

Quality of life in Persons
with Diabetes

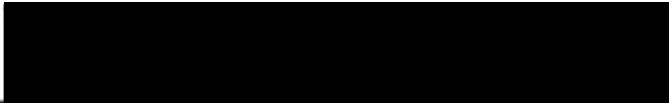
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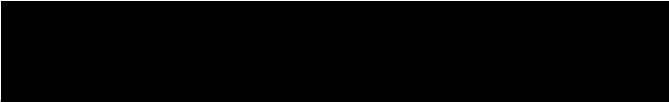
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Chapter 1

Introduction

Quality of life (QOL) has become an important issue in the planning, implementation and evaluation of social policy and health care since it became a concept following the second world war (Campbell, 1981).

Nursing and medicine have been interested in quality of life as an outcome for evaluating the impact of various medical treatments and nursing interventions.

Throughout the literature, the most common problem in addressing quality of life is finding a consistent definition for the concept. George and Bearon (1980) concluded that defining quality of life was a problem because people value different things. Researchers define the concept in both global terms and by describing the dimensions which determine quality of life. Padilla and Grant (1985) said that quality of life referred to those things which make life worth living. Young and Longman (1983) defined it as "the degree of satisfaction with perceived present life circumstances."

Burckhardt (1985) suggested that determining the factors which influence an individual's perception of quality of life is necessary to plan nursing care and set goals with patients which will enhance quality of life. Indeed, most researchers define quality of life

in terms of the factors or dimensions which influence quality of life. In their review of quality of life literature, Ferrans and Powers (1985) found that the following dimensions were included in at least two of the studies reviewed: subject's opinion of own quality of life or life satisfaction, socioeconomic status, physical health, affect, perceived stress, friendship, family, marriage, life goals, housing and neighborhood, city and nation, self-esteem, depression, psychological defense mechanisms, and coping. What is missing from the definitions is the importance of these facets to the individual. For the purpose of this exploratory study, quality of life is defined as satisfaction with those aspects of life which the individual perceives as important.

Quality of life has been studied in both the general population and in individuals with chronic disease. However, one population whose quality of life may be greatly influenced by their disease, people with diabetes, has not been studied extensively.

As a chronic illness which affects more than ten million people in the United States alone, diabetes mellitus has a major impact on the health of this country due to the many complications of the disease. Blindness, renal failure, atherosclerosis and neuropathy are costly problems both personally and

financially (Cahill, 1985). Treatment of this disease involves lifestyle change as well as daily medication and monitoring with a high level of self-care responsibility. The impact of diabetes on quality of life seems formidable.

Nurses have the opportunity to assess and enhance the quality of life for these individuals through teaching and counseling. Assisting the person to learn the tasks that are necessary and to adapt to the changes in lifestyle that are needed can enhance the person's quality of life. Helping the person control their blood glucose levels may prevent or diminish the impact of complications and therefore, improve or maintain their quality of life.

The lack of quality of life studies in the diabetes literature limits nursing in its understanding of this disease and in its ability to have a positive effect on the person's life. A better understanding of the effects of diabetes on quality of life is needed to provide realistic patient care planning and goal setting.

There is a clear need for further research in two areas: (1) understanding quality of life from the perspective of the individual and (2) the study of quality of life in a group of people with a chronic disease which has been assumed to affect quality of

life. This descriptive study addresses the following questions:

1. What does quality of life mean to the person with diabetes?
2. What kinds of things are important to the quality of their lives?
3. To what factors do people attribute a change in their quality of life?
4. Is diabetes a factor in the person's perception of the quality of their lives?
5. Is there a relationship between the presence of complications and the persons' perception that diabetes influences their lives?

Chapter 2

Literature Review

The review of the literature is divided into three sections: (a) quality of life in the general population, (b) quality of life in a variety of chronically ill populations and (c) quality of life in people with diabetes mellitus.

Quality of Life - General Population

Three studies are described briefly and obviously do not constitute a comprehensive review. The studies by Flanagan (1978) and Campbell, Converse and Rogers (1976) are classic studies of the general population using very large samples. They provide valuable data with which comparisons can be made. The George and Bearon (1981) study is included because their population may be similar to an older group of people and diabetes affects a disproportionately older population.

Campbell, Converse, and Rogers (1976) emphasized the need for a subjective measure of QOL so that individuals could define QOL in their own words. Their study of quality of life in random samples of Americans included 12 domains: (1) health, (2) marriage, (3) family, (4) national government, (5) friendships, (6) housing, (7) job, (8) community, (9) religious faith, (10) nonwork activities, (11) financial situation and (12) organizations. They reported that subjects most

often responded in terms of life satisfaction when asked about their quality of life. This approach is further supported by a listing of over 400 studies which have examined life satisfaction for all age groups (American Psychological Association, 1967-1985).

Flanagan's (1978) work is important not only because of his large sample but also because of his use of the critical incident technique which provided the researchers with the information from the individual's perspective. In 1971 the American Institutes for Research initiated a major effort toward improving the quality of life of Americans. The first step in this effort was to empirically define the critical components of quality of life. Nearly 3,000 people representing various ages, races, backgrounds and regions of the country were surveyed using the critical incident technique. More than 6,500 critical incidents were collected from open-ended survey questions which provided a rich source of data from differing points of view and experiences. These critical incidents were sorted and through an inductive process, refined into 15 categories listed under five headings described as the components of quality of life: (1) physical and material well-being; (2) relations with other people; (3) social, community and civic activities; (4) personal development and fulfillment; and (5) recreation. The use of regional samples and diverse

groups insured that a variety of experiences and points of view were represented.

George and Bearon (1980) said that defining quality of life was a matter of preference based on the individual or group values of the population. As social scientists interested in assessing the quality of life of older people, they defined QOL as consisting of two subjective dimensions (life satisfaction and self-esteem) and two objective dimensions (health and functional status and socioeconomic status). They evaluated numerous instruments used to measure these dimensions. The question arises now as to the applicability of these dimensions to people with chronic illness and more specifically, diabetes.

Quality of Life in Chronic Illness

The assumption that chronic illness affects an individual's quality of life is seldom questioned in health care. How QOL is affected by chronic illness is important to consider in planning care and treatment. This review of the literature addressing chronic illness and quality of life will address the following questions: (1) Are the dimensions of QOL determined from the perspective of the person experiencing the chronic illness? (2) Is there consensus between studies regarding the dimensions of QOL? (3) Is there a relationship between QOL and severity of illness?

(4) Are the dimensions identified in the chronic illness literature applicable to diabetes mellitus?

Several studies address quality of life as one of several outcomes of care in chronic disease. QOL as an outcome measure is especially important in cancer nursing where quality of survival is emphasized over length of survival. Holmes and Dickerson (1987) designed a self-assessment instrument which consisted of two sections. The first section measured the changes related to symptoms of the disease and side-effects of treatment. The second section assessed psychosocial problems of isolation, activities, worries, and communication problems. The results of the study confirmed the authors' hypothesis that severity of symptoms has a significant impact on the activities of daily living and therefore significantly influenced the individual's quality of life.

Padilla and Grant (1985) studied quality of life as an outcome measure to evaluate the impact of cancer nursing care. Referring to Flanagan's work, they developed a Quality of Life Index based on a five dimensional concept of quality of life that included psychological well-being, social concerns, body image concerns, physical well-being and diagnosis/treatment response for use with cancer patients. Psychological well-being was found to be the most important dimension

of quality of life. The remaining dimensions, in order of importance, were physical well-being, body image, responses to diagnosis/treatments, and social concerns.

