

A CLIENT AUTHORED CURRICULUM FOR
DIABETES MELLITUS USING
THE APPROACH OF
PAULO FREIRE

By

MARY KOSIK SCHOEN

Bachelor of Science in Nursing
University of Connecticut
Storrs, Connecticut
1970

Master of Science in Education
Western Connecticut State University
Danbury, Connecticut
1977

Submitted to the Faculty of the
Graduate College of the
Oklahoma State University
in partial fulfillment of
the requirements for
the degree of
DOCTOR OF EDUCATION
July, 1996

Copyright[®] by

Mary Kosik Schoen

July, 1996


A CLIENT AUTHORED CURRICULUM FOR
DIABETES MELLITUS USING
THE APPROACH OF
PAULO FREIRE


Thesis Approved:



Thesis Adviser









Dean of the Graduate College

ACKNOWLEDGMENTS

I wish to thank my thesis adviser and chair, Dr. William Segall and committee member Dr. Betty Edgley whose long term support and guidance have been with me throughout this entire project. I also wish to thank the other members of the committee, Drs. W. Hwu and B. Petty for their advice and generosity in their willingness to join in this project. During earlier phases of project Dr. Russell Dobson, Dr. J. Randall Koetting of the University of Nevada at Reno, and Dr. William Reynolds of Purdue University provided guidance and encouragement and I thank them.

I am indebted to the staff, patients and family members at the facility where the study was conducted. I would like to thank Ms Janice Filicetti, Assistant Administrator and Director of Nurses and Dr. Benjamin Eng, Medical Director for their support of this project. I must also express my great appreciation to this study's participants for their willingness to teach their lived curricula.

I wish to acknowledge my family members who have cheered me on throughout this work. Thank you to my parents Molly and John Kosik, my brother John, my sisters Judy and Linda and my nieces Molly and Kelsey. They also know about living the curriculum. For my closest family, my son Matt and my husband Al, I thank them for their understanding and support. Especially for my husband Al, who has taught me patience and two word processing programs, who typed, edited, critiqued, encouraged and supported me. Thank you with all my heart.

TABLE OF CONTENTS

Chapter	Page
I.	DEVELOPMENT OF A CLIENT AUTHORED CURRERE 1
	Lenses and Cameras: Metaphor for Choosing a Tool 1
II.	CHOOSING A LENS: SORTING THE CURRICULUM CHOICES 4
	Variety of Groupings of Curriculum Theory 4
	Eisner's Cognitive Processes 6
	Alternatives Similar to Eisner's Cognitive Processes 6
	Academic Rationalism 8
	Categories Similar to Eisner's Academic Rationalism 8
	Personal Relevance 9
	Categories Similar to Eisner's Personal Relevance 10
	Social Adaptation and Social Reconstruction 11
	Curriculum as Technology 15
	What Does This Mean? 16
III.	THE U.S. HEALTH CARE SYSTEM AND ITS DOMINANT TEACHING PARADIGM..... 20
	Nursing, As It Fits Into Health Care 22
	Nursing's Historical Background 24
	The Dominant Paradigm 26
	Alternative Traditions in Nursing and Health Care 26
	Nursing: A Short Personal Definition 27
	The Dominant Paradigm for Diabetes Education 28
	Diabetes Mellitus-The Pathophysiology 29
	Diabetes Mellitus-The Curriculum 32
	A.D.A.'s Education and Clinical Goals 36
	I.D.D.M. 36
	N.I.D.D.M. 36
	Rationales For and Against this Curriculum 38

Chapter	Page
IV. METHODOLOGY.....	40
Quantitative Methodology Part of the Dominant Paradigm.....	40
Limitation.....	41
Quantitative Methodology From the Alternate Paradigm.....	42
Paulo Friere's Methodology.....	45
An Alternative Tool to Facilitate Praxis.....	47
Project's Design.....	49
Research Setting.....	50
Methodology for Data Analysis.....	52
Coding the Study's Field Notes.....	53
V. CURRICULUM, CURRERE, CURRERE(S).....	54
Introduction.....	54
Limits and Strengths of the Method.....	55
The Participants.....	59
Personal Definitions of DM.....	62
Terms: Diabetic versus Person with Diabetes.....	64
Learning about the Diagnosis.....	67
Initial Reaction to the Diagnosis.....	69
Fear.....	70
Anger and Denial.....	71
Lifestyle Changes/Skills Recommended by Care Givers.....	72
Diet.....	74
Dichotomy or Integration/Congruence: Context for Diet Choices.....	77
Context for Learning Diet: Adaptation or Compliance.....	78
Patient and Family Attitude.....	82
Context: Taste and Enjoyment.....	84
Special Conditions - Eating Out.....	87
Special Conditions - Holidays.....	88
Opportunities for Dietary Congruence and Integration.....	89
Other Dietary Adherence Strategies.....	91
Cheating: Participants Evaluation of Dietary Compliance.....	92
Participants' Evaluation of Successful Congruence.....	94

Chapter	Page
Medications	95
Insulin: An Ambivalent Proposition	95
Learning Context for Insulin Administration.....	97
Special Circumstances - Plan Ahead for Travel.....	101
Oral Hypoglycemic Agents	102
Participant's Recommendations for Oral Hypoglycemic Agents	102
Other Participant Identified Skills.....	104
Foot Care.....	104
Smoking	106
Weight Loss	107
Hyperglycemia, Stress and its Management	109
Exercise.....	110
Monitoring.....	111
SMBG and Euglycemia.....	111
Special Circumstances	118
Benefits of Monitoring.....	118
Alternatives to Mechanical Monitoring- Signs, Symptoms and Activities	119
Evaluating the Alternatives	120
Individual Euglycemic Goals and Short Term Complications	122
Long Term Complications.....	123
Direct Evidence of a Different View.....	125
The Process of the Intuitive Grasp of Reality	126
The Three Staged Process	126
Learning to Manage Resources	131
Managing Resources: Significant Others.....	134
What Families Need to Know	134
Dietary Gatekeepers	135
Nagging, The Gatekeeper's Tool.....	136
Net Result for Families	139
Characteristics and Management of Institutions	139
General Recommendations for Institutional Reform	141
Managing Health Care Teachers	142
Criteria for Staff Evaluation: Respect	144
Evaluation of Physicians	146
Professional Relationships	149
Managing Curriculum and Instruction	150

Chapter	Page
Participants as Beginners and Experts	150
Rx: A Dose of Currere for Beginners and Experts.....	152
Expert's Seminars.....	154
Beginner's Classes.....	155
Obstacle Course	156
Other Resources	157
More Obstacles to the Course	158
 VI. SUMMARY, CONCLUSIONS AND RECOMMENDATIONS.....	 160
Introduction	160
Summary	161
Discussion of Results	166
Recommendations for Future Studies	171
 REFERENCES.....	 174
 APPENDICES.....	 191
APPENDIX A - DOCUMENTATION OF IRB PERMISSION.....	 192
APPENDIX B - SELECTED TRANSCRIPTS OF PARTICIPANT INTERVIEWS AND GROUNDED THEORY MEMOS.....	 195

Glossary of Health Care Terminology

cardiovascular	An adjective used to refer to the heart and blood vessels.
C.H.F.	Congestive Heart Failure, a type of heart disease in which the heart muscle is impaired in its ability to pump blood. Persons with this condition are likely to have edema (swelling from excessive fluid) in the lower body and have shortness of breath.
C.V.A.	Cerebrovascular Accident. This a general term used to describe conditions of ischemic damage to the brain usually caused by blockage or hemorrhage of a blood vessel. Also called stroke or shock.
Diabetes (Mellitus)	A term used to identify several diseases. Three major categories of this disease are: Insulin Dependent. Diabetes Mellitus, Non-Insulin Diabetes Mellitus and Gestational Diabetes. These diseases are characterized by higher than normal blood sugar (glucose). The immediate cause of high blood sugar is either the relative lack of or inability of the body to use insulin.
D.K.A.	Diabetic Ketoacidosis, a life threatening condition induced by the relative lack of insulin to assist in the metabolism of sugar. Because of this inability the body begins excessive metabolism of fats, producing toxic levels of waste products called ketones. It is more common to I.D.D.M.
glucose	The specific type of sugar which is a normal blood component. It is primarily the product of the metabolism of sugars and starches (carbohydrates).
H.H.N.K.	Hyperosmolar Hyperglycemia Nonketotic (Syndrome), a group of symptoms occurring as a result of extremely high blood sugar and the dehydration which is the result of the excessive concentration of glucose. It is more common with N.I.D.D.M.
hyperglycemia	Abnormally high level of blood sugar. Extreme levels of this condition are not compatible with life. This condition can lead to D.K.A. or H.H.N.K. Both are sometimes called diabetic coma.

hyperlipidemia	An abnormally high level of fatty substances in the blood. It is associated with an increased incidence of vascular disease i.e. heart disease and stroke.
hypertension	High blood pressure. This health problem is a risk factor for many of diseases including heart disease, stroke and kidney disease. It is usually manageable with medication, diet, weight loss and stress reduction.
hypoglycemia	Abnormally low level of blood sugar. Extreme levels of this condition are not compatible with life. Sometimes called insulin shock.
I.D.D.M.	Insulin Dependent Diabetes Mellitus, a type or several related types of diabetes which require the administration of insulin on a daily basis. It is also called Type I (One) Diabetes and used to be called Juvenile Diabetes. Because of the significant lack of residual capability to produce insulin, excessive high blood sugar can lead to D.K.A.
insulin	This substance is one of many hormones, normally produced in the body. Its primary function is to maintain normal levels of blood sugar. It is the substance which allows the sugar out of the blood stream and into the cells where it is used.
N.I.D.D.M.	Non-Insulin Dependent Diabetes Mellitus, a type or one of several of related types of diabetes. Some persons will require treatment with insulin, others may be treated with oral hypoglycemic agents, diet and exercise. It is also called Type II (Two) and used to be called maturity onset diabetes. Excessive high blood sugar is likely to produce H.H.N.K.
polydypsia	One of the symptoms of high blood sugar. It is a strong thirst causing a great increase in fluid intake.
polyphagia	One of the symptoms of high blood sugar. It is an increased appetite and ingestion of food in the presence of weight loss.
polyuria	One of the symptoms of high blood sugar. It is increased urination and is the result of polydypsia.
renal	An adjective used for referring to the kidney, its parts or functions.
retinopathy	A progressive ocular disease in which the small blood vessels are damaged. This can lead to vision problems and eventually blindness.

CHAPTER I

DEVELOPMENT OF A CLIENT AUTHORED CURRERE

The major goal of this project was to develop a coherent view of curriculum, useful as determined by health care clients, their significant others and lastly to their health care providers. This goal was a reflection of valuing individual autonomy and the belief that a curriculum autonomously developed will be useful to those it was designed to serve. As this project concerned curriculum development, it surveyed major curriculum theorists in order to select the most appropriate basis for its own development. As it also drew upon concepts from health care and health education on nursing theory, they too were also reviewed. Finally, the desire to explore such a topic acknowledges the writer's belief that there is no commonly available curriculum designed by and for health care clients.

Lenses and Cameras: Metaphor for Choosing a Tool

Many people have used the metaphor, or the analogy of a concept functioning as a camera's lens. Curriculum may serve in that metaphor, as a lens, to make both itself and the greater society and institutions more visible. This metaphor shows a parallel influence for choosing a curriculum or a camera lens. Both choices can be made on the basis of what the observer truly wishes to see. A professional photographer chooses the

lens with the correct focal length and F stop based on three criteria. The first criterion is determining a the focal length which is appropriate to the distance for the object(s) or model which the photographer wishes to see; second, choosing lens aperture which will allow the appropriate amount of light to pass through; third the camera's shutter speed must be compatible, which is to say a shutter speed which is physically able to fit and function with the lens. The photographer may base the final choice upon: what options are readily available, what financial resources are available and how precisely and aesthetically the photographer or potential buyer wishes to see the image projected on the film.

A curriculum theorist chooses his or her curriculum lens based upon the subject to be illuminated, photographed and preserved. A different lens will be required based upon whether the observer or theorist wishes to view an efficient and effective written document, a fluid learner centered process, or an emancipatory process for societal change. Having made the appropriate choice, curriculum theorists are able to provide clear pictures for both the general process of education and the specifics of health education. The curriculum theorist has a choice. He or she may choose his or her own lens of curriculum, or passively accept the standard version which comes with the camera. Either option will effect what is made visible and that which remains invisible.

If we assume the inherent value of the camera and lens are their combined ability to take photographs, then the value of the lens can best be appreciated though its work with the rest of the camera and photographer. In order to judge the worth of the camera and lens the following type of questions may be considered. Do the camera and lens visualize and record what the photographer wishes to see? Does the photographer know

how to operate the camera and lens? Or, is the photographer willing to risk learning to use new equipment? Does anyone in the photographer's society wish to see the pictures which would be recorded by this system?

Curriculum theorists have constraints similar to those of the photographer. The choices of both are influenced by the marketability and mores of the society in which he or she works. Parallel curriculum as lens questions should also be asked. Does the curriculum visualize and record what its authors wish to see? Does the curriculum worker wish to consider and learn non-standard methods and processes? Do people in the curriculum worker's world wish to see the standard, (Three by Five's from Walmart) curriculum or invest in an alternative process developed by another system? When curriculum is seen as a lens in the camera of the greater society and the value system which holds what its institutions represent, it can be better understood and be focused on the issues it claims to address.

CHAPTER II

CHOOSING A LENS: SORTING THE CURRICULUM CHOICES

Common sense suggests reviewing the alternatives before making a choice. As Gross and Gross point out, there are probably as, “many theories as there are teachers, learners, parents, taxpayers and politicians” (1985, p. 15). Gestalt learning theory suggests a method of understanding. Its theorists (Bigge, 1982) believe human beings seek out patterns to make sense of what they perceive. Sorting out patterns of curriculum theorists should aid in choosing the appropriate curriculum lens. Although the sorting process remains a useful tool, knowledgeable use also requires an awareness that among the major theorist's classification systems there are both commonalities and areas of contention.

Variety of Groupings of Curriculum Theory

In developing a system for comparison, many theoreticians have divided individual theories into three or more groups, paradigms, frame of references, orientations or camps. One of these terms is Kuhn's paradigm (1962) and although over-used, it remains one of the more interesting. Kuhn looked at the general field of science and observed that progress was built on conflicting theories. Conflicts arose from the

proponents of each theory's attempts to account for all the data available and prescribe both the parameters and acceptable methods of inquiry for the fields (Suppe, 1977).

Eisner follows Kuhn when he examines education. Eisner observed that different groups, paradigms or camps within education are divisible by the parameters on content, process and methods of inquiry. Eisner (1985) suggested five paradigms or groups: Cognitive Process (p. 62), Academic Rationalism (p. 66), Personal Relevance (p.69), Social Adaptation and Social Reconstruction (p.74), and Curriculum as Technology (p. 79).

Other theorist suggested other groupings. McNeil (1990), identified four types of curricula: Humanistic, Social Reconstructionist, Technology and Academic Subject (p. 1). Schubert (1986, p. 13) suggests three orientations which he terms "intellectual traditionalist, behaviorist and experientialist." Joyce and Weil (1980) discuss families of models of teaching which correspond to these concepts, specifically the Information Processing Family, The Social Family and Behavioral Models of Teaching. Giroux, Penna and Pinar (1981) identify the three major schools of thought as Traditionalists, Conceptual-Empiricists and Reconceptualists. Apple (1981) groups curriculum theorists into: the behavioral-objective movement (p. 127), the Marxist tradition (p. 131), and the phenomenological tradition (p. 139). Zais (1976) in his section on curriculum design points out three prototypical types: Subject Centered Designs, Learner Centered Designs and Problem Centered Designs. Freire (1970) compares his praxis to both the humanists (p. 65) and traditional or Banking Methodology (p. 57-74). Garcia (1982) and Banks (1981) call for alternatives to the predominant methodology with an emphasis on multiculturalism. Dobson and Dobson (1981) suggest three designs or camps, identified

by the letters "A", "B", and "C." Each is respectively described as Essentialism-Behaviorism, Experimentalism-Cognitivism, and Existentialism-Humanism.

Eisner's five orientations described most of the content and criteria used by the curriculum theorists noted in the previous two paragraphs. His classifications provided a wide frame of reference from which to compare the other cited theorists.

Eisner's Cognitive Processes

Eisner's first camp, the Cognitive Processes Orientation was described primarily with teaching children how to learn. Eisner notes its early basis was the now “debunked phrenology movement” (p. 63). He felt its current proponent's viewed their major function as helping children learn how to learn by providing them with opportunities to strengthen the variety of intellectual faculties and to reason. It based its practices on the acceptance of such concepts as mental discipline which is supposed to strengthen students ability to reason. This system valued the development of intelligence over the acquisition of information or ideas. Eisner suggested Guilford, Bloom, and Brunner as proponents. He found Guilford's psychology of empirical articulation, which proposed over a hundred types of abilities, led to a process oriented curriculum. He included Benjamin Bloom's “Taxonomy of Educational Objectives: Cognitive Domain” and also a third proponent, Brunner. Eisner felt all had interest in improved cognition.

Alternatives Similar to Eisner's Cognitive Processes

There are additional curriculum authors who propose categories, groups or camps similar to some of Eisner's. McNeil (1990) used four categories: Humanistic, Social

Reconstructionist, Technology and the Curriculum, and the Academic Subject Curriculum, thereby avoiding having to differentiate between the Academic's emphasis on content and process from the knowledge of development of higher processes for their intrinsic value. The hallmarks of McNeil's Academic Subject Curriculum included viewing knowledge as "justified belief" (p. 70), thus rejecting a "fixed view" of knowledge (p. 78). Some of its members valued the structure of the discipline as a basis for curriculum (p. 73); others emphasized the value of modes and skills of inquiry. He noted that this humanists group is in "disarray" (p. 70) and "under criticism" (p. 69) both internally and externally.

Schubert used three categories, the Dominant Paradigm, a second, the Practical Curriculum Inquiry and the third, or Paradigm of Critical Praxis (1986 p. 10). Under the Dominant Paradigm, for which he cites Tyler as the premier theorist, he found that the group focuses upon analysis of purpose, content or learning experiences, organization and evaluation (p. 10). Joyce and Weil (1980) used the concept of cognition as an essential element of one of their major families, camps or paradigms. Their list of proponents included Brunner, Taba, Suchman, Ausubel, Jerry Lucas to Piaget and Kohlberg and Schaub. Joyce and Weil (1980) noted that this "family," their term for orientation or camp, is primarily concerned with the ways people handle stimuli. They also note some models within this family are concerned with the ability of the learner to solve problems while others with general intellectual ability. Their common criteria are that nearly all are concerned with social relationships and an "integrated self" (p. 9).

Giroux, Penna and Pinar divided their camps or groups into Traditionalists, Conceptual-Empiricists and Reconceptualists. They saw the beginning of this second

group at Woods Hole in 1969, its chief architect as cognitive psychologist, Jerome Bruner and its foundation in many academic disciplines. They also noted “little consistency” among its proponents (p. 5). Dobson and Dobson (1981) labeled their similar camp as Essential Behaviorism. They felt proponents believed that humans were evil, truth was absolute and existed outside of individual, there were necessary basic facts to be learned, and learning occurred by reaction. Based upon these assumptions, curriculum should be predetermined by structured logical with content centered outcomes.

Academic Rationalism

Eisner described this as one of the oldest and most basic orientations to curriculum goals and content. Its major task was to foster intellectual growth in subjects worthy of study, typically those of the classical liberal education. Its mainstream proponents generally valued neither changes nor additions to these studies. Science was allowed an exception as seen as relevant and represented a special mode of thought useful to human understanding. Eisner further described one of this groups proponents, Hutchins, as “optimizing the dialectic discussion as the most appropriate pedagogical mode” (p. 66-68).

Categories Similar to Eisner's Academic Rationalism

McNeil's (1990, p. 1) view of the Academic Orientation found that curriculum introduces learners to subject matter disciplines to assist with personal and local problems as well as enhance the learners' mind. He noted some proponents sought to develop a

“cadre of elite” (p. 84) while others required the same curriculum for all, for example, the Paideia Proposal (p. 90). Neither mainstream Joyce and Weil (1980), nor reconceptualists Giroux, Penna and Pinar (1981), Apple (1981), Freire (1970) differentiated these theorists from the information processing family and dominant paradigm respectively. Zais (1976) on the other hand devoted a good deal of attention to what he termed the subject centered designs. He noted that these "proponents find society as (properly) hierarchical... individuals naturally evil...learning a mechanistic process which conforms to these laws" (p. 397).

Personal Relevance

Eisner noted this orientation emphasizes personal meaning. Its primacy required students must invest, develop and participate in their education. He suggested:

In operational terms, this requires that teachers develop educational programs in concert with the students rather than from a mandate handed down from the central office (p. 69).

He regarded the following assumptions as necessary: teachers must regard children as individuals, rapport is necessary, children as stimulus seeking organisms will seek out that which they need. As proponents of the values of this system, he cited A.S. Neil, and John Holt. He also included some of the persons he also classifies as primarily reconceptualists, such as Van Mannen, Grumet and Pinar. This duality was necessary because they have also emphasized authentic personal experience. Eisner stated that some of the proponents have found the earlier assumption that each child has enough experience to determine his needs, has become limiting. To resolve this possible lack of ability of the child and still continue with the required needs assessment, the process may

be sought in the community as well as with the child. Evaluation should depend on the child. It should include the meaningfulness to the child and what he or she learned from his or her experience.

Categories Similar to Eisner's Personal Relevance

Comparisons between Eisner's and other classification systems to this group were easier because of the consistent preeminent constellation of goals and values. McNeil's (1990) humanist orientation held that the curriculum should provide personally satisfying experiences for each person (p. 1) which contributes to personal liberation and development. The new humanists were self-actualizers, a term used by A. Maslow. McNeil described Maslow as a "third force," which is to say non-Freudian and non-behaviorist in his approach (p. 6 7). This group requires that the teacher: listen, respect the student and be authentic. It stresses integration and may appear to lack sequence. The humanist concerns for wholeness and Gestalt lead to a curriculum that encourages comprehensiveness in experience... (p. 10).

Schubert (1986) gave only passing note to the term humanist. In his discussion of reconceptualist he noted Paulo Freire and his desire to identify the needs and interests of the students. His second classification of Practical Inquiry which he felt was brought into focus by J. Schwab (p. 10), sought "situational knowledge" for understanding, decision and action (p. 10). Schubert noted many of the humanists use of Habermas' work and emphasis on Hermeneutic Inquiry as these concepts closely following the values, parameters and conclusions of the group. Finally, where many of the other theorists took a highly descriptive approach somewhat akin to a good anatomical text, Dobson and

Dobson (1981) and Dobson, Dobson and Koetting (1985) took the physiological approach, that is to say they looked at how education functions. Both texts included the examination of the use of language. Language controls the ability to perceive and therefore a "root of the reality," on which education is based (p. ix). They name the third of their three camps as "Existentialism-Humanism." In the Language of Schooling, the following interactive facets in this frame of reference are illuminated: "Humans are basically good, truth is an individual matter, learning occurs with personal meaning, knowledge is personal and based on the Gestalt, the purpose of education is to live a full life, learning is learner directed, the curriculum unfolds and is process centered" (p. 37-8). They cited Maslow, May, Perls and Carl Rogers, Combs and Snygg as proponents of this view.

This group is essentially different from the Pragmatism-Experimentalism, their second group, which included Lewin, Brunner, Piaget, Dewey, and James. Learning Theorist Morris Bigge (1982) also notes a differentiation between the "psychedelic-humanistic self-actualization" and the current positive-relativistic cognitive-field psychologists (p. 66). In short because two of the three world views are devoted to examining education to theorists having at least some basis to non-reductionist theory, they are able to illuminate the difference among theorists which others would lump together. The curriculum-lens sees clearly where it is focused.

Social Adaptation and Social Reconstruction

This was Eisner's fourth orientation. He grouped two major and opposing philosophical opposites for their commonality of analysis of the community and the

school in terms of its service to that community (p. 74). Both "look to society to determine what the aims of the school should be" (p. 78). The social adaptation proponents, also identified as the social relevance, argues that "schools are essentially institutions created to serve the needs of the society" (p. 78). He went further to argue that the school was to take into account those needs and to provide relevant programs as the needs, "often emanate from what is regarded as pressing social ills" (p.78). The curriculum becomes the vehicle for remedying such situations. The needs that are perceived are not radical in nature: that is they seek no fundamental change in the basic structure of society" (p. 75). He cited Cubberly, Sears and of course F. Bobbitt as early proponents of this group (p. 78-79).

If one were a proponent of the Social Adaptation Orientation, then the negative, which is to say the mirror image with opposite color and light values of this picture was the Social Reconstruction movement. Agger identified the Social Reconstruction's foundation as the Frankfurt School. (1991). Eisner found the radical social perspective and the social reconstruction movement sought to become "aware of the society's ills to become motivated to alleviate them" (p. 76). "One uses knowledge provided by the academic disciplines as a tool for dealing with what is socially significant" (p. 78).

Eisner suggested Steven Mann (p. 76), John Galtung and Michael Apple (p. 78) as members of this group. Apple (Apple & Christian-Smith, 1991) would certainly be pleased with this inclusion as his own divisions of reaction to text books are: "dominated, negotiated and oppositional" (p. 15). Eisner suggests the major goal of this group is to recognize the real problems and do something about them. Having a focus other than curriculum categorization, Goodlad (1984) also notes the historical role of

“education, institutionally carried out by the powerful triumvirate of family, home and school” (p. 40). “Schools were to transmit much of the dominant culture and imbue commitment to that culture” (p. 11). Certainly he sees the historic role of schools as consistent with adaptation to the social milieu.

McNeil took the social reconstruction half of Eisner's fourth group and divided it into revolution, critical inquiry, and futurism (p. 30). He felt the primary purpose of social reconstruction was, “to confront the learner with the many social problems that humankind faces” (p. 45).. He grouped and compared this group to social adaptation, which was its opposite. Social adaptation sought to provide a “mechanism for adjusting students...no attempt is made to develop a critical consciousness” (p. 45) Compared to the traditionalist's concern with scope sequence and integration, McNeil felt this group had no universal objectives or content. He did note that learning must be “real, require action and teach values” (p. 31-32). He cited Giroux, Bramwell, Counts and Freire as members of this orientation. Giroux (1981) himself related that members of this group have “drawn selectively on existentialism, phenomenology, psychoanalysis, Neo-Marxism, the Frankfurt School of critical theory and ethnographic school studies” (p. 7). He felt the reconceptualism ought to be thought of as a mode of theorizing rather than a distinct and integrated mode of thought. Reconceptualism’s primary concern is to combine theory and practice which promotes “self reflection, dismantles form of false consciousness” (p. 7). Joyce and Weil (1980) do not address the issue of the society as frame work, and so have neither considered the social reconstructionists nor made visible that education may promote social adaptation.

It should also be noted that among some of the proponents of this group are those who are self described as post-modern (Aronowitz and Giroux, 1991). Dickens and Fontana (1994) cited the probable first use of the term in 1870 when it was used to describe a British painting "supposedly more modern than the French impressionist" (1994, p. 1). They found "American discussions of postmodernism in the social sciences reappear only later in the 1980's...under the influence of French post structural theory" (p. 2). The reoccurring theme in much of post-modernism was that traditional standards no longer apply and that issues such as the "present condition of... knowledge and experience are defined not so much in themselves but by what they come after" (p. 2). This implied a "radical break" with the past including the old belief progress will naturally bring the "liberation of human beings.." (p. 3). They looked at Lyotard's contribution as did Aronowitz and Giroux who also examined this multi-factored movement. Aronowitz and Giroux (1991) and noted Lyotard's rejected grand narratives and look for meaning where it is connected to the changing conditions of knowledge and technology (p. 60). McLaren and Leonard (1993) noted that Freire's work does not completely fit into the this sub-camp. They noted while "poststructuralists reading both complement and extend Freire's position on language" (p. 57), Freire's work "speaks to the limitations within poststructuralism when he recognizes that the oppressed are more than the subject positions constituted discursively, but rather are subjectively produced by the material effects of economic, social and psychological conditions" (p. 60).

Curriculum as Technology

Eisner's fifth and last curriculum orientation was curriculum as technology. He found its proponents claimed that it was purely normative, an ends-means model and a technical undertaking (p. 79). He groups B. Bloom, F. Bobbitt, John Dewey, Vergil Herrick, Hilda Taba and Ralph Tyler in this group (p. 80). Curriculum was viewed as applied science. Eisner felt that these values were reflected in , "the accountability movement, contract teaching, precision teaching and programmed instruction" (p. 80). It sanctioned specification of sequential objectives uses evaluation after a relatively short time (p. 81). Goal ambiguity was to be eliminated. The content of objectives was less important than how well they had been stated, and technique was seen as "value neutral" (p. 81).

One of McNeil's four camps, Technology and the Curriculum, was very similar to Eisner's Curriculum and Technology. McNeil noted this group focuses on "effectiveness of programs, methods and materials in the achievement of specified ends or purpose...it is used in industrial and military training programs, is a major factor in the competency testing movement, is based on behavioral science's emphasis the specification of instructional objectives" (p. 51-52). He felt that systems technology (p. 53), instructional alignment (p. 54), and Mastery Learning fit within the group. He cited as proponents: Bobbit (p. 50), Skinner (p. 53) and Gagne' (p. 68). McNeil observed an unexpected and unique characteristic of this subset. He identified proponents' assertions that if the intended learner did not attain the objectives of the program, the program rather than the learner, was inadequate because the curriculum was based on the belief that:

the curriculum materials themselves, when used by those learners for whom the materials are developed, should produce specified learner competencies (p. 59).

Zais addressed this issue briefly when he compares and contrasts what he terms "Training: The Technical Model and Education: The Humanist Model." He notes training as a process where "teachers behaviorally manipulate their learners to effectively acquire prescribed behaviors" (p. 317). Apple and Giroux do not differentiate the training or technical paradigms from the traditional or dominant camp; the lens does not see clearly beyond its focal point.

What Does This Mean ?

There are many versions of curriculum. As Joyce and Weil (1980) observed their camps or the families, they noted they "generally achieve the purposes for which they were designed" (p. 476). One of the initial tasks for this project was choosing a curriculum lens consistent with the development of a curriculum useful first to the health care clients and their significant others, followed by health care professionals in the management of diabetes mellitus. Reviewing the curricula options, dividing them into groups, placing those groups on lines of continua, allowed the writer to critically identify a group or paradigm consistent with that goal

This writer began by joining with most of the other curriculum theorists by dividing the major theorists into several groups. Choosing those divisions acknowledges the author's thoughts on curriculum. From that personalized frame of reference there was a dominant paradigm which values efficient compliant learning. This learning was concerned with affective, cognitive and motor skills for the unspoken purpose of the

continuation of that system, usually a given societal unit. There was a second group primarily interested in the humanness of each individual and in a curriculum which supported the individual's quest toward what Maslow (1970) termed self-actualization. Finally there was a third group which viewed curriculum from a politically left of center position, sought to heighten the awareness of all the participants in order to rethink or reconstruct that society. This writer used a frame of reference in both education and health care, and chose a progressive position between the second and third groups. This position has a precedent in health care as it follows Redman (1988, p. 9), who defines the teaching process as activities by which the teacher and student both learn about the subject matter, its relationship to themselves and the greater society.

Using an expansion of this summation, a search can begin for an approach to identify a currere, a term Schubert notes Pinar developed (1986, p. 134). For this writer, currere has come to describe an active, critical searching curriculum process, which uses the participant's understanding of their life experiences. This concept is consistent with the writer's hope for what diabetes education could become. Ellsworth's in Stone (1994) has suggested a pattern of development for a program differing in content but similar in goals. In Stone (1994) she set out an a clear agenda for a curriculum to increase the visibility of racist acts and structures on a university campus. Her agenda can be adapted to the work of this project. This writer suggests that this curriculum process will best fit those persons who want to acquire knowledge of the present, standard system of diabetes, for the purpose of guiding their own education, using praxis, critical theory and practice linked together. This praxis incorporates current and historical general and critical education, sociology (grounded theory), nursing and medical management of diabetes

theory. It identifies some of the typically invisible and powerful beliefs, predominantly variations on elitism as it exists between health care providers and patients, which prevent all of the participants from being able to see that an active role for all is both necessary and appropriate. The context under study is the lived experience of the participants and that, by definition, must include the effects of racism, sexism, classism in this specific context, as expressed in the relationship between health care provider and patient. This description, like Ellsworth's, also assumes that the old stereotypes will have to be unlearned. This project is process rather than product oriented and, as such, the work will never be absolutely perfect and complete. It must be ongoing and self critical in order to be useful to those persons it seeks to serve.

The writer believes there are many persons who may use such an approach. Among those persons, presently identified as health care educators and patients with learning needs, are those who already believe in conscious and active self-management of diabetes. A second group consists of those persons now labeled noncompliant, who have a general dissatisfaction with the present system and outcomes but are unaware of the widespread nature and general societal and interpersonal influences on their discontent. Finally there are others who may not immediately see the connection to this approach or are very new to the personal experience of diabetes. Those who feel they do not know enough to begin to author their own curriculum because they know less than the experts will have to begin at Ellsworth's last point. They must unlearn that they do not know enough and relearn that they are rich resources of information. They are the only individuals who know directly of their own lives. Without beginning with that personal knowledge, none of the technical knowledge will be of much use to them. In order to

support this last group's efforts, fellow participants will have to be generous with both their own personal knowledge and technical knowledge.

Curriculum creation is not an easy task. Client authored curriculum should be more difficult to create if it is to account for the input and authorship of many people. Using both education and health care as a theoretical base for this process also tends to further complicate reaching the goal. In order to account for these seemingly dichotomous positions, an examination of these theoretical platforms is an appropriate place to begin to identify aspects of the disciplines which will assist in reaching the goal. This affirmation of a seemingly dichotomous position can be best understood by examining its position from the view of health care and education as well as curriculum and instruction.

CHAPTER III

THE U.S. HEALTH CARE SYSTEM AND ITS
DOMINANT TEACHING PARADIGM

Health care sociologists have reviewed health care in a similar manner to the curriculum theorists' review of curriculum. Light (1990) observed that the United States has a unique system, which is inconsistent with other industrialized countries. It provides neither general medical care nor reimbursement for care for its citizens. The health care that is available, can be categorized into models similar to those found in the field of curriculum. Light categorized U. S. health care and its provision systems into camps or models in order to emphasize their commonalties and differences. He suggested four models: the Mutual Aid, the State Model, the Coporist Model and the Professional Model. Of these four, he found only two exist in the United States. They were the Mutual Aid Model as is seen in the woman's health movement. This model tends to lead to epidemiological rather than clinical interventions. Light also noted the dominant Professional Model. This model serves the power and effectiveness of the medical profession. The Professional Model has a "political value on dependency, on technical and cultural power over the patient." He further noted the "cost is a lower rate of compliance...and has blinded the profession from adjusting to the need for active knowledgeable patients in managing chronic disorders" (p. 455).

Conrad and Kern (1990) noted,

That we have a medical care system (as distinguished from a health care system) organized around the cure and/or control over serious diseases and the repairing of physical injuries rather than the "caring" for the prevention of disease (p. 173).

Other researchers found similar or related problems. Rankin and Duffy (1983) observed,

The traditional health-care system in the United States, with its emphasis on acute management, leaves the physician very little opportunity to assist the client in accomplishing self-care activities (p. 23).

Several authors, Redman (1983), Rankin and Duffy (1983), Bates and Winder (1984), and Leininger (1985), reviewed intervening work and the original Rosenstock's 1950s Health Belief Model. These studies acknowledge the availability or lack of medical service and perceived benefits as variables in determining patient's use of medical care.

Ivan Illich's *Medical Nemesis* (1976) classic critical analysis is consistent in being able to perceive the limits of the dominant United States' type of health care. He was able to accurately chronicle the limits of medical care in 1976, limits which the medical community cannot acknowledge. He also accurately noted iatrogenesis (physician caused) illness and a historical lack of identification of social and cultural iatrogenesis. Other authors, Oakley (1989), Simon (1980) and Drummond (1975) find similar results varying from negligible to fatal when western (as it is practiced in the United States) health care is imposed upon other cultures. Illich's (1976) general argument of the U.S. orientation toward high tech and clinical prevents most of its practitioners from perceiving how money spent on preventative maternal-child health programs can preclude the need for another Pediatric Intensive Care Unit.

This is not to say all of Illich's arguments remain valid. This writer has the advantage of twenty years of additional data and the a somewhat positive view of a participant-provider of U.S. health care. This writer views Illich's statements concerning the lack of usefulness of chemical interventions for changing the outcomes of mental health and neoplastic diseases as no longer accurate for those as Rooks (1900) noted can afford the care.

Nursing, As It Fits Into Health Care

Nursing is one of the major disciplines in health care. It is influenced by forces from within and without the discipline. Nursing practice is influenced by the American Nursing Association (A.N.A.) and its state organizations. It is defined by state law (in New Jersey P.L. 1947, c 262, as amended). As a professional practice it is a regulated entity and is subject to the effects of any other lobbying force, most specifically the American Medical Association (A.M.A.), and the American Hospital Association (A.H.A.) (Law, 1990; Meyer, 1992; Reverby, 1990).

Nursing practice is also regulated through accreditation bodies such as individual state or county or municipal boards of health, via institution licensure, and groups such as the Joint Commission on Health Care Accreditation Organization (J.C.A.H.O.) and Commission on Accreditation of Rehabilitation Facilities (C.A.R.F). The status and power of these and other similar bodies come from their unique relationship with groups called third party payers. Third party payers are the health [sic] insurance companies. Two of the largest of these are groups are "Blue Cross" and "Blue Shield."

Among the "Blues," as they are called within health care, formal responsibilities are: to offer insurance benefits which are to provide American hospitals with a stable source of income; to obtain quality health care services economically; and to monitor the quality of care (Law, 1990). This gives the Blues great financial power. Based in part upon the evaluation of the accrediting bodies, the third party payer determines whether a health care provider is worthy to receive payments. A health care organization that does not provide care in the standard manner, cannot bill to a third party payer. Since few persons could or would be willing to privately pay their health care costs, the standards that are set by the accreditors and the relationship between the accreditors and the Blues are what determines reimbursable care.

Added to the above is the rise of Health Maintenance Organizations (H.M.O.s). These are separate organizations or divisions of insurance companies which manage care by approving only the care which they (as opposed to the health care provider and patient) feel is necessary (Cerne 1995). They also may choose the providers from whom they will accept billing. This choice is likely to be based in part based on the lowest bidder they deem qualified. This can go as far as capitation, replacing both fee for service and pre-set fee for service methods of payment (Lumsdon 1995).

The economics of health care directly effect nursing. As employees of health care agencies, nursing has been greatly affected by Diagnostically Related Groups (D.R.G.s). This is a system developed in 1983-4 by Medicare, a federal Health Insurance program and administered by the Blues. This program pays a preset price for each of the specific DRGs. If the hospital can provide services for less, they may keep the remaining funds. If they keep the patient longer or spend money on services disallowed, they are

financially responsible for the costs (Aries & Kennedy, 1990; Conrad & Kern 1990). Reverby (1990), also noted that the nursing field professional and technical levels are predominated by women and minorities and are not surprisingly financially and socially less powerful than medical or hospital associations. Haire-Joshu (1992, p. 17) noted an additional force for compliance, the “threat of a legal suit” when national standards are not met.

Assuming that the U.S. health care industry as represented by the A.M.A., A.H.A., Medicare and Blue Cross and Blue Shield, the legal system as represented by each state's Nurse Practice Act, and in general by the socioeconomic milieu, all effect how nursing has come to define itself and be defined.

Nursing's Historical Background

Marriner-Tomey (1989) suggested nursing has four non-mutually exclusive major philosophical categories of theory. These philosophical categories are in some ways also similar to those developed by curriculum theorists. The beginning of each one of the major nursing groups roughly corresponded to the historical development of Nursing in the United States. The first group the "Art and Science of Humanistic Nursing" began with Nightingale and included Orem, Henderson and Leininger. This group includes such diversity as Nightingale who did not accept the "germ theory" to Henderson who based some her work on Thorndike's and later Maslow. Their common theme is that nursing is “both an art and a science”(p. 7). Within this group, teaching is viewed as a method of assistance or care as is determined by the nurse assessment of the patient's needs. Leininger's work (1985), was particularly concerned with health care issues as they are

experienced by the individual and as individual as a member of a particular ethnic group and emphasizes the qualitative approach to research.

Marriner-Tomey (1989) cited the following as groups evolving after the first group. The second or Interpersonal Group came into use in the 1950s and was a part of the curriculum for the author's undergraduate work (1966-70). It stressed the nurse-patient over the more technique oriented emphasis of the immediately preceding theorists. The third group was the systems group. Its proponents viewed persons through a systems approach. This includes the organizations in which the person functions. It addressed the needs of the patient's in terms of separate systems, i.e., psychological versus self-concept. Neuman is a more wholistic (her choice of term spelling) member of this group. Also in it are Dorothy Johnson and Sister Callista Roy. Marriner-Tomey (1989) noted Johnson began in the 1940's however Roy began her work in the 1960's (p. 11). Other theorists, Matheny, Nolan Ehrhart and Griffen (1968) while calling for an active learner, suggested the nurse as teacher should, "select, plan, organize and evaluate the learning experience" (p. 146). Roy's theory is holistic (her choice of spelling) and humanistic valuing the person's opinions and viewpoints (p. 328).

The last group which Marriner-Tomey calls Energy Fields includes: Levine, Neuman and Martha Rodgers. They were concerned with wholeness and creativity. Rodger's theory is concerned with patterns, sentience, open systems and four way dimensionality. Some of the members of this group have argued against the nursing diagnosis. This argument noted this technique fitted more closely to the medical model after which it was patterned than to nursing which they see as more holistic. Persons are viewed as active participants. While some theorists, such as Rodger's are concerned

with prediction, others such as Neuman are concerned with description (Marriner-Tomey, 1989).

The Dominant Paradigm

Although Nursing is an independent discipline, it is certainly effected by forces apart from itself. Understanding this, nursing theory can be reviewed to demonstrate the historical progression to the dominant nursing paradigm and its alternatives. The A.N.A., (1981) suggests the following as a standard for the practice of nursing:

The practice of nursing means the performance for compensation of professional services requiring substantial specialized knowledge of the biological, physical, behavioral, psychological, and sociological sciences and of nursing theory as the basis for assessment, diagnosis, planning, intervention, and evaluation in the promotion and maintenance of health; the case finding and management of illness, injury, or infirmity; the restoration of optimum function; or the achievement of a dignified death. Nursing practice includes but is not limited to administration, teaching, counseling, supervision, delegation, and evaluation of practice and execution of the medical regimen, including the administration of medications and treatments prescribed by any person authorized by state law to prescribe. Each registered nurse is directly accountable and responsible to the consumer for the quality of nursing care rendered (p. 6).

