today's Date

NAME: _____

This questionnaire is designed to measure the degree of contentment that you feel about your life and surroundings. It is not a test, so there are no right or wrong answers. Answer each item as carefully and accurately as you can by placing a number beside each one as follows:

- 1 Rarely or none of the time
- 2 A little of the time
- 3 Some of the time
- 4 Good part of the time
- 5 Most or all of the time

Please begin.

1. I feel powerless to do anything about my life _____
2. I feel blue _____
3. I am restless and can't keep still _____
4. I have crying spells _____
5. It is easy for me to relax _____
6. I have a hard time getting started on things that I need to do _____
7. I do not sleep well at night _____
8. When things get tough, I feel there is always someone I can turn to _____
9. I feel that the future looks bright for me _____
10. I feel downhearted _____
11. I feel that I am needed _____
12. I feel that I am appreciated by others _____
13. I enjoy being active and busy _____
14. I feel that others would be better off without me _____
15. I enjoy being with other people _____
16. I feel it is easy for me to make decisions _____
17. I feel downtrodden _____
18. I am irritable _____
19. I get upset easily _____
20. I feel that I don't deserve to have a good time _____
21. I have a full life _____
22. I feel that people really care about me _____
23. I have a great deal of fun _____
24. I feel great in the morning _____
25. I feel that my situation is hopeless _____

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NAME: _____

GOAL ATTAINMENT SCALE (PRE)

DATE: _____

TYPE: DIABETIC CONTROL

GOAL 1

GOAL 2

GOAL 3

DURATION OF GOAL PERIOD _____ WEEKS	GOAL 1	GOAL 2	GOAL 3
LEAST FAVORABLE OUTCOME			
LESS THAN EXPECTED LEVEL OF SUCCESS			
EXPECTED LEVEL OF SUCCESS			
MORE THAN EXPECTED LEVEL OF SUCCESS			
MOST FAVORABLE OUTCOME			
VERIFYING SOURCES			

Adapted from Kiresuk & Sherman (1968)

NAME: _____

GOAL ATTAINMENT SCALE (POST)

DATE: _____

TYPE: DIABETIC CONTROL

DURATION OF GOAL
PERIOD:

GOAL 1

GOAL 2

GOAL 3

____ WEEKS

LEVEL
OF
SUCCESS
ACHIEVED

LEAST FAVOURABLE OUTCOME			
LESS THAN EXPECTED LEVEL OF SUCCESS			
EXPECTED LEVEL OF SUCCESS			
MORE THAN EXPECTED LEVEL OF SUCCESS			
MOST FAVOURABLE OUTCOME			

Adapted from Kiresuk & Sherman (1968)

DAILY DIARY (FABRICATED DATA)

DATE	COMMENTS
Feb 28/91	Diet - ok
Thurs.	Exercise - walked 1.2 miles. Was snowing
	Weight - 227 lbs.
	Urine - Once in morning
	Blood - took equipment to work today. Did test 3 times. Was down
Mar. 1/91	Diet - ok
Fri.	Exercise - walked 1.6 miles in 35 min.
	Weight - 228 lbs.
	Urine - Did again once in am
	Blood - higher than yesterday.
	Missed phoning doctor.
Mar. 2/91	Diet - fair
Sat.	Exercise - walked 2 miles in 33 min.
	Weight - 229 lbs.
	Urine - Once in morning
	Blood - Twice. Lower in afternoon
Mar. 3/91	Diet - ok
Sun.	Exercise - Walked Macs & back 3 miles.
	Weight - 228 lbs.
	Urine - Only once - a.m.
	Blood - Only once - a.m.
Mar. 4/91	Diet - Not feeling well. Didn't eat much
	Exercise - Walked only ½ mile. Not feeling well
	Weight - 230 lbs.
	Urine - Once - a.m.
	Blood - Morning only
	Talked to doctor. To increase insulin.

APPENDIX XI

GOALS FOR GROUP MEMBERS

- . to increase self-esteem
- . to accept the reality of one's limitations
- . to decrease behaviour that prevents intimacy
- . to learn how to trust oneself and others
- . to become freer and less bound by external "shoulds" and "musts"
- . to increase self-awareness and thereby increase the possibilities for choice and action
- . to learn the distinction between having feelings and acting on them
- . to free oneself from the inappropriate early decisions that keep one less than the person one could or would like to be
- . to recognize that others struggle too
- . to clarify the values one has and to decide whether and how to modify them
- . to be able to tolerate more ambiguity - to learn to make choices in a world where nothing is guaranteed
- . to find ways of resolving personal problems
- . to increase one's capacity to care for others
- . to become more open and honest with selected others
- . to deal with one another in a direct manner in the here-and-now group situation
- . to provide support and challenge for others
- . to confront others with care and concern
- . to learn how to ask others for what one wants
- . to become sensitive to the needs and feelings of others
- . to provide others with useful feedback

GOALS FOR DISABLED PEOPLE

- .to express anger, grief, and resentment about the disability;
- .to learn to deal with the reduced privacy caused by the disability
- .to learn to work with the limitations imposed by the handicap;
- .to establish a support system

Reprinted from Corey & Corey, 1987 (p.117)

APPENDIX XII

My Favorite Affirmations

"I am in harmony and in divine order today."