Spitzer, et al. (1981) considered the perspective of the person with a chronic illness in the development of a quality of life index (QL-Index). Cancer patients and other patients with chronic diseases were on panels charged with the job of identifying the factors that could enhance or decrease quality of life. However, the panels also included family members of the patients, healthy people, physicians, nurses, social workers, other health professionals and clergy and this may have distorted the patients' perspective.

The QL-Index consisted of five dimensions: activity (involvement in own occupation), daily living (activities of daily living), health (perception of own health), support (of families and friends), and outlook on life. The instrument discriminated between healthy subjects and chronically ill patients and between patients with moderate manifestations of their disease and those who were seriously ill. The QL-Index correlated well with patients' self-assessments, although the patients consistently scored themselves higher than did their family, physicians, and other health professionals. This again emphasizes the need for the patients' perspective.

Schipper, Clinch, McMurray, and Levitt (1984) also included health professionals with cancer patients on panels to design the Functional Living Index-Cancer (FLIC) as a measure of quality of life. They defined four functional dimensions of importance: vocation/activity; affect/psychologic state; social interaction; and somatic sensation. The inclusion of health professionals on these panels makes it impossible to elicit a pure sense of the patients' perspective of quality of life.

Stegman, Duncan, Pohren and Sandtrom (1985) emphasized the patient's perspective in their use of data from Cantril's Self-Anchoring Scale to identify the hemodialysis patient's perception of maximum and minimum quality of life. The scale is depicted as an 11 rung ladder and is based on the individual's own values and goals. The bottom rung represents the worst life situation the person can imagine with the top rung illustrating the best life situation imaginable. The researchers asked the subjects which rung they consider themselves to be on now and in the future. Because the authors felt that an individual's health state might be associated with their quality of life, they asked the subjects to rate the quality of their health in the same way. The researchers also assessed physical ability from the patients' perspective by use of a 105

item activity profile which listed the activities according to progressive energy expenditure. A vocational status profile assessed past and present work status, educational level, and vocational rehabilitation participation. The researchers obtained demographic and clinical data about the subjects and identified concomitant diseases. The study demonstrated that physical activity was the single most important indicator of quality of life and health status. The use of Cantril's ladder provided a global measure of the person's quality of life from the person's perspective. However, the dimensions chosen as indicators of QOL were from the health care providers' perspective.

Burckhardt (1985) studied quality of life experienced by ninety-four people with arthritis using the Quality of Life Index, a weighted, composite score from three indicators: (1) overall quality of life, (2) the Life Satisfaction Index, and (3) the Domain Satisfaction scale. Variables measured included severity of pain, socioeconomic status, social network configuration, perceived support, severity of impairment, self-esteem, internal control over health, negative attitude toward the illness and demographic and disease history data. The results indicated that self-esteem, a sense of personal control and supportive

relationships were the most important variables associated with quality of life perceived by people with arthritis. Symptom and disease-specific variables did not have the importance that one might expect.

In a study of life quality for patients with chronic obstructive pulmonary disease (COPD) McSweeney, Grant, Heaton, Adams and Timms, (1982) used three self-report inventories to get data from the patient's perspective. Another inventory provided data from the perspective of someone who interacted with the individual regularly. The researchers assessed four dimensions of quality of life: emotional functioning, social-role functioning, activities of daily living, and recreational pastimes. Patients with COPD had impaired quality of life all four dimensions. Depression was the most common emotional disturbance; reduced social interaction and problems managing the home were primary deficits in social-role function. The person's mobility, sleep/rest and recreational participation were also severely affected. Severity of illness related to life quality; age and economic status functioned as possible moderators of life quality.

Kaplan, Atkins and Timms (1984) designed a Quality of Well-Being (QWB) Scale using a functional approach. They studied COPD patients to determine the impact of

medical and psychosocial interventions. The Quality of Well-Being scale consisted of three dimensions of daily functioning (mobility, physical activity and social activity) and functional levels within each dimension. Scores from the scale correlated with performance and physiologic measures. The researchers emphasized that physiologic measures alone are insufficient to determine quality of life and that the QWB scale provided a unit of measurement for cost/benefit analysis of treatment. Again the researchers determined the dimensions to be measured, not the people with COPD.

Brown, Rawlinson and Hilles (1981) proposed a life satisfaction model to describe the impacts of coronary artery disease (CAD) and chronic obstructive pulmonary disease (COPD) on quality of life. They chose four variables as possible predictors of life satisfaction: physician-assessed level of disability, the individual's perceived health status, extent of the person's social activity and the person's perception of locus of control as internal or external.

The CAD patients were significantly more satisfied with life than the COPD patients ($t = 2.94$, $df = 81$, $p < 0.01$). Those with COPD were less active socially, somewhat more disabled, and perceived their health as poorer than the CAD patients. There was no difference

in the two groups' perceptions of locus of control. Social activity was the variable most closely associated with life satisfaction. The findings supported the proposition that life satisfaction varies with the type of chronic disease. This further suggests that quality of life studies in chronic illness need to start with the perceptions of the people living with the specific chronic disease.

Flynn and Franz (1987) studied quality of life during early convalescence following coronary artery bypass surgery to determine the subjective perceptions of the patients. Subjects were 21 years of age or older and 6 - 10 weeks postoperative. The study investigated the following: (1) patients' perceptions of life satisfaction and health; (2) the relationship between life satisfaction and health; (3) the relationships between specific life domain satisfaction and domain importance; (4) the greatest predictors of life satisfaction and (5) the relationship between life satisfaction and social support. The domains of life included relief of symptoms, physical activity, leisure, social participation, family relationships, sexual activity, material wealth or possessions, ability to return to work, and mood or morale.

The researchers used four instruments in this study to measure quality of life: (1) a self-anchoring

scale; (2) a sociologic-health status inventory developed for this study; (3) an exercise tolerance test; and (4) a social support scale. The majority of patients reported an enhanced quality of life because of the relief of their angina. Subjects were optimistic about their own health and their future quality of life despite reported complications and physical symptoms. None of the demographic characteristics or occupational variables related to life satisfaction. The researchers found a significant difference ($t = 2.46, p < 0.05$) in life satisfaction between subjects with social support and those with little support.

A study by Penckofer and Holm (1984) also assessed quality of life in the early postoperative period following coronary artery bypass surgery. The researchers compared two similar groups of patients to each other on objective and subjective indicators of quality of life. The objective indicators were degree of angina, activity and employment. Subjective indicators were over all life satisfaction and satisfaction with family, social, occupational and sexual life.

One group was three to five months postoperative and the second group was six to eight months postoperative. Both groups viewed their future life

satisfaction as better than their preoperative life satisfaction. All patients reported significantly less pain and more activity after surgery. The physical limitations caused by angina pain had prevented them from participation in family, social and recreational activities before surgery. Free from anginal episodes, they became more actively involved. The researchers found sexual satisfaction to be significantly improved post-bypass. Overall, the study did show that there were measurable improvements in the quality of these individuals' lives. However, the researchers determined the dimensions to be measured.

In the 11 studies cited, researchers chose the dimensions of QOL to measure. There were no studies in which the chronically ill populations alone determined which dimensions were important to them. The dimensions were quite varied but overlapped primarily in two general areas: physical and psychological well-being. Researchers found that severity of disease did affect QOL. The next section will describe how diabetes is assumed to affect quality of life and will review the diabetes QOL literature.