Alternative Traditions in Nursing and Health Care

While always not written by a U.S. Nurse-Educator (the term usually applied to U.S. nurses who primarily teach), health care curricula, which can be easily grouped with the reconstructionists and reconceptualists of the curriculum field, do exist. Theresa Drummond's, monograph on nutritional education with Brazilian peasants (1975) incorporated Paulo Freire's praxis into her group's work. Peter Oakley's program for W.H.O. (1989) developed a process model for "Community Involvement in Health

Development." Similarly in the United States, Doress and Siegal's, "Ourselves, Growing Older" (1987), noted the critical effect on woman's health issues. Had Rankin and Duffy (1983) been curriculum practitioners rather than nurses, their chosen identification as progressives places them with both the humanists and the reconceptualists. Editor and author Madeline Leininger (1985) identified and spoke out against the reduction of "people and nursing to machine-like operations or sensual empirical data" (p. xi). She also developed the "Sunrise Conceptual Model For Culturologic Interviews, Assessments and Therapy Goals." Munhall and Oiler (1986) also stress a qualitative, personal approach. Some changes in health care that are labeled "Wellness" (Mullen 1986), "High Level Wellness" (Dunn, 1961), "Well-Being" (Ruffing-Rahal 1985), describe approaches similar with curriculum issues consistent with the personal or humanists' camp. Drummond (1975), Doress and Siegal (1987), Oakley (1989) and Hernandez (1995) among others also clearly fit the radical camp. This grouping would be consistent with their descriptions of the role of learners, teachers and use of critical theory..

Nursing: A Short Interpretation

The author's personal theory of nursing is a reflection of her own practice. Nursing is a profession, or specific area in health care, characterized by core skills, knowledge and the nursing process. These skills and knowledge are continuously being refined and expanded. Their use requires independent judgment on matters which include life threatening situations. The knowledge skills and judgment are concerned with providing health care to persons for the purposes of restoring or maintaining health or assisting that person to a peaceful and dignified death. It requires, as Magnan (1989,

p. 221) states, “authentic caring” and as Powell (1989) describes, nursing science in service to its art.

The author also generally supports the A.N.A.'s standard nurse practice act. As part of the nursing process, the author supports assessment of a client or patient's problems and assets. The writer has also found that use of such devices as the prefabricated North American Nursing Diagnosis Association's (N.A.N.D.A.) list of approved nursing diagnosis, is too restrictive for real world practice. The writer also differentiates between the somewhat overlapping health care disciplines of medicine and nursing by the respective emphasis of cure and care. Among the major nursing leaders who have influenced these thoughts are: Henderson (1967), Travelbee (1966), Orem (1985), Martha Rodgers (1970) and Leininger (1967, 1985). The issue becomes choosing the appropriate frame of reference to review the standard curriculum lens and determine the need for an alternative. How are these camps, traditions or paradigms represented in Diabetes Education Curricula?

The Dominant Paradigm for Diabetes Education

There is a standard curriculum for Diabetes Mellitus (DM) education. Among the chief proponents is the American Diabetes Association (A.D.A.), and the Juvenile Diabetes Foundation (J.D.F.). The A.D.A.'s curriculum is available in its Physician's Guides, (Sperling, 1988), (Lebovitz, 1988), Goals for Diabetes Education (Franz, Krosnick, Mashal-Carey, Parker and Wheeler, 1986), Diabetes Education Goals (Brink Siminerio, Hinnen-Hentzen, Deeb, Daly, Anderson and Agrin, 1995) and the A.D.A.'s journals: Diabetes, Diabetes Care, Diabetes Forecast, Diabetes, and the IDF Bulletin.

This diabetes curriculum gains prestige and influence as the product of a large not-for-profit institution. Both organizations derive further power and authority by providing funding for care and education. Waitzkin (1990) observes how powerful this type of a relationship can be when illuminated by the American Heart Association's role in the development of Cardiac (Intensive) Care Units. As Waitzkin notes "...Humanitarian goals were no doubt present but profit consideration were not lacking" (p. 230). This relationship is not difficult to understand when recalling that most U.S. health care is in fact medical care. The primary mode of medical care is to diagnose and cure the illness rather than promote health.

Acknowledging the primacy of the discipline of medicine in health and the power of its dominant paradigm, it is an appropriate beginning for wider understanding of Diabetes Mellitus. The material is part of the of the writer's frame of reference. It is also the dominant curriculum to which many individual persons, in their role as patient, have been exposed. Finally, it is also representative of the way U.S. society is supposed to see diabetes.

Diabetes Mellitus-The Pathophysiology

Diabetes mellitus (DM) is a group of disorders characterized by fasting (no caloric intake, usually for at least eight hours) hyperglycemia (higher than normal levels of blood sugar/glucose) and the classic symptoms of polydypsia (excessive thirst and drinking), polyuria (excessive urination), polyphagia (excessive eating in the presence of weight loss) and blurred vision; or plasma (the liquid part of lymph and blood) glucose (a simple sugar) levels above defined (by the National Institutes of Health National Data Group)

limits during oral glucose tolerance testing on two occasions (Christman and Bennet, 1987; Lebovitz, 1988, p. 1; Tomky, 1989). There is no present medical cure for D.M. There is only medical treatment, education and research.

DM chronic disorders are: (1) characterized by hyperglycemia; (2) associated with major abnormalities in carbohydrate, fat and protein metabolism; and (3) accompanied by a marked propensity to develop relatively specific forms of renal (kidney), (Bloomgarden, 1992), ocular (eye), (Wise, 1993), neurologic (nerve tissue) and premature cardiovascular (heart and blood vessel), disease (Lebovitz, 1988; Peterson and Drass, 1991).

Microvascular changes which appear to cause retinopathy (Lebovitz, 1988, p. 65; Lee, Lee, Lu & Russel, 1992) and nephropathy (Hoops, 1990), and macrovascular changes (cardiovascular disease) appear to be specifically related to hyperglycemic (too high levels of blood glucose) and hyperlipidemia (too high cholesterol and triglyceride levels) well as hypertension (high blood pressure), (Wosniak, 1988) smoking and lack of exercise (Lebovitz, 1988). Wise (1993) notes however the growing evidence for genetic factors for protecting or promoting these complications (p. 40).

DM is classified into three clinically (and possibly pathogenically) different types: insulin dependent diabetes (type I or I.D.D.M.), non-insulin dependent diabetes (type II or N.I.D.D.M.) (Christman and Bennet, 1987), and other types of diabetes associated with other specific conditions or syndromes (Nettles and Weinhandl, 1990; Sperling, 1988).

It should be noted that the term Non Insulin Dependent may appear to be an oxymoron as up to 50% of all N.I.D.D.M. persons require daily doses of insulin to maintain euglycemia (normal blood sugar) and therefore prevent short and long term

complications such as, pH or osmotic changes, micro and macro vascular changes and neuropathic changes (Haire-Joshu, 1991, p. 6). The true difference between insulin and non-insulin dependency is that the Non Insulin Dependent Diabetic person probably has some remaining ability to produce some insulin and is therefore clinically unlikely to develop diabetic ketoacidosis (DKA). DKA refers to an acidic shift of the body's metabolism caused by the excessive use of fats as fuel. Insulin Dependent Diabetic persons can develop DKA within a short period of time; this condition, left untreated, is not compatible with life. DKA is always a potential complication for the I.D.D.M. patient. (Lebovitz, 1988, p. 3). The term "insulin dependent" refers to the need or exogenous use of insulin to prevent immediate life threatening sequela. Persons who are not insulin dependent are not without short term life threatening problems. Those persons with uncontrolled N.I.D.D.M. are likely to develop Hyperglycemic Hyperosmolar Nonketotic Syndrome, (H.H.N.K.S.) or severe dehydration secondary to the body's attempts to compensate for the hyperglycemia (a hyperosmotic/too concentrated solution). Left untreated, this condition is also not compatible with life (Peterson and Drass, 1991).

There is clinical significance in the likelihood that DM may be several distinct entities. They suggest different medical management regimens, based upon the differing pathophysiological processes to optimize care and eventually to correct the underlying problems (Christman & Bennet, 1987; Palmer & McCulloch, 1991; von Boehmer & Kisielow, 1991). The classifications which we now view as I.D.D.M., N.I.D.D.M. as well as diabetes resulting from specific other syndromes i.e. Cushing's or Cystic Fibrosis, Huntington's, Acanthosis Nigricans, those secondary to medications such as

glucocorticoids, (Sperling, 1988, p. 6) as well as Gestational Diabetes Mellitus, (G.D.M.) and Impaired Glucose Tolerance (I.G.T.) (Lebovitz, 1988, p. 4), may be the only the visible parts of one, several or totally different problems.

Sperling (1988) and Haire-Joshu (1992), Rennie (1990), Atkinson and Maclaren (1990), note key research for at least some interrelatedness of I.D.D.M. to other autoimmune diseases by discussing research on the histocompatibility (HLA) complex located on chromosome number six. These complexes or clusters of genes are believed to code for transplantation antigens and regulate the immune response.

The physical juxtapositioning of these functions and problems occurring with I.D.D.M. give further evidence for D.M. as an autoimmune disease. Inheritance of the HLA types (patterns) labeled either DR3 and or DR4 increases the chances of I.D.D.M. twenty times over the general population (p. 10). While N.I.D.D.M. is not associated with an HLA type, "90 to 100% of identical twins show concordance" (Lebovitz, p.5) and recent research shows MODY (Maturity Onset Diabetes of Youth) may be associated with a glucokinase defect associated with a mutation of Chromosome Number 7 (McCarren, 1992).

Diabetes Mellitus-The Curriculum

There is no medical cure or safe and reliable prevention for DM. There is only medical treatment, education and research. At present the American Diabetes Association (A.D.A.), a voluntary, not-for-profit agency, whose mission "is to prevent and cure diabetes and to improve the lives of all people affected by diabetes," professional education, recommends a separate system of management (medical

treatment) and education for both I.D.D.M. (Sperling, 1988) and a second for N.I.D.D.M. (Lebovitz, 1988). The 1986 A.D.A.'s "Goals for Diabetic Education" (Franz et al, 1986) lists goals and behavioral objectives separately for initial and in depth curriculums for I.D.D.M., N.I.D.D.M. with a third also available for pregnancy with overt diabetes and Gestational Diabetes.

The preface of "Goals for Diabetes Education" (Franz et al., 1986) contains the following sentence:

The educator who succeeds in instilling all of the behavioral objectives described will provide the diabetic patient with a sense of independence and control that hopefully will make life for the diabetic much easier (preface).

The authors continue with the body of the work with the prescription of objectives for: definitions, nutrition, exercise, medication, monitoring acute complications, psychological adjustment, health habits, long term complications, community resources and benefits and use of the health care system. Nowhere in the booklet is there demonstrated an awareness of the dichotomy between a prefabricated curriculum and the goal of an independent self-managing person. The 1995 version of this document (Brink, et al.) retains the same type of predetermined behavioral objective format with the addition of some negotiated type changes. This version of the curriculum allows for a three paged discussion of: learning style, Health Belief Model., Locus of Control and Self- Efficacy model. In it there is an acknowledgment that learning should be a "voluntary adaptation" (p.6) but it continues to leave the educator, "responsible for initiating teaching actions designed to bring about learning.(p. 6). With this dichotomy of predetermined behavioral objectives and acknowledgment of learning style, its classification falls between the negotiated and the dominant paradigms.

There is second standard curriculum developed for Certified Diabetes Educators.

These persons are a subset of health care providers. In addition to their license or registration to practice within their state as an R.N., R.D., social worker, exercise physiologist, pharmacist or physician, these persons have joined this professional organization, passed a certification examination given by the American Association of Diabetes Educators (A.A.D.E.) and have the required extensive teaching experience. The A.A.D.E. has published "A Core Curriculum for Diabetes" which may be used as a "body of knowledge" for clinical practice and as a "preparation tool for the exam" (Peragallo-Dittko, 1993, p. iv). In the introduction this curriculum follows that of the A.D.A. in that it identifies the following as content of diabetes education:

should include but not be limited to the following topics: Pathophysiology of diabetes mellitus, nutrition management and diet, pharmacologic interventions, exercise and activity, self-monitoring for glycemic control, prevention and management of acute and chronic complications, psychosocial adjustment, use of the health care delivery system (p.ix).

This section of the curriculum is completed with the instructions that the diabetes educator is responsible for: assessment of educational need, planning of the teaching-learning process, implementation of the education plan, documenting the process and performing an evaluation based on outcome criteria. While this section is in concert with the dominant paradigm, the curriculum later hints at its limitation and expands its practice recommendations to what Apple would term a negotiated relationship. This curriculum bases its requirements for practice on Knowles' adult learning. Knowles work is used, "because the techniques listed below can enhance involvement and learning of most patients" (Peragallo-Dittko, 1993, p. 15). Peragallo-Dittko advises educators to incorporate seven of his concepts in their work. Educators should relate learning to what

the learner already knows and fitting it into the patient's frame of reference. They should also reinforce the idea that the patient can master self-care skills. This may be done by structuring a series of carefully planned success experiences. Educators should also provide practice for psychomotor and social skills and for feedback. Educators should shift through the possible topics for those which are needed for immediate or repeated use, e.g., do not teach insulin administration skills to those persons who do not have insulin requiring diabetes. Educators may occasionally "adjust the pace to accommodate variations in the patient's abilities." Educators are also responsible for review and updating patient's skills and knowledge on a regular basis (p.15-16).

The second standard curriculum has much to offer over that of the A.D.A. as it assigns a more active role to the patient as learner. It also has several major limitations. First it is marketed which is to say readily available only to members of the A.A.D.E. In practice, this option becomes limited to persons receiving diabetes education only from members of the A.A.D.E. The practice recommendations also have internal limitations. The predominance of planning is for, rather than with its learners, thus limiting the learner's role to that of patient rather than co-author. In doing so, the curriculum does not teach the participants to critically examine the care they are offered. It does not make visible that they are expected to learn independence through a series of negotiated educator determined compliance activities. The recommendations for the implementation of the curriculum are also expressed in the A.A.D.E.'s professional journal, "The Diabetes Educator." Many of the articles go further for individual empowerment and the need for assertiveness and encouraging patients to solve their own problems, (Arnold, Butler, Anderson, Funnel, & Feste, 1995) This application also may, by design, remove the goal

of helping others (Arnold et al., 1995, p.309). This alternative is a major shift in the favor of the person with DM but it does not go far enough for personal empowerment and does not address collective efforts or problems.

A.D.A.'s Education and Clinical Goals

I.D.D.M.

For I.D.D.M., the A.D.A. recommended educational (objectively testable knowledge and operationally defined skills and attitudes) goals are listed as: pathophysiology, skills related to insulin administration, monitoring, food and exercise; enlisting the help of others to deal with life threatening hypoglycemia (too low blood sugar) and diabetic ketoacidosis (DKA). Clinical goals are based on metabolic stabilization, restoration or maintenance of desirable body weight and elimination of hyperglycemic symptoms. The two ongoing goals are “maintenance of normal physical and psychological functioning and minimizing the adverse impact” of diabetes on the patient's life (Sperling 1988, p. 13). He notes various emotional reactions to diagnosis, motivation waning over time, anger and guilt over chronic complication. He then suggests that physicians take a consultive rather than directive manner but follows this with a discussion of adherence and its common causes (p. 89).

N.I.D.D.M.

For N.I.D.D.M., there are two major objectives of treatment. They are: achieving normal metabolic and biochemical control and prevention of vascular complications. The

three recommended treatment modalities are: diet, increased physical activity and pharmacological intervention. The listed curriculum then notes patient education is necessary for successful management and lists the major subject titles as: dietary modification, appropriate physical activity and pharmacological intervention. It further notes the special management problems associated with pregnancy and that assessment of treatment should include self monitoring of blood glucose (smbg) (Lebovitz, 1988, p. 21-25).

Lebovitz (1988) includes two additional chapters entitled "Helping the Patient Cope" and "Detection and Treatment of Compliance." In those chapters the patient is seen in terms of factors which are outlined as the basic personality, self image, the Health Care Belief Model, the social and economic environment and issues of patient compliance (determinants, common reasons for noncompliance and techniques for enhancing compliance). He notes that some patients will react with denial, anger hostility or depression. These reactions to the news of a chronic illness are then discussed as barriers to be overcome. The author suggests that these reactions be viewed through the Health Care Beliefs [Model]. It is used descriptively rather than in its full equation form as developed by Becker and Maiman (1975), that the physician can understand and control for the problem factors. Rankin and Duffy (1983, p.81) note this theory was originally developed to predict the consumption of health services. The Sperling description notes the factors of the patient's attitude towards susceptibility to the disease, consequences of the disease, value of treatment and risk versus benefits of treatment.

Rationales For and Against this Curriculum

The dominant paradigm's influences encourage the nursing profession to accept this standard type of curriculum. Using Zais (1976) frame of reference this type of curriculum is consistent with the Training Model. Its proponents assume that objectives are clearly understood, not open to question and is consistent with the "clearly defined terminal professional behaviors...of nurses...teachers"(p.316). The curriculum appears predefined, efficient and complete in terms of known mainstream medical knowledge.

Fortunately these assumptions do not go unquestioned. There is a growing group of diabetes educators who are dissatisfied with the status quo. Some authors such as Feste (1992), Funnel et al (1991) are concerned for what traditional medical care cannot accomplish. Lockwood, Frey, Gladish and Hiss (1986, p.32), report an "up to 87 percent lack of knowledge-type" problems. Anderson (1985) and Pinch (1986) argue against the success of medical care over the patient's wishes. Many such as Funnel, Arnold Donnelly, and Taylor-Moon (1991), Anderson and Nowecak (1989) are calling for empowerment, self care motivation (Horowitz, 1985) and Diabetes Education: A Consumer View (Sims, 1986) and Wellness: The Mode in the New Paradigm (McClary, Zahrt, Montgomery, Walker & Petry 1985).

The goal of this project remains the development of a client authored currere, useful to those clients for the management of D.M. The methodology chosen for the project should demonstrate that it is a part of what Drummond (1975) calls the "necessary humanizing or emancipatory process" and "in doing so will make the education more effective, bringing about deeper and more real changes" (p. 2) in the self care of the

participants. These goals differ from the diabetes education's dominant paradigm and its primary methodology.

Many researchers categorize methodology into two usually distinct categories, quantitative and qualitative, and then go on to defend a single choice. Most researchers choose the quantitative approach, others acknowledge both forms of data are necessary (Glaser and Strauss, 1967, Chapt. 1). Although this writer has used quantitative methods in the past, (Schoen, 1978) and will use them again should they be appropriate to the area of study, the primary lens with which this writer views reality is personal and political rather than stochastic modeling. Therefore the commonly accepted "Gold Standard"(Ahern, Bates and Tamborlane, 1988, p. 37) for evaluating clinical compliance the A1c also referred to as the glycosated hemoglobin (Ahern, Bates and Tamborlane, 1988) and glycated hemoglobin (Haire-Joshu, 1992) is not the closest match for the measurement of a curricular project. This is because this blood test is an accurate measure of only one aspect of such a person and political centered curriculum. The work of this project and its evaluation remains with its participants not in laboratory tests.

CHAPTER IV

METHODOLOGY

Quantitative Methodology Part of the Dominant Paradigm

Many proponents of the dominant paradigm support their chosen methodology to the exclusion of alternatives. In their classic booklet, "Experimental and Quasi-experimental Designs for Research," Campbell and Stanley (1963) defined the major problem for educational research as the difficulty in finding the correct "methods of securing adequate and proper data to which to apply statistical procedure" (p. 1). Later they direct that educators ought to choose this paradigm: "as the only means for settling disputes regarding educational practice" (p. 2). In another work Jaccard (1983) proposes statistical analysis as the methodology for teaching students basic skills for analyzing data (p. ix).

Bernard (1988) argued for a more physical science than purely mathematical approach. In "Research Methods in Cultural Anthropology," he suggested that the "norms of science are objective, logical and reliable analysis" (p. 11-12). He traced the development from proponents of the reformation and renaissance to Newton, Comte, de Saint-Simon, Quetelet, Mill, Hume and finally Mach and the Vienna Circle of logical positivists. Pereles (1987) described the aims of quantitative method as "hypthetico-deductive particularistic, inferential, vericatory, context-free and outcome

oriented” (p. 13). Bernard suggested using the concepts of “variables, measurement, validity, reliability, cause and effect and theory...one should be able to reduce any complex human phenomenon to a set of useful measurable traits” (p. 27).

Limitations

The dominant paradigm’s proponents assume that good quantitative research has good qualitative research as a precursor (Imle & Atwood, 1988; Pereles, 1987). In fact as Jean Watson pointed out in Leininger's compilation of qualitative nursing research (1985), and Hutchinson in Munhall's and Oiler's work (1986) that a qualitative study is an independent alternative to the dominant method of understanding, and should not be limited to the role of precursor. Bernard (1988) noted quantitative proponents claim that, "It is to be objective, the general method is the scientific method, the real world is external to persons perceiving it, and is reliable and observable." He also argued that it proponents valued prediction and control and that “a phenomenon can be understood by studying its parts” (p. 23).

From within the dominant paradigm there are two major criteria for judging the value of the work, reliability and validity. Campbell and Stanley subdivide validity into internal and external validity. They treat term of internal validity as truth within the design. while Gronlund (1981) refers to it “as the extent to which the results of an evaluation procedure serves the particular uses for which they were intended”(p. 65). Campbell and Stanley note that external validity always a matter of degree and is a measure of an ability for generalization to other similar subjects, factors, or variables. They use the term reliability to refer to the consistency of the results. Campbell and

Stanley further cite the following limitations to the suggested methods: content validity, criterion related construct validity history, maturation, testing, instrumentation, statistical regression, bias selection, experimental mortality, selection-maturation interaction, reactive or interaction effect sensitivity, interaction effects of selection biases and the experimental variable, reactive effects of experimental arrangements, multiple-treatment interference (p. 5-6). Considering the above criteria, the goal of this body of work appears to be the quantification, control and prediction of results.

Returning to the differing philosophical camps or groups in education, this type of methodology has internal consistency with practitioners who wish to find efficient training programs which appear to address such issues as compliance behaviors. A standard or dominant methodology should also fit with a dominant curriculum proving it has produced success. This is not the case for DM. The standard has failed in terms of DM mortality and morbidity rates and because it does not provide an alternative way to meet its own criteria. Both another approach and another way of knowing are required.

Qualitative Methodology From the Alternative Paradigms

Leininger (1985) states:

The qualitative type of research refers to the methods and techniques of observing, documentation,, analyzing and interpreting attributes, patterns, characteristics, and meanings of specific, contextual or gestaltic features of phenomena under study (p. 5).

Bogdan and Biklen (1982), Bernard, (1988), Leininger (1985), Hammersley and Atkinson (1990), Agger (1991) and Freire and Macedo (1987) all suggested qualitative or qualitative or qualitative-critical methods for praxis. Bogdan and Biklen (1982)

described the focus of qualitative studies as seeking to gain an understanding of the behavior from the subject's own frame of reference. They noted others referred to their data as "soft." They saw this as positive as they viewed useful data as, "rich in description of people places and conversations" (p. 2). They termed their particular methodology as "ethnographic" and applied it to similar qualitative research and not to a particular method (p. 3).

Hammersley and Atkinson (1990) and Schubert (1986) noted qualitative proponent's studies included detailed reviews of social patterns and holistic analysis. They further noted it was essentially descriptive and had as Glaser and Strauss required an emphasis on development and testing of theory (p. 1). For these theorists, research must be faithful to the phenomena under study not a prefabricated methodology. They also discussed "Naturalism." This was another general term for this type of an approach, Hammersley and Atkinson (1990) felt it evolved from the following traditions: symbolic interactionism, phenomenology (descriptive analysis of subjective thought processes and analysis of the historical and temporal character of the phenomena in human existence), hermeneutics (originally used to interpret religious texts and now used to understand communication as a form of dialectical logic contributing to the advancement of society), linguistic philosophy and ethnomethodology (p. 7).

Zais (1976) viewed the historic roots of phenomenology as based upon one of the "Man-Centered Philosophies rooted in pre-Christian Greece" (p. 145). He then traced the roots through Existential Philosophy thus requiring that the reality is, "self operating-in cosmos-of choice and that the validity of knowledge can only be the individual self" (p. 152-3). Bernard included F. Schiller in the 1800s. Schubert (1986) and Bogdan and

Biklen (1982) both cited the University of Chicago as a proponent of a qualitative approach to research in the 1940s. As for the radical education camp, Giroux traces its specific growth to the “heavy influence of the Frankfurt School/Institute for Social Research” and its Marxist's orientation (p. 11).

Schubert differentiated these methodologies as “descriptive” for the phenomenologists and prescriptive for the radical camp or group (p. 131-2). Agger (1991) argued that there are specific methodological implications required for any type of critical analysis. These included: “requiring that sociological empiricism must integrate its own exemption from perspective..and politics, contribute to the development of a post-positivist philosophy of science, show we can read non-discursive texts as rhetoric, reveal how language helps constitute reality, reject the view that science can be spoken in a singular, universal voice” (p. 35-6).

O'Hara (1989) compared the two groups for similar elements. She noted that unlike other post-positive groups it was essential to avoid domestication order use Freire's Marxist/Christian ideology. She also noted the radical approach had similar roots and methods to others of these groups. Both O'Hara (1989) and Bell and Schniedewind (1989) analyzed both the humanist and critical theorist for a joint ground. They noted educators can tie themes from personal experience to large social themes. In short the point of individual growth towards self-actualization for the radicals is to function for “self-determination for all” (p. 204)

Paulo Freire's Methodology

Dr. Paulo Freire was born in Recife, Brazil in 1921. He studied to become an attorney but as Drummond noted, found he did not wish to practice law and returned to education. As an educator, he was jailed for his radical pedagogical work in Cultural Extension Service at the University of Recife. He then worked for agrarian reforms in Chile as a special consultant to the Office of Education of the World Council of Churches (Drummond, 1975, p. 4-5). He has also developed literacy programs in Latin America, Africa, Europe, North America and Australia (Freire & Macedo, 1987). He has served as both Secretary of the Worker's Party and as Sao Paulo, Brazil's administrator or Municipal Secretary of Education for the Bureau of Education. He retired in 1991 after serving for one year (Freire 1993). He has written: "Pedagogy of the Oppressed" (1970), "Education for a Critical Consciousness" (1973), "The Politics of Education" (1985), also "A Pedagogy for Liberation" (1987) with Ira Shor, "Literacy: Reading the Word and the World", (1987) with Donaldo Macedo, "Learning to Question" with Antonio Faundez (1989), "Pedagogy of the City" (1993) and "Paulo Freire on Higher Education" (1994) among others. While his work revolves around teaching critical awareness through literacy, others have adapted his work to counseling (Alschuler, 1986; O'Hara; 1989; Bell and Schniedewind, 1989) and to health and nutritional counseling (Drummond, 1985). Freire himself notes the appropriateness of his approach, "around the core issues of...health problems and the need to develop effective methods of responding to new challenges" (1985, p. 23).

In order to approach Freire's work there are two dialectical points to understand and balance. His praxis for literacy work requires as he puts it both reading the word and reading the world (1987). While he acknowledges that programs need for technical training, e.g., "reading the word," that training must never be allowed to become a "narrow alienating specialization" which would prevent a critical consciousness, "reading the world" (Freire & Macedo, 1985, p. 67). Freire and Macedo stated:

...literacy cannot be reduced to the treatment of letters and words as purely mechanical domain. We need to go beyond this rigid comprehension of literacy and begin to view it as the relationship of learners to the world, mediated by the transforming practice of this world taking place in the very general milieu in which learners travel (1985, p. viii).

A description of a pattern of actions in Freire's approach shows how this can be better understood. In the introduction to Freire's "Education for a Critical Consciousness," Denis Goulet outlines the following as the essential format to Freire's work:

- participant observation of educators "tuning in" to the vocabulary universe of the people;
- their arduous search for generative words at two levels: syllabic richness and a high charge of experiential involvement;
- a first codification of these words into visual images which stimulate people "submerged" in the culture of silence to "emerge as conscious makers of their own "culture";
- the decodification by a "cultural circle" under the self-effacing stimulus of a coordinator who is no "teacher" in the conventional sense, but who has become an educator-educatee in dialogue with educatee-educators too often treated by formal educators as passive recipients of knowledge;
- a creative new codification, this one explicitly critical and aimed at action, wherein those who were formerly illiterate now begin to reject their role as mere objects: in nature and social history and undertake to become "subjects" of the own destiny (p. viii).

An Alternative Tool to Facilitate Praxis

There is another body of health and sociologist research: The Discovery of Grounded Theory (Glaser & Strauss, 1967), *Advances in the Methodology of Grounded Theory: Theoretical Sensitivity* (Glaser, 1973), *Chronic Illness and the Quality of Life* (Strauss, 1975), *Having Epilepsy: The Experience and Control of Illness* (Schneider & Conrad, 1983), *A Time for Dying* (Glaser & Strauss, 1965), *Qualitative Research Methods in Nursing* (Leininger, 1985), and *On Death and Dying* (Kubler-Ross, 1969). These authors use some Freire-like thematic analysis but do not seek to enhance either their own or the client's critical consciousness. As Glaser and Strauss note in their own introduction their goal is "directed toward improving social scientist's capacities for generating theory that will be relevant to their research" (p. vii). Members of the radical camp echo that goal with the self-criticism of calling for the needs to avoid "becoming fixated on understanding why things are the way they are as distinct from what must be done for things to be otherwise" (McLaren , 1986 p. 392).

Noerager-Stern (1985) described the key concept to this method as the:

Scientist generates constructs (or theory) from data rather than applying a theory constructed by someone else from another data source, the generated theory remains connected to or grounded in the data (p. 149).

She noted that while the steps of this method do not follow an orderly predefined path. In order to do classical grounded theory the researcher: "collects, examines, compares and then hypothesizes qualitative data, then checks the hypothesis with more data for verification" (p.159). Hutchinson (1986) felt the chief aim is understanding how a group of people define, "via social interactions, their reality" (p. 112).

Glaser and Strauss (1967) outlined the following elements to their work: generating theory, theoretical sampling, differentiating substantive from formal theory, the constant comparative method of qualitative analysis and clarifying comparative studies.

In their original work Glaser and Strauss (1967) first described the two major categories of theory and appropriate applications for them. Substantive theory was developed for “substantive or empirical areas such as patient care, race relations, professional education....” Formal theory was developed for an area of social inquiry such as: “deviant behavior, socialization, reward systems and others” (p. 32). They were both considered mid range theory. The difference between them is their focus. Substantive theories were designed for “specific, circumscribed, and empirical areas of inquiry, such as schizophrenic patients in an alternative treatment setting. Substantive theories have been used to “build formal theories” (Hutchinson, 1986, p. 111).

In a later work, "Advances in the Methodology of Grounded Theory, Theoretical Sensitivity," Glaser (1973) detailed the following methodology:

As one moves forward, one constantly goes back to previous steps. As we have improved our formulations of the method, these steps have grown. The steps, as now formulated are collection of research data, open coding of the data soon after, theoretical sampling generating as many memos as with as much saturation as possible and emergence of core social psychological problems and processes, which then become the basis for more selective theoretical sampling, coding and maiming as the analyst focuses on the core. This goes on all at once (p. 16).

Glaser suggested beginning with what he terms a recipe for pacing in which the researcher “collects, codes and analyzes data” (p. 22). The collection of data as described in Glaser and Strauss in "A Time for Dying" (1967), described the field work of interviews with health care professionals and patients. Interviews had to be carefully

tailored to meet the “time and working conditions” of the interviewed person (p. 261). The semistructured interviews were changed throughout the process as new data illuminated further areas of study.

Glaser and Strauss' methods required that data first be collected before a “review of the literature is performed” (Glaser, p. 23). This order prevents the development of preconceived ideas. This method also decreases the chance attempting to make the data fit the theory. It also prevents unnecessary time spent on non-related data (Noerager-Stern, 1985). Unfortunately much of the review of the literature incorporated into this chapter of the project was completed before the writer was familiar with this methodology and as such this project does not use pure Grounded Theory. Additional literature review does continue as part of the project. This was done for both methodological consistency and as part of routine professional practice. This completed section of the literature review must be acknowledged as part of the writer's present frame of reference and as a potentially confounding variable.

Project's Design

Freire, Glaser and Strauss all strongly caution against preconceived ideas. While this project must meet that criteria, it must also be focused to meet one of the specific educational requirements of an institution of higher learning (implying a documentation of the project's relevancy to education). Another pro-focus force was the writer's goal of exploration of DM education from the client's point of view. Functioning in the role of both learner-teacher and participant-observer the author is allowed some latitude in curriculum development and has chosen to maintain a semistructured approach.

Research Setting

The site of the field work for this project was a mid sized rehabilitation facility. This facility is located in the state of New Jersey and is operated a religious organization. As a part of the health care offered, patient education was provided to patients, family members, and community groups. People from these groups who identified themselves as having a diagnosis of DM and had confirmation of D.M. by their medical record were requested to participate in the study.

Unlike standard dominant paradigm studies, purely qualitative studies do not use be predetermined criteria. This may include are both the number of subjects and the specific questions. The requirement for an organized inquiry remains. The following information describes protocol used for this study. Persons at the facility with a previous diagnosis of DM were invited to participate. All patients who agreed were included as participants in the project. They were offered a letter of informed consent and were requested to read and sign a copy of the form. Because the participants were contacted as a result of an admission, the writer also had the additional requirement of obtaining the consent of both their physician and the administration of the facility. Informed consent is required by accrediting bodies (J.C.H.O.A. Accreditation Manual RI.1.1.7 p. 106) and to minimize the opportunity for events which followed the Stanley Milgram experiments (Napier & Gershenfeld, 1985).

After conducting each interview, data was evaluated. All information was evaluated by the writer using Glaser's and Strauss' constant comparison of the:

...collection of research data, open coding of the data soon after, theoretical sampling generating as many memos as with as much saturation as possible and emergence of core social psychological problems and processes, which then

become the basis for more selective theoretical sampling, coding and memoing as the analyst focuses on the core social psychological problems and processes (Glaser, 1973, p. 16).

Interviews were done on an individual basis. Participants were asked if the interview could be audio taped. Identified data that could compromise the participants right to privacy was deleted from the transcripts. With permission, handwritten notes were taken as a back-up, a method to include non-audio information, and when possible, as an opportunity to capture real time opportunities for memoing. When possible, transcripts of the audio tapes were presented to the participants for clarification, correction and for additional information. The writer had hoped to gain consent for group meetings for further clarification, correction and additional information. It was also hoped that members of the group would formally also support each other as they grew toward more autonomous management of their DM.

As a function of that role of participant-observer and learner-teacher, the following questions were proposed as both a point of departure and as an introduction to the field work of the project:

- What do you think a person needs to learn about DM?
- What do you think your family needs to learn about?
- How did you learn to manage your DM?
- Where else can a person go to learn about DM?
- Can you suggest some resources for that information?
- What has been helpful to you?
- What has created problems for you?
- What else should I be asking about?

This was a departure from a more mainstream study which would begin with classical demographic information. Some of this more typical biographical and medical data was gathered as the clients allowed and felt they were relevant to their story. Ideally name, age, sex, diagnosis, time since diagnoses, disease management tools (medication, diet, exercise, monitoring equipment, type of health care provider, use of health care provider, significant others who are or were persons with DM) were included. As Hutchinson points out (1986) "additional slices of data" such as chart review are appropriate sources for this type of study (p. 115). Most important to this process was what the client's view as useful and relevant to their lives. The more information was shared the richer the data became.

Methodology for Data Analysis

The chief objective of classical Grounded Theory research is to sift through data, organize and reorganize data around fewer and fewer subsuming categories. When the work is completed a core variable or Basic Social Psychological Process is identified and thoroughly described. The required criteria for this core variable qualifying as a Basic Social Psychological Process are that it occurs frequently in the data, links various data together, and explains much of the variation in the data. When core variables qualify as a Basic Social Psychological Processes they illustrate social processes as they continue over time, regardless of varying conditions (p. 118). A single dissertation study is unlikely to acquire enough information to warrant the title Basic Social Psychological Process.

Coding the Study's Field Notes

Data was collected, coded and analyzed from the first day. Hutchinson (1986)

describes the following questions to be considered when coding the data:

1. What is going on with the data?
2. What are these data a study of?
3. What is the basic social psychological problem with which these people must deal?
4. What basic social psychological process helps them cope with the problem? (p. 122).

In consideration of these questions, Glaser suggested and this writer wrote memos and memos about the memos of these issues. Sample transcripts of the interviews and this writer's memos are included as appendices to this paper. As suggested by Glaser (1973, p.73), information was sorted on Glaser's Six "C"s: causes, contexts or ambiance, contingencies, consequences, covariances (a connection of variables without forcing the ideas of cause) and conditions. In his discussion of theoretical coding Glaser suggested other possibilities including the following: "Families" Process, Degree, Dimension, Type, Strategy, Identity-Self, Cutting Point, Means-Goal, Cultural, Consensus, Mainline (Social Control), Theoretical, Ordering or Elaboration, Temporal Ordering, Conceptual Ordering and Reading. He also suggested : "Models" could be also be sketched as in a flow chart (Glaser, 1973, p.81). He also felt the researcher could invent his or her own codes to fit the specific data. The key concept to Grounded Theory analysis is that all codes evolve out of the data and not from prefabricated ideas or interpretations (Glaser, 1973).

CHAPTER V

CURRICULUM, CURRERE, CURRERE(S)

Introduction

The field work of this project began with the participants because as Freire and Faundez note, "Any Health Education programme [sic] should begin not by imposing knowledge, but by discovering what knowledge about health the people already have and by according due importance to its positive aspects" (1989, p.92). This is in contrast to the dominant paradigm in which patient education is commonly prescribed via a predetermined curriculum. This curriculum is deposited into the learners who are also referred to as patients, clients and participants. The chosen paradigm is also somewhat in contrast to the personal paradigm. That alternative paradigm would have suggested one reflective of the participants', presently perceived desires for individual growth. It would have sought to jointly author a curriculum to meet the learner's spontaneously identified needs. The curriculum which was developed, approached the radical paradigm. This choice suggests, a curriculum recreated jointly by the learners and teachers, both active participants who transform their world view through a dialogical process.

The author did not develop one curriculum, the patients-learners did not develop one currere; however, each participant created his or her individual currere or running of his or her course. Each participant was able to point out the major land marks or points

of progress along the way. Some of the points existed only for the individual. Some were held in common. The viewing stands were the dominant paradigm's goal of compliance. The starting line for these racecourses was, "precisely at the level of the people's aspirations and dreams, their understanding of reality and their forms of action and struggle" (Freire & Faundez, 1989, p. 27). The landmarks during the race were goals, barriers and strategies and the finish line for this point in time was critical awareness and autonomy.

The following racecourse-like processes or curreres were developed by the study's participants at the rehabilitation center. All of the in-patient participants' DM were medically managed with diet, standard diabetes medications and exercise in the form of physical therapy. These participants stepped outside of their usual role of patient and family members, which is to say the perceived passive role of receiver of health care. They were willing to share what they knew as their individual experience of diabetes and what they felt would be of benefit to a person newly diagnosed with DM. As Freire noted in describing the interviews in the first phase of his approach, he observed, "These interviews reveal longings, frustrations, disbeliefs, and an impetus to participate" (1973, p. 49).

Limits and Strengths of the Method

Qualitative research is not quantitative research. This study did not produce bits of data which fit into a computer program, it did not demonstrate a statistically significant improvement in the group's mean A1c (Glycosated hemoglobin). Qualitative research asks different questions and produces different types of information. One form of

qualitative research, Grounded Theory, records the participants' and writer's description of the participant's experiences with DM as each person's currere. One of the primary methodology formats used in Grounded Research is the semi-structured interview. This technique was chosen for the project. Each interview revealed a sample of the participants' ongoing process of understanding and so can be considered a part of their living curriculum. Taken together the interviews provided a collected view of a participant authored curriculum.

The lengthy interviews given by this project's participants combined with the qualitative analysis have produced complicated, interwoven results. In order to maintain the project's cohesiveness, the analysis and discussion are presented as one chapter. The main body of the discussion was divided into separate but related sections. These sections were differentiated on the bases of the thematic analysis of the interviews. These sections are: The Personal Definitions of DM, Diet, Medications, Other Individual Skills, Monitoring, Euglycemia, Long Term Complications, The Three Staged Process and Learning to Manage Resources.

Grounded theory may be used as tool for analysis in a manner consistent with Freire's approach. Both the mechanics of Grounded Theory and Freire's approach thematically analyze the data, in this case the participants' interviews. Grounded theory requires a line by line thematic analysis and Freire suggests a thematic analysis for the participant's areas of contention between the dominant culture's views and interests and their own. In this way the participants transform their reality in which they are active subjects and no longer passive objects. The translation of the original term which refers to

this awareness with action is "conscientization" (Freire, 1970) and although Freire (1993, p. 107) no longer uses this word, the process and goal remain.

Grounded theory analysis also requires a review of the literature. Since the theoretical aspect of the praxis for this project rests in both education and health care, both sets of theory are used in the review of the data's analysis. These paradigms are sometimes at odds with each other, however the writer found a complementary synthesis which provided a more wholistic understanding. Freire and Faundez (1989) suggest a rational for an even greater more generic knowledge synthesis. They suggest a synthesis of that common sense knowledge and official or scientific knowledge.

Changing reality involves bringing these two forms of knowledge together so as to achieve a greater knowledge, which is true knowledge that can translate itself into action to change reality. The division between these two forms of knowledge destroys any possibility of understanding the whole or of changing the whole (p. 49).

The first of several limitations for this methodology was identified by the participants. The transcripts of the participants' interviews record an interpretation of the participants' understanding of their past and present experiences. Four of the participants choose to identify this as one of the limits. These participants self-labeled what they felt were their own knowledge limits. They stated they felt they were not experts, were fearful they would omit something significant or offer poor advice (Participant 5, 9/11/93; Participant 16, 12/23/93; Participant 14, 11/18/93; Participant 8, 10/30/93). A similar cautionary argument is noted by educational theorist Eisner (1985, p.9), who suggested persons dealing with curriculum should critique programs to see that "...omissions were not out of ignorance." Critical education theory also argues against low standards (Freire & Faundez, 1989, p.79) such as omissions. This participant identified criticism also

shows the underlying assumption that they value their natural knowledge less than what appears to be scientific or expert knowledge.