"I do not depend upon persons, situations or other external circumstances for my good. No person, thing, or condition can keep my good from me. I call forth the best and highest good for my life now."

"Today I bless all that I have or hope to have. I give thanks that my needs are being met now."

"Today the best and highest good will come from every situation."

"Today I take only the best from every situation and leave the rest."

"I forgive everyone and everything in my life that has hurt me—no longer do others control my life through unforgiveness."

"Today I say 'no' to all anger, fears, and insecurities in my conscious and subconscious mind."

"Today I say 'yes' to life, health, and happiness."

"I am confident and secure today."

"I now open my heart, mind, and spirit to be receptive to the highest and most perfect healing that is right for me. I receive it now."

"All the good I need, including health, happiness, and appropriate finances, are mine now."

"Today I am guided and led by the universal spirit of peace, and I receive all I need to be happy."

"The perfect plan for my life now unfolds easily and in peace."

"I now take all I need from the universe to be perfectly healthy, happy, and content."

"I go forward in confidence, knowing that my life is improving drastically now."

"I give thanks for all the wonderful good that I am now experiencing in my life."

Reprinted from Coffey-Lewis, 1982 (p.199)

APPENDIX XIII

DIABETES SUPPORT GROUP EVALUATION

1. Were your expectations met in this group?
Yes _____ No _____

2. Did you learn anything new?
Yes _____ No _____

If yes, what did you learn?

3. What was the most beneficial for you about this group?

What was the least beneficial for you about this group?

4. Would it be helpful for you to participate in a group like this in the future?
Yes _____ No _____

5. Were there any issues that were not addressed for you?
Yes _____ No _____

If yes, what were they?

6. Were there too many sessions? Not enough sessions?

7. Were you comfortable with the size of the group?
Yes _____ No _____

If no, how many members would have made the group ideal for you?

APPENDIX XIII continued

8. Did the facilitator make you feel comfortable?
Yes _____ No _____

Please comment.

9. Did the support group help you to manage your diabetes better,
practically and psychologically?
Yes _____ No _____

If yes, how?

10. Did your family/significant others notice any changes in you
throughout this group process?
Yes _____ No _____

If yes, what were they?

Other comments

NAME: ROBIN

GOAL ATTAINMENT SCALE (PRE)

DATE: OCT. 10/90

TYPE: DIABETIC CONTROL

	GOAL 1	GOAL 2	GOAL 3
DURATION OF GOAL PERIOD ____ WEEKS	To quit smoking	To exercise on a regular basis.	To follow my diet to the amount of calories I need per day (3000 calories)
LEAST FAVORABLE OUTCOME	To smoke a whole pack of fifteen cigarettes	No exercise	Two meals per day
LESS THAN EXPECTED LEVEL OF SUCCESS	To smoke more than ten cigarettes	To exercise once a week	Two meals per day
EXPECTED LEVEL OF SUCCESS	To smoke five to eight cigarettes	To exercise three times per week	Three meals per day
MORE THAN EXPECTED LEVEL OF SUCCESS	To smoke less than five cigarettes	To exercise four times per week	Four meals per day
MOST FAVORABLE OUTCOME	To be totally free from this habit	To incorporate an exercise routine as an enjoyable part of life	To continue four meals per day on an ongoing basis
VERIFYING SOURCES			

NAME: ROBIN

GOAL ATTAINMENT SCALE (POST)

DATE: December 15, 1990

TYPE: DIABETIC CONTROL

DURATION OF GOAL
PERIOD:

GOAL 1

GOAL 2

GOAL 3

 WEEKS

LEVEL
OF
SUCCESS
ACHIEVED

LEAST FAVOURABLE OUTCOME			
LESS THAN EXPECTED LEVEL OF SUCCESS	reached this level	reached this level	
EXPECTED LEVEL OF SUCCESS			reached this level
MORE THAN EXPECTED LEVEL OF SUCCESS			
MOST FAVOURABLE OUTCOME			

see schedule
"A"

Schedule "A"

December 15, 1990

At the onset of this group, we were required to pick goals that we wanted to meet during the following twelve weeks. At the end of this twelve week period, my goals were basically less than satisfactory. I do not see this as failure because a funny thing happened during the twelve weeks that I was involved with this group.