Quality of life and Diabetes

Diabetes is a disease that places many demands on a person and coping with those demands is more than a full time job (Armstrong, 1987). Some people with diabetes are required to make major lifestyle changes

and perform daily self-care tasks that most people would find difficult, such as multiple insulin injections, frequent blood glucose testing, and regular exercise. They must be aware of everything they eat and how it affects their blood glucose and then use the information to make decisions about their care. Others are told they need to lose weight and to eat differently than they have for most of their lifetimes. They are asked to monitor their blood glucose levels and start exercise programs.

Backscheider (1974) identified 50 activities essential to therapeutic self-care for people with diabetes taking insulin. Numerous physical, mental, emotional and motivational limitations can interfere with the ability of the individual to perform these activities. The diabetes regimen can be very complex and time consuming. The high level of self-care management necessary in diabetes is in addition to the demands and responsibilities of daily life. Current management recommendations for the treatment of diabetes with insulin include two to four injections per day and as many blood glucose tests. This intensive therapy puts the person at risk for hypoglycemia and requires greater vigilance on the part of the patient. Based on the fact that the goal of therapy in chronic disease is improvement in function,

not cure, Wenger, Mattson, Furberg and Elinson (1984) emphasized that evaluation of new therapies should include quality of life measures and not be limited to biomedical measures.

An individual with diabetes also lives with the constant threat and presence of debilitating complications (Citrin, Kleiman & Skyler, 1986). Peripheral vascular insufficiency, neuropathy, retinopathy, nephropathy and increased risk of cardiovascular disease contribute to the morbidity and mortality of the disease.

From these descriptions it would seem obvious that a diagnosis of diabetes which can affect so many dimensions of an individual's life would also affect the quality of that person's life. These descriptions, however, are from the health care professional's perspective, inductively derived from experiences in the health care setting with people who have diabetes. The viewpoint of the health care professional is problem-oriented and disease focused.

Nurses are in an excellent position, as patient educators, to help these individuals develop their self-care skills and enable them to adjust to living with a life-long disease. However, if nurses and other health care providers are going to influence the person's adjustment to this chronic condition, they must first

understand the individuals' perceptions of their disease and what they see as relevant (Bury and Wood, 1979). Health care providers need the perspective of the people who are actually living with diabetes 24 hours a day, every day of their lives, as to how having diabetes affects the quality of their lives.

Despite the increased interest in quality of life research, little has been done to investigate quality of life for the person with diabetes from their perspective. In only three studies have researchers measured quality of life in populations of people with diabetes.

Mazze, Lucido and Shamoon (1984) adapted the Mooney Problems Checklist for diabetes and used it to measure quality of life and its correlation to glycemic control. This instrument is self-administered and describes 100 problems grouped into six categories: health perception, personal problems, job related problems, interpersonal problems, and sexual problems. The purpose of the study was to determine whether glycemic control was related to personality, anxiety, depression, and/or quality of life. Anxiety, depression and QOL was found to have a significant relationship to metabolic control at the beginning and throughout the study. The Mooney Problems Checklist focuses on problems assumed by the researchers to be important to the person with diabetes. The researchers

did not measure the subjects' overall perceived quality of life to validate the findings.

The purpose of the second study undertaken by the Diabetes Control and Complications Trial (DCCT, 1988) was to develop an instrument which would measure outcomes of diabetes treatment regimens. The instrument is intended to determine the extent to which intensive diabetes treatment regimens affect quality of life in patients who have insulin-dependent diabetes mellitus (IDDM). The investigators derived the items for the Diabetes Quality of Life (DQOL) measure from clinical practice, a review of the diabetes literature, and from patients who have diabetes.

The DQOL is a 46 item, multiple-choice, self-report measure and consists of four subscales (satisfaction, impact, diabetes worry, social/vocational worry). Responses are made on a five-point Likert scale. The DQOL had high degrees of internal consistency (Cronbach's $r = .66-.92$) and test-retest reliability ($r = .78-.92$). Results showed that subjects were generally satisfied, not worried, and that diabetes made only a modest impact on their lives. Although the investigators designed the DQOL specifically for use in the trial, they suggest it may be useful in evaluating the quality of life for other groups of patients with IDDM.

While this is the first QOL instrument to be designed specifically for use with people who have diabetes, the researchers developed the items primarily from the health care providers viewpoint. The instrument is also intended for use with a relatively young group (mean age 28 ± 7 yrs), predominately male (60%), insulin-dependent and in generally good health, without advanced complications. This sample does not represent the general population of people with diabetes of which approximately 80% are >40 years of age, obese and female and have non-insulin dependent (or Type II) diabetes.

Kaplan, Hartwell, Wilson and Wallace (1987) used physiologic and general quality of life outcome measures to evaluate diet and exercise programs for people with non-insulin dependent diabetes. Subjects were randomly assigned to one of four treatment programs: diet, exercise, diet and exercise or education. The researchers measured glycosylated hemoglobin and relative weight as well as general quality of life prior to the program, and at three, six, 12 and 18 month intervals. Researchers used the Quality of Well-being (QWB) scale previously described in the chronic illness literature (Kaplan, Atwell & Timms, 1984). The QWB scale is a five level, functional measure of mobility, physical activity and

social activity. Patients assigned to combined diet and exercise programs had better QOL outcomes than the other groups. In this study, the researchers chose a QOL measurement that was based solely on functional status. This scale does not measure any aspect of psychological well-being, nor does it provide any global measure of QOL. It is, however, a self-assessment instrument. The investigators in this study make the assumption that functional ability is the most important indicator of QOL to people with diabetes

This review illustrates the complexity of quality of life research in chronic illness and a lack of descriptive studies regarding quality of life for people with diabetes. Descriptive studies of quality of life from purely the person's point of view are absent from the diabetes literature. In several chronic illness studies the value of determining quality of life as a treatment outcome measure has been documented and reinforces the need for descriptive studies of quality of life and diabetes from the individual's perspective. Questions remain regarding what QOL means to people with diabetes, what factors are important to QOL for these people and which of these factors contribute to a change in their quality of life. Also, none of the studies cited thus far have examined the possible relationship between QOL and

complications or whether people with diabetes even perceive the disease to be a factor in the quality of their lives.

Chapter 3

Methods

Design

This study is a qualitative, descriptive, secondary analysis of data collected for a larger study of quality of life and chronic illness. Interview data were collected on patients with arthritis, COPD and diabetes mellitus. Data from the people with diabetes will be used for this study to describe quality of life from their perspective.

Sample and Setting

The subjects were patients from the diabetes outpatient clinic roster at a health sciences university. The researchers obtained verbal consent by telephone and used chart audits and mailed questionnaires to collect demographic and disease-specific data. To be included in the study the subjects had to be English-speaking adults with a diagnosis of diabetes, having no other chronic diseases that they considered worse than their diabetes and with no obvious cognitive deficit which would prevent them from completing the interview and questionnaire.

The sample consisted of 24 men and 36 women, ranging in age from 20 years to 90 years with a mean age of 58 years and a median age of 63 years. Twenty-

one subjects were retired, 13 were disabled, six were unemployed and no employment status was noted for 20 of the subjects. Table 1 describes occupation and education characteristics of the sample. Table 2 describes yearly income reported by the sample.

Fifty-eight of the subjects lived in Oregon and two people lived in Washington state. Thirty-nine subjects were urban residents, ten were rural residents and eleven were suburban residents.