A second limitation is a caution against attempts to replicate the specific findings of this project in another place. As Freire (1970) and Freire and Macedo (1987), warn against attempting to deposit a standard curriculum into the heads of learners, neither can these client authored curreres be transplanted as a prescription for others. Rather it is an example of a process to focus on the lived currere which may be recreated and offered and to others. As Faundez in Freire and Faundez notes the challenge of using this method is that it must be "reformulated as the situation demands and thus respond to different concrete situations" (1989, p.30).

Other parameters were a reflection of the level of participants' critical consciousness. The original proposed design reflected this writer's hope for formal group participation. None of the seventeen participants were willing to join in a group discussion. As predicted by Illich (1976, p.8) and Freire (1973, p.xix), participants failed to view themselves as able to provide for their own learning, in this case participate in a group experience. Shor in McLaren and Leonard also observed (1994, p.33) that people have become de-socialized as a part of their learning to a point where they have developed a "run away individualism" and Freire himself characterized "...the United states, you find, for example an undeniable taste for individualism" (Freire & Macedo, 1987, p.48).

As noted before, some of this project's participants cited the following rationales for avoiding group participation: poor role model (Participant 5, 9/11/93), being afraid of giving bad/mistaken or inaccurate advise (Participant 2, 8/31/93), experience was

awkward or embarrassing, not knowledgeable (Participant 10, 11/11/93 and Participant 16, 11/27/93), poor grammar when compared to formal written sources and therefore less valuable (Participant 12, 12/2/93 and Participant 16, 12/12/93) and not able to remember all necessary issues during the interview process, (Participant 13, 11/18/93). These limitations were the learned context for the participants despite their years of experience.

The participants who devalued their own speech patterns did not question the values behind their beliefs. They did not reflect any questioning for example, "Who determines whether a particular speech pattern is correct, or educated?" (Freire & Faundez, 1989, p.81). Freire and Faundez (1989, p.3) honored one of these differences, the spoken language, in their own work citing, "The style is different, because the language is different, because the language is spoken-with a more colloquial touch, more feeling, more freedom." Another educational researcher, Kvale (1988, p.97) echoed the issue of grammar but placed a different significance on the limitation. Kvale agreed that oral discourse was not a written narrative but noted that what was important was that transcription transformed the data into a different mode, and in an important sense changed it from the "evolving conversation between two people."

The Participants

Besides describing themselves as having diabetes and or being a diabetic (terminology to be reviewed later), most of the participants described themselves in terms of their occupations, vocations and family relationships and responsibilities. These descriptions included the following vocations and occupations: nurses (Participant 3, 9/3/93 and Participant 6, 9/18/93); teachers (Participant 8, 10/ 30/93 and Participant 13,

11/18/93); a clerk (Participant 1, 8/13/93); a volunteer firemen (Participant 7, 10/30/93); grocery store employee, bartender and bowler (Participant 12, 11/18/93); two former military personnel (Participant 12, 11/18/93 and Participant 15, 11/26/93); widowed person (Participant 7, 10/30/93; Participant 9, 11/8/93 and Participant 15, 11/26/93); spouse (Participants 1 through 5, 11, and 14 on 8/24/93, 8/31/93, 9/15/93, 8/31/93, 9/3/93, 11/17/93, 11/18/93); parents (Participant 1, 8/31/93, Participant 3, 10/22/93, Participant 4, 9/4/93, Participant 10, 11/11/93); and grandparents (Participant 7, 1/23/93 and Participant 14, 11/18/93); family transportation provider (Participant 4, 9/4/93) and member of a religious order (Participant 13, 11/17/93). Three participants described themselves as retired (Participant 1, 8/24/93, Participant 10, 11/11/93, and Participant 11, 11/17/93); one participant felt her racial-ethnic background was important (Participant 6, 9/18/93) and one for his experience and values from having lived through the Great Depression (Participant 10, 11/11/93).

Of the seventeen participants in the sixteen sets of interviews, nine were males and eight were females. At the suggestion of an earlier participant (Participant 10, 11/11/93), the spouse of one primary participant, also a nurse, was included in the eleventh interview. Two participants, a nurse and a school teacher felt their occupation particularly affected how they viewed a diabetes curriculum (Participant 3, 10/22/93 and Participant 9, 11/24/93), a third, Participant 11 (11/17/93) agreed that work/employment was a part of who he was. One of the nurse-participants was looking for a measurable quantitative focus for her own understanding and correct responses for her interview. These participants acknowledged that their own definition of self was affected by their perception and experience with DM.

All of the participants who reviewed the typed transcripts of the interviews (Participants 1,3,4,6,7,9,10-16) acknowledged that the texts accurately recorded the verbal exchange of the previous interview. Four participants were discharged before typed manuscripts were available for their review and comment. Two other persons who were invited to participate, declined. All participants in the study were contacted while at a rehabilitation facility.

Some participants identified additional diagnoses consistent or associated with the long term complications of diabetes, similar to those noted by Ginsberg and Mazze (1994). These included amputation for non-viable tissue (Participant 1, 8/24/93; Participant 11, 11/17/93; Participant 14, 11/18/93); problems related to healing of lower extremities (Participant 5, 9/11/93; Participant 13, 11/18/93; Participant 14, 11/18/93); hypertension associated with coronary heart disease, (C.H.D.) (Participant 3, 9/3/93, Participant 8, 10/30/93, Participant 11, 11/17/93); cerebrovascular accident, (C.V.A. also known as a stroke) (Participant 6, 9/18/93 and Participant 12, 11/18/95); renal or kidney failure (Participant 11, 11/17/93), retinopathy which is a type of eye problem with potential for blindness, (Participant 6, 9/18/93). These diagnoses were consistent with Hirsch's, Paauw's and Brunzell's finding that most hospitalizations for persons with DM are related to complications of the disease (1995). Illich (1976, p.17) attributes the rise of "diabetes, hypertension and obesity", among others to social and clinical iatrogenesis. These hospital admissions can also be viewed as a failure of the present curriculum.

Personal Definitions of DM

The writer began this project based upon the assumption that participants in this study were sentient persons who, based upon their experience of DM had the potential to act in a critical capacity to act in their own self interest. The writer further assumed the participants would share their understanding of what DM means, his or her goals for dealing with it, and would make recommendations for the skills and techniques used to reach his or her goals. This was their learned currere. As one participant stated, "it's not about the professional's...its how you...it works better" (Participant 11, 12/2/93).

"DM is a long term experience... It will change your life forever" (Participant 1, 8/24/93). It changes your self identity, you are now "a diabetic." Use of this term "can make you feel like a set of symptoms, not a person" (Participant 3, 9/3/93). It affects your life from something as simple as being able to walk barefoot in the grass (Participant 1, 8/24/93); or having to wear an identification bracelet/visible sign (Participant 3, 9/3/93); to having a fatal illness (Participant 16, 11/27/93). It can interfere, through its requirements for care, by interfering with each meal, for activities such as insulin (Participant 6, 9/18/93) or all aspects of life (Participant 13, 11/18/93). It can also interfere with independence by its potential to develop complications which can prevent a person being judged medically fit to drive a car (Participant 4, 9/4/93); or being strong enough to mow one's own lawn, or accept the need for an early retirement (Participant 11, 11/17/93) or steal a retirement [plan] away (Participant 6, 9/18/93). It can also limit the amount of traveling one participant felt able to manage. It also made her friends afraid of her both because of needles and fear that she would have an insulin shock or episode of

hypoglycemia (Participant 6, 9/18/93). Participant 11 summed up his assessment that having DM was similar to his experience of being in military service, "you go by a set of rules" (12/2/1993). All of these lifestyle changes illuminated part of Hampton's, Glasgow's, and Foster's (1995) study which included the heavy impact on lifestyle and emotions.

Other researchers have also found that DM affects a significant specific portions of a person's life. On a personal level Ehman (1995) found that it was difficult, "to hear the news of acquiring a chronic disease, requiring treatment consisting of a food plan, exercise, smbg, and medical supervision and having the potential for complications." He also found that due to the high impact on their lifestyle, persons may also experience anger, sadness and feelings of being overwhelmed. On a vocational level Peragallo-Dittko (1993) found choices limited for persons requiring insulin. They cannot "join the military, hold a pilot's license or drive an interstate truck" (p.39). Modifications for federal government criminal investigators (Kippen, 1995, p. 20) and interstate license restriction have only recently changed these "a case-by-case decisions" in 1994 (Diabetes Self-Management, p.17). Peragallo-Dittko (1993) saw only part of the meaning of a loss of driver's license, interpreting it as limited to affecting leisure activities not as an access barrier to health care and food shopping. Steinburg (1994) also noted limitations on the ability to continue in the military as Mazur found similar limitations with special agents for the Bureau of Alcohol, Tobacco and Firearms (1995). Jacobson, De Groot and Samson (1994) found that employment was prohibited because the department's view was that persons with both "Type I and Type II diabetes are typical of chronic illness because

the treatments are burdensome and the complications can be debilitating and life-threatening" (p. 267).

Terms: Diabetic versus Person with Diabetes

Some of the participants refer to themselves or others as a diabetic, (Participant 1, 9/7/93, Participant 2, 8/31/93, Participant 3, 9/3/93) others prefer to say that they have diabetes (Participant 2, 8/31/93 and Participant 4, 9/4/93), still others that they have a chronic illness or a chronic condition (Participant 3, 9/3/93). This overlapping use of terms demonstrates both the preference for avoiding being labeled as "a diabetic" as the word makes one a "category not a person" (Participant 5, 9/11/93) while at other times using the same term to describe the self. The editors of Diabetes Forecast (1994 p.78) surveyed their readership in reference to the term "diabetic." They found 77 percent were comfortable with the term, 14 percent used it themselves but preferred others not to use it and 9 percent found the term offensive and demeaning.

Returning to the process rather than the name, one participant spoke of a worsening disease process characterized by impaired blood sugar, followed by needing pills (oral hypoglycemic agents) and finally "real diabetes, needing insulin" (Participant 13, 11/18/93). Funnell and Merritt (1993, p.46) while agreeing with the professional criteria for DM noted that it can appear in this pattern in adults both with and without symptoms. They found some, "older people with N.I.D.D.M. may convert to I.D.D.M. in the course of the illness." Haire-Joshu (1992, p.10-12) in noting the differences of the pathogenesis of Type II DM, noted that "50 percent of all persons being treated for D.M. require insulin, while the remaining do not". Similar results were found by Polly (1992).

Another participant quoted patient and professional literature. She learned about the pathophysiologic process and spoke about DM's signs and symptoms such as tiredness, or as polydipsia, polyuria and polyphagia. (Participant 16, 11/27/93).

Some of the aspects which are cause for concern are the multitude of life style changes, described as a loss of independence as the cost of health (Participant 1, 8/24/93); they will be discussed in a separate section. Some participants see DM as a hereditary disease. For some, this has implications for sharing information for early diagnosis with family members (Participant 14, 11/18/93). One participant decided not to have children because of DM, not out of fear of medical problems but because she did not want to "pass it on" (Participant 6, 9/18/93).

The above view of Participant 3 differed from the view of health care researchers in that DM does not preclude a successful pregnancy nor does maternal DM guarantee DM in children. Briefly, for Type I DM, Ginsberg-Fellner's in Lebovitz (1994) research found that mothers with Type I DM had a slightly lower incidence of children with DM. Ginsberg-Fellner also observed the difficulty generalizing this to a wider population because of a possible combination of Type I and II in either parent and the several apparent modes of transition in Type II. Other researchers, Mitchell, Kammerer, Reinhart and Stern (1994, p. 567) also noted the "specific genetic modes" are not yet known. This participant did not report ever having discussed either her rationale or her decision with her health care providers nor did she report anyone asking about her perceptions and experiences.

In a comparison to experience coming out of standard care, critical praxis requires that knowledge be used differently. Sharing knowledge is required from all participants.

As an example, Freire and Faundez reported (1989, p.93-5) that a health care worker needed only to ask Aymara villager parents why eggs and milk were considered unacceptable sources of protein for malnourished infants for the parents of the village to share their belief system. Once beliefs could be discussed and critically understood, they were changed. In that case the parents could reach their intended goal of healthy children.

Participants were aware of long and short term complications from both the disease and treatment (also discussed later). For most people DM is a permanent condition with hope for less restrictive requirements or finally a cure. One participant felt the exact cause could never be identified (Participant 1, (8/24/93), nor which persons in a family would develop the illness. One participant felt her prognosis for her diagnoses was in the "hands of God", noting that since she had been diagnosed with metastatic bone cancer she was no longer concerned about her diabetes (Participant 5, 9/11/93).

Freire notes an educational concept similar to this thought which is common to persons who have not yet come to evaluate their world critically. He speaks of, "Magic consciousness, in contrast, simply apprehends facts and attributes to them a superior power by which it is controlled and to which it must therefore submit" (1973, p. 44). This in contrast to Participant 9, who had been diagnosed among other problems with non-metastatic cancer and felt that no matter what problems occurred DM must always be managed in order to prevent infections, but that taking precautions had some limitations since the "Ultimate cause is God" (11/8/93 and 11/23/93).

A review of the literature shows some differences in opinions of the participants and researchers concerning the predictability of the development of DM and it's ultimate cause(s). Both of the major types of DM need to be considered separately. For type I the

Human Biological Data Interchange, having surveyed 6,000 families with questionnaires and blood samples "has identified pinpoint genetic regions that increase or decrease a person's risk for developing diabetes" and perhaps ways to prevent it (Cuverwell 1995, p. 29). While this project does not address the role of God in the development of DM, other researchers have addressed whether or not a person's beliefs concerning internal versus external causes effects the outcome of illness or disease. Byham and Vickery (1988) reviewed and compared two theoretical bases of explanation for this type of understanding. Using both the Health Belief Model and the Locus of Control Model to examine compliance, they found that those who tend to view behavioral control as "up to...family, friends, luck...fate... find prescribed regimens as out of his/her control" (p.9).

Learning about the Diagnosis

Some of the participants began his or her own experience with DM before his or her own diagnosis. As a result, they also acquired some information and skills before their own diagnoses. This was most common in the role of family members to others diagnosed at an earlier date (Participant 4, 9/4/93; Participant 6, 9/18/93; Participant 8, 10/30/93; Participant 9, 11/8/93; Participant 11, 11/17/93; Participant 12, 11/18/93; Participant 13, 11/18/93 and Participant 16, 1/27/93) or as a part of professional training (Participants 3, 9/3/93; Participant 6, 9/18/93 or spouses as was secondary Participant 11, 11/17/93).

When discussing learning of his or her own diagnosis, the participants reported two interactive themes. The first was dealing with learning about with the diagnosis and the second is learning the life style changes recommended by the health care provider.

Learning about the diagnosis occurs in three typical ways: firstly, by accident from the participant's health care provider, secondly, in answer to a request for diagnosis and treatment for the problems are in fact DM and lastly by self or family recognition of symptoms of DM and making the diagnosis.

"Found by accident" describes a process of going to a physician for another problem such as a cold or injury and having a physician diagnose DM as well as treating the complaint which caused the person to seek care. Sometimes the original problem is non-related, (Participant 13 11/18/93 and Participant 15, 11/26/93), however it may make the symptoms more visible. An infection, such as a cold, (Participant 4, 9/4/93), is likely to raise both blood sugar and the "symptoms of hyperglycemia", clinically pointing to the possibility of DM (Genuth, p. 65-66). In the second group, some participants became acutely or chronically ill with hyperglycemia, sought and then received both diagnosis and treatment. The process which Participant 5 (9/18/93) recalled, included initial visits to her physician. She was treated with Vitamin B12 injections for tiredness and by implication to this writer no accurate diagnosis. Schwartz (1995, p. 29) also found that "there are still medical doctors in all types of practice who have not kept up with the latest advantages in diabetes care." Engel, Shmoon, Basch, Zonszein and Wylie-Rosett (1995) also found physicians who were non-compliant with national standards of care.

The members of the second group had at least some awareness of the possibility of DM before a physicians' official or formal diagnoses. One participant, Participant 10, (11/11/93) was told he had a borderline problem, though he was unable to define what this meant, nor was he initially told he had a potential to develop DM. Other participants sought confirmation of his or her self-diagnoses which he, she or a family member had

already made. They were able to make this diagnoses because of specialized knowledge.

This knowledge was obtained as a student of health care, or based on experience as a child, sibling or spouse of a person with DM, (Participant 11, 11/17/93 and Participant 12, 11/18/93). Based upon knowledge of the symptoms of hyperglycemia (polydypsia, polyuria, polyphagia, and or difficulty with vision) some persons will self diagnose with or without smbg as an adjunct to their judgment (Participant 11, 11/17/93). Unlike these participants reports of timeliness, McCarren (1995a, p.16-21) found that many people had DM which had been undiagnosed for years. McCarren attributed this to a common lack of understanding of: the "polys" symptoms, obesity, age, heredity and large birth weight of offspring all as risks factor or markers of DM.

Initial Reactions to the Diagnosis

Reactions to the official news of his or her own diagnosis varied. Although the reactions vary it is typically strongly negative, ranging from denial, especially during the honeymoon phase or period early after treatment is initiated when glucose level may approach or become euglycemic (Participant 1, 8/31/93); "shock" (Participant 14, 11/18/93); to "not surprised" because of family members previous diagnosis (Participant 16, 12/12/93) and would have "been surprised if I had escaped it" (Participant 13, 11/18/93). Participants' feelings were directed toward the diagnosis and toward the prescribed management regime.

Health care researchers found similar reactions. Tucker (1995) observed a process she felt subsumed under the concept of grief for lost good health. She observed that this began with shock, numbness and denial and was followed later by anger and depression, a

process following Kubler-Ross' work, "On Death and Dying." Almeida (1995) found similar feeling for parents of children diagnosed with DM. Roberts' (1995) work surveyed a method for alleviating the feeling identified with the problems of newly diagnosed persons. She surveyed the use of on-line bulletin boards: to feel less alone, to get emotional support, to put problems in perspective, to share what you've learned, to get practical help, to make friends, to learn more about diabetes, to not feel self-conscious and to learn about products.

Fear

...And fear is normal. You only have to be alive to experience fear. It is a condition of living. But it is also necessary to understand the limits of fear so that the limits of resistance can also be understood (Freire and Faundez, 1989, p. 44).

The participants were able to graphically share the limits or parameters of their fears. The specific fears listed were: loss of independence, in terms of not being able to drive, (Participant 4, 9/4/93); loss of independence in choosing what and when to eat, fear of not being able to follow the prescribed diet, (Participant 3, 9/3/93); vascular problems, (Participant 13, 11/18/95); foot problems and loss of limbs, especially after viewing of post amputation patients (Participant 4, 9/4/95); death, (Participant 16, 11/27/1993); fear of needles, learning to give self injections of insulin, (Participant 2, 8/31/93 and Participant 5, 1993); of the disease becoming worse and of having my retirement "stolen" (Participant 6, 9/18/93 and Participant 11, 11/17/93).

Researchers found many similar concerns with participants in their own studies. Swencionis, Wylie-Roset, Peters and Cimino (1994, p.130) found some of their participants were unable to follow diets and had issues concerning feeling "in control".

Farkas-Hirsch's and Hirsch's (1994) had concerns for their participants having, among other problems: fear of needles, "severe eating disorders or history of severe unresolved depression or other psychiatric history" (p.84). Some researchers note that based on the results of the D.C.C.T., that the potential for long term complications remains as a threat, the incidence in groups can be greatly diminished (Hazlett 1993; McCarren, 1995b).

Anger and Denial

Anger and denial are two other reactions. The specific causes of anger listed were: not eating what you want, being different from others and being unable to tell people to stop behavior that is hurtful (Participant 3, 1993). Related but not specific to dietary were: being asked to do things that don't make sense, such as to change an insulin dose by one unit, the loss of privacy, skin irritation from medic alert bracelet (Participant 5, 9/11/93). Other dietary related sources of anger are; the burden of setting a good example by participants who are also health care workers (Participant 3, 1993 and Participant 6, 9/18/95) and having to think about food all of the time in terms of type and portions (Participant 3, 1993).

Anger also occurred when the required routine for DM interfered with work and caused other illnesses (Participant 6, 9/18/95). Anger as it related to complications and their symptoms was another problem. Anger was also the reaction to the pain which can be managed only with medication. Another source of anger was inadequate resources which will be explored in another section (Participant 13, 11/18/95). These are the areas of contention and potential resistance.

The reaction to DM may also be denial (Participant 3, 9/3/93). The level of denial changes over the course of the disease. Some initial reactions include an acknowledgment that advice would be of benefit to the individual, however since the person is in denial it is seen as nagging and discounted (Participant 3, 9/3/93). This changing process of denial which these participants demonstrated will be discussed later. Other researchers found series of changes which included this. Kelly (1995) saw: pre-contemplations, contemplation, preparation, action, maintenance and termination. Haire-Joshu (1992) also observed a complex process of: "disbelief, anger, reorganization, identity change and adaptation" (p.569).

Lifestyle Changes/Skills Recommended by Care Givers

Whether participant or health care provider initiated, if euglycemia is desired, diabetes management requires change. As Participant 2 (8/13/95) suggested, a person who is new to DM must learn "everything." What "everything" entailed varied according to the participant. Recommendations made by the participants varied. Participants' goals generally concerned with compliance of the individual skills. The following are the categories or sets of skills the participants choose: diet (All participant's first interview); smbg (Participant 1, 8/24/93; Participant 3, 9/3/93; Participant 8, 10/30/95 and Participant 11, 11/17/95); medications which included adaptive injection techniques and oral hypoglycemics (Participant 3, 9/3/93; Participant 4, 9/4/95; Participant 9, 11/8/93 and Participant 11, 11/17/93); signs and symptoms of hypo/hyperglycemia (Participant 3, 9/3/93 and 10/22/95; Participant 4, 9/4/95; Participant 5, 9/11/95; Participant 11, 11/17/93); exercise (Participant 4, 9/4/95; Participant 5, 9/11/95 and Participant 8,

10/30/95); long term complications which included foot and eye care (Participant 1, 8/24/93; Participant 4, 9/4/95; Participant 8, 10/30/95; Participant 11, 1/17/95; Participant 13, 11/18/93 and Participant 16, 11/27/93); family problems, staff problems, (Participant 5, 9/11/95 and Participant 13, 11/18/95); transportation to health care providers (Participant 4, 10/5/95 and Participant 9, 11/8/95); wearing a medic alert bracelet (Participant 3, 9/3/93); how to travel (Participant 6, 9/18/95 and Participant 8, 10/30/95) and strategies for dealing with feelings (Participant 1, 8/24/93; Participant 3, 9/3/93; Participant 5, 9/11/95 and Participant 15, 11/26/95). Discussions of both compliance versus adherence, and barriers and strategies to follow these suggestions will follow in separate sections.

Parallel to management skills recommended by participants, health care providers' overtly focused on maintaining euglycemia and the prevention of short and long term complications. The subtext or more covert issue of compliance for its own sake, will be discussed later. The curriculum recommended by the American Diabetes Association (A.D.A) is a standardized in the sense that it has required content (Franz et al., 1986) for all and is individualized in the sense that it requires age, ethnic and reading level adjustments (Haire-Joshu, 1992). The content recommended is divided for Type I, Type II and Gestational, and also presented at Initial and In-Depth Counseling levels. They cover: the specific identified pathophysiological problems, nutrition, exercise, medication, monitoring, acute complication, psychological adjustment, health habits, long term complications, community resources and benefits of using the health care system, (Franz et al., 1986). The curriculum is developed and the patients are expected to accept

and comply. Freire would describe this as "factors which make them accommodate or adjust" (1973, p.5).

Diet

As Participant 4 (9/4/93) stated, "diet is the most important skill" and while this remains as reality for persons with diabetes in all parts of the world, this section of the curriculum is not transferable to many other persons with DM. It is not applicable to persons with incomes that cannot support the food choices financially available to these participants. For example it is not useful to the people who participated in the nutrition projects discussed by Freire and Faundez (1989, p.88) and Drummond (1975) because the nutritional issues for those groups were adequate calories and minimum protein sources, not the luxury of a special diet.

It is interesting to note the manner in which this difference is seen in an American nutritional text. For example Brigg and Galloway (1979, p.1) begin their first chapter asking questions such as "Why do I need to eat?, What should I eat to keep physically fit? What is the best way to keep my weight down?" They conclude their text with "Malnutrition: A Global Perspective", (p. 607) where the issues for the United States are the over supply of empty calories for many and the problems of malnutrition for a minority and the wide spread problems of hunger in the third world. What a reframing for the word "calorie"!

Returning to this project, as Participant 4 (9/4/93) stated "diet is the most important skill." Participant 1 (8/24/93) also noted that the major problem of DM is learning to stick with the diet every day. Funnell and Merrit (1993, p.48) agreed and

described diet as the cornerstone of metabolic control. What "following" the prescribed diet meant varied greatly. Additionally several participants noted there was a difference between what they were told to eat and what they chose to eat. As Participant 3 (9/3/93) noted, "Let's face it, they say 1200 or 1500 or 1800 calories but what you put in your body is up to the individual." The participants called the difference between the two plans "cheating" (Participant 6, 9/18/93; Participant 11, 11/17/93). Freire would call it resistance.

There is usually a frequently used plan prescribed by health care providers. It is referred to as the exchange system. Participant 9 (11/8/93) described her understanding of this as a prescribed diet in terms of portion control and avoidance of concentrated sweets i.e., table sugar (as did Participant 11, 11/17/93). Participant 16, (11/27/93) described her system using the terminology used to teach nurses to give medications correctly, in this case as the right foods in the right dose or portions. Participant 3 (9/3/93) continued this medication parallel, adding the parameter of the right time. Both of these comments suggest the medication-like efficacy of the diet, the altered frame of reference in which to perceive food and the potential for posology type errors (Segatore, Edge and Miller, 1993). Purchasing the correct foods and following proper cooking procedures, were noted by Participant 7 (10/30/93). Correct determination of portion control was also noted by Participant 7 (10/30/93), Participant 10 (11/11/93) and Participant 15 (11/26/93).

In looking at the results of social roles rather than the causes affecting older mens' ability to follow a diet, Funnell and Merritt (1993) also found that wives of older men diagnosed with diabetes must "accept care responsibilities." These include some food

serving "precursors" which they identified as shopping, food preparation and then serving size. Participants 9 (11/17/93) and 16 (11/28/93) felt that alcohol should be avoided. Participant 6 (9/18/93), Participant 9 (11/8/93) and Participant 11 (11/17/93) also noted their other restrictions of salt, fats and fluids.

Unlike the participants, health care researchers noted that recommendations have changed since their inception in the 1950s (Haire-Joshu 1993, p.24). The most recent set of recommendations (Norton 1995) noted that when the exchange system was used for non-pregnant adults, specific calorie recommendations are made. These took into account: sex, height, desirable body weight, calorie expenditure, type of diabetes, laboratory values indicating lipid and renal status" (Peragallo-Dittko, 1993). Other alternatives included carbohydrate and or fat counting systems; calorie point systems; Month-of-Meals, a prefabricated menu system; No Concentrated Sweets System and regular (non-restricted) balanced meals (Peragallo-Dittko, 1993). These systems were all reflective of the position statement from the 1994 American Diabetes Association which included recommendations for protein, fats, sweeteners, fiber, sodium, alcohol, micro-nutrients (vitamins and minerals). Other researchers also found diet to be the most important skill. Pratt-Gregory and Davis (1994, p. 406) found from their own work and the review of others that, "Diabetes control requires constant attention to diet, yet the diet remains the most difficult aspect of the diabetes regimen for patients to follow consistently."

Other health care researchers found problems very similar to the participant's finding. Watson and Dunford (1992) in reviewing both the literature and their own study found the following influenced behavior: time required to acquire knowledge from

dietary counseling, problem solving skills, individuals viewing their condition as chronic, having self discipline, the influence of other people, events in eating away from home and the time required to plan and prepare food.

Dichotomy or Integration/Congruence: Context for Diet Choices

The participants' context of diet and foods was generally different from that of their health care providers. Unfortunately their context for diet usually remained within the context of compliance versus noncompliance and within that of the standard health care provider. Only a few participants were able to critically change this compliance to congruence or adherence. The difference between the levels of understanding was not unlike health care researchers who misuse the terms interchangeably (Wuest, 1993). The common participants' context was in terms of external events and reactions.

A few researchers looked at this differently. Leininger (1988) suggested that goals can be viewed as either dichotomous or congruent, differing or chosen together. Within the framework of critical praxis, Freire (1970, p.168) defined authentic adherence as "the free coincidence of choices: it cannot occur apart from communication among men, mediated by reality." When the goals were congruent they reflected the difference between integration or a capacity to adapt oneself to reality plus the critical capacity to "make choices and transform that reality" (Freire, 1986, p. 4) and that of compliance is an imposition of one man's [sic] choice on another (Freire, 1970, p.31).

There are many conditions which the participants identified as influencing them to agree, be congruent or adapt to his or her health care providers' recommendations or to choose an alternative. There were two major and several smaller related organizing

themes for understanding the context of meaning for food and diet. The first of the major themes was the loss of autonomy, which is to say a critical thinker and director of one's own life in the community. The second theme revolved around gustatory and experiential enjoyment.

Context for Learning Diet: Adaptation or Compliance

Hinnen (1993) observed, "Nobody likes to be told what to do" and the participants agreed. Participant 6 (10/14/93) agreed with the summary of what she really wanted from her diet, "I like to eat what I want, when I want to, without negative consequences."

Other participants perceived a loss in autonomy in terms of several issues. Those diet related autonomy issues were: feeling deprived (Participant 3, 9/3/93 and Participant 11, 11/17/93); "makes you feel you are not in charge" (Participant 6, 9/18/93); having someone else (health care provider, co-workers, friends or family member) choose or critique what type, amount or timing of foods to be eaten (Participant 3, 9/15/93; Participant 4, 9/4/93; Participant 10, 11/11/93; Participant 11, 11/17/93). Participant 7 (10/30/93) felt, "real people" did not weigh their food to determine their portions. Participant 3 reported, "Food used to be a comfort now has a high price ... when I see food I see amputations." Dieting made her feel like a "non-regular person", this emotional cost was too high and so she had chosen not to follow her diet, "I know it will hurt me and I do it anyhow." She has learned to judge everything in her home refrigerator to as to whether or not it is a "low blood sugar food." This participant wished she no longer had to eat because it was now always a conflict (9/3/93). Interpreting her understanding of the word control as "keep dependent", Shor in McLaren and Leonard

(1993, p.29) paralleled this participant's words. He noted that Freire's work pointed out that, "Uncritical citizens who deny their own intellects and blame themselves for their own failures are the easiest to control."

Other health care researchers also found diet or food plan related issues very complicated. Kelly (1995) found poor patient adherence to prescribed treatments, diets, and exercise plans are still the single greatest barrier to controlling diabetes and preventing the serious long-term complications of the disease. Kelly attributed this to: poor patient education, financial constraints, and burdensome daily regimens. Kurtz (1990) and Glasgow (1989) found similar complex rationale for non-compliance/adherence, while another group of researchers, Orlandini et al., (1995) attributed some adherence problems to personality style.

Education researchers used a different frame work to review the issue of compliance/noncompliance, particularly when it is expressed as an inability to follow an educator's prescribed program. Barker (1995) looked at this problem at the student level and found students could learn helplessness as well as math and art. These students used avoidance based on the premise that they "can't do this", had feelings of hopelessness, despair and a lack of motivation to try. Keith (1995) looked for an explanation of the expression of resistance as "can't do it " on the school level. He found when the "service provision" model was used with its exclusion of community ownership the system failed but when the model changed to a participatory one, Community Schools, the children learned, the parents and community members became stakeholders. Arnove (1994) looked at the level of entire educational systems and found that "attempts to use educational systems to promote particular sets of values whether they be politically or

religiously inspired, are likely to backfire and lead to resistance..."(p.120) While Lankshear in Freedbody and Welch (1993, p.119) agreed with Arnove's concept he also noted that an educational system which promises praxis and then returns to "serving only a few of its constituents" will also fail. Finally, Freire also cautioned against the externally imposed "sectarian" efforts for compliance (1970, p.11) supporting the benefits of a problem posing method which "forges the curriculum with, rather than for" (1973, p.33) its participants.

This study's participants reported that the threat to autonomy becomes an important issue when family, co-worker or health care providers acted as gatekeepers, for example serving only approved foods and or exceptions or treats chosen as appropriate by the gatekeeper. The interpersonal consequences of non-compliance or non-adherence was punishment in terms of "bossing" (Participant 10, 11/11/93); "nagging" (Participant 3, 9/3/93; Participant 11, 11/17/93; Participant 14, 11/18/93 and Participant 16, 11/27/93); also "giving hell" (Participant 11, 11/17/93); "gossiping" (Participant 13, 11/18/93); and making the person "feel guilty" (Participant 16, 11/27/93).

Health care researchers have also noted this problem. Polonsky (1995) noted with some humor that persons with DM are "Besieged by the Diabetes Police." The strategies include: labeling a person as suicidal, give advise, helping, shaming in front of others, criticize food choices, ranting, raving, going into a person's home and removing "illegal foods" and blaming. His list of diabetes police officers, similar to that of the participants', included family members, co-workers, spouses, physicians and close friends. Taibbi (1995) also found that friends can "kid and tease" a person when they are attempting to encourage him or her to adhere to his or her program. Freire and Faundez (1989)

illuminate how this could occur as the result of the power of a family member or friend.

As an alternative, they pose a set of questions to look at the power structure within the family unit. They ask:

Who possesses power? How is this power created? In a family, it is the husband who determines the power and lays down limits, when he accords a certain measure to his wife and children. Friendship is also power relationship (p. 70).

Certainly these questions would function as a therapeutic intervention for both a diabetes support system and more general autonomy within a person's daily life.

A sub-theme for problems with autonomous functioning is difficulty processing information. Participant 6 described issues which interfered with her learning. She defined a situation of lack of learning as when before her present admission, she had not understood the concept of a meat exchange and so would eat three types of meats rather than approximately three ounces of meat equal to three exchanges. She attributed this to difficulty in learning this, noting that being upset made it difficult to process information correctly (9/18/93). Participant 13 (11/18/93) also noted that the act of thinking about her diet was upsetting, thus creating problems for her.

Two health care researchers also found both of these issues as part of the context or the relationship between eating and learning. Wierenga, Browning and Mahn (1990, p. 469) who looked at the psychosocial aspects of eating found comments similar to the participants such as, "I eat because I'm lonely or mad." Gold looked at two biological foundations for learning, the effects both stress and glycemia (1995). He studied both rats and healthy humans, looking at both the micro or single neuron level and macro or learning level. He found improved memory and verbal learning tasks with ingestion of a glucose drink soon after learning, particularly with older subjects. Ingestion of glucose

and or treatment with epinephrine, a counterregulatory and stress hormone, are contraindicated for persons with DM as they produce hyperglycemia. Assuming that the effects of glucose epinephrine (adrenaline) are similar to food and stress or excitement, and persons with DM are attempting to maintain euglycemia, they would not have access to either of these strategies to enhance his or her learning. Participants additionally reported difficulty thinking when not euglycemic (Participant 3, 9/3/93 and Participant 16, 11/27/93).

Patient and Family Attitude

In terms of interpreting this context, Participant 10 (11/11/93) noted a different experience which affected his choices. From time to time, health care institutions served food outside the parameters that its staff had said were necessary. From this, he had learned a different framework for food choices. Their serving inconsistencies gave him a perceived permission to eat previously forbidden foods. Anderson (1994) also found one of her participants unknowingly wished to follow the non-compliant choice in hospital served food. Analyzing this situation, the potential perniciousness of compliance becomes visible because the act of uncritical compliance promoted hyperglycemia. As an alternative to compliance, Participant 6 (9/18/93) found a similar serving error was a decision making opportunity to avoid hyperglycemia causing foods.

There were other issues. Participant 13 noted that when she was upset she felt her diet did "not work anyhow" (11/18/93). Skelly, Marshall, Haughey, Davis and Dunford (1995) found that based on Bandura's theories, only those participants who had the perception of the consequences that result from performing a particular regimen behavior

had a short term positive effect upon dietary compliance. Participant 3's (9/3/93) lack of belief went further. She noted that she both developed a "so there" attitude, in a sense "creating a counteridentity by defining oneself and one's discourses only in terms of opposition", as also seen by McLaren and da Silva in McLaren and Leonard (1993, p. 49). For Participant 3 (9/3/93), this also was defined as a need to test the reality of her DM by deliberate hyperglycemic choices. Participant 2 (8/31/93) reported her family members believed one extra food will not make a difference and so would give her extra food. Participant 11 (11/17/93) noted that when given foods he did not enjoy he refused to eat them. Colantonio (1988, p.3) similarly observed that the lay person's lack of agreement may be responsible for low adherence. In short, from this study's participants' view of following someone else's choices took away autonomy and so making one's own choices meant not following the diet. There was no way for a participant to win if he or she accepted compliance as a goal.

Sometimes participants wanted to try to settle for compliance and still found difficulties. Participants observed that barriers or increased difficulties occurred when the recommended dietary regime was different from the way they saw themselves or had previously chosen to live his or her life. D'eramo-Melkus and Demas (1989) also found the amount of behavior to be modified was a factor. To avoid the difference problem, Norton (1995) suggested that all dietary counseling begin with the patient's preferences and that modified ethnically familiar foods be included.

Participants also experienced problems when the benefits of the changes were not visible to them. Examples of participant barriers were: not believing it makes any difference or will work for you due to not experiencing a direct correlation of food intake

and blood sugar (Participant 13, 11/18/93); not considering portion control as relevant (Participant 7, 10/30/93); and the ability to go overboard for portions of a favorite food, not seeing the self as a (self) disciplinarian or that a single addition will cause harm (Participant 5, 9/11/93). Kulkarni and Thom (1992) also found that participants' food measurement was inaccurate or omitted. Living alone made it easier to avoid portion control (Participant 10, 11/11/93); as did the use of alcohol (Participant 4, 9/4/93; Participant 9, 11/8/93; Participant 11, 11/17/93 and Participant 15, 11/26/93); or having a history of compulsive eating, missing old favorite foods such as high fat ice cream (Participant 3, 9/3/93). Leininger (1988, p.18) also found people are quick to identify favorable aspects about food use in all cultures and they make choices about what to eat based on their cultural preferences.

Some of the participants found that "diabetic foods" cost more. This increased costs was a barrier or potential barrier. Participant 1 (8/24/93) noted an impact on financial independence both for the financial barrier itself and his unwillingness to spend the extra money as barriers. Hinnen (1993, p. 118), Funnell and Merrit, (1993, p. 52) and Dawson (1994) found that finances or cost had impacts on their participants choices. The other participants in this study noted other barriers which are identified as special circumstances and are also problems. They will be discussed later and as Participant 1 noted, the other major cost of good health is autonomy (8/24/93).

Context : Taste and Enjoyment

The second major context issue for diet adherence, taste/enjoyment, documented both the perceived barriers and the opportunities for independent choice. The participants

were well aware of loss of enjoyment as a barrier to adherence. Participant 2 said, "You are not supposed to enjoy your food too much"... "Eating fruit is a mistake if you enjoy it"... and "Eating when you are hungry is a mistake", (8/31/93). A similar comment, "If it tastes good you can't have it" was made by Participant 4 (9/4/93).

Taste preference while a generally personal or subjective concept, has been observed by psychological, biochemical and nutritional studies. Capaldi and Vandanbos (1991) noted taste is affected by previous experience, dislike of new foods, previous associations with similar foods or flavors, variety, post-ingestion factors, social factors and a genetically determined preference for fat (p. 42). Falcigia and Norton (1994) also noted through a monozygotic and dizygotic twin study that there appeared to be a biological basis for food tasting and therefore food preferences. Drewnowski and Rock (1995) found similar results in studying familial patterns for sensitivity in acceptability of bitter tasting vegetables such as brussel sprouts. This adds evidence for the difficulty of participants ability to change food patterns. Even educational theorists Freire and Faundez (1989, p. 17) noted that there are cultural and regional differences in among other things "taste as regards to food."

Among the participants there was a general consensus that a diet prescribed for the management of DM was not as "satisfying" (Participant 11, 11/17/93), as non-restricted diets. Among the criticisms listed, participants noted the diets were: lacking favorite foods (Participant 1, 8/24/93 and 8/31/93; Participant 2, 8/31/93; Participant 4, 9/3/93; Participant 10, 11/11/93; Participant 13, 11/18/93; Participant 14, 11/1/93 and Participant 16, 11/17/93); lacking anything that tastes good (Participant 4, 9/4/93); lacking food which is enjoyed (Participant 1 8/31/93) or ethnically appropriate food

choices (Participant 6, 9/18/93); characterized by inappropriately small servings (Participant 7, 10/30/93); and boring redundant choices particularly in health care institutions, (Participant 11, 11/17/93 and Participant 2, 8/31/93). Participant 2 who is a female, (8/31/93) felt that meat/protein limitation were more difficult for men than for women. Participant 1 (8/24/93) also noted that DM food cost more and tasted worse. The perception of choices and opportunity for independence with foods and diets will be discussed in terms of shopping, preparation and beliefs.

Health care researchers, primarily within the nutritional services, have also studied barriers to adherence. Schlundt, Rea, Kline and Pichert (1994) found their participants identified: negative emotions, resisting temptations, eating out, feeling deprived, time pressure, tempted to relapse, planning, competing priorities, social events, family, support food refusal and friends support. Marlatt (1994) suggested that regarding relapse prevention each person must learn what works for them in coping effectively with high urge situations. Schundt, Rhe, Kline and Pichert (1994) also found that although their own research had identified barriers, a personalized assessment typically was not done with patients working with dieticians to address this issue and therefore dieticians were unsuccessful in assisting their clients. In the dominant paradigm the dieticians prescribe a diet and the clients are judged on their compliance.

In an alternate view, the context of food as well as any recommended restrictions may have many meaning. Besides basic nutrition, the act of eating may be representative of many emotions and experiences. It may bring good or bad memories, provide an opportunity for rest or social interaction, success or failure, support, comfort or the lack of all or some of the personal meanings noted by the participants. Food or diet in any

externally recommended form can change that previously established pattern. Martinez (1993) found:

a person is a reflection of a multitude of environmental, sociologic, psychological, physical, and spiritual, internal and external forces that in combination account for behavioral outcomes such as those evident in self-care management of diabetes.(p.91)

Special Conditions - Eating Out

There were two special conditions acting as additional barriers to adherence. They functioned similarly to the quantitative paradigm's confounding variables by interfering with what would have been the participants' adherence. Eating out and holiday meals changed the experience of eating. Participant 6 (9/18/93) noted the value of eating out with co-workers when they were received their salaries was marred by her experience of "eating everything in sight." Participant 7 (10/30/93) noted that co-workers could be "instigators" by encouraging him to eat foods not on his diet. Participant 16 (11/27/93) noted that even other patients who were her table-mates in the communal dining room at the rehabilitation center generously would offer her food from their own meal trays. Another participant noted that food not prepared by someone who understood the dietary requirements could have hidden table sugar added (Participant 7, 10/30/93); and that a health care institution or restaurant may not stock items such as juices or diet sodas in flavors or ingredients which are allowed or enjoyed. Because of these omissions and not feeling well he is no longer able to enjoy eating out (Participant 11, 11/17/93). Schlundt, Rea, Kline and Pichert (1994) also observed that eating out was a problems for their participants.