My ideas and perceptions of myself gradually changed over the weeks. At the beginning, my goals were picked because of outside influences. The "rules" had to be followed to be healthy and happy. On this basis, I chose my goals:

1. to quit smoking
2. exercise more
3. eat more regularly

I still want to achieve these goals to a more satisfactory level for myself, not what others expect of me.

These group meetings have given me the realization that I must be happy with myself and when I am happy with who I am then I can make the change if I choose to do so -- not what others are telling me to do.

The self-esteem of a diabetic is an extremely important issue that is probably the most forgotten aspect of being a diabetic. We are told by various professionals and non-professionals what we "have" to do or else. These people expect us to follow these rules and regulations without regard to our emotional well-being. For the most part, those people are not diabetic and do not know the anguish that follows after being diagnosed. I firmly believe that if the diabetic was made to feel normal and a vital part of society rather than be led to believe that they can't do this or feel like they are a segmented part of society, then a diabetic will tend to follow his or her regimen more closely. This is not attributed to what others tell him or her, but is due to their sense of self worth.

This is the single-most important thing that I have realized during this twelve week period. Perhaps, I should have used this point as a goal. Once a person realizes this, more physical goals can be attained more easily.

After all, we are human and we will always make mistakes, we are not robots who can do the same tasks day-in and day-out.

NAME: DAREL

GOAL ATTAINMENT SCALE (PRE)

DATE: Oct. 1/90

TYPE: DIABETIC CONTROL

	GOAL 1	GOAL 2	GOAL 3
DURATION OF GOAL PERIOD _____ WEEKS	Blood testing & Insulin (testing & injecting when I need to, where I need to)	Diet - Eating more nutritiously - Eating less inappropriately	More exercise - walking more - exercise more
LEAST FAVORABLE OUTCOME	Not being allowed to test or inject/becoming crippled and rely on others	Not being able to get supplies or relying on inappropriate food/becoming crippled and having to be fed.	Not having the opportunity to use my body as I do now
LESS THAN EXPECTED LEVEL OF SUCCESS	Stay as I am	Stay as I am	Stay as I am
EXPECTED LEVEL OF SUCCESS	To test & inject freely without guilt To be motivated to do so To welcome the challenge	To eat more nutritiously and more appropriately	To be less lazy to welcome challenge to have pain and weakness nullified
MORE THAN EXPECTED LEVEL OF SUCCESS	Miraculous recovery from Type I	To make the change easily To be successful	To make the change easily To be successful
MOST FAVORABLE OUTCOME	To take goal in a relaxed manner To be less self-conscious	To take goal in a relaxed manner To be less self-conscious	To take goal in a relaxed manner To be less self-conscious
VERIFYING SOURCES			

NAME: DAREL

GOAL ATTAINMENT SCALE (POST)

DATE: December 17, 1990

TYPE: DIABETIC CONTROL

DURATION OF GOAL
PERIOD:

 WEEKS

GOAL 1

GOAL 2

GOAL 3

LEVEL
OF
SUCCESS
ACHIEVED

LEAST FAVOURABLE OUTCOME			
LESS THAN EXPECTED LEVEL OF SUCCESS			
EXPECTED LEVEL OF SUCCESS	More assertiveness in being attentive	A little more nutritious eating	
MORE THAN EXPECTED LEVEL OF SUCCESS			Am walking more
MOST FAVOURABLE OUTCOME			

*I realize that it is up to me to change my outlook on life and that it will take conscious effort with a good deal of time involved.

APPENDIX XV

Darel

DIABETES SUPPORT GROUP EVALUATION

1. Were your expectations met in this group?

Yes No

2. Did you learn anything new?

Yes No

If yes, what did you learn?

Everything we talked about was on a personal level. I learned how they cope and reason things out. I voiced my opinion on things I haven't put into words before. There are many things about Type I that I just think to myself because no one around me can identify with.

3. What was the most beneficial for you about this group?

This group was beneficial for me because I found that we all had something in common; that I could say what I wanted to say; I could identify with what the others said and empathize with their difficulties.

What was the least beneficial for you about this group?

4. Would it be helpful for you to participate in a group like this in the future?

Yes No

5. Were there any issues that were not addressed for you?

Yes No

If yes, what were they?

There are many things that come up through conversations that lead to other things. It is difficult to identify them and then write them down in an accurate, cohesive manner. Generally, to do with attitudes and mannerisms that encourage me not to give up on trying to do the impossible.

6. Were there too many sessions? Not enough sessions?

To me, it doesn't matter. It is the content of each and every session that is important to me. A lively, energetic session stimulates me. The more we meet, the more personally revealing I get.

7. Were you comfortable with the size of the group?

Yes No

If no, how many members would have made the group ideal for you?