The subjects were classified as to the type of diabetes they had using the classification system proposed by the National Diabetes Data Group (1979). Diabetes mellitus is present when the fasting plasma glucose is above 140mg/dl. Type I diabetes (also called Insulin Dependent Diabetes Mellitus or IDDM) is characterized by age at onset under 30 years with a slight male predominance. Inherited histocompatibility antigen types are encoded on chromosome 6 and with various degrees of both serologic and cell-mediated autoimmunity. There is total insulin deficiency with a tendency for ketosis in the presence of hyperglycemia. Complications of the disease are frequent. Islet cell mass is severely reduced and exogenous insulin is required. Approximately 15-20% of diagnosed cases of diabetes in the general population are classified as having Type I

Table 1

Occupation and Education Characteristics of the Sample

| Occupation | Number of Subjects | % of Sample | Education | Number of Subjects | % of Sample |
|----------------|--------------------------|-------------------|-----------------|--------------------------|-------------------|
| Domestic | 7 | (12%) | Graduate school | 3 | (5%) |
| Operative | 3 | (5%) | College grad. | 5 | (9%) |
| Service | 9 | (15%) | 1-4 yrs college | 15 | (25%) |
| Protection | 1 | (2%) | High sch. grad. | 15 | (25%) |
| Skilled labor | 6 | (10%) | Grades 9-11 | 6 | (10%) |
| Clerical/sales | 14 | (23%) | Grades 7-9 | 14 | (23%) |
| Managerial | 13 | (22%) | < 7 years | 2 | (3%) |
| Semi-Prof. | 4 | (6%) | | | |
| Professional | 3 | (5%) | | | |

Table 2

Average Yearly Income of the Sample

| Family Income per Year | Number of Subjects | Percent of sample |
|------------------------|--------------------|-------------------|
| < \$5,000 | 16 | (27%) |
| \$5,000 - 10,000 | 19 | (33%) |
| \$10,001 - 15,000 | 3 | (5%) |
| \$15,001 - 20,000 | 8 | (14%) |
| \$20,001 - 25,000 | 2 | (3%) |
| \$25,001 - 40,001 | 4 | (7%) |
| \$40,001 - 65,000 | 5 | (9%) |
| > \$65,000 | 1 | (2%) |

diabetes.

Type II diabetes (also called Non-Insulin Dependent Diabetes Mellitus or NIDDM) is the more common form of the disease with approximately 80 % of cases. It is characterized by age of onset over 40 years, genetically influenced without specific histocompatibility antigens or autoimmunity. Ketosis is rare and islet cell mass is only moderately reduced. Management may be accomplished by diet alone or with oral diabetes pills and for some, insulin. Type II diabetes is associated with obesity in approximately 80% of cases. Complications are often more frequent in this group due to advanced age at diagnosis and delayed diagnosis (Riddle, 1985).

Complications of diabetes include coronary artery disease, neuropathy, retinopathy, cataracts, glaucoma nephropathy, hypertension, stroke, skin ulcers and peripheral vascular disease. The exact biochemical basis for these complications is not yet certain. However, the most current models being proposed are directly related to the harmful effects of hyperglycemia (Riddle, 1985).

A third category of diabetes may be referred to as secondary diabetes. However, it is not true diabetes mellitus. It includes drug-induced diabetes, destruction of beta cells by chronic pancreatitis and

diabetes caused by other chronic and genetic diseases. It is characterized by a fasting plasma glucose of over 140 mg/dl and is treated with diet control and if necessary, insulin or diabetes pills. Two subjects in this study had secondary diabetes and included one person whose diabetes was steroid-induced following a kidney transplant. The second person developed diabetes because of chronic pancreatitis.

Characteristics of the sample are presented in Table 3. The majority of subjects were female in the 61-80 year old age range, with Type II diabetes treated with insulin. Most of the sample (84%) had complications.

Subjects in this sample were not totally representative of the general population of people with diabetes. Nearly half of the subjects had Type I diabetes compared to only 15-20% in the general diabetes population. More females than males were in the Type I group, the opposite of the usual pattern. However, more females were represented in the Type II group which is expected in the diabetes population.

Many more subjects in the Type II group were treated with insulin than is generally found; however, this may have been due to the use of more aggressive treatment regimens in the university clinic than is found in private practice. Another explanation may be

Table 3

Disease Specific Characteristics of Sample by Type of Diabetes

| Characteristics | TYPE I | | TYPE II | | SECONDARY | |
|--------------------|--------|-------|---------|-------|-----------|------|
| | number | % | number | % | number | % |
| Totals by type | 17 | (29%) | 39 | (67%) | 2 | (3%) |
| Gender: | | | | | | |
| Male | 7 | (12%) | 16 | (28%) | 0 | |
| Female | 10 | (17%) | 23 | (40%) | 2 | (3%) |
| Age Group* : | | | | | | |
| 20-40 yr. | 12 | (22%) | 1 | (2%) | 0 | |
| 41-60 yr. | 3 | (5%) | 7 | (12%) | 1 | (2%) |
| 61-80 yr. | 2 | (4%) | 26 | (47%) | 1 | (2%) |
| 81-99 yr. | 0 | | 2 | (4%) | 0 | |
| Treatment: | | | | | | |
| Insulin | 17 | (29%) | 26 | (45%) | 2 | (3%) |
| Oral agents | 0 | | 9 | (16%) | 0 | |
| Diet only | 0 | | 4 | (7%) | 0 | |
| Complications: | | | | | | |
| Present | 13 | (22%) | 36 | (62%) | 0 | |
| Absent | 4 | (7%) | 3 | (4%) | 2 | (4%) |
| Years of Diabetes: | | | | | | |
| 0-10 yrs. | 3 | (5%) | 15 | (26%) | 2 | (3%) |
| 11-20 yrs. | 6 | (11%) | 14 | (24%) | 0 | |
| 21-30 yrs. | 4 | (7%) | 8 | (14%) | 0 | |
| 31-40 yrs. | 1 | (2%) | 2 | (3%) | 0 | |
| 41-50 yrs. | 3 | (5%) | 0 | | 0 | |

* No age was given for three subjects.

that these individuals were referred to the clinic after efforts to control the blood glucose levels with diet and oral agents had failed. Both subjects with secondary diabetes were treated with insulin.

Subjects in both Type I and II groups experienced high rates of complications: 70% of the people with Type I diabetes and 85% of those with Type II diabetes. These percentages are not unexpected. Complications are frequent in both types with Type II diabetes resulting in more complications due to advanced age at diagnosis and delayed diagnosis (Riddle, 1985).

Ages of the subjects also correspond to the general diabetes population. The Type I group tended to be younger but with a surprising two individuals in the 61-80 years age group. Both were in their 70's and they both had had diabetes for about 50 years. Seventy-two per cent of the subjects with Type II diabetes were 61-80 years of age. The next largest age group of the people with Type II diabetes was 41-60 years of age. People with Type II diabetes are typically over 40 years old.

The individuals with secondary diabetes were included in this study because the same things that could affect the quality of life for people with Type I and II diabetes could also affect people with secondary

diabetes. The subjects with secondary diabetes required treatment regimens the same as those subjects with Type I diabetes. They were also included because they experience hyperglycemia, putting them at risk for the same complications of Type I and II diabetes.