Participant 6, (9/11/93) noted that eating out had additional problems: There is no private and clean place to give insulin, and public management of invasive procedure may offend friends or other customers. Strategies for dealing with specific food issues included: have waitress or at a friends home have the friend serve only the correct amount of food and enjoy rest as left-overs or ask for a doggy bag. This had the added benefits of "not having to cook the next day" and "nothing is wasted" (Participant 3, 9/3/93; Participant 8, 11/8/93; Participant 10, 12/2/93 and Participant 11, 11/17/93). Participant 3 found the fast food guide, provided at a American Diabetes Association Seminar, was very helpful, (9/3/93). Participant 11 (11/17/93) also suggested giving extra food to the family dog and that persons with DM should band together to lobby restaurants to have more soda pop flavors served. While Freire would have encouraged this participant's call for an active role in changing his world, he would have the participants' actions not remain limited to soda flavor or economic issues but a connect them to a struggle which goes "toward cultural and political dimensions" (1994, p. 97). The praxis would become an ongoing frame of reference and not one particular ad hoc issue.

Special Conditions - Holidays

Holidays were the hardest time of the year for some participants in both home and work environments. They were difficult because they were defined in part by unhealthy traditional foods and delayed meal times. These foods were high in calories, fat and sweets (Participant 1, 8/24/93; Participant 3, 9/3/93; Participant 4, 10/5/93 and Participant 14, 11/18/93); avoiding sweets was difficult (Participant 3, 9/3/95); one nurse-participant noted that family members of patients frequently bring in treats for the nursing staff and

that family meals for fall and winter holidays were not timed to coincide with the peak action of medications (Participant 3, 9/3/93).

Specific dietary strategies for managing this risky situation included: calming down, have a family member ration sweets (Participant 14, 11/18/93), take home a doggie bag (Participant 8, 10/30/93) and avoid having to choose between hurting feelings and hurting yourself and eat at regular times and eat less if the food is not good for you (Participant 3, 9/3/93).

Opportunities for Dietary Congruence and Integration

Freire and Faundez suggested that "any health programme [sic] should, begin by finding out what knowledge about health a particular people has" (1989 p. 92).

Paralleling Freire's and Macedo's call for subordinate students to become "actors in the reconstruction process of a new society (1987, p.159), the participants became creative cooks, shoppers and food designers in order to make the dietary restrictions more livable.

Despite the barriers to adherence previously noted they found strategies to help themselves and gladly offered their ideas to others.

The participants had many suggestions for handling the daily issue of dietary management. These included: avoid high fat meats and although it is difficult, avoid sweets (Participant 14, 11/18/93); don't fry food, use Pam (a brand of non-caloric no-stick cooking spray), Mrs. Dash's (a brand of spice and herb salt substitute), use "herbs and spices" on food and in cooking (Participant 9, 11/9/93); "cutting" down or no salt, sugar free (Participant 11, 11/17/93); serve food attractively i.e. add "fake" (non-nutritive or non-caloric) sugar to bananas, sprinkle sugar and salt after cooking so you can add less, if

diet foods taste awful "add stuff to improve taste" (Participant 16, 11/27/93); avoid sugar in coffee, keep [diet] ice tea mix, diabetic chocolates, diet jello and pudding in the house (Participant 11, 11/17/93); make foods similar to those chosen before the diagnosis (Participant 5, 9/11/93); include small amount of favorite foods and stick to the rest of the requirements (Participant 10 11/1193); have crunchy foods available (Participant 3, 9/3/93); learn and follow correct serving i.e. ice cream is a dip not a 1/4 gallon (Participant 11/11/93); meals should be balanced (meat, starch, vegetable and fruit) (Participant 13, 11/18/93); use approved "goodies" (non-caloric sweetened) as treats and use usually forbidden foods as treatment for hypoglycemia, (Participant 3, 9/3/93); don't omit requirements for other health care or dietary issues such as lactaid for lactose intolerance or potassium and fluid restrictions for renal problems (Participant 5, 9/11/93 and Participant 11, 11/17/93). Participant 11, (11/17/93) also noted that additional medical problems require additional restrictions which create even fewer food choices. Health care researchers found evidence for similar strategies. Schmit's, Rost's, McGill's and Santiago's work found that persons who skip meals and snacks and are hungry frequently add excessive carbohydrates at subsequent eating times (1994).

Other related issues were included. Participant 2 (8/31/93); Participant 7 (10/30/93); Participant 11 (11/17/93); and Participant 14, (11/18/934) observed that meal preparation and exchange calculation may fall to the spouse's responsibility rather than to the person who has DM. Both the person who has DM and the person who does the food shopping and preparation can learn the correct foods to buy, how to prepare them and judge food portions. As Participant 11 (11/17/93) noted, married couples should be supportive of each other and their integrative efforts for congruence/adherence .

Other Dietary Adherence Strategies

Other suggested strategies for following diet recommendations were: understand the rules (Participant 6, 9/18/93); don't let yourself be hungry (Participant 2, 8/31/93); ask for more if you are hungry, write down what you need to remember (Participant 9, 11/8/93); make your own daily schedule, keep a food diary of what you had to eat, how much and how you were feeling when you ate it (Participant 13, 11/18/93); be aware you are not the only one with feelings of being denied (Participant 6, 10/14/93); serve a variety of foods and have food preferences honored (Participant 11, 11/17/93). Keeping a sense of humor was suggested by Participant 5 (9/1/93); "remember your family is healthier for your habits" i.e. drinking diet soda (Participant 6, 9/18/93) and if the kitchen (at a health care facility) sends dessert, define the situation as your opportunity for making a choice (Participant 6, 10/14/93).

The two nurses who were primary participants reported that time at work sometimes seemed to hold an advantage for two reasons. Co-workers in health care observed them for compliance demonstrating group pressure, and for anyone "keeping busy" is an advantage (Participant 3, 9/3/93 and Participant 6, 9/18/93). Other participants suggested portion control using some of the following ideas: have family serve proper proportions, cooking for yourself, Meals-On-Wheels (Participant 16, 11/27/93) and have family member prepare food out of sight and limit your servings, T.V. dinners because you can't go back for seconds (Participant 11, 11/17/93); your whole family can participate (Participant 6, 9/18/93 and Participant 11, 11/17/93). A final

strategy for dealing with an urge to have something off the diet is "eat it and get it over with and understand this is part of your program" (Participant 11/23/93).

Cheating: Participants Evaluation of Dietary Compliance

All sixteen primary participants reported that they have "cheated", further, several reported that they felt everyone else who had DM also did though not everyone would admit to this practice (Participant 3, 9/3/93 and Participant 7, 10/30/93). The term "cheating" had no set definition. Participant 9 (11/8/93) defined cheating as "anything" where a participant made an alternative choice or "change" which was not following his or her diet. Participants said it should not include recommended snacks built into the diet to prevent nocturnal hypoglycemia, however two participants noted even these therapeutic interventions felt as though they were an example of cheating (Participant 11, 11/17/93 and Participant 16, 11/27/93). At the most strictly defined limit, Participant 4 (9/4/93) and Participant 11 (11/17/93) stated that anything that tasted good felt like cheating. It should be noted that these definitions did not include a relationship between eating and euglycemia and remained true even if the food in question was part of the general diet or was used therapeutically (Participant 11, 11/17/93). They were split off from the technical or health care provider's understanding that the purpose of the diet was euglycemia.

At the other extreme, participants would dispense with this self defined impossible goal. Participant 5 (9/11/93) reported talking herself into believing she had hypoglycemia so that she would have an excuse to eat candy. Another participant, Participant 13 (11/18/93) reporting she would binge when someone "hurt my feelings."

Participant 2 (8/31/93), Participant 3 (9/3/93) and Participant 11, (11/17/93) defined the problem in terms of eating junk food. This ranged from a single bite of a perceived forbidden food (Participant 2, 8/31/93) to a "pig out" (Participant 6, 9/18/93). Some other felt that changing portion size was not cheating. Changing portion size however was not to be discussed with the participant's physician (Participant 3, 9/3/93 and Participant, 7, 10/30/93). Freire reports similar efforts to hide strategies from physicians. He reported (1989, p.44) that when Guevara was working as a physician, part of his medical practice included observations of the ploys used by the people to protect themselves.

Information about this activity would only be shared with a nurse or physician if the participant would not be harassed (Participant 11, 11/17/93). This behavior can be repeated despite the belief of the consequences of, "I know I will get sick, will need more insulin, blood sugar may go up, and there is the possibility of D.K.A. or H.H.N.K.", (Participant 3, 9/3/93). When asked about why this was so common, one participant suggested that when someone else determines the diet "everything" feels like cheating (Participant 6, 10/14/93). Another suggested that the real cause of bad feelings concerning diets is not wanting to hurt yourself and because the diet doesn't cure it (Participant 1, 8/24/93). Mannucci et al. also found an increase in disturbances in eating attitudes related to anxiety with women with I.D.D.M. (1995). This constant discomfort and conflict with a required activity of daily living is a reflection of the major internal inconsistency with the dominant paradigm of diabetes education. Hernandez (1995) succinctly identifies the dominant paradigm's problem as: "take charge but comply/adhere"(p.33).

Participants' Evaluation of Successful Congruence

Participants evaluated congruence in terms of gains and losses, positive or negative impacts on their lives. They identified the loss of autonomy and loss of the pleasures of a non-restricted diet as the negatives and the knowledge that compliance doesn't cure DM. Despite these problems, participants found his or her defined goal of dietary compliance had advantages as compared to the health care provider's goal of euglycemia and possibly a daily net caloric loss (from a program of balanced calorie intake and use). Following a personally accepted and incorporated diet: makes a person: feel better, can contribute to weight loss (Participant 3, 9/3/93). Lebovitz (1994) also noted that generally that the symptoms of hyperglycemia, polydipsia, polyuria, polyphagia, weight loss and increased fatigue usually disappear at blood sugar levels of less than 200 mg/dl.

One participant felt that her own and her families eating habits improved specifically in terms of her nieces learning to choose diet soda and diet cookies (Participant 6, 9/18/93). Participant 10 (11/11/93) defined his success in weight loss. He did not own a scale however he knew of the loss by observing the loosening of his watch band. Participant 3 (9/3/93) knew she has been successful when she reached her target SMBG reading. Participant 15 (11/18/93), defined his success based on his physician's judgment. He was successful when his physician told him he was successful. He learned both his diet and compliance very well.

Medications

According to Hoyson (1995, p. 34), standard DM medication management is one of the following: OHA, insulin or a “combination” of both. None of this study’s participants were being medically managed by either diet or diet and exercise alone at the time of study. According to the participants, learning about medication was very important. Medication for the treatment of DM was mentioned in all interviews with the exception of Participant 8 (10/30/93). Participant 2 (8/31/93), reported it was the second most important thing

Insulin: An Ambivalent Proposition

All of the participants who were taking insulin had learned the required sets of skills prior to this admission. The participants (Participant 1, 8/24/93; Participant 2, 8/31/93; Participant 3, 8/31/93; Participant 4, 9/4/93; Participant 5, 9/11/93; Participant 6, 9/18/93; Participant 11, 11/17/93; Participant 14, 11/18/93; and Participant 16, 12/13/93) who discussed insulin, spoke about two visible themes. These themes of difficulties with insulin (primarily self-administration of insulin) were those which surrounded the difficulty with skill acquisition. They also had fears and anger concerning the insertion of a foreign body (a needle) into one's own or a family member's body. To a smaller extent, they also expressed a fear of insulin and or insulin induced hypoglycemia. There was also an undercurrent or a less visible theme. This undercurrent was the notation of the pressure which had to be placed on the participants either by their

instructors or by themselves to comply, however the issue of power as motivator was not critically examined.

This multi-leveled process began with being told by his or her physicians that insulin was necessary. This was described as a very difficult experience. Several participants began their first learning experience with self administration of give insulin. Participant 5 (9/11/93) noted that having to take insulin "makes diabetes real." Participant 5 further described her initiation as, "had to be threatened" by her health care professionals and was only able to learn after three weeks of denial (9/11/93). Participant 2 found it "a terrible thought" and at first refused (8/31/95). Participant 9, was denied discharge until she was able to master this set of skills (11/8/93). Although participants were able to discuss the difficulties learning the skills of insulin administration, they did not critically examine the coerciveness of the power over them or its effects on their belief of self-efficacy. Participant 3 (9/3/93) noted that in terms of medication compliance, the difficulty was not always the medication itself, "sometimes the issue is who is in charge not the medication", echoing the issue of autonomy made visible with the dietary discussion.

Other participants learned this procedure under different circumstances. This learning was split off from the experience of self injection. Participant 6 (9/18/93) and Participant 16 (11/27/93) learned the procedure of administering insulin when they gave insulin to family members before their own diagnosis. On a related issue, Participant 11 (12/2//93) noted that the required skills for learning insulin administration had changed. Since disposable syringes had become available, syringes and needles no longer had to be cleaned and boiled as a means of sterilization. Despite the procedure becoming much

less work, Participant 11 found it required new skills. Rapaport (1994) also found reactions similar to the participants' concerning invasive procedures, injections and smbg. She also noted fear of needles was a common occurrence and more importantly that it was a normal reaction.

Learning Context for Insulin Administration

The specific context of insulin is its invasive parental administration. Within this framework the participant's recommendations for insulin varied. Participant 5 (9/11/93) stated that, "the most important thing is to take it." She also recommended timeliness medications and then reported not being able to do so. Learning insulin administration techniques is frequently seen as a daunting task. It requires good perception (Participant 1, 8/24/93), however the major problem is the idea of painfully sticking oneself with a needle and the "idea of doing it", or as Participant 9 stated "needles were disgusting" (11/9/93).

Lesser problems include monitoring for the occurrence of site bleeding or bruising. Participants found this could be managed by: being gentle (Participant 3, 9/3/93); not pinching the skin "too hard" (Participant 2, 8/31/93); alternate site selection which included a comfortable one, avoiding spider and varicose veins on the legs (Participant 9, 11/8/93); and preferring a respite from self administration of insulin when hospitalized, assuming the nursing staff gives a comfortable injection (Participant 1, 8/24/93). Participant 4, felt the most important criterion was dose accuracy, (9/4/93). Other than cleansing the skin site selected, participants were not concerned with infection control techniques (Participant 3, 9/3/93).

One comment in particular showed the power of insulin. Participant 16 warned, "Don't change the dose on your own or you can die" (12/13/93). Clearly this showed her understanding of what a powerful force insulin is in her life. She learned this fear as she felt someone she knew died as the result of changing the dose of her insulin by herself. Based upon that vicarious experience, she lacked a confidence in her own emancipatory awareness or trust in her skills to consider any questioning or joint adaptation, with her physician, of her medication. This participant experienced a deep and specific embodiment of a term Freire adapts from Fromm, the "fear of freedom", (Freire, 1970 p. 31). Certainly the use of power in this part of the patient-health care provider relationship becomes visible.

Freire, Escobar, Fernandez and Guevara-Niebla looked at power in the teacher-learner relationship. They base their remarks on Gramsci's work and note that "a pedagogical relationship involves a relationship of power, of domination, but a domination conceived of not exclusively as coercion, not only as an external exercise of power, but also and basically as a consensus..." (1994 p.28). This project's participants consented to the power of their health care providers because they uncritically accepted that it was for their own good. In agreeing to learn under these conditions they also learned to be dependent which is a problematic mind-set for diabetes.

Review of the technical literature created another interesting contrast in this situation. Concerning the standard technical skills required for insulin administration, Zehrer, Hansen and Bantle (1990, p.479) and White and Campbell in Haire-Joshu (1992, p. 119-120) suggest the following teaching objectives: appropriate procedure for insulin storage, dose preparation and administration, pros and cons of various insulin regimes,

complications and treatments. These were generally consistent with the participants suggestions however they also included step by step guidelines for the procedure and included appropriate syringe disposal. One significant exception was the lack of the professional experts' notation of the necessity of avoiding the affected arm of a post-mastectomy patient. Unlike Participant 9 (11/8/93), a self-identified as a post-mastectomy patient and the knower of the necessary specialized knowledge, the above noted diabetes experts did not demonstrate an awareness of the standard post surgical recommendation for post-mastectomy patient's need to avoid, blood pressure readings, injections and venipuncture (Loeb, 1991), on the edematous affected side's arm. This difference clearly illustrates the value of the informed client for the health care provider as well as the decreased risk of injury to the participant.

When approaching this task the participants also suggested the following: take it easy, choose the proper site, for comfort and easy to reach (Participant 4, 4/4/93); "Tap the spot first if you think you are afraid or will jump when you do it (Participant 5, 9/11/93); "you will only forget it once" because of becoming so ill without it (Participant 6, 9/18/93); being accurate with the dose is easy, remember the 5 rights, "be on time...don't forget 1/2 hour before breakfast" (Participant 11, 11/17/93). This last comment showed the value of participant incorporation of the technical knowledge of insulin. Specifically this shows the now useful personal or experiential knowledge that the regular insulin or part of the mixture which is regular insulin, will have the time required to begin lowering blood sugar as the ingested food begins to raise blood sugar, with both effects keeping the person in balance, (Participant 11, 11/17/93); pre-mixed insulin such as 70/30 (70 percent intermediate acting and 30 percent regular or fast

acting) is easier to use than having to mix two types yourself (Participant 9, 11/8/93). Participant 11 also noted that some things have also changed about insulin, in that the bottle in use no longer has to be kept refrigerated (11/17/93).

Participants had learned that good technique means that injections will be comfortable and that when they experienced less physical pain the emotional pain or fear also decreased (Participant 1 8/24/93 and Participant 9, 11/23/93). They suggested learning to practice with water (Participant 5, 9/1/93 and Participant 9, 11/23/93). Participant 4 (9/4/93) noted that in order to control DM she had to learn to give herself insulin. In order to do that she had to learn to find a site where self administration was comfortable. Participant 14 also suggested alternatives for persons having physical or dexterity problems. These included have “someone else draw up” the insulin if “you have trouble seeing, then you can still give it yourself,” obtain adaptive devices, magnifying glasses help for reading (11/18/93). Somewhat in the manner of children who speak a non-standard version of their country's language(s) and became literate, these participants found creative ways to “mastering the so-called standard patterns so that they became empowered to fight for the necessary re-invention of their world” (Freire, 1993, p. 42).

Participant 6 (9/18/93) told of a different and jointly authored strategy for improvement. She found her biggest improvement with a change in the length of duration of action in her medication. With the direction of an endocrinologist her insulin was changed to a short acting type, creating a more flexible schedule. In this way the medication (physician's knowledge) followed her life style (participant's knowledge) rather than changing her life to meet her medication's safety needs. Although this

particular client was not elderly, Funnell and Merritt (1993) also made similar recommendations for elderly clients. Because of their concern for the elderly person's common day to day changes in eating habits, they felt it was critical to adapt insulin to fit eating habits, rather than fit food intake to insulin. Freire and Faundéz (1989) took a more global stance on this type of issue. They observed that:

"Scientific" knowledge only becomes scientific as it takes on board the knowledge of the people. And knowledge of the people becomes knowledge for action and effective change when it in turn takes on board in a creative way the "scientific" knowledge offered by intellectuals. (p.46)

Special Circumstances - Plan Ahead for Travel

Participant 6 (9/18/93) was the participant who spoke most about travel issues. She recommended "keeping documentation with you if you travel." This was especially true for leaving the country. She also suggested planing to obtain extra medications for extended trips . For local trips, she suggested using the host's refrigerator or a portable cooler. She further suggested that as part of her insulin-travel regime: keep checking smbg, and carrying insulin, syringes paperwork and documentation in her purse. With this type of organization, and carrying her paperwork she felt she would prevent diabetes related problems. She also found it prevented any problem of her being mistaken for a "drug addict" (9/18/93). Freire and Macedo (1987, p.127) note that this participant's world view as an Afro-American woman included "terms that encapsulate the drug culture, daily alienation, the struggle to survive ..." Her world view also included her previous employment as a nurse at a hospital across the street from a state facility which worked with many youth with substance abuse related problems (9/18/93). Health

researcher Haire-Joshu (1992, p. 624) also noted travelers with DM had extra concerns. She suggested the referral to such services as "The Diabetic Traveler" and Intermedic referral service for physicians and specialists. Peragallo-Dittko (1993) made suggestions similar to this study's participants. These included: carrying rather than sending as baggage needed supplies which included carbohydrates for hypoglycemia, snack meter and supplies, a letter from the physician about syringes, medic alert medallion, prescriptions and glucagon emergency kit. She also recommended additional plans for temperature changes and time zone changes.

Oral Hypoglycemic Agents

Participants who spoke about Oral Hypoglycemic Agents, (OHA), spoke only about skills to take them safely and correctly (Participant 1, 8/24/93; Participant 2, 8/31/93; Participant 3, 9/3/93; Participant 9, 11/8/93 and Participant 10, 11/11/93). Participants generally recommended that everyone learn about the skills which they needed. Participants taking insulin recommended that everyone one who had DM learn about insulin. They did not differentiate between his or her own needs and someone who required less invasive medical management (Participant 1, 8/24/93; Participant 2, 8/31/93; Participant 3, 8/31/93; Participant 4, 9/4/93; Participant 5, 9/11/93; Participant 6, 9/18/93; Participant 11, 11/17/93; Participant 14, 11/18/93; and Participant 16, 12/13/93).

Participant's Recommendations for Oral Hypoglycemic Agents

Participants noted that it was important to know how to take oral medications. Both of the primary participants who were nurses (Participant 3, 9/3/93 and Participant 6,

9/18/93) referred to methodology taught to nursing students as they learn to administer medications. This methodology includes teaching "the five rights." Those rights are: patient, medication, dose or amount, route or the method of administration which includes oral for swallowed pills and subcutaneous or intermuscular for most injections, and the last "right", the correct time. Segatore, Edge and Miller (1993) for example used the same standard criteria for evaluating medication dispensing performance errors.

Other research also found the issue of medication to be a large problem. Nagasawa, Smith, Barn and Fincham (1990) observed in their meta-analysis of patients' management of medication that "medications remained a problematic compliance issue both from the lack of a consistent definition and the serious impact on patients", noting for example only 47 percent and 42 percent rates as examples of compliance. Mason, Matuysuyama and Jue (1995) found that despite the potential benefits of the Sulfonylureas (predominant category of oral hypoglycemic agents), that "47 percent" of their participants were non-adherent (p.52). They also found that those judged to be compliant or adherent also experienced problems classified as operator measurement problems, non-cooperation with the study and a group of patients with good adherence but poor metabolic control indicating some under dosing by physicians. Although the important issues were defined differently from each other and from those of this study, both the participants and the health care researchers found this a significant and complicated issue.

Participant 5 (9/11/93) and Participant 9 (11/8/93) stressed the correct timing of medication and also noted this applied to diuretics. Participant 10 (11/11/93) told of an unfortunate experience of an esophageal burn secondary to not swallowing his medication with enough water. The participants noted the ongoing need for medications. Participant

15 (11/26/93) also noted his disappointment when he learned that the medication did not cure his DM and another voiced her frustration that oral medication becomes ineffective when her DM progressed to requiring insulin (Participant 2, 8/31/93). Participant 7 also noted that despite taking his medication correctly he did not feel better or worse when it was in use (11/17/93).

Other Participant Identified Skills

Before addressing the next major issue, which is monitoring, the participants discussed a variety of issues. From a clinical standpoint these issues, foot care, weight loss, weight loss, hyperglycemia, stress management and exercise are important parts of the curriculum (Franz et al., 1986). From the participants' frame of reference the issues also remained very important as is clearly seen in their concern over foot care and potential amputation. There is also a difference in the discussion of these issues. It is less extensive. This change is consistent with a lesser perceived burden of management issues impacting on their daily lives and so provides a link for this grouping of issues.

Foot Care

Participants were asked what they felt a newly diagnosed person need to learn about DM. One of the issues about which they were concerned was the potential loss of their feet and or legs. Funnel and Merritt (1993) also found this issue present for elderly participants because they are at risk for foot problems. Participant 1 (8/24/93), Participant 11 (11/17/93) and Participant 14 (11/18/93), were admitted to this study's rehabilitation facility in part to due to recent surgical amputation of lower limbs. All of

the other inpatient participants received physical therapy and ate meals on their unit or floor at tables with other patients who had undergone recent amputations. Participant 4 (9/4/93), spoke of her distress at seeing persons with this problem. Participant 3 (9/3/93) made the emotional association between amputation and food because of her difficulties managing her diet. Participant 10's remark, "Foot care is important" (11/11/93), was confirmed by Participant 1 (8/24/93) and Participant 2 (8/31/93). Participant 13 (11/18/93) believed other persons with DM would develop foot ulcers if they did not follow his or her diet (11/18/93). Because of these contexts the participants made many recommendations.

Participants wanted to avoid amputations. In their efforts to do that they made the following recommendations: don't go barefoot (Participant 11, 1/17/93); wear sox, noting that ankle sox were easiest to wear (Participant 9, 11/8/93); wear closed shoes for protection, use lanolin if your skin is dry, use a towel small enough to fit between the toes to dry feet, if you can't reach to carefully :dry between your toes after washing, "use a hair dryer without the heat," to dry them and avoid a thermal burn (Participant 9, 11/8/93). Other comments concerned shoes: don't wear old shoes and stretch out new shoes before wearing if they are too tight (Participant 10, 11/11/93). They also recommended the use the services of a podiatrist (Participant 4, 9/4/93; Participant 8, 10/30/93 and Participant 10, 11/11/93).

Health care researchers found similar risk factors and made similar recommendations. Plummer and Albert (1995) suggested an algorithm for screening and referral. In their recommendation they considered a history which included questions on toenail cutting, over soaking feet, walking barefoot, type and fit of shoes worn, smoking

behaviors, and included an assessment for: foot trauma or disease, circulation and neuropathy using the Semmes-Weinstein monofilament test to evaluate the person's ongoing ability to feel pain or discomfort so as note injury or irritation immediately.

The participant's observations were that DM can lead to amputations but good foot care can diminish the chance of requiring this procedure. These participants gave indirect evidence that he or she believed he or she could impact on this potential long term complication. In evaluating these efforts Participant 9, noted that despite washing and drying her feet and wearing sox and shoes she still acquired a fungal infection, putting her at higher risk for amputation.

Smoking

Tobacco use was discussed by only a few participants. Participant 4 (9/4/93), Participant 5 (9/11/93), Participant 11 (11/17/93) Participant 12 (11/18/93), and Participant 15 (11/26/93) all reported smoking generally was bad for a person with DM. Participant 15 (11/26/93) felt it caused cancer. Participant 12 (11/18/93) was able to reduce his smoking to "an occasional cigar" and the "second hand smoke" he inhaled while working as a bartender. Participant 11 (11/17/93) felt smoking had the health impact of the equivalent of "like inhaling sugar" and was therefore able to "stop cold turkey." Participant 5 (9/11/93) found it more difficult to stop smoking. She was able to stop only after being told she would die. Participant 4, (9/4/93), warned that although beneficial, stopping caused weight gain. Malarcher et al. (1995) found that smoking was still a common health threat for persons with diabetes and that although increased

percentages of those persons were requested by their physician to stop smoking, they were still as likely to smoke as those in the general population.

Weight Loss

Obtaining or maintaining optimum weight usually meant weight loss for the participants. Participants saw weight loss as desirable but difficult to obtain. Although connected with euglycemia, it was viewed as a separate issue. Weight loss was generally seen as something both difficult, an "aggravation" as per Participant 11 (11/17/93), and desirable, a "goal" per Participant 3 (9/3/93). For two participants it became an issue when recommended by a their physicians (Participant 8, 10/30/93 and Participant 11, 11/17/93). It remained a difficult goal to obtain (Participant 3, 9/3/93; Participant 8, 10/30/93; Participant 11, 11/17/93 and Participant 16, 11/12/93). Weight loss was seen to be primarily determined by food intake and exercise but it was also affected by an predisposition to retain or lose weight (Participant 9, 11/23/93). Weight loss was valued for: esthetics, better blood glucose control and general good health such as excess weight's role in other than DM pathophysiological processes (Participant 3, 9/3/93).

Many health care researchers found similar results. Pascale, Wing, Butler, Mullen and Bononi (1995, p. 1241) found, "weight loss to be the treatment of choice for N.I.D.D.M.", and also noted that few patients are successful in maintaining weight losses of the magnitude necessary to bring about long-term improvements in glycemic control and coronary heart disease. Another study however, noted that weight loss was not associated with improvement in mortality. Chaturvedi and Fuller (1995) noted that due to the multiple factors influencing obesity including such items as the likelihood of

difficulty maintaining a new lowered weight without fluctuation and confounding variables such as blood pressure and cholesterol, that at best only a "U" or "J" shaped curve could be observed from their multinational study. Researchers and the participants found it a complex and frustrating issue.

Concerning the frame of reference for weight loss issues, participants listed a number of problem context areas for them. Participant 11 (11/17/93) noted that advice from a "fat" physician can be ignored. Several participants noted that weight loss was affected by other disease processes which limited both the ability to formally exercise or be able to perform activities of daily living. Decreased activity caused weight gain (Participant 4, 9/4/93). They noted vascular complications (Participant 6, 9/18/93); cancer (Participant 5, 9/11/93); arthritis and joint replacement surgery (Participant 8, 10/30/93); and the affects of diuretics (Participant 9, 11/8/93) as activity limiting events in their lives.

Participants also listed a number of strategies which had been successful for them. They have used: diet and exercise (explored in separate sections), thinking about wasted money on junk foods (Participant 13, 11/13/93) or calling a friend (Participant 15, 11/26/93). Participant 11 (11/17/93) suggested that this is a process which must be approached indirectly by working toward a change in habits rather than a formal diet. Due to limited income, balance problems from C.V.A.s or amputations, not all participants use a scale to measure progress toward weight control at home. One participant did note that progress could be gauged by looking at the fit of his watch band (Participant 10, 11/11/93).

Hyperglycemia, Stress and its Management

Some of the participants linked hyperglycemia, too high blood sugar, and stress. A few participants felt knowing about stress and how to handle it was important. Participant 11 (11/17/93) felt stress could cause hyperglycemia, while Participant 16 (11/27/93) had been told that this was a factor but had not seen the results in her life. Participants did not differentiate between physical and emotional stress. They listed the following stressors: being hospitalized because a person is away from home (Participant 4, 9/4/93); being discharged from a hospitalized environment with supportive staff and fellow patients to home and independence (Participant 6, 10/14/95); infections (Participant 13, 11/18/93); feeling generally overwhelmed and seeing persons who had amputations (Participant 4, 9/4/93); a process with the specifics of stress causing overeating (Participant 3, 9/3/93) and not being able to maintain her former role of housewife (Participant 2 (8/31/93). Participants also described at length the difficulties associated with diet, medications and monitoring but did not list them separately as stressors.

Participants also had many suggestions which they felt were successful in generally relieving stress and in sticking with the program. Participants suggested increasing non-diabetes related activities such as: call a friend/buddy therapy (Participant 15, 11/26/93); ask neighbors to help (Participant 2, 8/31/93); take it easy (Participant 14, 11/18/93); to just sit quietly, or join the choir, (Participant 13, 11/18/93); bible study classes and if problems arise from DM or complications arise obtain live-in help (Participant 2, 8/31/93); family members may purchase an I.D. bracelet (i.e. Medicalert)

and place it on the participant's wrist as a reminder and a symbol of love (Participant 3, 9/3/93). Participant 5 also recommended keeping a sense of humor (9/11/93).

Researchers have looked at the role of stress and efforts to reach euglycemia. Because generic relaxation training has been used in the past for many stress related disorders and because blood glucose levels are affected by counterregulatory (stress) hormones, researchers Bailey, McGardy, and Good investigated the use of Bio-feedback (1991) with some success. Health care researchers Jennings, Morgan, and Barnett (1986, p. 390) found a "support group for persons with I.D.D.M.," improved both their knowledge and glycated hemoglobin.

Exercise

Exercise was noted as a stress-reducing strategy. It had non-stress related benefits but could also generate negative feelings (in that it could be difficult to remain motivated). Participants found it caused weight loss, lowered blood sugars, decreased nausea and vomiting, and increased spirits (Participant 2, 8/31/93); weight loss (Participant 5, 9/11/93). Despite these benefits participants noted that: people "back off when you talk" about it (Participant 2, 8/31/93), it was "harder than dieting" to actually do (Participant 8, 10/30/93); was like a diet, in that it is "hard to follow", people tend to "talk more about it than actually do it" (Participant 5, 9/11/93). Other issues which can interfere with exercise are: other illnesses such as arthritis (Participant 8, 10/30/93); cardiac limitations and their associated shortness of breath, (Participant 6, 9/18/93); fear of hypoglycemia (Participant 5, 9/11/93). Participant 16 (11/27/93) felt that this was one issue, unlike that of medication or diet, that should be determined by her. Participant 8

suggested to increase use of exercise as a blood glucose management strategy, classes should be offered in age and sedentary or ability grouping (10/30/93). Persons who exercise also needed to know of the necessity of good socks and sneakers as were other foot care recommendations for this activity (Participant 8, 10/30/93). Health care researchers found very similar results. Yamanouchi et al. (1995) tested persons who had been in good control and had no complications, found walking, which was safely performed, benefited their participants by body weight reduction and increased insulin sensitivity. Regenstenier et al. (1995) also found improvements from habitual activity in terms of lower fasting glucose values and a lowered measure of insulin resistance. The second study included persons with complications, who also showed improvement.

Monitoring

SMBG and Euglycemia

There was a difference between the meaning of Self Blood Glucose Monitoring (smbg) for the project's participants and health care providers. This difference clearly illuminates the inherent limits of the dominant paradigm in diabetes education. Since the dominant paradigm does not allow compliance for its own sake to be a visible goal, the act of monitoring in itself has no intrinsic value, other than the clinical or research application of the data. Monitoring's value becomes its measurement of glycemia. Tomky and Clark (1990) noted smbgl is a widely accepted standard practice for this visible goal, particularly for I.D.D.M. (Nathan in Lebovitz, 1994).

Participants have a different understanding or meaning for smbg. Freire's notion of knowledge and evaluation accounts for this. "Knowledge ..does not.. possess any inherent meaningfulness in and of itself but depends on the context in which such knowledge is produced and the purpose to which such knowledge is put" (McLaren in Freire, 1994, p.xvii). For the participants the issue of the meaning of smbg became confounded by context of compliance to the health care provider. The usual pattern for the context included the health care provider initiating the implementation of the procedure, the retaining the management of the data and independently changing the therapeutic modalities based on his or her interpretation of the results. As a result, smbg was reduced to a set of skills split off from a potential of self regulation.

Significantly the participants did not make this connection nor did they use this information to manage their own blood sugar. The participants' most common description of the understanding of smbg, is that it is comprised of a set of skills combined with the issue of compliance to the wishes of the health care provider (Participant 11, 11/17/93 and Participant 16, 11/27/93). Frequently the issue of evaluation of the glycemic status is separated away from monitoring and is deferred to the health care provider (Participant 10, 11/11/93). The participants divided this area into two separate issues monitoring and euglycemia. As such, both participant issues will be discussed separately. This differs from the standard health care frame of reference where the goal remains euglycemia and skills are a subset to this end.

With the exception of Participant 9 (11/17/93), who was reported being monitored with venous samples only, all of the participants who were in-patients at the rehabilitation facility were monitored at least daily, with bedside capillary blood samples

and periodic venous blood glucose monitoring. The participants described a different routine or currere that he or she maintained at home. They described their monitoring activities as varying from periods of time when no monitoring was done or done only by the physician during appointments (Participant 2, 8/31/93; Participant 5, 9/11/93; Participant 7, 11/14/93; Participant 8, 10/30/93 and Participant 14, 11/26/93); monitoring was limited to urine testing (Participant 15, 11/26/93) at present or had in the past; to the other extreme using multiple times per day for smbg (Participant 1, 8/31/93; Participant 2, 8/31/93; Participant 3, 9/3/93; Participant 4, 9/4/93; Participant 5, 9/11/93; Participant 8, 10/30/93; Participant 9, 11/23/93; Participant 11, 11/17/93; Participant 13, 11/18/93 and Participant 16, 12/12/93). Dunning (1995) also found that her participants' number of blood tests performed each day was based on personal preference and lifestyle rather than the physician's recommendation.

As noted above, the most common method of non-institutional monitoring of DM was smbg. Participants refer to it as "monitoring...blood sugar" (Participant 3, 9/3/93); using a meter to check "sugar" (Participant 4, 9/4/93); checking the blood, a blood test (Participant 8, 10/30/93); or "fingersticks" (Participant 1, 8/24/93). The parameters in which this issue was understood were: who initiated the testing, determination of whether or not the prescribed course was followed, what characteristics were considered in using the meter, what constituted a "good stick", how often testing was done, understanding and reacting to the information obtained, and alternative ways of knowing or measuring glycemia.

Both the act of smbg testing and its frequency (Participant 1, 8/24/93 and Participant 2, 8/31/93) or the lack of smbg is typically initiated by the physician

(Participant 7, 10/30/93 and Participant 15, 11/27/93). Participant 15, (11/26/93), who was using urine testing reported he would be willing to use smbg if asked to do so by his physician. Participant 11 (11/17/93) reported a previous physician had refused the participant's request to learn because the physician was afraid the participant would misuse the information by himself. The initial part of this participant's process illustrated the physician's power as gatekeeper and the participant's naive acceptance of the status quo as natural to the relationship and not an example of cultural hegemony.

Whether learning about a new meter or learning about their first meter, participants used various sources to succeed. Participants were able to describe the context of how and when monitoring was done at home. At one end of the variation, two participants had their monitoring of their blood sugar initiated by family members. These participants, Participant 5 (9/11/93) and Participant 12 (11/18/93) reported family members with access to an individual home blood sugar meter/monitor had offered to check their blood sugar at home before their diagnosis. More typically, monitoring was recommended or initiated by his or her physician (Participant 1, 8/24/93) but the practice is determined by the participant. Whether testing actually performed or not performed was the choice of the participant (Participant 4, 9/4/93 and Participant 5, 9/11/93) or family (Participant 2, 8/31/93). The ongoing part of this process illustrated the opportunity for participant autonomy and usual lack of a congruent curriculum. It also demonstrated that the participant authors his or her own currere because the final decision to monitor was based upon the participant's perceived benefits and barriers.

The participants listed the following barrier themes. They were: physical discomfort of the fingerstick, difficulty using and trusting the meter, emotional

discomfort in self or others because of an invasiveness, including dealing with the results and costs. These themes were similar to those in the 1994 Diabetes Forecast Buyers Guide suggesting the following criteria for purchasing an using smbg: expense, ease of use, accuracy, cleaning and maintenance, portability, quality assurance tasks required before performing a test, and availability of audio metering for the visually impaired (1993, p.60-1).

One major participant issue which could be defined as either a barrier or an easy task was the ability to obtain a good stick. A "good stick", meant enough blood, so that a second stick was not necessary, and did not hurt (Participant 1, 8/24/93). A bad stick caused physical discomfort. Participant 1 (8/24/93) noted smbg hurt more than insulin injections. Physical discomfort or pain was one of the issues that participants used to influence their use of smbg. The act of lancing the finger tip was considered a painful, or potentially painful experience by some participants (Participant 1, 8/24/93; Participant 2, 8/31/93; Participant 5, 9/11/93 and Participant 11, 11/17/93).

The problem of potentially painful was addressed in terms of avoidance. This was done in several ways. Pain could be minimized by improved technique (Participant 1, 8/24/93). Improved technique included: choosing the site at the side of the finger pad area in relationship to the individual's callused area from previous sticks (Participant 11, 11/17/93); making use of the numbness from neuropathy to choose a more central location (having a better blood supply) and not having the former amount of discomfort (Participant 1, 8/24/93); using comfort measure such as bathing the area with Witch Hazel (Participant 2, 8/31/93). Participant 1 (8/24/93) acknowledged that a major factor of the pain in finger stick lancing was that it was a repetitive act, which re-injured an

already lanced area. Despite his understanding of this he felt, a technically reliable alternative, using the ear lobes was not an acceptable alternative because he could not "see" himself doing this.

Elinski (1993) also acknowledged the discomfort from this repetitive procedure was a problem. The participants' major strategy to pain relief, besides good technique was to skip the procedure (Participant 1, 8/24/93). This was confirmed by Participant 2 (8/31/93) who stated she had omitted the procedure for months at a time due to the discomfort. Participant 1 (8/24/93) also noted that improved technique improved the comfort of the stick. Participant 6 (9/11/93) noted that in general improved skills gave her a sense of pride for maintaining her health. Tomky (1993, p.38-43) echoed the participants' concern for comfortable fingersticks, ease and accuracy of the meter and maintenance chores such as cleaning and testing each new batch of strips before use.

Participant 6 (9/11/93) differed from the other participants in that she was also concerned with potential problems for blood borne pathogens and infection control measures. No other participant spoke about concerns for infection control either in lancing-fingersticks technique or sharing a family member's meter. Freire and Macedo (1987) discussed a similar necessity of making infection control measures visible. They noted that in terms of prevention of fomite vectored infection and parasitic infestation, that these measures had to made part of the curriculum for them to become a visible and be managed by the literacy learner-participants.

Use of individual meters/monitors can also be viewed as a barrier or an asset. When smbg was a new skill, it required a change in routine (Participant 16, 12/13/93). The choice of brand and model of meters was based upon what other people recommend

and how much work they require (Participant 16, 12/20/93). Participant 1 (8/31/93) demonstrated the power of institutional role modeling for choice of meter by requesting a demonstration of the brand of meter chosen by staff and being at the project's site facility. Participant 5 (9/11/93) noted the lack of ease of use and trustworthy or reliable results prevented her from the continued use of her meter. Inaccurate perception of trustworthiness in a meter and one's own abilities can also be a problem; Participant 16, unknowingly demonstrated unsafe technique (applying two separate drops of blood separated by time which would give invalid results and was also inconsistent with the manufacturers recommendations for safe use). Tomky and Clark (1990) also found this type of error, which they termed a critical error despite formal instruction.

One of the aspects of DM care/management which has changed for participants, is that newer model meters are easier to use (Participant 1, 8/24/93 and Participant 11, 11/17/93). Cost however remains a potentially prohibitive factor as the single use disposable strip can cost from fifty cents to approximately one dollar (Participant 11, 12/2/93). Even accurate results can be a problem. Participant 16 reported that when her meter showed her that her blood sugar was high or varying she felt out of control and was angry (11/27/93).