APPENDIX XV continued

8. Did the facilitator make you feel comfortable?
Yes No

Please comment.

9. Did the support group help you to manage your diabetes better, practically and psychologically?
Yes No

If yes, how?

Mainly psychologically; chronic diseases need lots of self-respect, self-assertion, perhaps a touch of arrogance, and a touch of self-centredness and a bunch of other intrapersonal thoughts and feelings to be more consistent on the practical end of Type I. Emotionally, I get down, I hope to modify this behaviour in the future.

10. Did your family/significant others notice any changes in you throughout this group process?
Yes No

If yes, what were they?

Other comments

APPENDIX XV

Rick

DIABETES SUPPORT GROUP EVALUATION

1. Were your expectations met in this group?
Yes No

2. Did you learn anything new?
Yes No

If yes, what did you learn?

3. What was the most beneficial for you about this group?

The input of others, wisdom shared, personal experiences similar to my own expressed.

What was the least beneficial for you about this group?

4. Would it be helpful for you to participate in a group like this in the future?
Yes No

5. Were there any issues that were not addressed for you?
Yes No

If yes, what were they?

6. Were there too many sessions? Not enough sessions?

Not enough.

7. Were you comfortable with the size of the group?
Yes No

If no, how many members would have made the group ideal for you?

APPENDIX XV continued

8. Did the facilitator make you feel comfortable?
Yes No

Please comment.

No expectations were placed on us. We had the freedom to speak our minds and basically decide what to discuss.

9. Did the support group help you to manage your diabetes better, practically and psychologically?
Yes No

If yes, how?

The biggest benefit was psychological. My physical needs had already been met. The support group made me feel better about myself.

10. Did your family/significant others notice any changes in you throughout this group process?
Yes No

If yes, what were they?

After each session, my significant other noticed I was more open to talking about my feelings and that my self-esteem improved.

Other comments

Having a group support of this type is an extremely important aspect of being a diabetic. The psychological make-up of a diabetic is often neglected. I firmly believe that if the emotional aspects of diabetes were incorporated with the physical aspects of diabetes, we would be much more prepared to tackle or cope with everyday life. Self-esteem would increase; confidence would increase; and our role in society would be greatly enhanced.

APPENDIX XV

Dianne

DIABETES SUPPORT GROUP EVALUATION

1. Were your expectations met in this group?
 Yes No
 I did not know what to expect and I was pleasantly surprised.
2. Did you learn anything new?
 Yes No
 If yes, what did you learn?
 From Robin, a bit on intensive care.
3. What was the most beneficial for you about this group?
 Talking with other real diabetics - realizing they have problems too.
 What was the least beneficial for you about this group?
4. Would it be helpful for you to participate in a group like this in the future?
 Yes No
5. Were there any issues that were not addressed for you?
 Yes No
 If yes, what were they?
6. Were there too many sessions? Not enough sessions?
 Not enough.
7. Were you comfortable with the size of the group?
 Yes No
 If no, how many members would have made the group ideal for you?
 Would have liked some more female members.

APPENDIX XV continued

8. Did the facilitator make you feel comfortable?
Yes No

Please comment.

Marlene Clay never made me feel guilty - this was a new experience for me. I felt understood for the first time.

9. Did the support group help you to manage your diabetes better, practically and psychologically?
Yes No

If yes, how?

Psychologically, I realized what I was going through was normal for someone in my condition. I learned how to handle things related with this issue.

10. Did your family/significant others notice any changes in you throughout this group process?
Yes No

If yes, what were they?

I regained some dignity and hope.

Other comments

APPENDIX XV

Robin

DIABETES SUPPORT GROUP EVALUATION

1. Were your expectations met in this group?
Yes No

2. Did you learn anything new?
Yes No

If yes, what did you learn?

I learned to take it easy on myself. That it is ok to make mistakes and that we cannot expect to be perfect.

3. What was the most beneficial for you about this group?

Being frank with others and the feeling that no expectations were placed on us.

What was the least beneficial for you about this group?

4. Would it be helpful for you to participate in a group like this in the future?
Yes No

5. Were there any issues that were not addressed for you?
Yes No

If yes, what were they?

6. Were there too many sessions? Not enough sessions?
Yes. Sessions should be about once a month.

7. Were you comfortable with the size of the group?
Yes No

If no, how many members would have made the group ideal for you?

APPENDIX XV continued

8. Did the facilitator make you feel comfortable?
Yes No

Please comment.

She did not take the joking seriously and still let one joke.

9. Did the support group help you to manage your diabetes better, practically and psychologically?
Yes No

If yes, how?

Not manage - cope. I still have trouble managing - the insulin I'm on may not be what's best for me.

10. Did your family/significant others notice any changes in you throughout this group process?
Yes No

If yes, what were they?

Other comments

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