Table 4 illustrates the comparison of years of diabetes to incidence of complications in subjects with Type I and II diabetes. The incidence of complications for Type II diabetes is greater than for Type I for those subjects who have had diabetes for 30 years or less. This finding exemplifies the problems of delayed diagnosis of diabetes in an aging population.

Neither of the two subjects with secondary diabetes had complications. The person whose diabetes was steroid induced was 49 years old and had been diagnosed for four years. The subject with diabetes secondary to chronic pancreatitis was 65 years of age and had been diagnosed for less than a year. They were both being treated with insulin.

Data Collection Procedures

A doctoral student research assistant conducted a structured telephone interview. The researcher asked five open-ended questions and recorded the responses on an interview form. The questions asked in the

interview are listed below:

1. What does quality of life mean to you?
2. What kinds of things are important to your quality of life?
3. Has your quality of life changed in the past year?
4. Is it better or worse?
5. What has made it better or worse?

Table 4

Comparison of Years of Diabetes to Incidence of
Complications in Subjects with Type I and II Diabetes

| | | Number of Subjects and Percent of Sample per Years of Diabetes | | | | | | | | | |
|------------------|--|---|-------|-------|-------|-------|-------|-------|------|-------|------|
| | | 0-10 | | 11-20 | | 21-30 | | 31-40 | | 41-50 | |
| | | N | % | N | % | N | % | N | % | N | % |
| Type I: | | | | | | | | | | | |
| complications | | 1 | (2%) | 5 | (9%) | 2 | (4%) | 1 | (2%) | 3 | (5%) |
| no complications | | 2 | (4%) | 1 | (2%) | 2 | (4%) | 0 | | 0 | |
| Type II: | | | | | | | | | | | |
| complications | | 13 | (23%) | 13 | (23%) | 8 | (14%) | 2 | (4%) | 0 | |
| no complications | | 2 | (4%) | 1 | (2%) | 0 | | 0 | | 0 | |

Chapter 4

Results and Discussion

The first section of this chapter will present an overview of the data analysis procedures used in the study. Subsequent sections will describe and discuss the findings from the questionnaire according to the research questions.

Data Analysis Procedures

Each data set consisted of two forms: the chart audit which provided demographic and disease-specific information for each subject and the interview form on which the responses to the five interview questions were recorded.

Each subject was identified by a numerical code which was placed at the top of each of the two forms. Of the 60 data sets, two had to be discarded because there were two interview forms for each of the two identification codes. The remaining 58 data sets were included in the analysis.

Responses to each of the five questions from the questionnaire were transcribed to 3x5 cards. The identification code number was placed in the upper right-hand corner. The number for the question was included on the card as well as the response. The responses to question number one on the questionnaire were coded as either global definitions or dimensions

of quality of life.

Prior to coding the responses to question number 2, an initial list of 14 categories and the corresponding codes was developed based on dimensions found in the literature. The 58 subjects generated a total of 247 responses. Cards with those responses on them were coded using the initial 14 categories and an additional 26 categories which were developed as needed. The 40 categories provided lower level concepts which were eventually collapsed into five primary categories with 16 subcategories. Initial analysis of the data occurred at this time. As the response was read from the interview form, the information was broken down into phrases and words which appeared to have individual meaning. Care was taken to preserve the context of the response by not dividing or separating phrases or words which seemed to depend on each other for meaning.

The next step in the analysis was to begin coding the chart audit forms onto separate 3x5 cards. The identification number was placed in the upper right-hand corner. Information regarding type of diabetes (Type I or II and secondary), treatment (insulin, pills or diet only), age of the subject with a letter code for the age group, gender and a list of the complications. If no complications were noted, a 0 was

entered on the card. Years since diagnosis of diabetes was noted and a number code was assigned for each 10 years since diagnosis.

Research Question Number One: What does quality of life mean to the person with diabetes?

The first question on the questionnaire asked for the meaning of QOL to the respondent. Subjects in this study had difficulty defining QOL just as the researchers have. Five of the 58 respondents indicated that they did not know how to answer the question. Nineteen subjects (33%) gave global statements which defined quality of life for them. Their statements can be interpreted to mean life satisfaction. Ten of those subjects made statements referring to enjoying life or being happy. Another five subjects spoke of living well, a good life, living a better life. Four people referred to satisfaction with life and fulfillment in life. Although only 1/3 of the subjects were able to define QOL, the data supports the use of life satisfaction as the definition of QOL for this study.

The responses of six subjects were difficult to categorize. One person talked of living one day at a time and not letting "it get the best of you." Another said that it meant "everything." Three others spoke of "lifestyle," "being OK with the world," and "reason for living." One individual said "not much."

Twenty-eight subjects answered this question with statements pertaining to specific dimensions of life. Those responses will be included in the discussion of the second question.

Researchers used single measures of perceived life satisfaction in combination with measures of specific dimensions of quality of life (Penckofer & Holm, 1984; Burckhardt, 1985; Stegman et al., 1985; Flynn & Franz, 1987; Brown, Rawlinson, & Hilles, 1981). These studies demonstrated the relationship between life satisfaction and the specific dimensions or factors expected to affect QOL. In those studies the researchers determined which dimensions to measure based on knowledge of the disease and experience with the patients. To determine what dimensions or factors are important to people with diabetes the second research question must be answered.

Research Question Number Two: What kinds of things are important to the quality of their lives?

The responses to question number two on the questionnaire provided the data for this research question. The 247 responses made by the 58 subjects were categorized into the final five categories and 16 subcategories. The categories and subcategories listed with the number of subjects and responses can be found in table 5. The findings from each of the categories

Table 5

Frequency of Responses Within Categories and
Subcategories of QOL Dimensions

| <u>CATEGORY</u> <u>SUBCATEGORY</u> | Number of subjects responding | Frequency & % of total responses |
|--|----------------------------------|--|
| <u>Physical Well-being</u> | | |
| Health status | 29 | 44 |
| Mobility | 13 | 15 |
| Control of diabetes | 6 | 8 |
| TOTAL | 48 | 65 (27%) |
| <u>Psychological Well-being</u> | | |
| Self-esteem | 22 | 37 |
| Emotional status | 17 | 18 |
| Spirituality | 6 | 8 |
| Coping | 1 | 2 |
| TOTAL | 42 | 61 (26%) |
| <u>Being Active</u> | | |
| Recreation | 13 | 21 |
| Activities | 14 | 20 |
| Ability to do | 15 | 20 |
| TOTAL | 42 | 61 (25%) |
| <u>Social and Family Relationships</u> | | |
| Family | 18 | 19 |
| Social activities | 7 | 12 |
| Friends | 5 | 5 |
| TOTAL | 30 | 36 (14%) |
| <u>Material Well-being</u> | | |
| Economic status | 7 | 10 |
| Home | 5 | 6 |
| Help | 4 | 4 |
| TOTAL | 16 | 20 (8%) |

will be presented and discussed separately.

Physical well-being. This category is defined as functions of the body and general health status. A total of 67 responses were made in this category by 48 subjects. Forty-four responses were grouped into the subcategory of health status and included "feeling good," "good health," "not being sick," and references to eating and sleeping well and having energy. A subcategory of mobility was included meaning the physical ability to move. Subjects talked about "getting out and walking, being mobile and getting around without pain." A total of 15 responses were coded as mobility. Another important subcategory was control of diabetes mellitus. The comments included "lifestyle changes to control diabetes," being on insulin, getting off insulin, staying on the diet, and "the regimen of diabetes." Eight statements were made in this subcategory by six subjects.