Whether learning about a new meter or learning about their first meter, participants used various sources to succeed. Even though the newer meters are easier, learning to use them is a change and therefore not always seen as desirable. Participant 11 (11/17/93) suggested that the changes were like the changes in the Catholic Church's liturgy, something that he "had to go along with." Hernandez (1995) also found that learning to use a meter correctly did not always include education from a health care

provider. Her participants found their own alternatives. She also found that health care provided education was not prerequisite for what she termed a transformational experience which allowed her participants to manage DM well. Participant 1 requested instruction from health care providers (8/24/93). Participant 12 (11/18/93) suggested learning from family members. Participant 13 (11/18/93) found it easy to learn and Participant 15 (11/26/93) was willing to learn the skills.

Special Circumstances

Other problems included demands on participants' time which can interfere with a previous commitment to smbg. One participant (Participant 6, 9/18/93) in discussing both hyperglycemia and smbg, suggested that this was most difficult when it occurred or was observed via monitoring, at work. She also spoke about the difficulty of maintaining regulation with changing shift work. Being over-tired was also a problem as the resulting difficulty thinking created problems doing the test and could also be confused with the symptoms of hyperglycemia (Participant 6, 9/18/93).

Benefits of Monitoring

Being able to master the use of a smbg meter offered benefits as well as problems. There are benefits of having the immediate feedback of the numerical value and is pride in accomplishment of euglycemia (Participant 6, 9/18/93). In this way persons who use smbg have a tool to self manage his or her daily to hourly or more frequent status. Participant 11 (11/17/93) felt smbg prevented him from cheating on his diet. Other benefits noted by the participants include: meters have become simpler to use and using

them means having to make fewer trips to the laboratory for venous blood samples to be taken (Participant 11, 11/17/93 and Participant 13, 11/18/93). Venous samples were a painful procedure as per Participant 13 (11/18/93). Self monitoring was cheaper than visits to the physician's office or laboratory (Participant 4, 9/4/93 and Participant 11, 11/17/93). An additional benefit was that family could become involved; they could assist by either teaching (Participant 12, 11/18/93) or in doing the testing for the participant (Participant 4, 9/4/93).

Alternatives to Mechanical Monitoring- Signs, Symptoms and Activities

Medically, the primary purpose of monitoring is to quantify blood glucose. As noted above, participants monitor their blood sugar, have their blood sugar monitored or test their urine. They also monitor their blood sugar status indirectly by observing for signs and symptoms of hypoglycemia (Participant 2, 8/31/93; Participant 3, 9/3/93; Participant 4, 9/4/93; Participant 5, 9/1/93 and Participant 6, 9/18/93); and hyperglycemia (Participant 6, 9/18/93; Participant 7, 10/30/93; Participant 11, 11/17/93; Participant 12, 11/18/93 and Participant 13, 11/18/93). Participants recommended that all new persons be taught symptoms of hypoglycemia and hyperglycemia and in particular as Participant 8 (10/39/93) suggested that public schools teach this to all students.

The participants found the following specific activities or events could affect a blood sugar change: diet (Participant 3, 9/3/93 and Participant 13, 11/18/93); family or work stress (Participant 6, 9/18/93); exercise (Participant 2, 8/31/93 and Participant 8, 10/30/93); or infection (Participant 13, 11/18/93). Hyperglycemia was experienced as a set of symptoms. Observations were described as: "act up on me", (Participant 7,

10/30/93); a "funny sweet taste in my mouth"... and increased "going to the bathroom at night".. (polyuria) and weight loss (Participant 16, 11/27/93); tiredness and difficulty with vision (Participant 6, 9/18/93 and Participant 11, 11/17/93); polydipsia and polyuria and "fear of going into a coma" because of hyperglycemia (Participant 12, 11/18/93). Another participant however felt she had no problem with hyperglycemia because she never experienced any symptoms (Participant 2, 8/31/93). These short term complications were generally seen as the result of daily activities.

For hypoglycemia, participants noted: a difficulty thinking clearly (Participant 3, 9/3/93); "getting uncomfortable" (Participant 2, 8/31/93); or "sweating" (Participant 7, 10/30/93). They were also concerned with their immediate treatment of choice. Participant 2 (8/31/93) choose a starch food exchange (i.e. bread or crackers) because it also helped with her indigestion. Participant 4 (8/31/93) chose orange juice because it was also a favorite food; she also kept crackers with her when traveling. This participant also noted she increased her smbg when results of her fasting (before breakfast) blood sugar was not a desirable/euglycemic number.

Evaluating the Alternatives

There was no additional direct financial cost for the "alternative monitoring" experience, however the system was not without limitations. As two participants noted, interpretation of increased urination, polyuria, as a sign of hyperglycemia could be confused by the use of diuretics which are also called water pills (Participant 9, 11/8/93 and Participant 10, 11/11/93). Recalling Lebovitz's (1994) notation that generally the symptoms of hyperglycemia usually disappear at blood sugar levels of less than 200

mg/dl, this parameter effectively prevents this methodology from approaching the recommendations from the D.C.C.T. This method then, generally does not allow a person to identify hyperglycemia at or below this level of 200 mg/dl.

The participants found other issues also limited this system. Infections can cause hyperglycemia and also make a participant feel weak or tired in the absence of hyperglycemia and in this way confuse the interpretation of the symptoms (Participant 11/18/93). Two participants noted when blood sugar was too high or too low it was difficult to think (Participant 3, 9/3/93) specifically in attempting to follow the rules [diet] (Participant 4, 9/4/93). Participants also noted that other factors could distract his or her attention or ability to observe for symptoms. These were pain, paresthesias (numbness and or discomfort) (Participant 1, 8/31/93) and other illnesses and symptoms (Participant 5, 9/11/93 and Participant 9, 11/17/93). The participants defined the limits of hypoglycemia of which they were aware.

Review of the literature describes an issue not covered by the participants. Persons undergoing this phenomenon perceive it as a sudden onset of severe hypoglycemia, sometimes including a rapid loss of consciousness without experiencing any of the early or warning signs. Sperling (1988, p.61-62). Santiago, Levandoski, and Bubb in Lebovitz also discuss hypoglycemia unawareness:

This multifactored process generally occurs in persons with long standing I.D.D.M. and may be in part secondary to autonomic neuropathy and or the frequent occurrence of hypoglycemia and a loss of ability to produce the naturally occurring counterregulatory hormone glucagon (1994, p.173-4).

The participants did not discuss an awareness of hypoglycemia unawareness, it was not part of their curriculum. Eisner argues for an acknowledgment of what he termed the

"Null Curriculum" (1985, p.97) as "ignorance is not simply a neutral void; it has important effects on the kinds of options one is able to consider..."

Individual Euglycemic Goals and Short Term Complications

Even under ideal conditions, medical and individual management frequently fall short of the goal of euglycemia and problems do occur. Hypoglycemia (too low blood sugar) and hyperglycemia (too high blood sugar) are common short term complications. Hyperglycemia may continue with the possible sequela of D.K.A. (Diabetic Ketoacidosis, a potentially life threatening process based on inappropriate fat metabolism) and H.H.N.K. (Hyperglycemic hyperosmolar nonketotic syndrome, a metabolic process with extremely high blood sugar and dehydration) (Peragallo-Dittko 1993). In addition to these first hypoglycemia and hyperglycemia, that commonly affect persons with DM, some of the participants had increased the likelihood of hyperglycemia by the lack of a safe euglycemic goal and plan to reach it. Some of the participants' goals were identified as numeric and some were of general categories. Both hypoglycemia and hyperglycemia were addressed by the participants in a highly individual manner..

Not all of the persons who had glycemic goals maintained consistent monitoring efforts and in not doing so demonstrated the dichotomy between monitoring and euglycemia. Participant 11 noted that there were two things that influenced his choice of glycemic goals. He reported he was influenced first by what his physician wanted for him and by what he thought was reasonable and attainable (11/17/93 and 12/2/93). Not all of the participants who relied on their physician's tests knew what effect results had for self evaluation of their status (Participant 10, 11/11/93).

Some participants had knowledge of their physician's goals and choose to accept a different range for themselves (Participant 16, 11/27/93). Participants' goals ranged from 120 (Participant 3, 9/3/93); 160-180 (Participant 11, 11/17/93); 120-130 (Participant 14, 11/18/93); goal of 120 with usual range of 240-250 (Participant 16, 11/27/93). Participant 10 did not suggest any numerical value but said, "medium good... not perfect"... this is "ok" per his physician..." perfect is not possible" (11/11/93). Participants generally viewed the short term complications (hypoglycemia and hyperglycemia) as contingent upon their daily activities. Another did not know when to expect to feel ill from too low blood sugar and was surprised that she had no symptoms at 80, as she expected she would have some at that level (Participant 3, 9/3/93). Peragallo-Dittko (1995) noted that although "70mg/dL"(p.351) is the commonly accepted cut off for clinical hypoglycemia, that a person will have varying results as symptoms of mild, moderate or severe hypoglycemia at numbers as low as "40 mg/dL" (p. 352). The participant's minimally touched on DKA and H.H.N.K., noting only the possibility of severe health impact (Participant 16, 11/27/93 and 12/12/93).

Long Term Complications

As previously discussed, several references were made describing a mechanism of control for short term complications. The participants described a process of making choices which could affect blood sugar, these choices prevented or minimized short term complications. The participants predominantly viewed long term complications as a different matter. The participants held three views of long term complications. The first identified DM as the direct cause, with euglycemia having no relation to their

development. The second view was that hyperglycemia can cause long term complications but had no relationship to that individual's complications. The third view held that hyperglycemia of DM caused long term complications. The common thread of these views was that it was DM and not the individual control causing or being associated with complications. DM was reified as a separate causative entity.

Comments supporting the first view that euglycemia nothing to do with long term complications included Participant 11 (11/17/93) quoting what he recalled being told by a previous physician, as "You're going to be a diabetic in 10 years and you develop this with your eyes, you're going to develop this and you are going to develop that...it's not my fault."

Long term complications varied and covered many issues. Participants did not bring up any dental concerns. The one participant asked about this issue felt he was not at risk because he had previously had all his teeth pulled (Participant 15, 11/26/93). Among the complications Participant 11 felt were caused by DM and were risks for him included: eye problems, kidney and cardiovascular problems of coronary artery disease (C.A.D.), and congestive heart disease, (C.H.F.), (11/17/93). He also felt improved care and control leading to a longer life as compared to that of his mother who had DM (Participant 11, 11/17/93). He also noted that talking about the possibility that long term complication were related to hyperglycemia, was upsetting to hear.

The second view which saw DM as causing long term complications but had no relationship to that individual's complication, or lack of it was also proposed. Participant 4 (9/4/93) reported "my sugar is never up so why should I have complications.. neuropathy and vision problems." Participant 13 (11/18/93) warned that newly diagnosed

people needed to know that "if you don't keep on the diet you can get an ulcer like mine. I don't cheat...I am brittle...my ulcer is from vasculitis not diabetes."

The third view was that, "diabetes is dangerous and the implications in...many things like kidneys..." (Participant 8, 10/30/93). As a result, this participant was also concerned about DM requirements such as good foot care (Participant 8, 10/30/93). Participant 5 (9/11/93) said, "Oh God, ah well they should know.. what it can cause, because.. ah.. what do you call it?...heart trouble..yeah kidney trouble, get infections... need closed shoes..." (for foot injury protection). Participant 3 was concerned about eye disease as a result of DM (9/3/93).

Direct Evidence of a Different View

A minority alternative view, was marked by regret or punishment in relationship to already acquired long term complications. Participant 14 (11,18/93), who was a recovering from a surgical amputation, stated, "I'm sorry I didn't take care of myself." Participant 6, (9/18/93) quoted a phrase from her mother, "A hard head makes a soft behind" which described her perceived relationship between DM and her complications of cardiovascular problems and recent cerebral vascular accident (C.V.A. and commonly called a stroke) as punishment. Both participants gave direct evidence of a different understanding of DM. The differences shown by both this minority group and other indirect evidence shared from other participants and the other two understandings of the process of long term complications, is that individual perception or personal knowledge changes the meaning and implications of DM. All of these views also took into account the financial ramifications of complications: transportation problems (Participant 4,

9/4/93; Participant 6, 9/18/93 and Participant 9, 11/8/93); cost of medications (Participant 3, 9/3/93) and additional special dietary requirements (Participant 11, 11/17/93).

In another grounded theory study, Hernandez (1995) also found the initial stage of her transformation process was disorganization and was characterized by the comment "I don't care." She further found there was usually a disinterest in diabetes along with varying degrees of commitment toward managing the diabetes. Freire's and Macedo's (1987, p.13) literacy work creates a parallel picture to this situation. They suggest that there should be no surprise when members of the working class and other oppressed groups may consciously or unconsciously refuse to learn the specific cultural codes and competencies authorized by the dominant culture's view of literacy.'

The Process of the Intuitive Grasp of Reality

Just as the participants wrote individual curreres, the process of change was also individualized. Participants 5 (9/11/93) and 6 (9/18/93) noted it was "different" for everyone. The individual processes for the participants did have common features. The participants descriptions of the changes can be seen as a three staged process.

The Three Staged Process

Participants who observed parts of this process were willing to share their thoughts on why they were not able to use the information deposited on them by their health care providers. The common thread of the first stage was denial. Participants described this as "not giving it a thought and not paying attention to life style changes" (Participant 1, 8/24/93); "shrugging" it off" (Participant 8, 10/30/93). This stage of

understanding is visible by behaviors such as eating a pint of ice cream (Participant 1, 8/24/93). Initially participants believed, "I didn't think it would happen to me." As an example, one participant ignored poor sight for three months (Participant 6, 9/18/93). Participant 1 (8/24/93) had difficulty with "your body can't do what it used to do" and also noted that it is "tough" for any adolescent to follow any set of requirements. Participant 5 (9/11/93) thought that some people (including herself) were weak and undisciplined.

Participant 6 (9/18/93) noted this set of beliefs "preventing you from getting treatment." Other specific issues such as physical discomfort were barriers to smbg or gastric distress interfering with eating (Participant 2, 8/31/93). Freire (1970) and Shor in McLaren and Leonard (1993, p. 32) noted that in the lowest stage of growth from domination to critical consciousness which participants used was intransitive thought and was characterized by believing that fate is out of their hands.

Another aspect of the context of Stage One is the participants' limited understanding of their desire for autonomy. Participant 1 (8/24/93) described this as "stubbornness." He described the aspects of this as: "I do what I want", "I don't like being told what to do...I am independent...I'm a fighter..and you have to take things into your own hands." Participant 3 noted these types of feelings could be elicited in retaliation to people who "get on your case." This would occur when "families forget who is the expert". These feelings could be seen in such behaviors as "skipping insulin" for 2-3 days. The issue is, "who's in charge", not the medication (Participant 3, 9/3/93). Polansky (1995) also found that when family members acted like the "Diabetes Police" the underlying message was that you are incapable of managing your diabetes without their

active direction and criticism. He observed they were rarely successful at promoting better diabetes care. "Indeed their actions often make things worse" (Polansky, 1995, p.22).

The Second Stage was characterized as experiencing problems. As Participant 11 pointed out, not a result of being "told, nagged or aggravated" by health care workers, friends or family (11/17/93 and 12/2/93). Examples of these "enough consequences" experiences are: hypoglycemia and hyperglycemia (Participant 6, 9/18/93); having to take insulin, heart trouble, kidney trouble, getting infections, risk of foot ulcers (Participant 5, 9/11/93); kidney problems, risk of foot ulcers (Participant 8, 10/30/93); eye disease, hypertension, bladder infections (Participant 3, 9/3/93); amputations (Participant 1, 8/31/93 and Participant 15, 11/16/93). Hernandez (1995) also found the second stage which occurred was a turning point when some life event upsets the status quo and the individual is forced out of complacency to reassess living with diabetes. Freire (1970) and Shor in McLaren and Leonard (1993, p. 32) noted that in the second stage of Freire's literacy process, participants are partly empowered and they relate to problems one at a time in isolation.

Three participants noticed a follow up change in his or her understanding of DM and its requirements. Participant 8 (10/30/93) changed when he became aware of potential visual and renal problems. Participant 11 (11/17/93) changed when he developed congestive heart failure, (C H F) and Participant 13 (11/18/93) when she developed a foot ulcer. This resulting third stage was a new intuitive understanding. Participants described it as: "knuckle down," "take it to heart," "know yourself," know the possibilities of dangers, knowing long term complications and doing foot checks,

believing there is "no more free ride", knowing the norms, know the implications, "make wise choices", don't just take recommendations, accept and follow guidelines (Participant 8, 10/30/93); not letting yourself live in denial, change your view of DM (Participant 13, (11/18/93); stop smoking (Participant 5, 9/11/93); so you have to chose to be on or off the program (Participant 3, 9/3/93).

The process allowed the participants to grow past defining their struggle for autonomy as compliance versus non-compliance and begin to reach towards integration, critical awareness and congruence. In this way they gain better control over their lives with DM. The interviews were conducted in a facility with a religious affiliation as the Christmas and Epiphany Holidays approached. Since the word epiphany has also come to mean an intuitive grasp of reality through something as an event, usually simple and striking (Webster 1976, p.384), epiphany was an apt title to assign to this stage. These wise participants described a process which changed their understanding of DM from that of victim of the external factor diabetes to active participant who has control over his or her life with diabetes.

Stage Three or epiphany is a combination of the above general beliefs, set of personally accepted strategies and a wide approach of resource management. Hernandez (1995) described her last stage as the science of one and is characterized by a dramatic shift to living with diabetes. Greene, Beaudin and Byran (1991) quoted Mitlon to summarize their own finding "...what is more important is the ability to grasp the reality of a serious illness without resorting to denial or despair" (p.471).

Freire (1970) and Shor in McLaren and Leonard (1993, p. 32) noted that at the level of critical consciousness "those people begin to think holistically and critically

about their conditions reflect the highest development of thought and action. ..and sees herself or himself making the changes needed." Freire's dual work with the literacy and political literacy programs also noted a transformative process. His work always stressed the goal of integration or a capacity to adapt oneself to reality plus the critical capacity to make choices and "transform" that reality through a truly critical consciousness (Freire, 1973, p. 4). What differentiates both this project and Freire's work from the Hernandez and Greene studies is this newly gained knowledge did not belong only for the individuals who realized it. This project's participants offered their advise through the study to be used by other members of the diabetes community.

Of the persons in this study who described the change, all reported his or her change in understanding only after direct experiential learning with problems with long term complications. Participants were able to define the benefits of the third stage. As Participant 11 noted "its not about the professional's...its how you,...it works better" (12/2/93). One of Gertteis et al. (1993) participants echoed this conclusion with the following assessment, "If you feel you have a hand in it, even psychologically, I think it makes a difference." The above comment certainly this reflects one of Aronowitz's and Giroux's criteria for a postmodern education. "The values that constitute postmodern education are those of empowerment in the most profound meaning of the term. Students can appropriate the canon of legitimate thought without a prior pledge of reverence" (Aronowitz & Giroux, 1991 p.23).

The participants in this project also noted that the three staged process was not irreversible. As Participant 8 (10/30/93) pointed out, reaching the third stage did not prevent a return to previous patterns of understanding and behavior i.e. omitting smbg.

Further because this stage was initiated by the perception of additional health problems it also has an increase of health care interventions, i.e. medications for the management of hypertension, the care and work required for post-amputation gait training, or additional dietary requirements for renal (kidney) disease. This makes the new health care regime more complicated. Hinnen (1993) also noted in her own work and review of the literature that the increased complexity of a medical regimen was a barrier to compliance.

Although the third stage carries the hope of critical awareness its immediate cause is a personal burden and therefore a barrier.

Learning to Manage Resources

"Make wise choices, don't just take recommendations" (Participant 8, 10/30/93).

When participants function at a stage three level of DM management, they have learned to look for and evaluate resources. This surpasses the old barrier which Freire identified as "illusory" choice. He observed that choice remains illusory to the degree it represents the "expectations" of others (1973, p.7). These third stage participants have passed that barrier. Resources were now evaluated in terms of how they were useful to the participants. Among the resources they found could be useful were: his or her own history (Participant 3, 9/3/93; Participant 6, 9/18/93 and Participant 8, 10/30/93); family (Participant 5, 9/11/93; Participant 6, 9/18/93; Participant 10, 11/11/93; Participant 11, 11/17/93; Participant 12, 11/18/93 and Participant 13, 11/22/93); institutions which provide health care including, staff, general and patient education issues and activities (all participants); national voluntary diabetes associations and their support groups (Participant, 3, 9/3/93; Participant 11, 11/17/93 and Participant 13, 11/18/93); diagnoses

related television programming (Participant 11, 11/17/93); and ethnic or religious institutions which support DM groups (Participant 6, 9/18/93).

Participants found him or her self and family history to be very useful resources. The participants' experience with DM began in some cases as family members before his or her own diagnosis. The learning experience began as the child of a parent with DM (Participant, 3, 9/3/9; Participant 6, 9/18/93; Participant 11, 11/17/93; Participant 12, 11/18/93 and Participant 13, 11/22/93) or the spouse of a person with DM (Participant 7, 10/30/93). Although for example, Participant 9 found it a useful introduction, she also found that she did not perceive DM in the same manner as when she acquired it. She said, "I didn't really think much about it" (11/8/93). Others cited his or her beginning as part of an educational or vocational background, such as nursing for the participant, spouse or parent (Participant 3, 9/3/93; Participant 6, 9/18/93 and Participant 11, 11/17/93); or education (Participant 8, 10/30/93 and Participant 13, 11/18/93). The participants who cited family (Participant 5, 9/11/93; Participant 6, 9/18/93; Participant 10, 11/11/93 and Participant 11, 11/17/93) observed that their longer contact with the disease showed the following changes: the advent of smbg, additional dietetic foods and longer expected life span.

At the conclusion of her first interview, Participant 6, observed that the interview process itself was a valuable experience (9/18/93). She noted the difference from her usual interaction with health care workers, noting the interview process was in itself instructive because it was reflective. She stated, "You have a good idea here, nobody ever does that. "They just, even your doctor, they tell you but they don't ask" (9/18/93). This participant was able to critically identify part of "the real context," relationships that

were formally unperceived (Freire 1985, p.52). Further Freire and Faundez (1989, p.88) observe, "No one takes the trouble to ask, to inquire, since the 'incompetence' of the population is considered to be a characteristic of their nature." Wuest (1993) incorporates this back to health care. She describes why patients have the need to be given empowerment by their health care providers and calls for an alternative to this dependency. She felt that there was an important imbalance of power the relationship between families and health care providers and in quoting Levin, "we would not have to talk about empowerment if we did not disempower them in the first place"(p.217).

The dominant frame of reference frequently misses the rich resources of the experiences of the patient and the family. This project had other examples of a lack of focus on the participants' knowledge. The standard paradigm expects the patient to go to the physician and be given a diagnosis. In the real world of the participants other patterns occurred. Participant 11 and his spouse correctly identified his DM and sought treatment (Participant 11, 11/17/93). Participant 12's sister (12/2/93) offered him smbg to evaluate his blood sugar. Other participants had additional negative experiences with care health care professionals. Despite their discounting experiences at the hands of friends family and health care professionals, participants were still able to take some pride in his or her skill acquisition (Participant 6, 9/18/93). They felt their experience, in particular identifying and managing hypoglycemia, made them "experts" (Participant 3, 9/3/93). Unfortunately this pride and expertise was not always honored by family and coworkers (Participant 3, 9/3/93 and Participant 6, 9/18/93).

Managing Resources: Significant Others

DM is primarily experienced not in a hospital or rehabilitation center but at home with friends and family. The context of personal meaning of DM is set in part against the background of the participant's significant others. Many of their comments concerning family were discussed in terms of the participant's desire for self direction, independence and respect (Participant 1, 8/3/1/93; Participant 3, 9/3/93; Participant 11, 11/17/93 and Participant 13, 11/18/93). Participants primarily identified that their family members played an important role in their DM management and discussed his or her DM as it related to them.

Two participants also discussed DM in terms there relationship to close friends (Participant 8, 10/30/93) and other members of the religious order to which she belonged (Participant 13, 11/18/93). Participants also noted they had an extra responsibility other persons did not. They warned, "don't worry your family" (Participant 12, 12/8/93), burden your family (Participant 4, 9/4/93), or burden your friends (Participant 8, 10/30/93). Participant 3 also noted that caring for an ill parent can also interfere with dealing with DM first (9/3/93).

What Families Need to Know

Participant 8 noted that one of his of the things he wished to do was avoid adding the burden of his DM to his significant others (10/30/93). In part this was because, participants felt the family must have some knowledge of DM in order to be helpful. Participants varied their knowledge recommendations from "everything" (Participant 2,

8/31/93; Participant 10, 11/11/93; Participant 15, 11/26/93 and Participant 16, 11/27/93) to "nothing" (Participant 8, 10/30/93 and Participant 10, 11/11/93). Although Participant 10 stated there was nothing families "had" to learn he delayed his own instruction until family could be present (12/2/93). When asked what "everything" meant, the participants specifically noted the following: recognition and treatment for hypoglycemia (Participant 14, 11/18/93 and Participant 16, 11/27/93); learn and give insulin (Participant 6, 9/18/93; Participant 12, 11/18/93 and Participant 13, 11/23/93); learn and do smbg (Participant 11, 11/17/93 and Participant 12, 11/18/93); and learn and do foot care (Participant 4, 9/4/93). They also discussed "diet and nagging" at length as well as how to be emotionally supportive and listed a number of other helpful activities.

Dietary Gatekeepers.

One of the diet-related roles family members perform is gatekeeper. A dietary gatekeeper purchases, prepares and serves food portions as he or she (not the participant) chooses (Participant 11, 11/17/93). Participant's described their family-gatekeepers as creating over or incorrect feeding problems by: not having food choices consistent with the participant's understanding of the diet or saying "why should I bother they don't stay on the diet anyway" or using food to try to control the person (Participant 3, 9/3/93); serve an incorrect portion (Participant 7, 10/30/93); not serving food at the appropriate time, not asking ahead of time if choices are "on the diet", or providing acceptable alternatives (Participant 4, 9/4/93).

Gatekeeper as "bad food" pusher was also a problem. Family or friends or co-workers could also encourage or dispense usually forbidden foods as correct treatment for

complications (Participant 7, 10/30/93 and Participant 11, 11/17/93); as a treat, which was not consistent with the diet but acceptable since someone else had made the choice (Participant 2, 8/31/93; Participant 11, 11/17/93 and Participant 14, 11/18/93) or alternatively as Participant 8 was aware, offering food with the likelihood of potential weight gain and harm to his health (10/30/93).

Participants had different reactions to significant others who made poor food choices. In reacting to the role of treat-giver-gatekeeper, Participant 2 felt it was "mean" to deny family members the pleasure of giving treats (8/31/93) while Participant 11 understood that family members were caught between wanting to keep the person safe and wanting to provide treats (11/17/93). Another saw this as resulting from family members not understanding the diet (Participant 4, 9/4/93).

Nagging, The Gatekeeper's Tool.

Gatekeepers also limited or decreased food in choice or amounts. The major strategy for this task is nagging, also described as, "reminding" and "giving hell" (Participant 7, 10/30/93 and Participant 14, 11/18/93). Participants saw this role as almost always negative but with a small occasional potential if done in a modified form. Participant 11, who found nagging not useful and unhelpful said that he would rather "go to confession" than be nagged (11/17/93). Participant 16, suggested, "don't nag...just tell me I can't have it" (11/27/93). Participant 11 noted that when family member nags, "good advice can come out as nagging" and "you may know they are trying to help you and you don't want to listen" (11/17/93). Polonsky (1995, p.24) made very similar

observations: "They fail because everyone has a need to be independent, to control his own behavior, and to make his own decisions, especially with regard to health care."

Nagging can vary widely in its content and interpretation. Participant 15 reported a positive experience with his adult children who nagged him into following his diet by saying, "Stay alive Dad" (11/16/93). While Participant 6 noted families caused increased guilt for her taking "one bite of forbidden food" (9/18/93). Participant 11 (11/17/93) found family members could accuse him or ask him "Why did you snack on food not on the diet?" Participant 2, was comfortable with her family members telling her "what to do" (8/31/93).

Two participants suggested that grandchildren were exempt from creating problems. Grandchildren ask any question or eat forbidden foods in front of the participant (Participant 7, 10/30/93) because they are too young, and always mean well (Participant 14, 11/18/93). Participant 7 felt that family can let you know "once in a while" (10/30/93). One participant switched to the role of family suggesting that it was her responsibility, "as a diabetic parent to keep after diabetic" adult children (Participant 5, 9/11/93). Another participant also urged his adult children to be tested for DM (Participant 12, 12/2/93). One participant suggested that one of the reasons for the difference in opinion between himself and his adult children was that they had different value systems, such as having difficulty wasting food or throwing away old poorly fitting shoes after having lived through the Great Depression when his children had not learned this need to save or conserve resources (Participant 10, 11/11/93).

When participants felt they did not wish to accept advice from their significant other they noted two general strategies that were sometimes difficult but worked:

avoidance, and "tell them to just back off and tell them where to go" (Participant 3, 9/3/93 and Participant 7, 10/30/93). Participant 11 suggested that family members try "to understand the aggravation you have and to try to make each other content, not to bicker and argue" (11/17/93). Authors Rubin, Bierman and Toohey (1992) made the following recommendations for families: address your own fears first, don't act like a police officer, do not ignore diabetes, do not tempt, do not talk about your loved one's diabetes in public unless invited to do so, offer extra support and comfort when things aren't going well, have patience, find out what works and use it, keep a sense of humor. Norris (1969, 1990) also found the person affected with an illness had to begin the process of giving support to family members and that family members need to understand that they may need to set limits on the patient's behavior.

Besides acting as gatekeepers, family members were also able to help by performing tasks. This role may vary from family member to family member. In some families adult children or one particular child may take over part or all of the decision making role (Participant 10, 11/11/93 and Participant 14, 11/26/93). Participants felt that task doers should be knowledgeable. Among the tasks that the participants noted that family members had found helpful in the past were: know what's going on, to keep an eye on problems, make appointments with podiatrist (Participant 10, 11/11/93); when to call the physician (Participant 15, 11/26/93) and when to go to the physician, can choose healthy activities; get you to medical care, to go to the physicians office with you, this may include having to leave work, and also do foot care (Participant 4, 9/4/93); spoil the patient or allow them special status, do household chores and intervene when problems occur with nursing staff in institutions (Participant 2, 8/31/93); give insulin, cash checks

for you..."just go and see what you can do" (Participant 6, 10/14/93); smbg (Participant 12, 11/18/93); provide transportation to medical appointments and do shopping (Participant 16, 11/27/93).

Net Result for Families.

Participants noted there were both problems and benefits for his or her family members. Two participants (Participant 6, 9/18/93 and Participant 8, 10/30/93) spoke of DM as a burden, while others listed what duties families ought to do to help. Participants were also able to identify benefits for themselves or his or her family. They listed them as: my family has learned to eat better, I have pride in good health, (Participant 6, 9/18/93); special status (Participant 2, 8/31/93 and Participant 8, 10/30/93); "I have had my kids tested" (Participant 12, 12/8/93); people respect you for making decisions, family members can take time off from work (Participant 2, 8/31/93). In general participants suggested that "you trust your family" (Participant 12, 12/8/93), but to be aware that friends may become "afraid and back off" from the relationship (Participant 3, 9/3/93). Members of the study were able to identify what they wanted his or her family to do, what their family did, and areas where they felt problems had occurred and potential solutions.

Characteristics and Management of Institutions

One of the experiences common to all of the participants was their contact with health care institutions and health care providers. As Illich noted over twenty-five years ago, "Rich and poor alike depend on schools and hospitals which guide their lives, form their world view, and define for them what is legitimate and what is not" (1970, p.3).

Twenty years ago he also spoke about a physician based health care and said, "...it obscures the political conditions that render the society unhealthy; and it tends to mystify and to expropriate the power of the individual to heal himself and to shape his or her environment" (1976, p.90).

On an individual level, each participant has learned how to judge the adequacy of the general services, professional staff and educational experiences provided. On the level of social groups, these evaluations generally did not include a critical understanding as to why these situations "were produced or reproduced over time to reproduce the ideology of the dominant classes...preserving their power" (Aronowitz & Giroux 1991, p.31).

Among the general problems which affected their experiences with DM, the participants listed the following: access to the institution (Participant 13, 11/23/93); following the hospital's routine, not his or her own (Participant 1, 8/24/93 and Participant 4, 9/4/93); noise, no sleep, no access to usual health care providers (Participant 4, 9/4/93); dress code (Participant 5, 9/11/93); inappropriate or boring food (Participant 11, 11/17/93); wrong food (Participant 6, 10/14/93 and Participant 10, 11/11/93); losing contact with small children in the family to the point where he/she does not recognizes you and worries about managing after discharge (Participant 6, 9/18/93). Freire and Faundez noted a remarkably similar list of areas for contention and resistance. They noted "where the process imposes needs by determining what the people should eat, drink, hear, wear and learn" (1989, p.84).

General Recommendations for Institutional Reform

Participants viewed health care institutions as providers of service. While they evaluated the services they did or did not receive, there was little connection for example between the lack of choices and the dependency that health care fosters. Although some participants had begun the process of critical consciousness toward individual aspects and occurrences in their experience they did not generally note that these were reflective of the “uncontested meanings” and corresponding relations in the larger society (da Silva & McLaren, 1993, p.39).

Participant 13 (11/23/93) began this issue with transportation which did not tax her physical limitations. Participant 11 noted affordability as an issue for health care services (12/2/93). Other participants wanted scheduled activities, which were quieter, less tiring, allowed for choice in dress (Participant 5, 9/11/93); timing of activities, and more contact with family (Participant 1, 8/31/93; Participant 4, 9/4/93; Participant 6, 9/18/93 and Participant 16, 11/27/93). Participants wanted the following institutional dietary provisions: provide Mrs. Dash's, a brand of non-salt herb mix (Participant 13, 11/18/93); avoid serving the same boring food choices, ask patient preferences, add more variety (Participant 11, 11/17/93).

Participant 11 (11/17/93) also suggested using the in-patient identification bracelet. He suggested the use of color coded bracelets to protect patients from either their own or staff and volunteers errors of incorrectly serving meals and snacks (Participant 16, 12/13/93). This suggestion has a different context from some of the others. In fact some of the patients served at the rehabilitation facility had health care

problems which included aphasia or cognitive impairment to the degree that he or she would be unable to remember having DM. In these cases the issue's context appears to revolve only around safety. For that majority, the colored bracelet then would take away the individual's active choice and function more closely to Hester Prynne's "A". Freire (1985, p.53) analyzed this type of process when he said, "At the bottom, when the dominated classes reproduce the dominator's style of life, it is because the dominators live 'within' the dominated."

Some health care research on the issue of institutional improvement used interesting forms of language. These studies looked at what patients, who are usually labeled "customers", want from the health care institutions. Based on this language and their claim to the health care business paradigm, studies fit the management or marketing perspective. As Dube, Trudeau, and Belanger (1994)²³⁹⁴ were concerned with "surviving in the competitive jungle of the 1990s, administrative dieticians have been forced to focus their concerns on patient satisfaction", they found patient's perceptions of food service were concerned with: food quality, service timeliness, service reliability, food temperature, attitude of staff who deliver menus and serve meals, and customization.

Managing Health Care Teachers

There is a major difference between the dominant paradigm and the participants' more critical paradigm for diabetes management. It can be seen in the language and emphasis in the area "health care resources." Franz et al.'s "Goals for Diabetes Education" has a section entitled "Benefits and Use of Health Care Systems." This

section instructs the patient how to properly use the health care system to obtain its benefits (1986, p. 4).

The participants cover this issue differently. They include the need to more critically evaluate these services. The differences between the two curricula parallel those in literacy education programs. As an example, a literacy program in Texas claims to teach functional job acquisition skills. That program included skills such as how to present for an interview but omitted such skills as "collective wage bargaining, rights of organized labor, rights of tenant" etc. (Lankshear, in McLaren and Leonard 1994, p.90). Neither standard curriculum teaches its participants to criticize itself.

On their own, this project's participants found that learning to manage staff was an important skill. As Participant 1 noted, patients are dependent upon the technical skills of each staff person, (8/31/93). The participants found they had to deal with many health care providers (Participant 5, 9/11/93). Of these, four major health care disciplines and four sub-specialties were listed as potentially helpful resources for learning DM self management skills. Among the categories listed were: registered dietician at both hospitals and rehabilitation centers (Participant 8, 10/30/93; Participant 13, 11/18/93 and Participant 15, 11/26/93); physician (Participant 1, 8/31/93; Participant 8, 10/30/93; Participant 9, 11/8/93; Participant 10, 11/11/93; Participant 12, 11/18/93; Participant 14, 11/18/93 and Participant 15, 11/26/93); including physician-specialist (Participant 3, 9/3/93 and Participant 16, 11/27/93); or specifically endocrinologist and psychiatrist (Participant 11, 11/17/93 and Participant 12, 11/18/93); family practice physician (Participant 12, 11/18/93 and Participant 16, 11/27/93); nurses in hospitals and visiting nurses (Participant 3, 9/3/93 and Participant 4, 9/4/93); and social workers (Participant 4,

9/4/93). While they knew these persons as resources they also knew they may not be helpful. As Participant 6 cautioned, persons with DM should be aware that nurses and doctors are bound by rules and so may ignore your knowledge (9/18/93). Unfortunately Exercise Physiologists were not listed by these participants.

Criteria for Staff Evaluation: Respect

The participants shared one of the radical educators prerequisites for education attitude, respect. Freire (1993, p.11) requires that schools "respect the 'ways of being' of students." Participants were looking for staff who kept the participant involved in the management process. They also looked for an attitude of respect, and coming out of that respect, a technical competency. Freire (1993, p.11) also requires a similar "permanent ongoing preparation for teachers based on "reflection on practice" as a part of a plan for schooling reform.

Nurses and dieticians were frequently grouped together as fellow educators by the participants. Participants were looking to find the following characteristics in these health care providers: those persons were honest (Participant 11, 11/17/93); up to acknowledging expected problems and their management (Participant 10, 11/11/93); provide access to new technology (Participant 1, 8/24/93); would let you know about treatment changes (Participant 16, 12/13/93); would be an appropriate gatekeeper to technology or would share new knowledge with participants (Participant 1, 8/24/93 and Participant 16, 11/27/93). Staff should avoid responding to hyperglycemia by demanding "What did you eat?". Instead they should ask, "What has been going on?". They should not "gossip" about patients, talk down to them or treat them as a "naughty child". They

should treat patients "like adults" (Participant 13, 11/18/93). Staff should also have a sense of humor (Participant 5, 9/11/93).

Freire's praxis would provide the alternative these participants tried to choose for themselves. He noted that there are two interrelated contexts for adult literacy programs. The first calls for "authentic dialogue between learners and educators as equally knowing subjects." The second is the "context of facts...the social reality in which men [sic] live" (1985, p.51).

Other health care researchers had similar findings. Messner (1993, p.39-41) found that patients were able to identify what they wanted from their nurses. Her codification of their comments included: "really listen to me; ask me what I think; don't dismiss my concerns; don't treat me like a disease, treat me like a person; talk to me, not at me; respect my privacy, don't keep me waiting; don't tell me what to do without telling me how to do it; keep me informed; remember who I used to be; and let me know you care". Kane (1993) also found in his group of elderly patients in acute care hospitals, that hospital care givers do not properly brief patients about his or her condition. Kane found this led to fear and anxiety. Gerteis et al. (1993) also found that patients want respect for their personal property, coordinated care, communication from service providers, physical and emotional care including pain management, involvement of family and friends and good transition and continuity from one place to another.

Technical competency within the specific discipline was also important to the participants. They "should know what they are doing" (Participant 10, 12/2/93). Cross trained service providers were not seen as desirable, as Participant 14 observed, diet should be taught by a dietician, not a nurse (11/18/93). Participants expected nurses to

have the following competencies: able to wrap a stump (residual limb after an amputation) comfortably and correctly... able to a "good" fingerstick and give a good or comfortable injection (Participant 1 8/24/93); have experience, not be too "young" (Participant 10, 12/2/93); and as noted above be able to do a "good stick" for smbg (Participant 11, 11/17/93). Staff should also report appropriate information to other staff as repeating the same information is a burden to patients (Participant 1, 8/31/93).

Evaluation of Physicians

The participants had the same thematic requirements for good physician-educators, respect and technical abilities but used different criteria to evaluate them. Physicians must be knowledgeable concerning: when to share information that a patient will be "able to handle" (Participant 1, 8/24/93); when to hospitalize (Participant 15, 11/26/93); how to determine diet (Participant 16, 11/27/93); insulin and dose (Participant 6, 9/18/93 and Participant 16, 11/27/93); when and how to monitor (Participant 11, 11/17/93 and Participant 15, 11/26/93).

A physician shows respect by: "taking an interest in you, so you can tell the truth," knows when to tell what and "chooses words" which do not frighten a patient (Participant 11, 11/17/93); listens and negotiates with you so that medication that will fit your life (Participant 6, 9/18/93); offers you encouragement when it is deserved, and does not make sarcastic comments such as "You want a prize?" .. for weight loss, (Participant 8, 10/30/93 and Participant 11, 11/17/93). A physician may also show respect by accepting your opinion of brittleness and looks for all possible reasons of high and low blood sugar other than dietary non-compliance (Participant 13, 11/18/93) or

taking into account learning style, and not making sarcastic comments such as "are you writing a book?" (Participant 13, 11/18/93); or doesn't "give the patient hell" ... or yell (Participant 11, 11/17/93). A physician should be aware that criticism may be difficult to hear from him or her (Participant 13, 11/18/93). A physician should not keep information to himself or herself (Participant 10, 11/11/93).

Another way to show respect, specifically for a participant's time was accessibility. Physicians should keep appointments, be available more than two days per week, "keep you up to date about changes" in his or her planned retirement, and availability of office hours more than two days per week (Participant 4, 10/5/93). Appointments should be available, patients should not be waiting beyond his or her appointment time (Participant 3, 9/3/93 and Participant 15, 11/26/93). Physicians should see the whole person not a set of symptoms and should not view managing DM as a burden. Too many specialists and not enough coordination made one participant feel as though she were an automobile going to a mechanic (Participant 5, 9/11/93). The lack of house calls made Participant 13 feel as though her "life wasn't worth much", to her physician (Participant 9, 11/8/93). One of Kane's (1993, p.3) participants echoed this type of feeling when it was time for her discharge, she felt "pushed aside." Participant 6 preferred that her physician be the same sex and same ethnic background (9/18/93).