This category of physical well-being was one of the original 14 derived from the literature. The study by Flanagan (1978) had a combined category of physical and material well-being. Padilla and Grant (1985) isolated physical well-being as a category in their study. Others referred to health status (Brown, Rawlinson & Hilles, 1981), symptoms (Holms & Dickerson, 1987) and health and functional status (George & Bearon, 1980).

Psychological well-being. This category is defined as mental and emotional status. The sixty-five responses in this category made by 58 subjects were separated into four subcategories: (1) self-esteem, (2) emotions, (3) spirituality and (4) coping. Self-esteem included 15 comments about having personal control and personal rewards. References to working at a specific job and being employed were also included within self-esteem due to the emphasis by the subjects on productivity and usefulness rather than material gain. Other researchers viewed employment (Penckofer & Holm, 1984), workstatus (Stegman et al., 1985) and ability to return to work (Flynn & Franz, 1987) as separate categories or dimensions of QOL. Independence was a particularly important aspect of self esteem with 13 comments about living independently and being able to do things for oneself instead of depending on others. Seven comments about being normal or doing things like everyone else were also included in the subcategory of self-esteem. Burckhardt (1985) and George and Bearon (1980) included self-esteem as a separate dimension of QOL.

Eighteen responses in the subcategory of emotions referred to being happy, not being depressed and being without stress. The spirituality category was made up of eight comments about faith, the Lord, and church.

One individual said that church was important to her but that she has "had to give up church work". None of the studies made reference to spirituality as a separate dimension or subcategory. The two statements under coping referred to coping with "life in general" and coping "with diabetes".

Padilla and Grant (1985) included psychological well-being in their study of cancer patients and determined it to be the one with the greatest impact on the individual's quality of life. Other studies referred to mood or morale (Flynn & Franz, 1987), affect/psychological state (Shipper et al. 1984) and emotional functioning (McSweeney et al. 1982).

Being Active. This category is defined as the ability to participate in activities. Sixty-one responses made by 42 subjects were divided into three subcategories: (1) activities, (2) ability-to-do and (3) recreation. The 20 responses in activities referred to pursuing activities in general and to specific activities such as exercise, being a student, work at home, assisting others and being busy. Spitzer et al. (1981) included a category of activities of daily living referring to routine activities. Flynn & Franz (1987) and Penckofer & Holm (1984) referred to physical ability in their dimensions of quality of life.

In this study, the subcategory of ability to do

had 20 responses in it with references to being able to do what the person wanted to do or enjoyed doing. Two of those 20 responses referred to not being "impeded by diabetes" and doing things "in spite of it (diabetes)". This subcategory was supported in the literature by Brown, Rawlinson and Hilles (1981) However, they approached it from the opposite point of view (physician-assessed level of disability). Stegman et al. (1985) also referred to physical ability as an important dimension to measure.

The subcategory of recreation with 21 responses included comments about specific activities such as fishing, tennis, travel, camping and hobbies such as gardening, music, sewing and reading. Three studies in the literature included references to recreation (Flanagan, 1978 and McSweeney et al., 1982) and leisure (Flynn & Franz, 1987).

The number of responses in each category is a measure of how important that category was to the respondents' quality of life. Seventy-eight per cent of the responses to this question were in the categories of physical well-being, psychological well-being, and being active. The frequency with which these three categories of responses occurred is so close that it is impossible to say one is more important than the other.

The effect of physical well-being, psychological well-being and being active on each other is essential to the understanding of the data. As an individual's physical well-being is diminished, the ability to be active is also diminished. This, in turn, will affect the person's psychological well-being. A closer look at the subcategories will further illustrate these relationships.

Not feeling well and being less mobile can affect a person's self-esteem, especially when the person can no longer function independently. Burckhardt's (1985) study of people with arthritis demonstrated that as the impairment became more severe, self-esteem became lower. Within the subcategory of self-esteem, 13 of the 36 responses related to independence. Being independent and being able to do what you want to do was a common theme in the responses. The subjects in this study were aging as well as experiencing complications of diabetes. A total of 48 subjects were experiencing complications. Thirty-one or 65% of those individuals were over 61 years of age. Advancing age in combination with any one or more of the complications which could decrease mobility and interfere with a person's health could greatly affect a person's quality of life.

An interesting finding in the category of physical

well-being was the small number of responses in the subcategory of control of diabetes. Only six respondents made comments directly related to diabetes, a total of eight comments. Related to that finding were the two comments made by one subject in the category of psychological well-being which referred to coping with diabetes. The absence of a significant number of comments related to coping and the diabetes regimen is significant in itself. People in this study did not indicate that the diabetes regimen was of particular importance to the quality of their lives, either positively or negatively. Of greater importance than the diabetes regimen were the negative effects of complications on daily living. Individuals were much more concerned with being able to do what they wanted to do, to be mobile and to be independent.

Social/Family Relationships. This category is defined as interaction with family and friends and social activities. A total of 36 responses made by 30 subjects were included in this category. The subcategories were social activities, family and friends. Social Activities included 12 comments about being with people and activities with other people. Within the family subcategory 19 comments were made about family in general, children and grandchildren and spouse. One individual answered that "not much" was

important to his quality of life and added that his "wife died 1 1/2 years ago." His comment was included in this category because of the emphasis he placed on the loss of his wife.

The third subcategory was friends with five comments about having friends or being with friends. One individual said that friends were important but that her life lacked friends.

Social-role functioning (McSweeney et al., 1982), relations with other people (Flanagan, 1978), social activity (Brown, Rawlinson & Hilles, 1981), support of family and friends (Spitzer et al., 1981), social interaction (Schipper et al., 1984), social concerns (Padilla & Grant, 1985) and supportive relationships (Burckhardt, 1985) were dimensions of quality of life in the literature review.

Within the category of social/family relationships the subcategories of family and friends had the most responses (24 of 36 responses). Burckhardt (1985) found that supportive relationships accounted for 10% of the variance in quality of life. Spitzer et al., (1981) included support of family and friends in the Quality of Life Index designed for use with cancer patients.

In this study, respondents did not refer to support in their comments about family or friends.

Their comments were simply about having family and friends. The implications are that family and friends are generally supportive and the comments from the respondents about family and friends were positive. They spoke of enjoyment and "good" family and friends.

Material Well-being. The 20 responses in this category were made by 16 subjects. Ten of the responses were in the subcategory of economic status and referred to having enough money to pay bills, being able to afford things and working to earn money. In the subcategory of home six responses emphasized housing or the person's home. Having help with household chores and yard work was included in the subcategory of help with four responses.

Flanagan (1978) included this category in his dimension of physical and material well-being. George and Bearon (1980) had a combined category of socioeconomic status. Material wealth or possessions was one of six categories in the study by Flynn and Franz (1987).

Half of the responses in this category pertained to economic status. This is not surprising since 58% of the subjects in this sample earned less than \$10,000 per year. In view of the high cost of diabetes to the individual, it is surprising that more people didn't give financial considerations greater emphasis in their responses.

Miscellaneous responses. Two statements were difficult to categorize within the five categories. One person said that the MD's and RN's who have cared for her were important to her quality of life. This statement could refer to physical well-being as well as psychological well-being. Another person said that nothing was important to his quality of life.

Research Question Number Three: To what factors do people attribute a change in their quality of life?

When the 58 subjects were asked whether or not the quality of their lives had changed in the past year, 20 subjects (36% of the sample) responded "no." This does not indicate whether their perception of their QOL was good or bad, just not changed. Thirty-eight subjects (64% of the total sample) said that their QOL had changed in the past year. Of those subjects who said their quality of life had changed, sixteen subjects said that their QOL was better. Twenty-two subjects said that it was worse.

Subjects were asked what had made their QOL better or worse. The responses to this question were first divided into two groups: things that had made the quality of life better and things that had made it worse. Each of the two groups of responses were then analyzed according to the categories of quality of life dimensions which were developed from question number

two. The responses were further coded to indicate gender, age, years since diagnosis and presence or absence of complications and a color code for age group. This allowed the investigator to further analyze the responses according to these characteristics.

Improved quality of life. A total of 27 statements made by 15 subjects referred to what had made the individual's quality of life better. Fifteen responses were made by 12 individuals who were experiencing complications of their diabetes. Twelve responses were made by the 3 subjects who were not having complications.

Eleven of the 27 statements were under the category of psychological Well-being. The statements included "more satisfied now," less stress, "things are looking good right now" and references to enjoying life and doing well. Six of those subjects making the statements were experiencing complications; three were not.

Eight statements made by eight subjects referred to physical well-being, such as "back and hips feel better," weight loss, "have energy" and "less fatigue." Two of the eight statements referred to blood sugar control. Five of the subjects were experiencing complications.

Three of the 27 responses seemed to be a combination of both physical and psychological well-being. One subject said that she doesn't drink alcohol any more. Another said that she had changed doctors and things were "lots better." She said she "wasn't getting any attention" before changing physicians. The third subject said that the quality of her life was better because it was "not winter anymore." This individual was not experiencing complications and she was 38 years old.

The remaining five responses represented four categories. Two responses fit in the category of social/family relationships: one person said things were better because of her daughter; another said she had a "new boyfriend." Two responses were placed in the category of being active. The first individual said that life was better because she was busier; the second individual's response was "more able to ... be active. A better apartment was the reason another individual said her quality of life was better. This response was categorized as material well-being.

Psychological and physical well-being were the categories having the most impact on improved quality of life. The interplay between these two categories is important to note. Six individuals made statements in both categories. Feeling well physically seems to be quite clearly related to feeling well psychologically.

Worsened quality of life. A total of 49 responses made by 22 subjects described what had made their quality of life worse in the past year. Twenty-one (95%) of the subjects who indicated a change in QOL were experiencing complications of diabetes.

Twenty-six or 53% of the 49 responses were categorized as physical well-being. All of the 26 responses were made by 17 people with complications. Eleven responses indicated that vision problems and feet and leg pain were especially troublesome. Eight comments were about limited mobility. The remaining nine responses referred to specific diseases or general symptoms of weakness or fatigue.

Nine responses by eight subjects were categorized as psychological well-being. The responses included references to not feeling useful or productive; stress and having a "nervous breakdown"; being different from others; and giving up church work. One individual stated "giving shots to myself - freaks me out lately".

A combined category of psychological-physical well-being was used to classify three responses. One individual stated her life was more stressful because her diabetes was becoming harder to control. Another person had a positive biopsy for breast cancer. The third response referred to having heart surgery and things being more difficult.

The remaining seven responses were placed into four categories. Being active included three responses about not being able to read or drive or do other daily activities. Two responses about not working were labeled as material-psychological well-being. One person was 22 years old and not able to work due to poor eyesight. The other individual was 55 years old and had been fired from his job for unknown reasons. He was experiencing mild complications and had been depressed. "Not being with people" was categorized as social/family relationships. One person described the death of her son as stressful and caused her to require more insulin. This response fit in a combined category of psychological-physical well-being as well as social/family relationships.

This analysis demonstrates that those persons who experience decreased QOL attributed the change to physical problems. All of the subjects who said that physical problems had worsened the quality of their lives were experiencing complications of their diabetes. This finding is supported in the literature.

Specific disease-related factors were linked to QOL in several studies. Degree of dyspnea was linked to a diminished quality of life in persons with chronic obstructive pulmonary disease in the study by Brown, Rawlinson and Hilles (1981). Severity of pain had a

negative impact on the attitudes of people with arthritis (Burckhardt, 1985) and these negative attitudes, in turn were found to affect the individuals' quality of life. A decrease in anginal pain was found to increase the person's quality of life following coronary artery bypass surgery (Penckofer & Holm, 1984).

Research Question Number Four: Is diabetes a factor in the people's perception of the quality of their lives?

To determine how many of the subjects in the study actually made comments in the interview that pertained specifically to diabetes and its related problems, the data sets consisting of the interview form and the chart audit form were divided into two groups. The first group consisted of 25 subjects (43% of the sample) who made some reference to diabetes and related issues. Their comments were about being less mobile, physical symptoms and being more dependent on others due to complications of their disease.

Thirty-three subjects (57% of the sample) did not make any reference to their diabetes in their interview. Their comments were more about being active, being independent, having family and friends, and participating in church and recreation. The same things that are important to the subjects in Flanagan's

(1978) study of the general population are of greater importance than their diabetes to over half of the subjects in this study.

Research Question Number Five: Is there a relationship between the presence of complications and the perception that diabetes influences their lives?

The data sets were further analyzed to answer this question. In the group of 25 subjects who made some reference to diabetes in the interview, only one person (4%) did not have evidence of complications. Ninety six per cent of that group had evidence of complications. In the second group of subjects who did not mention diabetes, seventy six per cent had complications.

The findings show that the presence of complications is significantly related to the perception that diabetes influenced the subjects' lives ($df=1, n=58, \chi^2 = 5.18$). Although fewer people talked about diabetes in their interviews, more of the ones who did had complications.

Of the 76% who did not mention their diabetes in the interview, over half of them were experiencing two or more complications. One 70 year old man had profound neuropathy with neurogenic ulcers of his legs, and coronary artery disease. Another man had neuropathy, cataracts, hypertension, amputation of the

toe, cellulitis of his feet and coronary artery disease. It is surprising to find that these people did not talk about some aspect of their disease.

Summary

Although subjects had difficulty defining QOL, those who did define the concept referred to life satisfaction. Most subjects described dimensions of QOL. Subjects identified five main categories of QOL dimensions as being important to them. These categories were the same as the five dimensions of QOL described in Flanagan's study (1978) for the general population. Physical well-being, psychological well-being and being active were nearly equal in importance to the subjects of this study.

The categories having the most impact on QOL were psychological and physical well-being for the subjects who said the quality of their lives had improved. For those people whose QOL had worsened, physical problems were described as the cause. All of these people were experiencing complications which may have affected their physical well-being. Over half of the subjects made no mention of diabetes in the interview. However, of those subjects who did mention their diabetes, 96% had complications of their disease, indicating that diabetes does influence QOL.

Chapter 4

Summary

In this chapter a summary of the research study, its limitations, and implications for nursing practice and research will be presented.

Research Summary

Diabetes affects more than ten million people in the United States alone. Despite the occurrence of debilitating complications and the demands of lifestyle change, little is known about the impact of diabetes on quality of life from the individual's point of view. Review of the quality of life literature addressing diabetes revealed a small number of studies. There were no descriptive studies from the perspective of the person with diabetes. The purpose of this study was to describe quality of life from the perspective of the people experiencing diabetes.