Health care research showed similar results and comments. Bonheim (1983) noted when Diabetes Forecast surveyed its membership, it found persons with DM looked for the following in their physicians: kindness, calming, reassures, teaches in lay person's language, supplies them with diabetes literature, encourages attendance at classes. Bonheim also found the respondents also had differences as to the desired

amount of authority in the relationship, many preferred an open relationship and flexibility and wished to be listened to and have their suggestions considered. The survey found communication to be the key but also warned the personality style was not a substitute for: a clinical understanding of the disease, a consistent attendance at continuing education opportunities, and appropriate referrals to specialists.

Concerning the technical expertise aspect of the relationship, researchers noted that there have been professional standards for care to be offered since 1989; these were revised in 1994 (Roberts, 1994). These included goals for blood glucose control, treatment recommendations for blood lipids (fats), hypertension (high blood pressure) and kidney disease. These studies prescribe an interdisciplinary team approach. Other studies found results similar to these participants' emphasis on the personal. Kane (1993) who worked with elderly, "over 50" [sic], compared his participants with younger studies, finding both groups tended to evaluate care from the interpersonal rather than the technical standpoint.

While the participants generally addressed the problems as individual issues, Freire and Faundez (1989) looked at these issues in a more problem posing stance. They pointed out two examples of the radical-political approach required a "communion" with the people to be served. Speaking about the importance of the role of health education they said:

Their really important and fundamental role will be all the greater and all the more substantially democratic if, as they place themselves at the service of the interests of the working classes, they will never attempt to manipulate them by means of their scientific or technical competence or their language and skill with words. The more seriously they seek to play a complementary role, the more they discover the need to bring together "feeling" and "understanding" of the world. To the critical understanding of reality must be added sensitivity to reality, and to attain this sensitivity or develop it they need communion with the masses.

Intellectuals need to discover that their critical capacity is of neither greater nor less worth than the sensitivity of the people. Both are required for an understanding of reality (p.29).

Professional Relationships

Returning to the comments of Participant 1, patients are dependent upon the technical skills of each staff person (8/31/93). Participants were well aware of the power that staff had acquired. In particular in-patient staff members can make "life miserable" (Participant 5, 9/11/93). Other comments included, "Don't cause trouble" for staff because they can "aggravate" you (Participant 11, 11/17/93). Participant 4, reported she felt caught between reporting a problem and causing trouble (10/5/93). Not feeling secure enough to report problems or not having needs met caused resentment for Participant 5 (9/11/93).

Other participants had a major strategy for what to do about an unsatisfactory professional person: "Get a new one!" (Participant 3, 9/3/93; Participant 6, 9/18/93 and Participant 15, 11/26/93). Participants had various suggestions as to how to obtain a replacement: don't argue with a doctor (Participant 16, 11/27/93); choose a good one and work with him [sic]... look around, avoid "if just in it for the money" (Participant 15, 11/26/93). One of Kane's (1993, p. 12) participants echoed the power in the relationship stating, "If you offend them, then you're lost." The symptoms of the unbalanced and authoritarian power between themselves and physicians' were visible. They deferred to the physicians and other health care providers official knowledge. They did not view the imbalance as socially created. It seemed to be a natural though resented part of their lives.

Managing Curriculum and Instruction

Participants were able to describe his or her view of a positive educational experience. They wished to be treated with respect as unique individuals (Participant 5, 9/11/93 and Participant 6, 9/18/93); and as adults (Participant 13, 11/18/93). They wished to be taught by someone who spoke his or her primary language so that they could be better understood (Participant 14, 11/18/93). This even applied to a citizen of the U.K. who suggested a "British English" class (Participant 5, 9/11/93). Freire and Faundez (1989, p.120) suggested a rationale for this as there is a "different logic in the local languages spoken by the ethnic groups".

Most participants wanted classes (Participant 5, 9/11/93; Participant 9, 11/8/93 and Participant 15, 11/26/93); support groups and seminars (Participant 3, 9/3/93 and Participant 6, 9/18/93). Families should be able to attend (Participant 10, 11/11/93). Classes should be aged grouped (Participant 5, 11/17/93) and offered to both seniors groups and in schools for students (Participant 8, 10/30/93). Facilities which are were known to have DM educational opportunities were hospitals (Participant 11, 11/17/93); rehabilitation centers (Participant 3, 9/3/93); out-patient clinics (Participant 9, 11/8/93); HMOs (Participant 5, 11/17/93 and Participant 8, 10/30/93); and religious institutions (Participant 3, 9/3/93).

Participants as Beginners and Experts

One participant preferred individual instruction because she "liked to keep to herself" preferring one on one questions which could be asked and answered immediately

(Participant 4, 10/5/93). Her request shows a valuing of her individual needs over that of a group process. Shor in McLaren and Leonard (1990) discussed this issue in Freire's work noting the United States idiosyncratic "runaway individualism" (1990, p.33).

The dominant paradigm or mainstream education also honors the problem of balancing the needs of the individual against the needs of the group. Although generally unable to offer individual instruction, groups are divided by standardized ability level (Goodlad, 1984). Their research supports this view, that group instruction was not without its solvable problems. Jagacinski and Nicholls (1987, p.107) identified one aspect of this problem with group learning. They found that one of the factors which can be a problem in group learning is that participants may need to out perform others or do as well with less effort.

A second participant suggested classes but also stressed her need for an Afro-American program including a cooking class and enhancing her own skills by seeking someone else out with DM so that she could speak with him or her (Participant 6, 9/18/93). Ahjevych and Berhard (1994, p.86) also called for culturally competent health-promotion interventions which would include an assessment of the lifestyle of the persons served. Several participants suggested classes as the primary method of instruction (Participant 3, 9/3/93; Participant 5, 11/17/93; Participant 8, 10/30/93; Participant 9, 11/8/93; Participant 11, 11/17/93 and Participant 16, 11/27/93). Two participants further suggested that classes be divided up into sections for Beginners and later Seniors Seminars for more experienced persons with DM (Participant 3, 9/3/93 and Participant 16, 11/27/93).

Rx: A Dose of Currere for Beginners and Experts

Many of the participants felt group instruction could be very helpful. These participants were able to describe the a positive educational experience. One participant began with the suggestion that learning should be "bit by bit", not all at once (Participant 2, 8/31/93). Educational praxis as cited by Freire also supports moving gradually from words of less to those of greater difficulty. Traditional health care educators, Joos, Nelson and Lyness also suggest that learning needs to be distributed over time (1985, p.131). Diabetes researchers found this may be particularly necessary as they noted persons with N.I.D.D.M. had impaired control of their learning abilities particularly when they had "elevated serum triglycerides" (Helkala, Niskanen, Viinamki, Partanen and Uusitupa, 1995, p. 681).

Participant 5 (9/11/93) continued with the suggestion that learners should be grouped by age, with specific classes for children as she feels they are capable of learning "much more than they are given credit for." Freire and Faundez (1989, p. 126) proposed similar divisions: "divided by age, sex and their role in society," as they could each develop their own texts to restructure their lives. Hinnen (1993) also suggested stratifying classes but recommended only a division between adults and children. She based this recommendation upon a differentiation for adults needing to learn through experience and children through play.

Instruction such as classes should have videos and pamphlets (Participant 6, 9/18/93). The classes should not however consist only of someone who would "just hand out pamphlets." Even well prepared written material could be a problem. Unsuccessfully

trying to read written materials was a particularly difficult problem for a participant without his prescription glasses, something not always available during a hospitalization (Participant 7, 10/30/93).

Participants and health care researchers observed a difference between the potential value of group process and what actually occurred. Participants found that there was benefit from the group experience whether it was class or support group. Participant 5 felt her that motivation came from outside herself and could be enhanced by this type of experience (9/11/93). Group experience could also provide a place to: obtain support, good for change i.e. self esteem (Participant 3, 9/3/93); a place to express feelings such as shame (Participant 5, 9/11/93).

Health care research also observed that the noted that the learner's emotional content is not always addressed. Funnell and Herman (1995) survey Michigan Nursing Homes. Although they found other improvements over previous survey, their 1991 work showed no (n=0) policies or practice addressing the psychosocial adjustment to diabetes. Similarly Walker et al. concluded in their study via medical record audit, that despite professional staff members previous agreement to offer diabetes referrals and education, services were not offered. They used education researcher Goodlad's words "often innovations that are thought to have failed really have not; they were never really implemented" (1995, p.1292). Participant 6 also felt that this project's interview would be a helpful additional intervention to the learning process (9/18/93).

The participants' commitment to a group experience varied. Participant 5 noted that offering classes did not guarantee that a person would attend. She suggested a tutoring program for those who did not wish to attend classes (9/11/93). Alternatively,

Participant 3 felt the her group experiences were so worthwhile to her that she would encourage participation to everyone even if the person was not an innate group learner. She felt the benefits outweighed the discomforts of shyness (9/3/99 and 10/22/93).

Expert's Seminars

No participant felt a beginners class was appropriate for him or herself. They did however have a suggestions for both beginners and expert classes. As an introduction, one of the two school teachers in the group suggested sharing class objectives in advance so that the person could decide whether or not the class was appropriate for him or her (Participant 13, 11/18/93). There was a wide variety of topics for experts, as Participant 8 observed "you can never learn enough" (10/30/93). Suggestions for seminar topics included: changes such as the change to smbg from urine testing (Participant 15, 11/26/93); and new material and advances (Participant 1, 8/24/93). Participant 6 (9/18/93) felt the interview and reflection process used in this project was an advantage. Participant 1 was the only person to mention the insulin pump and he found the concept unacceptable for himself (8/24/93). Participant 3 recommended a fast food guide (9/3/93). Participant 16 suggested that in addition to classes that a newsletter be developed for whom she termed, "old-timers" (11/27/935).

Health care researchers found also found benefits to ongoing educational programs. When Devine and Reifschneider (1995) reviewed persons' with hypertension compliance with medication, monitoring and relaxation techniques, they found the need for ongoing education based on the large effect on knowledge and positive effect on compliance with health care appointments. Anderson et al. (1995) found their

empowered (using the term within the personal paradigm rather than the radical sense) program was effective in addressing the ongoing problems of living with diabetes, improving both glycated hemoglobin and self efficacy scale as a measure of participant management ability and positive integration of diabetes and their lives. Ahijevych and Bernhard (1994) found Afro-American women, as Participant 6 identified herself (9/18/95), were likely, having had a medical diagnosis, to participate in a health promoting life style. These studies found that education has been able to overcome some of these obstacles and make some improvements in the lives of persons with DM.

Beginner's Classes

Although the participants felt they were beyond this level, they did make specific suggestions for newcomers to DM. The participants' suggestions for beginners classes included: long term disease with complications (Participant 1, 8/24/93); know your medications (Participant 7, 10/30/93); smbg, A1c glycosated/glycated hemoglobin test, obtaining regular medical care, preventing complications (Participant 8, 10/30/93); diet (Participant 14, 11/18/93); diet, obtaining regular medical care and blood testing (Participant 10, 11/11/93); booklets with dietary exchange lists, video instruction for smbg, getting Diabetes Forecast (Participant 11, 11/17/93); "Stay on the diet!" (Participant 13, 11/18/93); avoiding dangers, learn about the pathophysiological disease process (Participant 16, 11/27/93). An alternative view was shared by Participant 2, who recommended, "everything" (8/31/93). Participant 12 also cautioned that teachers should be aware that learners may "not know enough to know what to ask for" (11/18/93).

Obstacle Course

Participants were also willing to share their thoughts on what types of learning experience were as Dewey would say, "mis-educative..that has the effect of arresting or distorting the growth of further experience" (1938 and 1963, p.25). Two participants found groups made up of persons who claimed that they all followed their diet were not useful, believable or acceptable because they felt this level of accuracy was not possible (Participant 3, 9/3/93 and Participant 7, 10/30/93). Classes should not ask a person to handle "more than they are ready for" (Participant 5, 9/11/93). Being asked to attend a class where the instructor did not seem to have specific information or a plan to offer was also a problem (Participant 16, 11/27/93).

Neither theory nor common sense appears to have a major impact on the present pace of learning. The forced pace of educational experiences is due to health care's financial context. Health care's third party payers' demand rapid discharges from health care facilities. Hinnen (1993) noted

gone are the days when patients were admitted for management of blood glucose levels and education. Today there is scarcely a discipline or resource that is not involved with inpatient and outpatient or out patient programs, trying to provide cost-effective patient education (p.113).

One of the problems experienced by the participants was particularly inconsistent with Freire's praxis. This was Participant's 16 (11/27/93) experience of a poorly prepared instructor. Freire's approach requires that critical education begin with "precisely at the level of the people's aspirations and dreams, their understanding of reality and their forms of action and struggle" (Freire & Faundez, 1989, p. 27) and that although the teacher-

learner must not impose his or her version of the truth, this does not imply that "you don't have anything to put forward" (Freire & Faundez, 1989, p. 34).

If all of these topics, attitudes and approaches suggested by the participants only replace the goal of compliance with adherence they will not be enough to permanently improve the world of persons with DM. In order to transform that world, these client authored classes require a praxis which keeps the participant as an ongoing author of his or her education. In part, this is because these classes cannot be independent and self sustaining in a vacuum. In order to maintain transformative, empowering education, Ragins (1995,) found out it must remain attached to a group experience. She found in her study of Sickle Cell clients (another diagnostic group in which the dominant health care establishment calls for self management) that teaching for autonomy, particularly for persons with limited access to resources, could only succeed when it included enough social support. The classes must remain linked to the rest of the participants' lives.

Other Resources

There are other resources that the participants have used as sources of information, support and health care. Among these is the American Diabetes Association. Participants have used the patient education magazine, "Diabetes Forecast", for updates on research and patient information (Participant 11, 11/17/93 and Participant 13 11/18/93). Another, Participant 3, has used printed patient material on exchange lists and fat content of fast foods. She has also attended patient education workshops. She found that the workshops also provided peer support or, "having someone where you can really talk about DM" (Participant 3, 9/3/93). Participant 11 used video instruction,

developed by the manufacturer. He found they were helpful for learning how to use a meter and for smbg instruction (Participant 11, 11/17/93).

Participants showed some creativity in developing other strategies for obtaining educational resources. They found help from speaking with others with DM outside of formal support groups (Participant 4, 9/4/93 and Participant 6, 9/18/93). These people were easy to talk with, although Participant 4 felt it was still difficult to talk about herself (9/4/93). Others found useful information on both PBS and commercial television programming, also reading copies of a neighbor's "Diabetes Forecast" (Participant 11, 11/17/93). One participant suggested books about the pathophysiological course of the disease (Participant 16, 11/27/93). Family members may be in the health professions and as such have additional resource value (Participant 11, 11/17/93).

More Obstacles to the Course

Finances may function as an obstacle to the most highly motivated participant. Participant 11 noted the value of an insurance plan which would cover all the health care supplies and medication needed. He had not considered what decisions were appropriately left to insurance companies and physicians. He had not considered that he should play a part other than choosing the best insurance plan available (11/17/93). This participant showed some understanding of insurance companies' role in the determination of which services are reimbursable. He did not discuss an understanding that services are generally evaluated on a cost-benefit analysis for marketability and profitability. Dawson (1994) also reviewed managing DM with limited finances. He reported that based on lack of money, persons with DM self limited insulin dose. Dawson also noted that the

lack of payment for the single-use strips for smbg by Medicare can affect use patterns and lack of payment for medical care for long term complications affected access and service use.

Patton (1995) also found the following other barriers for the Hispanic community she studied: lack of transportation, unpredictable and demanding work schedules, language and cultural differences, distrust of providers, racism on the part of some health care providers, lack of health education or information about health care services. Participant 8 was aware of Senior Citizens on fixed incomes who could not afford medications (10/30/93). Participant 3 was concerned about the cost of some of her oral medications (9/3/93). Skelly, Marshall Haughey, Davis and Dunford (1990) also found participants in their study self reporting omitting medications due to costs and their limited income. Participant 9 noted that because her physical limitation prevented her from using the free transportation, and she had limited funds to pay for private transportation some health and educational resources were not available to her (11/22/93). Resources become unavailable if individual cannot pay for them.

CHAPTER VI

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Introduction

This project began with the writer's dissatisfaction with the standard diabetes curriculum and its results. It also began with a belief that an alternative could and should be created with the participants who live the curriculum. Using curriculum theory as a lens, the work of this project began with a focus on the underlying assumptions and the rationales of the standard diabetes curriculum. This was accomplished by a review of the literature for health care and education theory. This included nursing theory, DM theory, critical educational theory with primary emphasis on Paulo Freire's approach and used grounded theory analysis of the interviews of 16 major and one secondary participants' curricula for DM. This combination illuminated the standard programs' limitations and provided a new opportunity for a reframed curriculum presently missed by health care providers stuck in the dominant paradigm. The major goal of this project was to demonstrate the opportunities inherent in the problems of the present system and use them to create an alternative, a curriculum useful to persons with DM.

Summary

The initial review of the literature began with a parallel review of the fields of education and health care. One of the nexuses of these two apparently different disciplines is diabetes education. This particular connection was not surprising because of their common societal foundations and health care's appropriation of some of education's theory for its teaching tasks. This joint review showed that neither of the standard world views or paradigms question the nature of knowledge, nor the role of teacher and learners. Goodlad in Gross and Gross (1985) characterized education as follows:

The intellectual terrain is laid out by the teacher. The paths for walking through it are largely predetermined by the teacher...Students seemed to become more compliant and accepting of the teacher's role as they moved upward. They were being socialized into classroom expectations, especially that of accepting authority of the teacher. Teachers are also inside the cage and, to a degree carry with them society's expectations for the classroom behavior. Society expects teachers to be in charge of their classrooms (p. 136).

Rifkin's preface to the American Diabetes Association's Goals for Diabetes Education (Franz et al., 1986), states: "Instilling all of the behavioral objectives" will make life with diabetes much easier. The introduction goes on to say:

The organization of the book emphasizes that education and counseling occur at different stages and are a continuous process. Individual needs can be expected to change as people adapt to the diagnosis of diabetes and as they begin to learn self-management skills and to make important behavioral changes in life-style (preface).

As noted by representatives of the critical groups in both health care (Conrad and Kern, 1990) and education (Freire, 1970), neither standard curriculum is able to deliver the implied benefits of education or health care for the systems' participants.

Some of the elements of the review of critical theory provided an alternative to the standard diabetes curriculum. The critical, sometimes referred to as the problem posing perspective, of both fields encourages alternative ways of understanding. They illuminate the experience of diabetes from the world view of the persons who live the curriculum. With critical theory as a foundation, the field work for this project began with sixteen sets of interviews with persons who had been previously diagnosed with DM. One of those interviews also included data offered by the primary participant's spouse. Using both Paulo Freire's approach and grounded theory for a line by line thematic analysis, the transcripts were analyzed with the memo format as required for grounded theory (Glaser, 1973).

As anticipated by Freire's work, the participants were able to author their own experience based curreres. They also showed much more. The participants began by offering both their own parameters for the methodology and their personal definitions of diabetes. Initially they also showed an effect of the standard curriculum, induced dependency. They voiced an initial fear of not being able to create their own curriculum. Despite their learned dependency, the participants later showed a creativity in their understanding of DM and for its daily management. For some, this experience began with self or family diagnoses of the problem. This was quickly followed by identification of his or her emotional reaction and with a list of individual management skills to be acquired.

These separate skills include: diet, medication, foot care, smoking, weight loss, hyperglycemia, stress and its management, exercise, smbg and euglycemia, alternatives to mechanical monitoring, euglycemic goals and short term complications, and long term

complications. Some participants also described a three staged process of change. This process occurred after the experience of complication. It reframed the participant's view. Their focus changed from compliance and adaptation to congruence and adherent choice. Based on this process and their general experience, they learned to manage resources. This included: significant others, institutions and health care providers. They were able to identify what they needed from their formal educational experiences as both beginners and experts. The participants were also able to describe the obstacles they had encountered.

The analysis used two concepts to interpret the interviews. These concepts were critical theory and the qualitative descriptive approach. Both of these theoretical bases seek an understanding that goes beyond a standard socially prescribed stochastically understood paradigm. The primary approach used was critical theory. Critical theory, primarily Freire's work, provided a framework for understanding the participants' progressive understanding of DM. Freire teaches that in general a standard paradigm will have difficulty maintaining its dominance because of its inherent problems, and by the existence of those problems, creates the implication of an alternative. McLaren and Leonard (1993) propose that much of critical theory also teaches that there are no universal truths and that in addressing any problem work must be located within (created jointly with) the specific group the solution is supposed to serve.

A second tool was necessary to categorize the data without dissecting it away from its authors. This was a qualitative methodology and evaluation, specifically grounded theory. Leininger (1985) describes one of the qualitative paradigm's advantages is having the ability to "reformulate and expand" the focus of study as it evolves (p. 15).

Further this approach forbids predetermined judgments. It must remain open, flexible and dynamic. It must follow the people, context, situation, and events of the study. Specifically because of the flexibility of a qualitative approach, a three staged process of change in the understanding of DM was revealed during the interview process. The open methodology facilitated the perception of a specific and unexpected process and teaching opportunity.

Some of this project's participants described a three staged process of a reformulation of DM. During their first stage, DM was unimportant or irrelevant to their daily lives. Logically then, they did not incorporate superfluous recommendations such as those prescribed by Franz (1985), Lebovitz (1988), Lebovitz (1994) and Sperling (1988). Recommendations made by health care providers, significant others and other persons with DM were discounted or ignored. Retrospectively, participants described this earliest rationale as not taking DM seriously. This was expressed as not developing or accepting a program of glycemic management. They reported that this resulted in hyperglycemia. The second stage of the process consisted of becoming aware of one's own complications and believing they were the result of hyperglycemia as opposed to direct and invariant results of diabetes. The importance of this was the change from the passive victim of a disease to active manager of one's own life. The participants' perception of a relationship between hyperglycemia and long term complications was also consistent with review of the technical literature (Lebovitz, 1994; Haire-Joshu, 1992). Both associated the pathophysiological processes with hyperglycemia. This awareness of complications initiated a third stage which was a reframing of DM.

The participants described three characteristics of the third stage, which was an epiphany or critical awareness. This stage occurred after complications which were visible to the participant. It was not a one way process. Participants could return to old dependent and non-choice ways of being. When they were actively functioning in the third stage, participants took active holistic charge of their DM and its care. Participants at the third stage were able to create their own picture of diabetes management and no longer need to rely on external standard instruction and compliance.

Participants were also able to describe both the content and the process for how they had received their DM education and how they would prefer to obtain it. First and foremost participants wished to be treated with respect. Based upon this respect, they wanted an active role in determining the content of what is offered to them. They are also aware of the need to manage resources including professional service providers. They noted that this is not usually part of the curriculum nor was being consulted about their experiences. They wanted a jointly determined curriculum and were able to enumerate the specifics.

Participants wanted health care providers to provide educational experiences which were accessible, affordable and convenient. They also wanted classes to be divided into expert and beginner categories, divided into age groups and be available in individual and group formats. They wanted diverse teaching tools such as booklets with print large enough to be read, to be provided in the language in which the learner is most comfortable, and to include significant others. They also wanted the experience to be relevant to the daily management tasks in their lives, to be provided at a rate that could be

assimilated, to be on topics of interest to the individual, to introduce newly discovered topics, to provide a place of support and most importantly to be asked what they wanted.

Discussion of Results

The short term result of this project was the successful completion of each participants' individual currere. Recalling that the original goal was to create a curriculum useful to its participants, it was a success. The project surpassed the original goal of simply providing an alternative because it illuminated a process specific to autonomy and congruence for DM. That process had been invisible and consequently unused by health care providers. Based on the results of this project, Freire's work in education and the work of Hernandez with the experience of living with I.D.D.M., it is logical to assume this process may be a common facet of D.M. Under these circumstances it should be available to many persons as a new resource for DM management. Further studies should confirm this hope.

Implementation of this type of approach will require joint authorship for the design and implementation of critical diabetes curricula. Freire cautions that learners and teachers must join together to study and restudy the material to be learned and develop knowledge which is truly their own. Both groups will have to step out of their usual role. Educators and recipients in health care may use critical educational theory in order to focus on several issues. Areas for this focus include their former roles as well as the subjects and sources they will consider legitimate forms of knowledge for DM education.

This approach can be best facilitated by using a group context. Within this context, participants have the resources of each other and the opportunity to interact and

benefit from other participants' lived experiences. A critically oriented support group holds the potential of becoming a place where each participant has the opportunity to jointly author his or her own currere. This process should then proceed to the next level and be linked to technical knowledge, previously split off from many of the participants.

Critical lectures and workshops have a great potential for addressing the prevention of long term complications because they require that technical knowledge be joined to the participants knowledge. As Freire and Faundez (1989) point out, the participant's may then make use of it. Specifying this approach to DM education has the potential to provide an enhanced and earlier perception of complications, newly visible therefore minimizing the pathophysiological damage. This has obvious application to several applications including minimizing long term complication complications.

This present problem is situated in a pathophysiological progression which is frequently invisible to the persons it affects. At present, laboratory tests, i.e. those measuring kidney function and damage, are generally considered the province of the health care providers. As some of this project's participants noted, they were willing to depend upon their physician's interpretation of test results. These decisions to defer to their physicians, illuminated the problem of dependency. Other parts of the participants' curriculum illuminated a solution.

Participants specified what they wanted for their DM education. They requested workshops for experts. That suggestion offers a potential alternative solution. A critical nephrology (kidney) seminar could look very different than the standard lecture of today. As Maillot, D'Eramo and Spollet (1996), noted, DM's long term complications such as kidney disease occur too often and are more likely to affect minorities. They also found

that culturally sensitive educational materials were more acceptable to their participants. Site specific renal lectures for persons with DM could be refocused on problematic prevention of kidney disease.

A radical approach could change from an expert's lecture to a dialogue. The content could concern the underlying reasons for how information is usually managed, and how and why participants have learned not to question their health care providers and the relationship between a passive state and long term complications. It is also important to note that because the frame of reference shifts to a dialogue, there is no implied permission to leave out or minimize any of the technical knowledge which would have been included in the previous standard nephrology lecture. In fact, if the process succeeds, active learners will demand more knowledge from their service providers. This will occur because successful dialogue connects the standard information to the participant's experience.

Continuing with the proposed example of a nephrology dialogue, a true dialogue must contain standard information such as that recommended by DeFronzo in Lebovitz, (1994). This includes: incidence rates including the recent improvement, attributed to better glycemic control, probable role of genetics, hypertension and excessive protein intake as they appear to be significant parts of the pathophysiologic process. Significantly it should also include the preclinical stage of renal failure. The preclinical stage is characterized by microalbuminuria, (tiny amounts of protein in the urine), which is measurable in a twenty-four hour urine test (Peragallo-Dittko, 1993). Participants have the right to claim knowledge of preclinical renal failure and the laboratory results which make it visible to health care providers. That knowledge has the potential to be used to

prevent renal failure. Laboratory testing ought to belong to the domain or understanding of the person with DM.

Laboratory tests could be used differently to provide information early in the pathophysiological process. Renal laboratory work can make visible and therefore provide for a critical understanding and an impetus for a shift in a client's understanding of DM without the loss of health, or body part. Persons with DM can learn to propose microalbumuria testing. In this way they would be able to see or focus for themselves and reverse the pathophysiologic process before they develop progressive renal insufficiency. Through the lens of what is now their health care provider's laboratory information, the issue can become part of the client-participant's concrete reality, and not the responsibility of someone else. The information cannot be used if it remains hidden in the technical texts and medical records, it must be found in the minds and lives of the participants.

The limitation of the present system and the identification of the process through a critical approach suggests a change for diabetes educators from practice to praxis. Other researchers such as Engel and Noblitt (1989) have called for similar changes. They proposed critical organization development to support more collaborative research. When diabetes educators adopt a critical praxis, they become able to offer their technical knowledge to be joined with the knowledge of persons living with DM. In order to maximize this potential resource, health care providers have the opportunity of adding to their clinical skills, a general study of education and critical education theory. Absent a continuous linkage to critical theory, use of the three staged process as a resource could

disintegrate into a tool to gain easy compliance rather than remain part of an emancipatory praxis

Assuming a critical approach is maintained, the new opportunity will still have some limitations. As the participants noted, even those who attained the third stage of understanding and self management did not always remain at that level. Remaining there required ongoing work. Ongoing work is also required by the progressive pathophysiological processes of DM. These requirements are not an easy fit with a health care system buffeted by high costs and the requirements of the "for profit" third party payers. Implementation of an emancipatory praxis (Freire & Faundez, 1989) requires the joint work of those now separately labeled health care providers and patients. In order to sustain this process, their curriculum must be connected with the rest of their lives.

The results suggest some recommendations for implementation for the participant-client and participant-family member using this type of approach. Engel and Noblitt (1989) incorporating Torbet's work called for a critical approach for "medical [sic] research" (p. 29). Their criteria is equally applicable to diabetes education as the first step must be a joint authorship of the curriculum as this process is essentially a discovery or qualitative research process. They suggest evenly balanced participation, which should include: "widely shared initiating, making and implementing decisions, an explicit disagreement interspersing other kinds of comments, and more positive (dialogical) than negative inquiry" (p. 29).

Implementing such a critical curriculum is complex. As Engel and Noblitt warn, this type of approach has an inherent problem. They warn that being critical will be difficult when gaining access to the organization and or "sponsorship of administration"

(p. 28). Gentle and persistent rhetoric and approach will be needed to gain and maintain the opportunity to offer what is likely to be viewed as radical departure and therefore in opposition to standard clinical care. This approach will require the use of standard medical jargon, already part of the socialized world view and rationale which may tap into the assumed innate desire to provide humane and euglycemic care.

Recommendations for Future Studies

Further studies should be site specific. They should also be designed, interpreted and evaluated based on a dual and equal standard for both an emancipatory curriculum process and physiologic improvement. In terms of specificity, Freire has suggested the use of curriculum development groups, called “cultural circles” (1973, p. 42), based upon age, location, vocation, and gender (Freire & Faundez, 1989). He recommended they begin by working among themselves to critically study their specific social situation in order to begin to learn their own curriculum. This study is another basis for that recommendation.

Participant-useful studies must show results in terms of a qualitative critical educational approach and clinically significant measurements such as laboratory testing. This should include measurement of glycosated hemoglobin. Studies designed to measure secondary effects of specific long term complications will also need the appropriate laboratory or physical examination to evaluate the clinical progress of complications. Examples of this include monitoring of hypertension, measurement of wounds healing, renal function tests and visual documentation of the progress of retinopathy. The dual approach will remain internally consistent to its critical values

because it can connect the previously separated technical and participant's knowledge for a jointly created evaluation process.

This study explored the holistic experience of DM for the study's 17 participants. Further site-specific studies are needed to expand this field of research, adding to the data for both the general process and identifying possible variations within it. These studies should seek to describe possible differences associated with particular site-specific characteristics such as ethnicity or gender and clinical differences such as those based upon a particular long term complication. All of these areas need to be explored and delineated.

Among the many long term complications are three recommended areas for study. These three have concrete clinical markers and unfortunately remain common to persons with DM. They are renal disease with its previously noted laboratory tests, retinopathy because of the increased availability of retinal photography and wound care because of the relatively objective measurements and increased requirement of patient or family management of the problem. These additional studies should seek to identify the potential reoccurrence of the three staged process and further identify its parameters. Assuming the results of the recommended studies support the findings of the present investigation, it is expected that health care research in this area of specialization will demonstrate opportunities for critical patient education change.

Finally, researchers for these proposed DM education studies should note that there is a difference between a critical, radical, problem posing or oppositional curricula from both the dominant and the negotiated curricula. Critical curricula requires that a third level, termed societal or political, be addressed in these studies. As the participants

pointed out, they live the experience of diabetes not only in hospitals but in their homes and their work places. They live that curriculum with their families, friends, neighbors and co-workers. They live the experience with their insurance companies, with their employer's human resources department's policies and their interactions with their health care providers. Based on that frame of reference, a long term critical curriculum must incorporate those experiences as a part of the curriculum. That curriculum must teach an emancipatory process where the participants learn that their status is that of active participants not the passive recipient of someone else's curriculum. If the work of both the health care providers and clients is going to be joined in a critical praxis it will have to address the more general issues of the society in which they live. Apple (1993) said, "What is necessary is to connect these decisions both to a wider sense of creating caring communities and social justice and to a larger movements whose ends and means embody this" (p. 9).

REFERENCES

- Adler, M. J. (1983). The Paideia proposal. New York: MacMillian.
- Agger, B. (1991). A critical theory of public life: Knowledge, discourse and politics in an age of decline. New York: The Falmer Press.
- Ahern, J., Bates, S., & Tamborlane W. (1988). Discrepancies between blood glucose and glycosated hemoglobin in intensively treated diabetic patients. The Diabetes Educator, 14(1), 30-32.
- Ahijevych, K., & Bernard, L. (1994). Health-promoting behaviors of African American women. Nursing Research, 43(2), 86-89.
- Almeida, R. (1995). Grief among children with diabetes. The Diabetes Educator, 21(6).
- Alschuler, A. (1983). Creating a world where it is easier to love: Counseling applications of Paulo Friere's Theory. Journal of Counseling and Development, 64(4), 492-496.
- American Dietetic Association. (1994). Nutrition recommendations and principles for people with diabetes mellitus. Diabetes Care, 17(5), 519-522.
- A.N.A. (1981). American Nurses' Association: Model nurse practice act. Kansas City: American Nurses' Association, Pub. Code: NP-52M5/76.
- Anderson, R. (1985). Is the problem of noncompliance all in our heads? The Diabetes Educator, 11(1), 31-34.
- Anderson R., & Donnely, M. (1990). Words and meaning a cautionary tale from diabetes educators. The Diabetes Educator, 16(2), 117-122.
- Anderson R., Funnel, M., Butler, P., Arnold, M., Fitzgerald, J., & Feste, C. (1995). Patient empowerment. Diabetes Care, 18(7), 943-949.
- Anderson, R., & Nowak G. (1989). Influencing the personal meaning of diabetes: Research and practice. The Diabetes Educator, 14(4), 297-302.

- Anderson, S. (1994). Seven tips for managing patients with diabetes. AJN, 94(9), 36-38.
- Apple, M. (1981). Ideology and curriculum. Boston: Routledge and Kegan Paul.
- Apple, M. (1993). Official knowledge: democratic education in a conservative age. New York: Routledge.
- Apple, M., & Weis, L. (1983). Ideology and practice in schooling. Philadelphia: Temple University Press.
- Apple, M., & Christian-Smith, L. (1991). The politics of the textbook. New York: Routledge.
- Aries, N., & Kennedy, L. (1990). The health labor force: The effects of change. In P. Conrad & R. Kern (Eds.), Sociology of health and illness: critical perspectives. (3rd ed.) (pp.195-206). New York: St. Martin's Press.
- Arnold, M., Butler, P., Anderson, R., Funnel, M., & Feste, C. (1995). Guidelines for facilitating a patient empowerment program. The Diabetes Educator, 21(4), 308-312.
- Arnove, R. (1994). Political and educational changes in Nicaragua. Horizons, 72(3), 118-121.
- Aronowitz, S., & Giroux, H. (1991). Postmodern education. Minneapolis: University of Minnesota Press.
- Atkinson, M., & Maclaren N., (1990). What causes diabetes? Scientific American, 293(1), 62-71.
- Bailey, B., McGrady, A., Good, M. (1990). Management of a patient with insulin-dependent diabetes mellitus. The Diabetes Educator, 16 (3), 201-205.
- Banks, J. (1981). Multiethnic education: Theory and practice. Boston: Allyn and Bacon.
- Barker, G.(1995). Don't work too hard. Horizons, 73(4), 160-162.
- Bates, I. & Winder, A. (1984) Introduction to health education. Palo Alto, CA: Mayfield Publishing Co.
- Becker, M. & Maiman, L. (1975). Sociobehavior determinants of compliance with health and medical regimens. Medical Care, 13(1), 10-24.

- Bell, L., & Schniedewind, N. (1989). Realizing the promise of humanistic education: A reconstructed pedagogy for personal and social change. Journal of Humanistic Psychology, 29(2), 200-223.
- Bernard, H. R. (1988). Research methods an cultural anthropology. Newbury Park: Sage Publications.
- Bigge, M. L. (1982) Learning theories for teachers. New York: Harper and Row.
- Bloom, B. (1956). Taxonomy of educational objectives: The cognitive domain. New York: Longsmans, Green and Co.
- Bloomgarten, Z., (1992). Pathogenesis, treatment and complications of diabetes. Practical Diabetology, 11(3), 18-22.
- Bogdan, R. & Bilken, S. K. (1982) Qualitative research for education: An introduction to theory and methods. Boston: Allyn and Bacon.
- Bonheim, R., (1983). What to expect from doctors. Diabetes Forecast, 36(2), 36-40.
- Briggs, G., & Gallaway, D. (1979). Nutrition and physical fitness. NY: Holt, Reinhart and Winston.
- Brink, S., Siminerio, L., Hinnen-Hentzen, D., Deeb, L. C., Daly, A. S., Anderson, B. J., & Agrin, R. J. (1995). Diabetes education goals. Alexandria, VA: American Diabetes Association.
- Brunner, J. (1961). The Process of education. Cambridge, MA: Harvard Press.
- Staff. (1993). The 1994 buyer's guide to diabetes products. Diabetes Forecast, 46(10), 48-88.
- Byham, L., & Vickery, C. (1988). Compliance and health promotion. Health Values, 12(4), 5-12.
- Cambell, D.T., & Stanley, J.C. (1963) Experimental and quasi-experimental designs for research. Chicago: Rand McNally.
- Capaldi, E., & VandenBos, G. (1991). Taste, food exposure, and eating behavior. Hospital and Community Psychiatry, 42(8), 787-789.
- Cerne, F. (1995). Learning to survive. Hospitals & Health Networks, 69(7), 47-50.

Chaturvedi, N., Fuller, J., & The WHO Multinational Study Group. (1995). Mortality risk by body weight change in people with NIDDM. Diabetes Care, 18(6), 766-774.

Christman, C., & Bennet, J. (1987). Diabetes: New names, new test, new diet. Nursing 87, 17(1), 34-42.

Colantonio, A. (1988). Lay concepts of health. Health Values, 12(5), 3-7.

Conrad, P., & Kern, R. (Eds.) (1990) Sociology of health and illness: Critical perspectives (3rd ed.). New York: St. Martin's Press.

Curtis, J.D., & Papenfuss, R.L. (1980). Health instructions: A task approach. Minneapolis, MN: Burgess Publishing Co.

Cuverwell, M. (1995). Putting diabetes on the map. Countdown, 16(1), 29.

da Silva, T. T., & McLaren, P. (1993). Knowledge under siege: The Brazilian debate. In P. McLaren & P. Leonard (Eds.), Paulo Frierie a critical encounter (pp. 36-46). New York: Routledge.

Dawson, L. (1994). Diabetes on a shoestring budget. Diabetes Forecast, 47(11), 28-34.

DeFronzo, R. (1994). Nephropathy. In H Lebovitz (Ed.), Therapy for diabetes and related disorders (2nd. ed) (pp. 256-269). Alexandria, VA: A.D.A.

D'eramo-Melkus, G., & Demas, P. (1989). Patient perception of treatment goals. The Diabetes Educator, 15(5), 440-443.

Devine, E., & Reifschneider, E. (1995). A Meta-Analysis of the effects of psychoeducational care in adults with hypertension. Nursing Research, 44(4), 237-244.

Dewey, J. (1938, 1963). Experience & Education. NY: Macmillian.

Staff. Diabetes update 90, (1990). Nursing 90, 90(2), 49-51.

Dickins, D., & Fontana, A. (1994). Postmodernism and social inquiry. New York: The Guilford Press.

Dobson, R. L., & Dobson, J. E. (1981). The language of schooling. New York: University Press of America, Inc.

Dobson, R. L., Dobson, J. E., & Koetting, J. R. (1985). Looking at, talking about and living with children: reflections on the process of schooling. Lanham, MD: University Press of America, Inc.

Doress, P., & Seigal, D. L. (1987). Ourselves, growing older. New York: Simon and Schuster.

Drewnowski, A., & Rock, C. (1995). The influence of genetic taste markers on food acceptance. American Journal of Clinical Nutrition, 62, 506-11.

Drummond, T. (1975). Using the method of Paulo Freire in nutrition education: An experimental plan for community action in northwest Brazil. Ithaca, NY: Cornell International Nutrition Monograph Series.

Dube', L., Trudeau, E., & Be'langer, M. (1994). Determining the complexity of patient satisfaction with foodservices. Journal of the American Dietetic Association, 94(4), 394-398.

Dunn, H. (1973). High level wellness. Arlington, VA: Beatty

Dunning, P. (1995). Young adult perspective of insulin-dependent diabetes. The Diabetes Educator, 21(1), 58-65.

Ehmann, K. (1995). Over 60 and newly diagnosed. Diabetes Forecast, 48(5), 35-38.

Eisner, E. W. (1985). Educational imagination: On the design and evaluation of school programs (2nd Ed.). New York: Macmillan.

Elinski, A. (1993). B-G-T-E-S-T: A basic review. RN, 56(6), 49-51.

Ellsworth, E. (1989,1994). Why doesn't this feel empowering? Working through the repressive myths of critical pedagogy. In L. Stone (Ed.), The education feminist reader (pp. 300-327). NY: Routledge.

Engel, J., & Noblit, G. (1989). Organizational development, critical theory, and purposive inquiry: An alternative for health care educators. Journal of Healthcare Education and Training, 4(2), 28-31.

Engel, S., Shamon, H., Basch, C., Zonszein, J., & Wylie-Rosett, J. (1995). Diabetes care needs of Hispanic patients treated at inner-city neighborhood clinic in New York City. The Diabetes Educator, 21(2), 124-128.

Falciglia, G., & Norton, P. (1994). Evidence for a genetic influence on preference for some foods. Journal of the American Dietetic Association, 94(2), 154-158.

Farkas-Hirsh, R., & Hirsh, I. (1994). Continuous subcutaneous insulin: Infusion a review of the past and its implementation for the future. Diabetes Spectrum, 7(2), 80-84, 136-138.

Feste, C. (1992). A practical look at patient empowerment. Diabetes Care, 15(7), 922-5.

Franz, M., Krosnik, A., Mashal-Carey, B. J., Parker, T., & Wheeler, F. (1986). American Diabetes Association Task Force Group on Goals for Diabetes Education, Goals for diabetes education. Alexandria, VA: ADA.

Freebody, P., & Welch, A. Knowledge, culture and power: International perspectives on literacy as policy and practice. Pittsburg: University of Pittsburg Press.

Freire, P. (1970). Pedagogy of the oppressed. New York: Continuum.

Freire, P. (1973). Education for a critical consciousness. New York: Continuum.

Freire, P. (1985). The politics of education: Culture, power and liberation. New York: Bergin and Garvey.

Freire, P. (1993). Pedagogy of the city. New York: Continuum.

Freire, P., Escobar, M., Fernandez, A. L., & Guevara-Niebla, G. (1995). Paulo Freire on higher education: A dialogue at the National University of Mexico. Albany: SUNY Press.