This descriptive study of quality of life and diabetes used a nonexperimental, qualitative methodology. The investigation was a secondary analysis of data obtained in a study of chronic illness which included people with arthritis, chronic obstructive pulmonary disease and diabetes. The original investigation took place in a university-affiliated clinic setting and patients being treated at the diabetes outpatient clinic constituted a

convenience sample. Semi-structured telephone interviews and chart audits were conducted by a graduate research assistant.

The research questions were:

1. What does quality of life mean to the person with diabetes?
2. What kinds of things are important to the quality of their lives.?
3. To what factors do people with diabetes attribute a change in their quality of life?
4. Is diabetes a factor in the people's perception of the quality of their lives?
5. Is there a relationship between the presence of complications and the perception that diabetes influences their lives?

Data from the interviews and the chart audits were coded and analyzed to answer the research questions. Quality of life was defined as life satisfaction by a small number of subjects. The remainder of the subjects either did not know how to define the concept or chose to describe factors which were important to QOL.

From a total of 247 responses of what the subjects felt were important to their quality of life five primary categories and 16 subcategories were identified

and defined. Physical well-being (27% of the responses), psychological well-being (26% of the responses), being active (25% of the responses), social and family relationships (14% of the responses) and material well-being (8% of the responses).

The categories and subcategories of quality of life dimensions found in this study compare well with Flanagan's (1978) five dimensions of QOL. All five categories from this study can be found in his study of the general population. In addition, three or more of the categories or subcategories are found in all of the studies of quality of life and chronic illness. However, 78% of the factors said to be important to QOL for this sample were in the categories of physical well-being, psychological well-being and being active. The complications of diabetes can be expected to affect all three of these categories.

Factors related to psychological well-being were cited most often in improved quality of life. Those whose QOL had worsened cited primarily physical factors as the cause. The majority of these individuals had complications.

Over half of the sample did not make any reference to their diabetes or diabetes-related problems when interviewed about the quality of their lives. Of those subjects who mentioned diabetes in the interview, 96%

were experiencing complications. Chi square analysis showed that complications related significantly to the perception that diabetes influenced their lives.

Limitations of the Study

Two major limitations of this study are noted. The first may affect generalizability and the second may affect validity of the findings.

The sample was not representative of the general diabetes population. More people with Type I diabetes were found in this sample and more people with Type II diabetes were being treated with insulin than is usually found in the general diabetes population. Additionally, the ability to generalize may be limited because the subjects were being treated in a university teaching facility.

Another limitation of the study may have been the use of a semi-structured telephone interview. The interview did not allow the use of probing questions which could have enriched the data. Also, the interviews were not tape recorded and the responses were written down by the interviewer as the interview progressed. This method of data collection allows for possible inadvertent editing of the responses.

Implications for Nursing Practice and Research

Findings based on the respondents' perception of QOL dimensions provide nurses with a key to

understanding quality of life as an outcome of diabetes management. Padilla and Grant's (1985) conceptual model of the relationship between the nursing process and the dimensions of quality of life as outcome criteria illustrates the usefulness of defining the patient's quality of life for nursing in its efforts to address the needs of the populations it serves. In this model the patient's perception of a caring attitude by the nurse correlates with psychological well-being. Perceived self-care ability impacts physical well-being. In addition, the ability to perform self-care activities increases self-esteem.

The role of the nurse as patient educator provides excellent opportunities to affect quality of life for diabetes patients by demonstrating a caring attitude that affirms the individual's self-worth and by providing self-care skills which promote physical well-being. In addition and central to the findings of this study, a thorough assessment of the person's psychosocial status as well their physical status will help to identify problem areas which can impact quality of life. Nursing cannot fix everything. However, they are often able to put the patient in contact with people who can help when they can't.

Being able to do what you want to do and being independent were important issues of QOL to the

subjects in this study. For example, if a person is no longer able to drive and unable to walk to the store, they will not be able to do their own shopping. Simply putting them in contact with a ride service will allow them to remain independent. A thorough assessment of the impact of complications on daily activities would elicit information that could be used to plan appropriate interventions.

A careful assessment for the presence of complications that even the patient may not be aware of can often prevent further deterioration and more severe consequences. Evaluation for peripheral neuropathy is an excellent example of an assessment that can lead to prevention of severe and debilitating complications. Early intervention for minor foot problems and teaching foot care skills can prevent ulcers, gangrene and possible amputation.

A better understanding of the dimensions of quality of life for people with diabetes can assist the nurse in the development of assessment instruments. These instruments must be sensitive to the specific needs of the diabetes population with a special emphasis on the impact of existing complication on activities of daily living.

Implications for Research

These initial findings provide a basis for further research in quality of life and diabetes. Much of the

research in diabetes focuses on the biophysical aspects of the disease while the patients continue to struggle with lifestyle changes, the consequences of complications and numerous psychosocial issues. The critical interplay between the QOL dimensions of physical well-being, psychological well-being and being active illustrates the need for an approach to diabetes care that considers all aspects of the individual's life (Popkiss-Vawter, 1983).

Additional studies describing quality of life from the perspective of the person with diabetes would be needed to confirm or refine the findings of this study. This study could be repeated using an interview process that would allow the interviewer to ask probing questions. This could provide more complete information and a richer source of data. Subjects in this study made statements such as "feel better now" but there was no opportunity to find out how she was feeling better.

Other studies could be undertaken to determine which strategies are useful for improving quality of life. Assessment tools that would quickly identify quality of life issues for the patient could be developed and tested.

Although there have been studies which have attempted to describe quality of life for individuals

in several settings and with a number of chronic illnesses, only three have studied diabetes mellitus. More importantly, none of these studies have simply asked the person with diabetes how they feel the disease has affected the quality of their lives. Most of the literature has focused on the disease from the health care provider's perspective. Knowing more about how this complex disease affects the lives of these individuals would broaden the perspective of the health care provider. Only with an understanding of the impact diabetes mellitus has on daily life can the health care team provide realistic and meaningful care.

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Abstract

Title: Quality of Life in Persons with Diabetes
Mellitus

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The purpose of this descriptive study was to describe quality of life (QOL) in people with diabetes. Fifty-eight subjects, 24 males and 34 females, ranging in age from 20-90 years, 29% with Type I diabetes, 67% with Type II diabetes and 3% with secondary diabetes from a university clinic setting were included in the study. Researchers conducted semi-structured telephone interviews and chart audits to obtain the data. The research questions were: (1) What does QOL mean to the person with diabetes? (2) What kinds of things are important to the quality of their lives? (3) To what factors do people with diabetes attribute a change in their QOL? (4) Is diabetes a factor in the people's perception of the quality of their lives? (5) Is there a relationship between the presence of complications and the perception that diabetes influences their lives? QOL was defined as satisfaction with those aspects of life

which the individual perceives as important.

Analysis of the data identified five primary categories of factors determined by the subjects to be important to their QOL: physical well-being, psychological well-being, being active, social and family relationships and material well-being. Seventy-eight percent of the factors said to be important to QOL for this sample were in the categories of physical well-being, psychological well-being and being active. Subjects cited factors of psychological well-being most often as improving QOL. Subjects whose QOL had worsened primarily cited physical factors as the cause. The majority of the subjects whose QOL had worsened had complications of their disease.

Over half of the sample did not make any reference to their diabetes or related problems. Of those who mentioned diabetes in the interview, 96% were experiencing complications. Chi square analysis showed that complications related significantly to the perception that diabetes influenced their lives. Findings of the study provide nurses with a key to understanding QOL and diabetes as well as a basis for QOL as an outcome of diabetes management.