Freire, P., & Faundez, A. (1989). Learning to question. New York: Continuum.

Freire, P., & Macedo, D. (1987). Literacy: Reading the word and the world. New York: Bergin and Garvey.

Freire, P., & Shor, I. (1987). A pedagogy for liberation: Dialogues on transforming Education. Granby, MA: Bergin and Garvey.

Funnel, M., Anderson, R., Arnold, M., Donnelly, M., & Taylor-Moon, D. (1991). Empowerment: An idea whose time has come. The Diabetes Educator, 17(1), 37-41.

Funnel, M., & Herman, W. (1995). Diabetes care policies and practices in Michigan nursing homes, 1991. Diabetes Care, 18(6), 862-866.

Funnel, M., & Merritt, J. (1993). The challenge of diabetes and older adults. Nursing Clinics of North America, 28(1), 45-60.

Garcia, R. (1982). Teaching in a pluralistic society: Concepts, models, strategies. New York: Harper and Row.

Genuth, S. (1994). Diabetic ketoacidosis and hyperosmolar hyperglycemic nonketotic syndrome in adults. In H. Lebovitz (Ed. in Chief), Therapy for diabetes mellitus and related disorders (2nd ed.) (pp. 65-76). Alexandria, VA: A.D.A.

Gertis, M., Edgeman-Levitan, M., Walker, J., Stokes, D., & Delbanco, T. (1993). What patients really want to know. Health management quarterly, 25(3), 2-6.

Gewirtz, G. (1994). Current thoughts on diabetes patient education in New Jersey. New Jersey Medicine, 91(4), 230-232.

Ginsburg-Fellner, F. (1994). Genetic counseling in Type I diabetes. In H. Lebovitz. (Ed.), Therapy for diabetes mellitus and related disorders (2nd ed.) (pp. 4-10). Alexandria, VA: American Diabetes Association.

Ginzberg, Z., & Mazza, R. (1994). Clinical consequences of the diabetes control and complications trial. New Jersey Medicine, 91(40), 221-224.

Glaser, B. (1973). Advances in the methodology of grounded theory: Theoretical sensitivity. San Francisco: University of California.

Glaser B., & Strauss, A. L. (1967). The discovery of grounded theory. Chicago: Aldine Press.

Glaser B., & Strauss, A. L. (1965). Time for dying. New York: Aldine Publishing Company.

Glasgow, R., Toobert, D., Mitchell, D., Donnelly, J., & Calder, D. (1989). Nutritional education and social learning intervention for Type II diabetics. Diabetes Care, 12(2), 150-152.

Giroux, H., Penna, A., & Pinar, W. (Eds.). (1981) Curriculum and instruction. Berkeley, CA: McCutchan Publishing Corp.

Gold, P. (1995). Role of glucose in regulating brain and cognition. American Journal of Clinical Nutrition, 61(suppl.), 987s-995s.

Goodlad, J. (1984). A place called school. NY: McGraw-Hill Book Co.

Goodlad, J. (1985). A place called school. In Gross B., & Gross R.(Eds.), The great school debate (pp. 134-141). NY: Simon & Schuster.

Greene, D., Beaudin, B., & Bryan, M. Addressing attitudes during diabetes education: Suggestions from adult education. The Diabetes Educator, 17(6), 470-473.

Gronlund, N. E. (1981). Measurement and evaluation in teaching (4th ed.). New York: Macmillan.

Gross, B., & Gross., D. (Eds.) (1985). The great school debate. New York: Simon and Schuster.

Haire-Joshu, D., Flavin, K., & Clutter, K. (1986) Controlling the insulin balance: Contrasting Type I and Type II diabetes. AJN, 86(11), 1239-1258.

Haire-Joshu, D. (Ed.) (1992). Management of diabetes mellitus: Perspectives of care across the life span. St Louis, MO: Mosby.

Hammersley, M., & Atkinson, P. (1983). Ethnography: Principles in practice. New York: Routledge.

Hampton, S., Glasgow, R., & Foster, L. (1995). Personal models of diabetes among older adults-relationship to self-management and other variables. The Diabetes Educator, 21(4), 300-307.

Harmer, B., & Henderson, V. (1967). Textbook of the principles and practice of nursing. New York: Macmillan Co.

Hazlette, J. (1993). The diabetes control and complications trial, how will the results affect your treatment? Diabetes Self-Management, September/October 1993, 6-8.

Helkala, E., Niskanen, L., Viinamaki, H., Partanen, J., & Uusitupa, M. (1995). Short term and long term memory in elderly patients with NIDDM. Diabetes Care, 18(5), 681-685.

Hernandez, C. (1995). The experience with insulin-dependent diabetes. The Diabetes Educator, 21(1), 33-37.

Hinnen, D. (1993). Issues in diabetes education. Nursing Clinics of North America, 28(1), 113-119.

Hirsch, I., Paaw, D., & Brunzell, J. (1995). Inpatient management of adults with diabetes. Diabetes Care, 18(6), 870-878.

Hoops, S., (1990) Renal and retinal complications in insulin-dependent diabetes mellitus: The art of changing the outcome. The Diabetes Educator, 16(4), 221-232.

Horowitz, L. (1985). The Self-care motivation model: Theory and practice in healthy human development. Journal of School Health, 55(2), 46-51.

Hoyson, P. (1995). Oral medications. RN, 58(5), 34-40.

Hutchinson, E. (1986). In P. Munhall & C. Oiler, Nursing research: A qualitative perspective. Norwalk, CT: Appleton-Century-Crofts.

Illich, I. (1970). Deschooling society. New York: Harper and Row.

- Illich, I. (1976). Medical nemesis: The expropriation of health. New York: Random House.
- Imle, M., & Atwood, J. (1988). Retaining qualitative validity while gaining quantitative reliability and validity: Development of the transition to parenthood concerns scale. Adv. Nursing Science, (11)1, 61-75.
- Jaccard, J. (1983). Statistics for the behavioral sciences. Belmont, CA: Wadsworth Publishing Company.
- Jacobson, A., De Groot, M., & Samson, J. (1994). The evaluation of two measures of quality of life in patients with Type I and Type II diabetes. Diabetes Care, 17(4), 267-274.
- Jagacinski, C. & Nicholls, J. (1987). Competence and affect in task involvement and ego involvement: The impact of social comparison. Journal of Educational Psychology, 79(2), 107-114.
- Jennings, P., Morgan, H., & Barnett, A. (1987). Improved diabetes control and knowledge during a diabetes self-help group. The Diabetes Educator, 13(4), 390-393.
- Joint Commission on the Accreditation of Health Care Organizations. (1992). Accreditation manual for hospitals. Chicago: JCAHCO.
- Joos, I., Nelson, R., & Lyness, A. (1985). Man, health, and nursing. Reston VA: Reston Publishing Co.
- Joyce, B., & Weil, M. (1980). Models of teaching. Englewood, NJ: Prentice-Hall.
- Kane, V. (1993). Listening to older patients. Health Management Quarterly, 15(3), 11-15.
- Keith, R. (1995). The community in the school. Horizons, 73(4), 169-173.
- Kelly, K. (1995) Patient compliance. Practical Diabetology, 14(2), 20-23.
- Kippen, C. (1995). A success story. Diabetes Forecast, 48(8), 20.
- Kubler-Ross, E. (1969). On death and dying. New York: MacMillian Publishing.
- Kuhn, T. (1977). In F. Suppe (Ed), The structure of scientific theories (2nd Ed.) (pp. 135-150). Urbana: University of Illinois Press.
- Kuhn, T. (1962). The structure of scientific revolutions. Chicago: University of Chicago.

- Kulkarni, K., & Thom, S. (1992). Weigh to go. Diabetes Forecast, 45(8), 68.
- Kurtz, S. (1990). Adherence to diabetes regimes emperical states and clinical applications. The Diabetes Educator, 16(11), 50-56.
- Kvale, S. (1988). The 1000-page question. Phenomenology and Pedagogy, 6(2), 91-106.
- Lankshear, C. (1993). Adult literacy in Nicaragua 1979-90. In P. Feebody & A. Welch (Eds.), Knowledge, culture & power (pp.113-141). Pittsburg: University of Pittsburg Press.
- Law, S. (1990). Blue Cross-what went wrong? In P. Conrad & R.Kern (Eds.), Sociology of health and illness: Critical perspectives (3rd ed.) (pp. 235-242). New York: St. Martin's Press.
- Lebovitz, H. (Ed. in Chief). (1988). Physician's guide to non-insulin-dependent (Type II) diabetes: diagnosis and treatment (2nd ed.). Alexandria, VA: American Diabetes Association.
- Lebovitz, H. (Ed.) (1994) Therapy for diabetes mellitus and related disorders (2nd ed.). Alexandria, VA: American Diabetes Association.
- Lee, E., Lee, V., Lu, M., & Russel, D. (1992). Development of proliferative retinopathy in NIDDM: A follow-up study of American Indians in Oklahoma. Diabetes, 41, 359-367.
- Leininger, M. (Ed.) (1985). Qualitative research methods in nursing. New York: Grune and Stratton, Harcourt Brace Jovanovich.
- Leininger, M. (1988). Transcultural eating patterns and nutrition: Transcultural nursing and anthropological perspectives. Holistic Nursing Practice, 3(1), 16-25.
- Light, D. (1990). Comparing health care systems: Lessons from East and West Germany. In P. Conrad & R. Kern (Eds.), Sociology of health and illness: Critical perspectives (3rd ed.) (pp. 449-462). New York: St. Martin's Press.
- Lockwood, D., Frey, M., Gladish, N., & Hiss, R. (1986). The biggest problem in diabetes. The Diabetes Educator, 12(1), 29-32.
- Loeb, S. (Ed.). (1991). Illustrated manual of nursing practice. Springhouse, PA: Springhouse Corp.
- Lumson, K. (1995). Working smarter, not harder. Hospitals & Health Networks, 69(21), 26-31.

Maillot, N., D'Eramo, G., & Spollet, G. (1996). Using focus groups to characterize the health beliefs of Black Women with non-insulin-dependent diabetes. The Diabetes Educator, 22(1), 39-46.

Magnan, M. (1989). Listening with care. AJN, 89(2), 219-221.

Malarcher, A., Ford, E., Nelson, D., Chrismon, J., Mowery, P., Merrit, R., & Herman, W. (1995). Trends in cigarette smoking and physicians' advice to quit smoking among people with diabetes in the U.S. Diabetes Care, 18(5), 694-697.

Mannucci, E., Ricca, V., Mezzani, B., Di Bernardo, M., Piani, F., Vannini, R., Carbas, P., & Rotella, C. (1995). Eating attitude and behavior in IDDM patients. Diabetes Care, 18(4), 326-327.

Marlatt, G. A. (1994). Mindfulness and metaphor in relapse prevention: An interview with G. Alan Marlatt. Journal of the American Dietetic Association, 94(8), 846-848.

Marriner-Tomey, A. (1989). Nursing theorists and their work (2nd Ed.). Philadelphia: C.V. Mosby Co.

Martinez, N. (1993). Diabetes and minority populations. Nursing Clinics of North America, 28(1), 87-95.

Maslow, A. (1970). Motivation and personality (2nd ed.). New York: Harper and Row.

Mason, B., Matsuyama, J., & Jue, S. (1995). Young-adult perspectives of insulin-dependent diabetes. The Diabetes Educator, 21(1), 52-7.

Mazur, M. (1995). Fightback. Diabetes Forecast, 48(8), 16-20.

McCarren, M. (1992). The Glukokinase connection. Diabetes Forecast, 45(12), 26-31.

McCarren, M. (1995a). Diabetes the invisible disease. Diabetes Forecast, 48(3), 16-25.

McCarren, M. (1995b). How tight for Type II? Diabetes Forecast, 48(1), 28-32.

McClary, C., Zahrt, L., Montgomery, J. H., Walker, H., & Petry, J. R. (1985). Wellness: The mode in the new paradigm. Health Values, 9(6), 8-12.

McLaren, P. (1986). Postmodernity and the death of politics: A Brazilian reprieve. Educational Theory, 36(4), 389-400.

- McLaren, P., & Leonard, P. (1993). Paulo Freire a critical encounter. New York: Routledge.
- McNeil, J. D. (1990). Curriculum: A comprehensive introduction. Glenview, IL: Scott Foresman/Little, Brown Higher Education.
- Messner, R. (1993). What patients really want from their nurse. AJN, 93(8), 38-37.
- Meyer, C. (1992). Nursing on the political front. AJN, 92(10), 56-64.
- Mitchell, B., Kammer, C., Reinhart, L., & Stern, M. (1994). NIDDM in Mexican-American families: Heterogeneity by age onset. Diabetes Care, 17(6), 567-573.
- Mullen, K. (1986). Wellness: The missing concept in health promotion programming for adults. Health Values, 10(3), 34-37.
- Munhall, P. & Oiler, C. (1986). Nursing research: A qualitative perspective. Norwalk, CT: Appleton-Century-Crofts.
- Nagasawa, M., Smith, M., Barnes, J., & Fincham, J. (1990). Meta-analysis of correlates of diabetes patients' compliance with prescribed medications. The Diabetes Educator, 16(3), 192-200.
- Napier, R., & Gershenfeld, M. (1985). Groups: Theory and experience (3rd. ed.) (pp. 146-148). Hopewell, NJ: Houghton Mifflin
- Nathan, D. (1994). Monitoring in diabetes mellitus. In H. Lebovitz (Ed. in Chief), Therapy for diabetes mellitus and related disorders (2nd ed.) (pp. 87-92). Alexandria, VA: ADA.
- Nettles, A., & Weinhandl, J. (1990). Diabetes secondary to cystic fibrosis: An increasing clinical problem. The Diabetes Educator, 16(6) 478-82.
- New Jersey P.L. 1947, c262 as amended.
- Noerager-Stern, P. (1985). Using grounded theory method in nursing research. In M. M. Leninger (Ed.), Qualitative research methods in nursing (pp. 149-160). New York: Grune and Stratton, Harcourt Brace Jovanovich.
- Norris, C. (1990, 1969). The work of getting well. AJN, 90(7), 47-50.
- Norton, R. (1995). The right mix of diet and exercise. RN, 58(4), 20-25.
- Oakley, P. (1989). Community involvement in health development. Geneva: W.H.O.

O'Hara, M. (1989). Person-centered approach as Conscientizacao: The works of Carl Rodgers and Paulo Freire. Journal of Humanistic Psychology, 29(1), 11-36.

Orem, D. (1985). Nursing: Concepts of practice (3rd Ed.). New York: McGraw Hill.

Orlandi, A., Pastore, M., Clerci, S., Balini, A., Parangeli, M., Maffei, C., & Pozza, G. (1995). Effects of personality on metabolic control in IDDM patients. Diabetes Care, 18(2), 206-209.

Palmer, J., & McCulloch, D. (1991). Perspectives in diabetes: Prediction and prevention of IDDM-1991. Diabetes, 40(9), 43-47.

Pascale, R., Wing, R., Butler, B., Mullen, M., & Bononi, P. (1995). Effects of a behavioral weight loss program, stressing calorie restriction versus calorie restriction plus fat restriction in obese individuals with NIDDM or a family history of diabetes. Diabetes Care, 18(9), 1241-1248.

Patton, S. (1995). Empowering women. Nursing Management, 26(8), 36-41.

Peragallo-Dittko, V. (Ed.). (1993). A core curriculum for diabetes education (2nd ed.). Chicago: American Association of Diabetes Educators and the AADE Education and Research Foundation.

Peragallo-Dittko, V. (1995). Acute complications. RN, 58(8), 36-42.

Pereles, G. (1987). An examination of the dominant and the alternative paradigms in curriculum evaluation. Unpublished doctoral dissertation, Oklahoma State University, Stillwater, OK.

Peterson, A., & Drass, J. (1991). Managing acute complications of diabetes. Nursing 91, 23(1), 34-40.

Pinch, W. (1986). Quality of life as a philosophical position. Health Values, 10(6), 3-7.

Plummer, E. S., & Albert, S. (1995). Foot care assessment in patients with diabetes: A screening algorithm for patient education and referral. The Diabetes Educator, 21(1), 47-51.

Polly, R. (1992). Diabetes health belief, self-care behaviors, and glycemic control among older adults with non-insulin-dependent diabetes mellitus. The Diabetes Educator, 18(4), 321-327.

Polonsky, W. (1995). Besieged by the diabetes police. Diabetes Self Management, July/August 1995, 21-26.

Powell, A. (1989) Reflections: Good nursing takes more than good intentions. AJN, 89(6), 902.

Pratt-Gregory, R., & Davis, L. (1994). Use of carbohydrate counting for meal planning in Type I diabetes. The Diabetes Educator, 48(50), 406-409.

Price, M. (1989). Qualitative analysis of the patient-provider interactions: The patient's perspective. The Diabetes Educator, 15(2), 144-148.

Raffel, L. (1993). The genetics of diabetes. Practical Diabetology, 11(3), 6-11.

Raggins, A. (1995) Why self-care fails: Implementing policy at a low-income Sickle Cell Clinic. Qualitative Sociology, 18(3), 331-353.

Rankin, S., & Duffy, K. (1983). Patient education: Issues, principles and guidelines. Philadelphia: J. P. Lippincott Co.

Rapaport, W. (1994). Needle fear a common phobia to be faced and overcome. Diabetes in the News, 22-24.

Redman, B. K. (1988). The process of patient education (6th ed.). Washington: C. V. Mosby Co.

Regensteiner, J., Shetterly, S., Mayer, E., Eckler, R., Haskell, W., Baxter, J., & Hamman, R. (1995). Relationship between habitual physical activity and insulin area among individuals with impaired glucose tolerance. Diabetes Care, 18(4), 490-497.

Rennie, J. (1990). The body against itself. Scientific American, 263(6), 106-115.

Reverby, S. (1990). A caring dilemma: Womanhood and nursing in historical perspective (pp.184-194). In P. Conrad & R. Kern (Eds.), Sociology of health and illness: Critical perspectives (3rd ed.). New York: St. Martin's Press.

Reynolds, W.M. (1989). Reading curriculum theory: The development of a new hermeneutic. New York: Peter Lang.

Staff. (1994). Roadblocks lifted for truckers. Diabetes Self-Management, May/June 1994, 17.

Roberts, S. (1994). The new standards. Diabetes Forecast, 47(6), 46-49.

Roberts, S. (1995). An electronic lifeline. The Diabetes Educator, 48(5), 22-26.

Rodgers, M. (1970). An introduction to the theoretical basis of nursing. Philadelphia: F. A. Davis.

Rooks, J. (1990). Let's admit we ration health care-then set priorities. AJN, 90(6), 38-43.

Rubin, R., Beirhman, J., & Toomey, B. (1992). But what can I do? Diabetes Forecast, 45(12), 58-61.

Ruffing-Rahal, M. (1985). Well-being and chronicity: Being singular rather than sick. Health Values, 9(5), 17-21.

Santiago, L., Levandoski, L., & Bubb, J. (1994). Hypoglycemia in patients with Type I diabetes. In H. Lebovitz (Ed.), Therapy for diabetes mellitus and related disorders (2nd ed.) (pp.170-177). Alexandria, VA: American Diabetes Association.

Scheiner, G. (1993). Exercise options-scuba-do. Countdown, 14(3), 26-28.

Schlundt, D., Rea, M., Kline, S., & Pichert, J. (1994). Situational obstacles to dietary adherence. Journal of the American Dietetic Association, 94 (8), 874-876, 879.

Schmidt, L., Rost, K., McGill, J., & Santiago, J. (1994). The relationship between eating patterns and metabolic control in patients with non-insulin-dependent diabetes mellitus (NIDDM). The Diabetes Educator, 20(4), 317-321.

Schneider, J. & Conrad, P. (1983). Having epilepsy: The experience and control of illness. Philadelphia: Temple University Press.

Schoen, M. (1978). A study of compliance behavior in the administration of oral medication for homebound patients. Unpublished master's project, Western Connecticut State University, Danbury, CT.

Schubert, W. (1986). Curriculum: Perspective, paradigm and possibility. New York: MacMillan.

Schwartz, S. (1995). Your diabetes bill of rights. Diabetes Forecast, 48(12), 29-32.

Segatore, M., Edge, D., & Miller, M. (1993). Posology errors by sophomore nursing students. Nursing Outlook, 41(4), 160-165.

Shor, I. (1994). Education is politics: Paulo Freire's critical pedagogy. In P. McLaren & P. Leonard (Eds.), Paulo Freire: A critical encounter (pp. 25-35). New York: Routledge.

Simon, J. (1980). Middle East health. W.H.O. Regional Office: Alexandria, Arab Republic of Egypt.

Sims, D. (1986). Diabetes patient education: A consumer view. The Diabetes Educator, 12(2), 122-125.

Skelly, A., Marshall, J., Haughey, B., Davis, P., & Dunsford, R. (1995). Self-efficacy and confidence in outcomes as determinates of self care practices in inner city African-American women with non-insulin dependent diabetes. The Diabetes Educator, 21(1), 38-46.

Sperling, M. (1988). Physician's guide to insulin-dependent (Type I) diabetes: Diagnosis and treatment. Alexandria, VA: ADA.

Steinburg, C. (1994). Diabetes on the frontline. Diabetes Forecast, 47(6), 20-26.

Strauss, A. (1975). Chronic illness and the quality of life. St. Louis: C. V. Mosby Co.

Staff. (1994). Stumbling block removed for commercial drivers with diabetes. Countdown, 15(2), 14.

Swencionis, C., Wylie-Roset, J., Peters, M., & Cimino, C. (1994). Psychological profiling to individualize nutrition and exercise treatment in people who are overweight. Diabetes Spectrum, 7(20), 130-132.

Taibbi, R. (1995). When friends don't get it. Diabetes Self-Management, March/April 1995, 28-31.

Tomky, D. (1989). A three-pronged approach to monitoring. RN, 52(5), 24-9.

Tomky, D. (1995). Advances in monitoring. RN, 56(58), 38-45.

Tomky, D., & Clark, D. (1990). A comparison of users' accuracy, techniques and learning time of various systems for self blood glucose monitoring. The Diabetes Educator, 16(6), 483-486.

Travelbee, J. (1966). Interpersonal aspects of nursing. Philadelphia: Davis.

Tucker, K. (1992). Working your way through loss. Diabetes Self-Management, March/April 1992, 12-14.

Van Manen, M. (1991). The tact of teaching: The meaning of pedagogical thoughtfulness. SUNY: SUNY Press.

von Boehmer, H., & Kisilow, P. (1991). How the immune system learns about itself. Scientific American, 265(5), 74-81.

Waitzkins, H. (1990). A Marxian interpretation of the growth and development of coronary care technology. In Conrad, P. & Kern, R. (Eds.), Sociology of health and illness: Critical perspectives (3rd ed.) (pp.218-230). New York: St. Martin's Press.

Walker, E., Wylie-Rosett, J., Shamon, H., Engel, S., Basch, C., Zybert, P., & Cypress, M. (1995). Program development to prevent complications of diabetes: Assessment of barriers in an urban clinic. Diabetes Care, 18(9), 1291-1293.

Watson, J. (1985). Reflections on different methodologies for the future of nursing. In M. M. Leninger, (Ed.), Qualitative research methods in nursing (pp.343-349). New York: Grune and Stratton, Harcourt Brace Jovanovich.

Watson, J., & Dunford, S. (1992). Perceived and actual knowledge of diet by individuals with non-insulin dependent diabetes. The Diabetes Educator, 18(5), 401-406.

White, J., & Cambell, R. K. (1992). Pharmacologic therapies in the management of diabetes. In D. Haire-Joshu, Management of diabetes mellitus: Perspectives of care across the life span (pp.120-148). Philadelphia: Mosby.

Wierenga, M., Browning, J., & Mahn, J. (1990). A descriptive study of how clients make life-style changes. The Diabetes Educator, 16(6), 469-473

Wise, E. (1993). Winning the war against retinopathy. Countdown, 14(1), 38-43.

Wolf, H. (Ed.). (1976). Webster's new collegiate dictionary. Springfield, MA: G. & C. Merriam Co.

Wosniak, L. (1988). Your teaching plan: The key to controlling Type II diabetes. RN, 51(8), 29-33.

Wuest, J. (1993). Removing the shackles: A Feminist critique of noncompliance. Nursing Outlook, 41(5), 217-224.

Yamanouchi, K., Shinozaki, T., Chikada, K., Nishikawa, T., Ito, K., Shimizu, S., Ozawa, N., Yoichiro, S., Katsumi, K., Oshida, Y., & Yuzo, S. (1995). Daily walking combined with diet therapy is a useful means for obese NIDDM patients not only to reduce body weight but also to improve insulin sensitivity. Diabetes Care, 18(6), 775-778.

Zais, R.S. (1976). Curriculum: Principles and foundations. New York: Harper and Row.

Zehrer, C., Hansen, R., & Bantle J. (1990). Reducing blood glucose variability by use of abdominal injection sites. The Diabetes Educator, 16(6), 474-477.

APPENDICES

APPENDIX A

DOCUMENTATION OF

IRB PERMISSION

BENJAMIN ENG, M.D.
Medical Director

MEMORANDUM

TO: Mary Shoen, RN
FROM: Benjamin Eng, M.D., Medical Director *BE/KH*
RE: Proposed Study Regarding Diabetic Education
DATE: April 2, 1993

I have reviewed your proposal to perform research for your doctrine dissertation regarding education of diabetic patients. I agree in concept with your proposal, I have the following comments:

1. All research should be done during time which should not interfere with the patient's usual care including therapies, access to physicians, or nursing treatments.
2. The Medical Staff should be approached prior to approaching the patient to ensure that it is performed with the physician's approval. There may be individual circumstances which would preclude the use of a particular patient in this research study.
3. That it should be made clear to the patient that this is a voluntary project. I've made recommended changes on your consent form to place this statement in a more prominent position.
4. That you should obtain clearance from Administration.

After addressing the above issues, you have my approval to proceed with your research proposal utilizing diabetic patients here at St. Lawrence.

BE:KH

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
FOR HUMAN SUBJECTS RESEARCH

Date: 04-30-93

IRB#: ED-93-89

Proposal Title: CLIENT AUTHORED CURRICULUM FOR DIABETES MELLITUS
USING THE METHOD OF PAULO FREIRE

Principal Investigator(s): Dr. WILLIAM REYNOLDS, MARY KOSIK
SCHOEN

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

APPROVAL STATUS SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW
BOARD AT NEXT MEETING.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A
CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR
BOARD APPROVAL. ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO
BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for
Deferral or Disapproval are as follows:

COMMENT:

Please remove Terry Macuila's name from the consent form as
the University Research Services contact. Just give the
office name and number.

Signature:

Maria S. Tilley
Chair of Institutional Review Board

Date: May 4, 1993

APPENDIX B

SELECTED TRANSCRIPTS OF PARTICIPANT
INTERVIEWS AND GROUNDED
THEORY MEMOS

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 1 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

- 1 Q: I'd like to leave this (audio recorder) here because I'm
2 much more interested in what you have to say than what I
3 have to say. And I would like to take notes too because
4 where I believe that machine will work , if it didn't , I want to
5 have notes so that I can reconstruct what we've had to say
6 to each other. (Sound of recorder being knocked over.
7 Laughter.) Oh sorry, that was me. Now lets see now , What
8 do you think a person needs to learn ?
9 A: Mary, I think , that your life is not really your own
10 anymore..you know, It's the time schedule. It interrupts a lot
11 of things when you have to have to stop and eat ,when you
12 have to stop and take your medication. Like when people
13 won't invite you anywhere anymore, cause it like interrupts
14 their schedule you know? And it's different, It changes things.
15 Q: That has happened to my niece, people are afraid they will
16 have to give an insulin shot.
17 A: They're afraid you're going to pass out on them, or
18 something, that you will go into insulin shock or something.
19 Q: Is that something that ever happened to you? Did you
20 ever get so low you, passed out?
21 A: At work, um-hmm, but not around friends.
22 Q: Not friends. mm-hmm. I would guess you were working
23 pretty hard too, is that what happened?
24 A: Yes and once I forgot to take my insulin but that was only
25 once in 16 years, that I forgot to take it.
26 Q: Sounds like a pretty good track record.
27 A: Yes.
28 Q: So it's a problem when friends are afraid cause they don't

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 2 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

29 understand what's going on?

30 A: (Affirmative nodding.)

31 Q: Is there anything you've found that helps them?

32 A: No, not really, just by doing and they see what you can
33 do, you know?

34 Q: Show them what you can do?

35 A: Right...Like my friends and I we used to go to Baltimore
36 and Connecticut and different places and at first they
37 wouldn't invite me but then, you know...

38 Q: That must have been hard.

39 A: But then later I went everywhere.

40 Q: Do you need to get your own (unintelligible)

41 A: Really when they first told me I had diabetes, I just
42 accepted it right away. Cause I couldn't change it.

43 Q: You might have seen it, say, different from the way a
44 person in not in health care sees it?

45 A: Oh yes, I can see the different people in my family. They
46 won't,...I just accepted it right away and I taught my 13 year
47 old niece when she was about 10 how to give me my insulin.
48 She was living with us, yes.

49 Q: I think they are not always afraid of some of the things
50 adults are afraid of.

51 A: Right.

52 Q: How did she do?

53 A: She did good. She's smart.

54

55 Q: Do you think she will be a nurse too?

56 A: I don't know she's smart. (Joint laughter) She excellent

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 3 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

57 in math.

58 Q: That's great.

59 A: I don't know what she want's to do.

60 Q: Well I guess she will make her own decision in that.

61 That's a neat story. So sometimes you can get family and
62 friends to relax and sometimes you can't. Ah, lets see ...boy
63 my next question was going to be "What do you think a
64 family member ought to learn about diabetes. It's funny how
65 the real world kind of moves the questions along. Ah, if the
66 family wasn't afraid what do you think they should learn?

67 A: That would be one.

68 Q: Mhh-hmm.

69 A: (No response)

70 Q: How about diet, we were taking about that a little bit ago,
71 meals and timing.

72 A: Yes, diet is important, umm. Mainly I do my own cooking
73 because they like a lot of junk food, "Big Brother" you know..
74 order in or eat it out and so I do a lot of my own cooking
75 unless we are cooking a big Sunday meal then I don't put
76 any seasoning on mine until it's done and then I season it.

77 Q: When you say seasoning do you mean salt..?

78 A: Right.

79 Q: Or salt and butter and stuff?

80 A: Yea.

81 Q: So that's cooking. Cooking is different than before?

82 A: Yes.

83 Q: So it's not just the eating?

84 A: No it's the cooking too. And my little great nieces, they're,

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 4 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

85 4 and 5 and the baby's 1, watching me drink diet soda and
86 eating diet cookies, you know and when they go out they ask
87 for a diet Pepsi in a restaurant.

88 Q: Awe. (Joint chuckle)

89 A: So they are used to eating my type of food too.

90 Q: So diabetic diet is usually pretty healthy, so that may be a
91 benefit. So do you think maybe indirectly some people can
92 pick up good habits?

93 A: (Affirmative nodding.)

94 Q: Sounds pretty sensible ?

95 A: Yes.

96 Q: So you can offer things to a family in a way?

97 A: Right.

98 Q. Your answer is probably going to be different from most
99 people, Where did you learn to manage your diabetes? Was
100 that from what you knew from being in nursing school?

101 A: Not really, I had given insulin shots to patients but um,
102 when I got it, in the hospital they sent film and videos for me
103 to watch in the room, that's when I really learned more about
104 it.

105 Q: What do you think do, Do they spend enough time on this
106 in Nursing School? Do you think nurses know enough?

107 A: That's hard to answer... You know I think they teach
108 them pretty well. They teach them pretty well about it. But
109 you know your own body, like one time at work I started
110 having a reaction and they wanted me to wait for the doctor
111 and I knew that the sugar and orange juice didn't work. I had
112 tried it several times and I just had to get out of there. I think

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 5 of 20

Patient Number: 6 Interview Number: 1 Interview Date: 9-18-93

- 113 if they knew more about the symptoms they would get you
114 right out instead of having to wait for the doctor who like
115 takes 15 or 20 minutes.
- 116 Q: The work place is not always a benefit?
117 A: Right.
- 118 Q: Sometimes we get into following the rules ..
119 A: Right.
- 120 Q: ..instead of listening to the person who knows what's
121 going on?
122 A: Right, and then when I did get down to the hospital. My
123 blood sugar was so low.
- 124 Q: You know your own body.
125 A: Right, better than anybody.
- 126 Q: What kinds of things..I wonder how you could teach
127 people to listen better?
128 A: That's hard to say because they are bound by rules.
- 129 Q: Mhmm hmm.
130 A: You know, when you're leaving the work place you have
131 forms to fill out and all this stuff. It's ridiculous (laughing)
132 when you are sick.
- 133 Q: It is. Sometimes looking at the paperwork and the rules ,its
134 ridiculous. So you are saying , "Look at the person, not the
135 rules not the paperwork?
136 A: Right.
- 137 Q: Did you have a monitor with you, or maybe there weren't
138 monitors when this happened.
139 A: No, I've only had my Glucometer about 2 years.
- 140 Q: Did you bring it to work?

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 6 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

141 A: I take it to work with me because my insulin was different,
142 I took my big doses at 2 o'clock in the morning and the lower
143 dosage 7:30 in the morning because I worked nights. I was
144 on a different time schedule.

145 Q: Eleven to seven?

146 A: Right.

147 Q: Real nights, not 3 to 11?

148 A: Yes, that would be different from most people too.

149 Q: So the insulin has got to fit your schedule not the other
150 way around?

151 A: But then I found I ran into problems on my off because I
152 would be up all day...

153 Q: Ahh..

154 A: So that might have helped my sugar, you know, go out
155 of wack. So mainly I was taking insulin four times a day,
156 because I would be high all of the time.

157 Q: Oh.

158 A: So I was on a scale, You know over 250 I took so much,
159 over 300 took so much, but my sugar would just read "High"
160 so I knew it was over 500.

161 Q: That was pretty scary?

162 A: I'd get angry.

163

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 7 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

163 Q: Stress?

164 A: Yes, I was having problems at home with my niece, and I
165 would get upset . And even at work, they would send you to
166 different buildings that you didn't ever work there before
167 and that would be stressful too.

168 Q: I don't like working on units where I don't know the
169 patients. Sometimes things get hairy and I don't know where
170 to find things in a hurry. Is that what you mean?

171 A: Yes, and they have cottages up there 6 to 12 cottages.

172 That's called transitional living area and sometimes they
173 would send up down there and you would be outside all night

174

175 going from cottage to cottage. And it would be scary because
176 a nurse was attacked by a ex-patient who came up on the
177 grounds and it isn't lit up there at night and with the tree
178 trunks and all I was afraid I was going to fall. I was pretty
179 upset when they told me I would have to go down there. My
180 blood pressure would go up.

181 Q: That doesn't help the arteries, does it?

182 A: No.

183 Q: So we've chosen a stressful job haven't we?

184 A:Yes, but it wasn't always that way, cause really used to
185 enjoy my work, since I got older and things started going
186 wrong, you know? I could care less whether I got there I still
187 did my job.

188 Q: But it wasn't the same?

189 A: No, and family problems

190 Q: So work stress and family problems can do it, and we

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 8 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

191 talked about diet. Did you ever notice a difference with
192 exercise?

193 A: (Unintelligible)

194 Q: Where are other places a person can go to learn about
195 diabetes? Where do you think people go to learn stuff about
196 it?

197 A: There are fairs that they have. I know at my job they have
198 a Health Fair every year and you can go and be tested for
199 different things. You can go to your doctor and ask there.

200 Q: Did you ever go to somebody in your family or say ask a
201 friend about diabetes.

202 A: I had a cousin who had it but she died at 29 with it but
203 somebody that I know that had diabetes. I got it first then my
204 mother then my father, I but I have 9 sisters and brothers and
205 none of them. So after I got it I would never get married or
206 have kids, because I wouldn't want them to get it. Its hard
207 enough on an adult I couldn't imagine for a kid.

208 Q: Were you also concerned with the difficulties that come
209 along with pregnancy?

210 A: No. I wasn't to much concerned about the pregnancy, if I
211 got pregnant, because my mother, when she was pregnant a
212 couple of times. They said her sugar was high because of the
213 pregnancy but after she delivered she was fine.

214 Q: What happened?

215 A: She was fine after she delivered.

216 Q: That does happened some women remain with sugar
217 problems and some don't. What do you think..

218 A: This may sound crazy but, the dietician spoke to us here

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 9 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

219 and I understood more from her than comments than I did in
220 all the 16 years that I have it, of managing the diet.

221 Q: What kinds of things did she say to you that were really
222 useful to you?

223 A: When I first got it and through the years they would tell
224 me, "This is your meal plan and cream of spinach soup, one
225 starch and one fat." you know . "Look on your list" and they
226 wouldn't tell you that one starch would be the bread or the
227 soup.

228 Q: Ahh

229 A: And three meats would be three ounces of meat not three
230 different meats, but she explained it so well. It's so easy to
231 follow this now, I just make my own choices.

232 Q: May I tell her you said that? I know she would be pleased.

233 A: It's true. (Nodding affirmatively).

234 Q: So, ah , just because you have seen the video doesn't
235 mean it makes sense?

236 A: It's the way you interpret it, which the way I was
237 interpreting it was wrong.

238 Q: So we need to listen to the person more to help them
239 understand?

240 A: Right.

241 Q: What do you think a good way would be for a new person
242 to learn that type of thing?

243 A: Well explaining it like she did, you know one fat would be
244 your margarine or butter or something like that. One fat would
245 be the bread or something which was the way I was looking
246 at it, you know.

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 10 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

247 Q: Do you think something like a cooking class would do it?

248 A: Yeah.

249 Q: So you need to see what it's like to prepare it for

250 yourself?

251 A: Yes.

252 Q: I understand a little better now.

253 A: You know even when you go out to eat in a restaurant and

254 you tell the waitress, you know, can tell her like if you have a

255 steak to please cut it in half and I'll take the other half home

256 for later instead of eating an 8 ounce or 12 ounce steak. They

257 could even cut...

258 Q: So.. to have your exchanges?

259 A: Right.

260 Q: And then enjoy it? You've paid for it and then enjoy it

261 tomorrow?

262 A: Just take the rest home and enjoy another meal. You can

263 tend to eat the whole thing when you go out to dinner, you

264 know instead of stopping.

265 Q: So being presented with the appropriate, ah, the right

266 proportions for you , would be a good way to help stay with

267 the program.

268 A: Right, A lot of people are diabetes and I think if they had a

269 diabetic menu in restaurants it would be so much easier.

270 Q: A restaurant might important because that's where the

271 family's going or you just might want a break?

272 A: Right, like about every pay day I like to go out to dinner,

273 you know with my friends and um I tend to eat everything

274 instead of stopping.

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 11 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

275 Q: I know what you mean (Joint laughter). And its hard isn't
276 it?

277 A: And its very hard

278 Q: Is that something that you have done all of your life?

279 A: Right, even when my mother was alive. You know I would
280 take her out for breakfast every morning and I just started
281 ballooning. She was ill and losing weight and I was gaining all
282 of it.

283 Q: It would be nice if we could eat what we want, but I guess
284 what you were saying was that even though that was nice it
285 is important to understand that there are consequences.

286 A: Right and I think they should have some type of exercises
287 program for diabetics that doesn't include walking which is
288 what my doctor told me to do because I have other problems.
289 I have a heart problem too and I tried walking around the
290 block and taking my time and by the time I got back home my
291 pulse would be 150..

292 Q: Woo.

293 A: And I would be palpitating and sweating, you know, even
294 though I walked slow. So I couldn't do that exercise and the
295 block was not a long block it was just too much.

296 Q: It was too much?

297 A: But it was too much, so I think some other kind of
298 exercise. Even if you sit in a chair and do something.

299 Q: Is that something that the physical therapist might be able
300 to help you with while you are here?

301 A: Yeah

302 Q: Who do you have ?

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 12 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

- 303 A: I have G...
- 304 Q: I'd ask her, put her to work while you 've got her.
- 305 A: Even my little nieces when the exercise programs come on
- 306 T.V. they want to watch it, you know, and they are down
- 307 there doing the exercises and want to do some of them but I
- 308 can't.
- 309 Q: Well with the diabetes, and the blood pressure in terms of
- 310 safety, you need to know what's okay for you.
- 311 A: Right.
- 312 Q: And maybe have somebody practice with you with good
- 313 breathing because holding your breath while you are pulling
- 314 against something.
- 315 A: They told me when I'm exercising to be sure to breathe,
- 316 because you tend to hold your breath.
- 317 Q: That's a good idea for anybody but it's terribly important
- 318 for with blood pressure and if you are having any difficulty
- 319 with your eyes.
- 320 A: Everybody doesn't exercise the same and when they
- 321 showed me diabetic films, it's all like you can do any kind of
- 322 exercise.
- 323 Q: We're not all 18 are we ?
- 324 A: No (joint laughter) we aren't.
- 325 Q: Let me check this (audio recorder), No I guess its going,
- 326 There we go. I wasn't sure. I take this very seriously and I
- 327 don't want to lose anything if it wasn't taping I wouldn't be
- 328 very happy with myself. Okay that's good and we are doing
- 329 okay on the time. Let's see, specific exercise for a diabetic
- 330 person.

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 13 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

331 A: You need to follow your own exercise program.

332 Q: That would be helpful?

333 A: Yes.

334 Q: Okay, what's created problems for you? With teaching
335 what has created a problem ?

336 A: Not really, like I said the only thing that was really a
337 problem. The only thing was misunderstanding the food
338 exchange thing, but I understand that now. And I don't think
339 people realize how serious the diabetes is when they follow
340 the rules. Can't ignore diabetes, because it can have some
341 serious, serious side effects, which I've found hard for so
342 long.

343 Q:Um, do you want to tell me about your complications?

344 A: My eyes, I have diabetic retinopathy now and my left eye
345 is seeping behind the eye and .. I think the hypertension is ...
346 and the bladder infections all of the time.

347 Q: When your sugar was up, do you think these thing are
348 results?

349 A: Yeah.

350 Q: When your sugar was up in the beginning, did you think
351 maybe just for somebody else?

352 A: No, I knew about them but I didn't think it would happen
353 to me. When I first got diabetes my sugar was high that I was
354 literally blind for three months.

355 Q: Wow.

356 A: I 'd have to use a magnifying glass to read something and
357 it would still be blurry. I should have realized then, but you
358 know, that you don't pay so much attention because you are

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 14 of 20
Patient Number: 6 Interview Number: 1 Interview Date: 9-18-93

359 always on the go. When it hits you is when you are
360 exhausted.

361 Q: Getting over tired will make it worse?

362 A: Oh yes, and when your family doesn't realize it's worse.

363 My sugar was high and I slept for 18 hours straight and
364 nobody came to check on me. They just thought I was tired
365 you know? So I told them if I ever sleep over 10 hours come
366 and wake me up to see if I am alright. You know, I have to
367 tell them cause they don't realize that whether your sugar is
368 high or not sometimes you don't even realize it.

369 Q: Sometimes they have to be your eyes and ears when your
370 not well?

371 A: Right .

372 Q: So that's one of the things family has to learn about, signs
373 and symptoms of hypo and hyperglycemia?

374 A: Right, and well I keep a card in my wallet that I'm a
375 diabetic and I need a new one because my insulin changes so
376 much it that I keep crossing out and putting in there and it
377 has all the signs of hypo/hyperglycemia .

378 Q: Do you wear a bracelet?

379 A: No I don't, it made me break out. I used to wear it but it
380 made me break out.

381 And I have so much wrong with me now I'd need 3 or 4 of
382 them (Joint laughter.) But I carry a little letter in my wallet
383 that says everything that I need, a little note from my doctor
384 that I'm a diabetic and I need to carry needles, in case
385 something happens to me and I have needles on me and they
386 think I'm a drug addict.

387 Q: We live in tough times don't we?

388 A: Yeah, and especially if you are going into a foreign
389 country like I like to travel in Canada, you know, that's when
390 I first got it 13 years ago, but that's 13 years I've been
391 carrying that letter around with me. One of those things,
392 when you travel take an extra bottle of insulin with you and
393 take extra syringes with you in case.. and don't put them all
394 in the same place. Put some in your pocketbook and put some
395 in your suitcase in case you lose the other. It's hard to get
396 medication in a foreign country.

397

398 Q: And it might not be the same insulin. It's pretty fussy, it
399 has to be the same brand as well as the same kind.

400 A: Yes, I've been through all of it.

401 Q: Awe. (pause) Let me just sum up here. Your life really
402 changes in every way . Its not really your own the way it
403 used to be, there is the time schedule and every day diet. You
404 have a pretty good background from your nursing school and
405 the videos, but what they don't tell you is that you have to
406 know your own body and the way that you can change the
407 program to fit you. Now the way you did that was to go to
408 regular insulin 4 times a day.

409 A: (Answering the phone).

410 Q: Okay what I was going to ask, Let me move this back
411 (audio recorder). When you have your days off, because of
412 the shift work that we do, going from nights back to a day
413 shift or I imagine even working a like a double or something?

414 A: Well I couldn't work a double..I haven't worked a double in

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 16 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

415 about 2 years.

416 Q: Oh, the diabetes affects how much work you can do too ?

417 A: Right.

418 Q: When you said, "Changing insulin" did you mean straight

419 regular insulin to cover just a couple of hours at a time?

420 A: Yes, yes.

421 Q: Was that with your doctor?

422 A: Yes they sent me to an endocrinologist and she worked

423 the schedule out for me.

424 Q: And that made it easier?

425 A: Oh yes.

426 Other staff person: Goodbye M...

427 A: Goodbye, be careful out there.

428 Q: Yes it has been really raining out there, oh I guess not right

429 now but it was coming down pretty hard when I came in.

430 Ah.. So you need to be able to really talk with your physician?

431 A: I have a very good physician. In fact I had my physician

432 changed because I wasn't satisfied with the one I had and I

433 asked for a woman doctor and I think I got very lucky with

434 the one I have because she had it you and I could talk with

435 her and feel very comfortable with her.

436 Q: That seems to make a big difference. I was speaking with

437 someone else whose been helping me with the study and that

438 lady said that sometimes you can tell her and sometimes you

439 just don't tell her you have been getting off your diet and

440 particularly when she was starting out she said they told me I

441 was a diabetic but I had to see that for myself by not

442 following the diet. Is that something you ever experienced?

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 17 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

443 A: No, not exactly but I would say Oh I'll eat this it won't
444 hurt me. And then after a while you are eating everything you
445 aren't supposed to eat, because nothing happened to you but
446 in the long run it adds up and it will catch up with you.

447 Q: You looked at your hand when you said that.

448 A: (Chuckling) Well my mother used to say " A hard head
449 makes for a soft behind. Now I'm beginning to believe it.

450

451

452 Q: So are there some things you think you are going to be
453 changing?

454 A: My diet for one thing and I 'm going to have to find other
455 interests not just to get out to eat properly and that's what I
456 'm going to have to do.

457 Q: We have lots of folks who come back as volunteers and
458 they are our best encouragement.

459 A: That's what I said my patient sit in geri-chairs all day and
460 one of staff will say to them, "Why are you so depressed?" I
461 know what to tell them that I know how they feel now.

460 Q: Damn straight

461 A: That's right.

462 Q: You said that diet was hard for you. What's been the
463 hardest part with the diet?

464 A: Well I think it's just the way it is, ... You know a black
465 person's diet is different, the way most of their foods are
466 fried and the way they cook with lard and stuff like that. I'm
467 just going to have to coke like broil instead of frying.

468 Q: Do you think it would be a good idea to have a "Black"

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 18 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

469 cookbook for people with diabetes ?

470 A: Yes, yes definitely.

471 Q: There are ..oh.. different doing a diabetic version of
472 foods or I don't know, foods, different ways to celebrate
473 holidays or that would be helpful?

474 A: Right.

475 Q: I wonder if it would be helpful to have somebody to talk to
476 who knows how it is (to be a Black person with diabetes). I
477 'm not aware of a specific one but if you would like I can look
478 into that.

479 A: I don't know I've never heard of one. All of them tell you
480 to follow this you know? (Pointing to an A.D.A. booklet). You
481

482 have this you have the American Heart Association's Diet and
483 you have this diet and that diet but I've never seen a black
484 diet, do you know what I'm saying?

485 Q: Yes, mmm-hmm. I'm not aware of where I can put my
486 hands on one but I will try.

487 A: I don't even know if there is one, but just 'm saying, it
488 would help.

489 Q: There is a national organization, no there are 2 national
490 organizations I bet they have a national clearing house and
491 I could ask. If they don't have one I guess you have your
492 project when you get out of here. Okay and you said sleeping.
493 you're going to change that. Let me see if I understand. Were
494 you telling me that you might have slept because you were
495 exhausted when maybe if you had gotten up earlier and
496 stayed closer to the schedule you would have done your

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 19 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

497 blood sugar some good.

498 A: You know what happened that when I woke up I knew

499 something was wrong. I just seemed so sluggish that I went

500

501

502 up to the emergency room. What I'm saying is that your

503 whole body changes by your sleeping habits too. You know

504 when I started working 11 to 7, on my days off I started to

505 sleep because I was so used to being up all night and that

506 wasn't very good either.

507 Q: I don't changes shifts very well.(Joint chuckling).

508 Let's see with diet and sleeping and (unintelligible) but in

509 particular for the black woman , ah I for the black man too,

510 they certainly get it but, for the black woman.

511 A: Yes.

512 Q: Is there anything else I should be asking?

513

514 A: I can't think of anything.

515 Q: Well um I would use your name here but we don't want it

516 on the tape.

517 A: You have a good idea here. Nobody ever does that,they

518 just even your doctor, they tell you but they don't ask.

519 Q: This has been a big help to me. I'll be very glad when I'm

520 done with the paper.

521 A: You have a big deal with it though.

522 Q: Well thank you. Now what I would like to do is ,you know

523 I have to be away ..

524 A: It's not easy.

Mary K. Schoen Transcript of Patient Interview - Diabetes Instruction Page 20 of 20

Patient Number: 6

Interview Number: 1

Interview Date: 9-18-93

525 Q: Away for awhile but if you are here when I return I will
526 come see you and if not would you like me to send you a
527 transcript of this interview.

528 A: Yes

529 Q: If you are here we can go over it If you would check to see
530 if I got it right. Each line will have numbers on it and you
531 could say for example what I really meant to say on say line
532 16 was...or I though about this or I thought about that and
533 this is..

534 A: Okay

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 1 of 11

Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

- 1 Q: This is October 14th. Here we go. Here's the transcript. Take all the
2 time to read it and then make comments. I'll just take notes, if I can,
3 also.
4 [Patient reading transcript].
5 Q: Can I turn the TV down a little bit?
6 A: Sure.
7 Q: 'Cause the recorder make pick it up.
8 A: Sure.
9 Q: And I'll turn it back up when we're done.
10 [Patient continues reading transcript].
11 Q: I know there's a couple of typos in there.
12 A: Oh. I wouldn't worry about it. Well, we had that many pages?
13 Q: Um-huh.
14 A: Is this mine? Or do I have to give it back?
15 Q: No, it's a copy for you if you'd like it. That's an extra for you.
16 A: Yes, I'd like a copy. So I can sit and take my time, and read it
17 through. I'm pretty upset right now. You know I've been saying
18 goodbye to so many people today, you know. M_____, a volunteer,
19 you know, she came up and everybody's coming up.
20 Q: She's pretty special.
21 A: Oh, she is. She remembered me from two years ago.
22 Q: It's important to be remembered, to be a person.
23 A: Yeah, I think that everybody's special up here. They really are.
24 Q: Thank you. Um, I wonder if I could flip though my copy. And ask
25 one or two questions. 'Cause I wasn't sure, um, do you think you get it?
26 Let me just. Does it, the part that you read, does it look like, that it was
27 accurate?
28 A: Oh yeah. Um-huh.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 2 of 11
Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

- 29 Q: There were, there was one um, part, ah, that I, there are one or two
30 things and it was my voice that I couldn't understand. Like on the
31 second page, on line forty. When we were talking about you traveling
32 and you weren't included at first. And then you went every place. And
33 then um, I said - "Do you need to get your own"? And I don't know
34 what I said. I wasn't able to understand. Um, does that ring a bell?
35 A: No.
36 Q: Okay.
37 A: I'm trying to figure that out too. I don't remember what that was, or
38 the answer either.
39 Q: Okay. It seems like the important part that we were talking about
40 there is it's hard to be left out.
41 A: Um-huh.
42 Q: And then you have to get, sort of get it together and then get your
43 own confidence. And then show people it will be okay.
44 A: Yes. Something like that.
45 Q: And then they'll respond to that?
46 A: Yeah.
47 Q: I really don't know what the word was. And then there's one a little
48 later, that I'm going to ah, have to find. And it was me again.
49 A: Ah, here's a gal.
50 Voice: Ah.
51 Q: Hello, RN.
52 Voice: How are you doing? Ha-ha-ha.
53 A: You got your hair down tonight.
54 Voice: Well I got it cut a little bit, you know.
55 A: Look's great.
56 Voice: Thanks. I, I think it's still not quite short enough, and it's not

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 3 of 11

Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

57 going to drive me crazy, in my face. But, ah. I haven't ah, I did bring
58 something to tie it back. And I thought, well, let me give it a try for a
59 little while.

60 Q: We can't live with them you know. They all passed.

61 [Laughter.]

62 Voice: Oh, it's so good that we all . . .

63 A: Do you think I could have the Talwin, Name?

64 Voice: Yeah. Let me see when you had it last.

65 A: This morning about 7:15, or something like that.

66 Voice: Alright. That should be okay.

67 [Sound of pages turning].

68 A: You find it?

69 Q: I'm looking. I thought it was towards the end. No, I guess I could be
70 confused. It might have been the first one. I just thought it was a bit
71 later. Okay. I guess that was it, what I really didn't understand and,
72 then the only other thing that I really wanted to ask you was, we were
73 lucky enough to find that there was a black support group. And I was
74 wondering if you had any more thoughts about that.

75 A: No. I'd like, I, I'm very interested in that. And, um, it will give me a
76 chance to get out of the house. The only thing that would be a concern
77 to me is transportation. I don't have a car now, and my niece has a van
78 but she's in and out. I can't depend on her to take me everywhere.

79 Q: Well, I'll bring it to you, and some support groups are able to, I'm not
80 guaranteeing, but some support groups have enough volunteers where
81 they can get rides for things like this. And I'm sure that varies. They
82 aren't going to have a meeting for a while. They're having an education
83 program on November 6th.

84 A: A-huh.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 4 of 11
Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

85 Q: And so they're going to let one of their meetings go back, skip over it.

86 A: Right.

87 Q: Okay. I think it is very important to have a support group that you're
88 comfortable with, and understand how things are. And I hope that's of
89 some use. You've been very kind.

90 A: Well.

91 Q: I appreciate it.

92 A: I got very friendly with Name. Who I meet two years ago, when she
93 had her stroke. And we were in therapy together. But we never talked
94 then. But I've gotten to know her and we exchanged names and phone
95 numbers so we could keep in touch.

96 Q: That's terrific.

97 A: And go to some groups that she goes to for the stroke thing. I plan
98 on keeping busy. I'm going to rest up for awhile, you know. And do the
99 therapy at home or what ever. And get used to being home again before
100 I start anything. I haven't set a time limit. I'll just see how things go.

101 Q: That's a big task.

102 A: Yeah. But I'm sure a lot of things I'm going to have to get used to
103 again. And like my little nephew came up, he'd just turned a year old.
104 And like two months he didn't know me, you know. And that upset me
105 so much.

106 Q: I think I would be upset too. I wonder if he didn't know you, or he
107 didn't know you here?

108 A: I don't know but, you know, I had a special name I called him. I
109 always called him Mr. Johnson, for some crazy reason. And I said -
110 What's the matter, Mr. Johnson? And he put his hand out like this, and
111 then he pulled it back. You know, like he wasn't sure.

112 Q: He wasn't sure.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 5 of 11

Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

- 113 A: Yeah.
- 114 Q: Aw. Well, it may be, this is a pretty noisy, scary, bustling place to
115 little people.
- 116 A: Ah-huh.
- 117 Q: And lots of out-going kids are like, looking around . . .
- 118 A: Yeah. Yeah.
- 119 Q: A little over whelmed.
- 120 A: And I have a new niece.
- 121 Q: Oh. Well, congratulations auntie.
- 122 A: Yeah. She was born the 29th of August.
- 123 Q: Oh.
- 124 A: She brought her up so I could see her last week.
- 125 Q: Aw. Congratulations, auntie.
- 126 A: Thank you. So I've got a bunch of great nieces and nephews.
- 127 Q: Well, they've got a pretty great auntie, too.
- 128 A: Well, I'd like to think so. Things are falling into place now, finally.
129 I've got my disability check. My dad cashed that for me, so my sister
130 could take care of a lot of the bills that were piling up.
- 131 Q: Finances are a problem.
- 132 A: Yes.
- 133 Q: Because this, diabetes and the things that can go with it, create havoc
134 in your life. You're sick and you've got to worry about the bills.
- 135 A: Right.
- 136 Q: I'd like to ask you one last general question that goes with this. It
137 seems to me that most people learn about diabetes, one to one, like
138 we're doing. And I'm wondering if group would be more helpful to a lot
139 of people?
- 140 A: I think so. I really do, because um, like I said I've been diabetic for 16

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 6 of 11

Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

141 years but I really didn't understand a lot of it until I came here and went
142 to some of the workshops they had on diet and so forth. I really didn't
143 understand how to read the meal plan, but I do now.

144 Q: I'm thinking to myself and somebody else might have asked a
145 question that kicked it off in your mind, that it would have been an
146 advantage. But, getting to group some place from where you are, one of
147 the problems could be transportation. Are there any other problems you
148 can see to working in a group?

149 A: No. Not to me. There maybe would be personality clashes,
150 something like that. But I think everybody goes with the idea that
151 everybody's there to help them. You know.

152 Q: The support group Mrs. Name was telling me about, the ones that she
153 started, seem to talk about, that the folks that come in are working for
154 them, instead of the other way around. And that sounds a little
155 different, the way most people think about health care. It seems to put
156 the person with the illness more in charge. Is that kind of a different way
157 of thinking about it?

158 A: I think what happens once you become a diabetic, you're not really in
159 charge anymore. You know, you have to be on a timetable to take your
160 medication, to eat, and a lot of that. It takes away a lot from a person.

161 Q: Your independence?

162 A: Your independence. You know, you feel tied to a schedule. You may
163 want to go somewhere where you're not going to be able to eat at that
164 certain time. And then you get anxious and you know, your sugar goes
165 up and all that. So, I think in that respect it's true. Q: You think illness
166 really makes you dependent, with other people and schedule and stuff?

167 A: Right. And a lot of people, they don't like that because they've
168 always been independent. You know? Like me.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 7 of 11

Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

169 [laughter].

170 Q: So that's a loss too. Independence, maybe as much as the other
171 things. We've talked about that, and that seems to be a reoccurring
172 theme with lots of folks.

173 A: Right.

174 Q: Is that something that we maybe should be telling new people, that
175 everybody feels this way?

176 A: I think so. Yeah.

177 Q: What do you think we could do to make that better? Who has the
178 power to change that?

179 A: I think each person should set up their own schedule. That's what I
180 had to do, because by me going on nights, I had to take my big dose of
181 insulin at two o'clock in the morning. You know, and then take smaller
182 doses like at seven-thirty before I went to bed. 'Cause I slept in the day
183 time. But I think if you make your own schedule and if you stick to that
184 schedule, you feel like you have more control. You know? Like taking
185 your medication at eight, and one and eight, you know? You take it even
186 though it's going to be eight hours or six hours or whatever, apart. You
187 make your own schedule.

188 Q: So . . .

189 A: You can bring it on in, because I'm ready.

190 Q: Hi.

191 Voice: Okay, that gives you a que to leave.

192 Q: I can leave if she wants, or I can stay.

193 A: Oh look at the fancy cups.

194 Voice: Oh yeah, they got new cups.

195 A: They sent me angel food cake. Boy they really want me to leave. Q:

196 Well, do you not like it?

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 8 of 11
Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

- 197 A: I love it, but.
- 198 Voice: It's a diabetic cake.
- 199 Q: You bet. Its got to be fit into the diet but it's a legitimate choice. It's
200 not cheating.
- 201 A: I believe it this time. She didn't mark down anything, she added on.
- 202 Q: Hum.
- 203 Voice: Oh they made a mistake.
- 204 A: The other day they sent me a piece of cake with chocolate sauce on it
205 and Name comes in and says - "Oh you can't have that!" I said - "Oh, I
206 should have eaten that first."
- 207 [laughter]
- 208 Q: Does it feel like cheating instead of making a choice on a day you
209 decide to have a dessert?
- 210 A: No, it feels like you're cheating. You do feel guilty about it. Q: So,
211 with this, I would think, how do you see that connecting to . . . Can I
212 help you sit up here?
- 213 A: No, I can do everything.
- 214 Q: Okay. It seems like an independent person making a choice isn't
215 cheating. And somehow, that gets confused.
- 216 A: You know, it you eat a piece of a candy bar, or you eat something
217 you're not supposed to, sometimes you say - "Oh boy, am I gonna get
218 sick? Do I have to take more insulin? You know. Am I going to go into
219 a, whatever." There we go.
- 220 Q: I do that too. (Having difficulty opening food package).
- 221 A: I asked somebody to open it for me, and they couldn't open it.
- 222 [laughter]
- 223 A: And I said well forget it, I'll just open it my way.
- 224 Q: That's what finger nails and teeth are for. Rotten little packages, it's

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 9 of 11
Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

225 like airplane food.

226 A: First time I've had a cup.

227 Q: Yeah, that is an improvement.

228 A: It is, because now we have the silverware and we have the plates
229 now that we didn't have for a long time.

230 Q: Well, after the interview, I know a little bit about the background and
231 I'll be happy to fill you in on the details. So it seems like independence is
232 a real important reoccurring theme. And somehow, until, especially
233 when somebody else gives you the schedule, everything is cheating.

234 A: Right.

235 Q: And that makes you feel badly about yourself. And, and less in
236 charge. So it seems like when you make a decision, it takes away from
237 you being in charge.

238 A: Yeah, because I know sometimes, my sister's a, you know, they like
239 those chocolate donuts, Enteman, whatever. I'll just take a bite and one
240 of the kids - "Oh you shouldn't be doing that. You know you're
241 cheating." And they make you feel so guilty, you know.

242 Q: And, does that encourage you not to do it, or does it not change the
243 behavior but make you feel bad?

244 A: It makes me feel bad. You know.

245 Q: But it doesn't do what they want it to do, and it makes you feel bad.
246 So families ought to think about that. Please go ahead with your dinner.

247 A: Oh, okay. What is it?

248 Q: Um, I'm not sure.

249 [laughter]

250 Q: Looks like some kind of beef and maybe egg plant.

251 A: That's what it's supposed to be. That's what I ordered.

252 Q: Um. Maybe egg plant lasagna.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 10 of 11

Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

- 253 A: Egg plant pharmagan, it's supposed to be.
- 254 Q: That's probably pretty edible.
- 255 A: We'll see. Like those potatoes, a couple of weeks ago. Oh my
- 256 goodness. They broke my fork.
- 257 Q: I believe you. Um, well that's probably the most helpful thing we got
- 258 out of the interview. It sounds like you're saying it all goes around.
- 259 Everything relates to independence.
- 260 A: Right. It does.
- 261 Q: Okay. Well, I appreciate it. Is there anything I should have asked that
- 262 I didn't ask?
- 263 A: I don't think so. The families could be a little more encouraging. You
- 264 know, to the diabetic. They should watch over them, but not be overly
- 265 critical. Let them do their own thing, until, you know, something's really
- 266 drastically wrong.
- 267 Q: Okay. Treat you like an adult?
- 268 A: Right.
- 269 Q: Okay. Thank you very much.
- 270 A: Oh, you're welcome.
- 271 Q: I really enjoyed working with you, both with my job and the paper.
- 272 A: Thank you. You're welcome any time.
- 273 Q: You're an asset.
- 274 A: Call me at home, anytime.
- 275 Q: Thank you. I need to go upstairs and get Mrs. Name friends number
- 276 and leave it with you. May I call her and give her your name and
- 277 number?
- 278 A: Yes.
- 279 Q: Okay. I will do both. It will take me a minute.
- 280 A: Okay.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 11 of 11

Patient Number: 6 Interview Number: 2 Interview Date: 10-14-93

281 Q: Great.

282 A: Alright.

283 Q: Thank you.

284 A: It's been a pleasure.

285 Q: Aw.

286 A: I'll look you up when I come back.

287 Q: I won't say goodbye because I'll be back in a minute.

288 A: Right. I don't want to say goodbye either.

289 Q: Okay.

Mary K. Schoen

Analysis of Patient Interview

Page 1 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

1	Line 9-18	The first point this lady makes about DM is that her life
2		is no longer her own. It has become a time schedule.
3		
4		DM care interrupts with meals and insulin shots.
5		
6	Line 17	People are afraid/fear they may have to help and assist
7		with injections and afraid of a person going into insulin
8		shock (this is an older health care term for severe
9		hypoglycemia).
10		
11	Line 22	Passing out with hypoglycemia has occurred once to this
12		lady while she was working.
13		
14		She has also omitted her insulin once in 16 years.
15		
16	Line 26-27	She is proud that this has occurred only once.
17		
18	Line 32	She has found the best way to help friends overcome
19		their fears is to "just go out and see what you can do."
20		
21	Line 35	DM has limited some of her ability to travel.
22		
23		
24		
25		
26		
27		

Mary K. Schoen

Analysis of Patient Interview

Page 2 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

28	Line 41	She reports she had no trouble accepting the diagnosis.
29		(This lady is an L.P.N., and would have learned some
30		information about DM and its problems/sequela before
31		it was diagnosed for her.
32		
33	Line 45	Different family members have learned to accept it and
34		deal with it differently.
35		
36	Line 46-47	Her 10 year old niece has been very helpful to her. She
37		agreed that this may be because children are not as
38		fearful about some things as are adults.
39		
40	Line 67	If family members are not too fearful, this lady believes
41		they should be taught how to draw up and administer
42		insulin.
43		
44	Line 72	Diet is also important.
45		
46		Salt restrictions are a part of this for her.
47		
48	Line 81	DM has changed how she cooks. She has changed her
49		use of salt and butter.
50		
51	Line 84-87	Her eating habits are improved in that she avoids
52		concentrated sweets by drinking diet soda and eating
53		diabetic cookies.
54		

Mary K. Schoen

Analysis of Patient Interview

Page 3 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

55	Line 84-87	Her great nieces have now begun to copy her behavior.
56	(continued)	
57		
58	Line 98-105	This lady was exposed to some DM teaching as an SPN
59		but feels her real education did not begin until she was
60		affected with DM.
61		
62		Her teaching consisted of films and videos sent to her
63		room.
64		
65	Line 107-108	She found the question difficult to answer when asked if
66		she felt her nurse's training was adequate to manage the
67		nursing responsibilities for DM.
68		
69	Line 109	This lady feels it is also very important to know your
70		own body.
71		
72		Nurses and physicians can cause problems when they
73		listen to what they feel are the correct signs and
74		symptoms and ignore what the individual is saying.
75		
76	Line 128	It will be hard to teach staff to listen better because they
77		are bound by the rules.
78		
79		
80		
81		

Mary K. Schoen

Analysis of Patient Interview

Page 4 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

82	Line 129-135	An example of this is requiring a person who becomes
83		sick at work to fill out paper work before they can
84		leave.
85		
86	Line 145	If you have a meter take it to work with you.
87		
88	Line 142-148	This lady found her shift work necessitated changing
89		when she took her "day" dose of insulin to 2 A.M. to
90		cover nights, because this was her normal day
91		time/daily work schedule.
92		
93	Line 153-160	Euglycemia was further complicated by changing back
94		to "days" during the day on her weekend/time off.
95		
96	Line 161	Her reaction to hyperglycemia was anger.
97		
98	Line 163	Work and family stress are two areas that she believes
99		increase her blood sugar and her hypertension.
100		
101	Line 190	This reference was to a conversation held between this
102		participant and the researcher before formal consent was
103		obtained for permission to interview for this study.
104		This participant is concerned about what she feels are
105		poor eating habits.
106		
107		
108		

Mary K. Schoen

Analysis of Patient Interview

Page 5 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

109	Line 200-212	This lady has chosen not to marry and not to have
110		children because of the fear of passing it on to her
111		children.
112		
113	Line 216-225	This lady feels she has reached her first understanding
114		of her diet in the 16 years she has had DM. She
115		believes she has finally reached this level of
116		understanding because the dietician explained how
117		foods/dishes which were prepared from several
118		ingredients, i.e., a cream soup could contain flour
119		counted as a bread exchange, fat, as well as the more
120		obvious vegetable, should be counted in the exchange
121		system.
122		
123		Additionally she learned that for example "3 meats"
124		meant 3 ounces of meat, not 3 different servings of
125		meat.
126		
127	Line 235	She feels these were errors of interpretation.
128		
129	Line 237	This type of error could be corrected by listening better.
130		
131		
132		
133		
134		
135		

Mary K. Schoen

Analysis of Patient Interview

Page 6 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

136	Line 246	A cooking class would be helpful to this lady.
137		
138	Line 252-261	There are skills for eating out:
139		Have the waitress request the meat be cut to the proper
140		amount of exchanges and bring the rest home as
141		leftovers.
142		
143		Enjoy the rest on the next day.
144		
145		Having a diabetic menu available at restaurants would
146		also help.
147		
148	Line 269-270	Eating out is important because her family may be going
149		there as a family activity in which she wishes to
150		participate or because she may need a break from
151		cooking.
152		
153	Line 270	Going out with friends on payday is an activity she
154		enjoys.
155		
156		It is a problem though because she tends to eat
157		everything she is served.
158		
159	Line 278-281	It is difficult for this lady to lose weight.
160		She would like to be able to eat whatever and
161		
162		

Mary K. Schoen

Analysis of Patient Interview

Page 7 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

163	Line 278-281	whenever she wants with no negative consequences.
164	(continued)	
165		
166	Line 284-303	This lady's ability to walk is limited by her physical
167		condition and her doctor's recommendation to limit her
168		activities because of her cardiac condition.
169		
170	Line 310	Exercises where you hold your breath aren't good for
171		you.
172		
173	Line 339	Ignoring DM has serious side effects:
174		
175		Diabetic retinopathy.
176		
177		Hypertension.
178		
179		UTIs (urinary tract infections).
180		
181	Line 351	She knew that these sequela were possible but did not
182		believe they would happen to her.
183		
184	Line 352	She also experienced difficulty seeing/blindness when
185		she was hyperglycemic. This lasted approximately 3
186		months.
187		
188		
189		

Mary K. Schoen

Analysis of Patient Interview

Page 8 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

190	Line 355-359	Becoming overtired makes the symptoms worse.
191		This is dangerous because a family may not be able to
192		differentiate between this and hyperglycemia.
193		
194	Line 370-371	This lady believes families should be taught the signs
195		and symptoms of hypo and hyperglycemia.
196		
197	Line 377-378	She does not wear a medic alert bracelet because
198		wearing it made her break out in the past.
199		
200	Line 379-384	She carries medical information in her purse.
201		
202		She also carries a letter indicating her need to carry
203		syringes.
204		
205		She is afraid people may think she is a drug addict.
206		
207		She also knows she needs documentation for crossing
208		the border into Canada.
209		
210	Line 412	Another way DM has affected her life is that due to her
211		scheduling needs, she does not feel she is able to work a
212		double (2 back to back shifts usually running a total of
213		16 hours).
214		
215		
216		

Mary K. Schoen

Analysis of Patient Interview

Page 9 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

217	Line 412	One thing that made her life easier was to find an
218		endocrinologist who ordered regular insulin, so that she
219		could change the dose to fit her needs.
220		
221	Line 430	She has also changed her physician.
222		
223		She is very pleased with the change because she finds it
224		easier to speak to another female rather than a male
225		physician.
226		
227	Line 439	For this lady, "getting off the diet" was not a test for
228		her, not a way of knowing that she indeed did have DM
229		but it was believing that one item would not hurt her
230		then adding another and another.
231		
232	Line 447	This lady said that her mother said, "A hard head makes
233		a soft behind" meaning that there are punishments for
234		people who stubbornly make bad choices.
235		
236	Line 450	These punishments (long term complications) will cause
237		her to make some changes. These are:
238		
239		Diet.
240		
241		
242		
243		

244	Line 454	She feels her present admission for a CVA
245		(stroke/cerebral vascular accident) and its resultant
246		decreased mobility will give her an understanding of her
247		patients who sit in Geri-Chairs. These chairs are
248		usually high backed vinyl padded chairs with small
249		wheels that can be pushed for short distances. They
250		also have a tray which can be used to serve meals or
251		allow the occupant to place a book or similar item. The
252		tray is also used to keep a person from getting up with
253		out assistance. It is almost impossible for a person with
254		any kind of physical impairment to get out of a chair
255		without assistance. These chairs are used for those
256		deemed restricted in their ability to walk, unable to
257		walk independently or walk safely. They are generally
258		viewed by staff as a safety device to prevent falls.
259		
260	Line 467	This lady is an Afro-American. She feels that a cook
261		book for Afro-Americans with DM would be a help.
262		
263	Line 487	This lady has been given generic cook books published
264		by the ADA and from the American Heart Association.
265		She feels they do reflect the usual food choices for her
266		ethnic background and therefor are not useful to her.
267		
268		
269		
270		

Mary K. Schoen

Analysis of Patient Interview

Page 11 of 11

Patient Number:6

Interview Number:6A

File:MEMO6A.WPW

271	Line 488	Both shift work and hyperglycemia are problems for this lady. The resulting states of being tired are difficult for her to differentiate.
272		
273		
274		
275	Line 514	This participant feels the interview process is a therapeutic idea in itself. She feels no one ever asks these questions of patients, questions are only asked of physicians.
276		
277		
278		
279		
280	Line 515	Rest of interview is an explanation of how the transcript will be returned and saying goodbye.
281		
282		
283		
284		
285		
286		
287		
288		
289		
290		
291		
292		
293		
294		
295		
296		
297		

Mary K. Schoen

Analysis of Patient Interview

Page 1 of 5

Patient Number:6

Interview Number:6B

File:MEMO6B.WPW

1	Line 17-22	This lady has requested a copy of the first interview
2		because she is having difficulty processing the
3		information because she is upset.
4		
5		It is difficult to process information when a person is
6		upset.
7		
8		A person can be upset at the time of discharge.
9		
10		Part of this is caused by saying goodbye to people who
11		have become significant to her.
12		
13	Line 60	This lady and the other patients have been very
14		supportive of the new graduate nurse. Several of the
15		staff members on this floor were recently graduated
16		nurses. They had just received word that they had all
17		passed their state boards/licensing exam and were now
18		newly Registered Nurses.
19		
20	Line 63	This lady is asking for her pain medication. In an
21		institution all medications are given only with a
22		physician's order/permission. This includes such items
23		as antacids, aspirin and vitamins. The orders include:
24		the name of the medication, how much, or the dose and
25		how frequently it can be given. A competent patient
26		may refuse.
27		

Mary K. Schoen

Analysis of Patient Interview

Page 2 of 5

Patient Number:6

Interview Number:6B

File:MEMO6B.WPW

28	Line 75	This lady is very pleased that an Afro-American support group near to her home has been located for her.
29		
30		
31	Line 78	Transportation is going to be a barrier for this lady as she does not have a car at present.
32		
33		
34	Line 92	This lady has sought out another lady with the same primary diagnosis. They have been a support to each other.
35		
36		
37		
38	Line 92	This lady will have to include physical therapy in her routine after her discharge.
39		
40		
41	Line 99-128	Family and her role in the family is very important to her.
42		
43		
44		It was upsetting when her year old nephew did not recognize her.
45		
46		
47	Line 128	Diabetes and its long term complication can "wreck havoc"/ be a problem with finances.
48		
49		
50		This lady deals with this by requesting her family help by cashing checks, etc.
51		
52		
53		

Mary K. Schoen

Analysis of Patient Interview

Page 3 of 5

Patient Number:6

Interview Number:6B

File:MEMO6B.WPW

54	Line 128	Finances cause stress and worry.
55	(continued)	
56		
57	Line 140	This lady feels learning in a group situation would be
58		more helpful than individual sessions.
59		
60		Possible problems with a group situation might be:
61		
62		Transportation.
63		
64		Personality clashes.
65		
66	Line 158	DM takes away a person's independence:
67		
68		They become dependent upon a timetable for
69		medication, eating and others.
70		
71	Line 162	She feels tied to a schedule.
72		
73	Line 163	This lady believes that stress makes her sugar go
74		up/hyperglycemia.
75		
76	Line 171	This lady feels that new persons should be told that
77		others have the feeling of losing their independence and
78		they are not the only person experiencing these feelings.
79		

Mary K. Schoen

Analysis of Patient Interview

Page 4 of 5

Patient Number:6

Interview Number:6B

File:MEMO6B.WPW

80	Line 177	This lady feels people would be empowered if they set
81		up their own daily schedule.
82		
83		"If you make it your own schedule and if you stick to it
84		you feel you have more control."
85		
86	Line 199	When you are in a health care institution the dietary
87		department can make a mistake, then you will have to
88		make a choice as to whether or not to eat the forbidden
89		food.
90		
91	Line 208- 212	Desserts which are included as a part of the diet still
92		feel like cheating.
93		
94	Line 217	An aspect of the guilt of cheating is the internal
95		questioning of consequences:
96		
97		Will I get sick?
98		
99		Will I need more insulin?
100		
101		Am I going into a whatever..
102		(hyperglycemia/HHNK/DKA).
103		
104	Line 232	When someone else determines the schedule,
105		"everything feels like cheating."
106		

Mary K. Schoen

Analysis of Patient Interview

Page 5 of 5

Patient Number:6

Interview Number:6B

File:MEMO6B.WPW

107	Line 238-244	Family can make this lady feel guilty for taking "one
108		bite of forbidden food."
109		
110	Line 263-268	Families should watch over a person with DM but not
111		be too critical.
112		This can be seen as: Let them do their own thing until
113		something is drastically wrong.
114		
115		Treat the person as an adult.
116		
117	Line 269	Rest of interview is closing and saying goodbye.
118		
119		
120		
121		
122		
123		
124		
125		
126		
127		
128		
129		
130		
131		
132		
133		

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 1 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

- 1 Q: I appreciate you being um even glad to help me out rather than just
2 doing it. I really do appreciate it. It's a big project.
- 3 A: Oh sure.
- 4 Q: Okay. And I'll just grab my pen and sit down.
- 5 A: Pen's over there.
- 6 Q: Okay. There it is.
- 7 A: Very good.
- 8 Q: Okay.
- 9 A: Alright.
- 10 Q: Now. Um, all set here. What do you a new person, who's just been
11 diagnosed with diabetes needs to learn about?
- 12 A: Diet.
- 13 Q: Diet.
- 14 A: Diet.
- 15 Q: What kinds of things about diet do they need to learn?
- 16 A: Well, ah, What to eat.
- 17 Q: What to eat.
- 18 A: What to drink.
- 19 Q: What to drink.
- 20 A: That's about it, I think.
- 21 Q: How about the amounts? Is that important? The amount of a . . .
- 22 A: Oh yeah! Yeah. Some of them, you know, they over do it. Seems
23 like, ah, when I, ah, when I used to drink beer, I used to over do it. I
24 used to drink a six pack in no trouble at all.
- 25 Q: And that has a lot of calories to it.
- 26 A: Sure. Yeast and all that stuff, got a lot of calories in it. And that's
27 what gave me the pressure.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 2 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

- 28 Q: Aha. You had high blood pressure?
- 29 A: Sure, high blood pressure.
- 30 Q: That's not a good combination, with diabetes, is it?
- 31 A: No, but I never knew I had diabetes until I had the broken leg. I got
- 32 into the hospital and they checked me out and they found the diabetes.
- 33 But they, they corrected it, Micronase, a medication.
- 34 Q: So uh, when was this that you found out?
- 35 A: Last year.
- 36 Q: Were you kind of surprised?
- 37 A: I was, very much.
- 38 Q: What did you think when they told you?
- 39 A: Had to get busy. Had to get busy on the diet, doing all the things
- 40 they tell me to do. What to eat. And so forth and so on.
- 41 Q:Ummhmm
- 42 A: You know? Which I did.
- 43 Q: So that was helpful and it has been behaving for you.
- 44 A: Oh yeah. It's been doing good for me.
- 45 Q: That's terrific, What does, "doing good", mean for you?
- 46 A: When they check me out and they say, "your count is low", then I'm
- 47 happy". Do you know what I mean?
- 48 Q: Yes, your blood sugar ?
- 49 A: Yes.
- 50 Q: Now when you have this checked is that at your doctor's office?
- 51 A: Ah, yeah, the doctor's office.
- 52 Q: Do you check it at home?
- 53 A: Ah, I have a thing, yeah I check it at home.
- 54 Q: Now how often do you use that about?

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 3 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

- 55 A: Oh about, every 2 weeks.
- 56 Q: Once every 2 weeks?
- 57 A: Once every 2 weeks.
- 58 Q: And what does it usually run?
- 59 A: You mean what does it cost?
- 60 Q: No, what are the numbers like usually?
- 61 A: I don't. I'm in pretty good shape, I go by the colors.
- 62 Q: Oh, you use by the colors.
- 63 A: That's working out pretty good.
- 64 Q: Which machine do you use .
- 65 A: I don't use one.
- 66 Q: Oh, you just use the "Chem-Strips"?
- 67 A: "Chem-Strips" like with (Dr.Name) used to use. He started me with
- 68 that. That's where I first saw how that works, because he told me to do
- 69 it and I said , "What's that for?" and he said, "That's to see if you have
- 70 sugar."
- 71 Q: And you check your finger's blood?
- 72 A: Yeah at the doctor's. I don't do it myself, but the doctor does.
- 73 Q: Okay.
- 74 A: So the doctor checks it.
- 75 Q: Oh, the doctor checks your blood and do you check your blood or
- 76 your urine?
- 77 A: I check my urine
- 78 Q: You check your urine.
- 79 A: Yes, I check my urine.
- 80 Q: Okay, Most people check their blood these days, but that means a
- 81 finger stick.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 4 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

- 82 A: Nah, a stick!
- 83 Q: You don't like that?
- 84 A: No, I don't mind it. It's real serious . You have to have a test, well
- 85 then I'll take it, you know? I've taken it before and I'll .. it's not much , a
- 86 little prick right over there (pointing to finger tip), on the finger, what
- 87 well. Shee.
- 88 (Shrugs)
- 89 Q: Not so bad?
- 90 A: No, not so bad. But you get checked out the proper way. You know
- 91 what I mean? Yeah.
- 92 Q: What does a family member need to know?
- 93 A: Well just like I do. Watch your food. Watch your intake of food. And
- 94 your diet and so forth and so on. If you feel not well, go to the doctors
- 95 and get yourself checked out.
- 96 Q: Has your sugar gone really high or really low and made you sick?
- 97 A: No.
- 98 Q: So you have never had what we would call the signs and of hypo or
- 99 hyperglycemia?
- 100 A: That's right. That's right.
- 101 Q: So that's not been a problem for you?
- 102 A: I caught it in time, so everything is okay. I stopped drinking beer so
- 103 everything is okay. I don't drink beer. I don't touch it.
- 104 Q: So that was a problem before?
- 105 A: Well, If you touch beer naturally they give you sugar. Like the doctor
- 106 said, "Hey (Name), it gives you sugar knock it off."
- 107 Q: The extra calories? Was it hard to let that go?
- 108 A: I quit the cigarettes, the same 15 years ago.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 5 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

109 Q: That's terrific .

110 A: I quit the cigarettes 15 years ago, my wife passed away and I had a

111 little coughing you know, and my kids said to me , "Hey Dad we want

112 you around. Mommy's gone. Oh Ho when they said that ... I said, "Oh

113 brother.."

114 Q: Had better do it?

115 A: Oh and how!

116 Q: How did you learn to manage your diabetes? Who taught you?

117 A: Well, Who taught me how to manage?

118 Q: Yes.

119 A: Well, A dietician at (Hospital) and right over here

120 (motioning to an part of the building) and right over here. At

121

122 Q: At

123 A: She gave me a booklet with everything I'm supposed to do, and eat

124 and so forth.

125 Q: So was that a year ago or..

126 A:: A year ago, yeah.

127 Q: And that has kept you in pretty good shape?

128 A: Oh yeah, it's kept me in pretty good shape. I can't complain.

129 Q: Did your doctor do any teaching with you?

130 A: Oh yeah, he told me that about a lot of it. He told me about the diet

131 and stuff like that.

132 Q: Can you think of any place else a new person can go to learn about

133 diabetes?

134 A: Ah... Well like I say they have these seminars.(Indicating an invitation

135 for diabetic classes). You could go to them. You know?

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 6 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

- 136 Q: Like we have here?
- 137 A: Yeah, you could go to them. That's why I go to for these. I mean, I
- 138 go to any of these that has to do with health. You know?
- 139 Q: Yes.
- 140 A: Any seminar that has to do with health, heart conditions, diabetes, all
- 141 that cancer, you know?
- 142 Q: All that is helpful?
- 143 A: Yes, sure.
- 144 Q: Where do they usually have things like that?
- 145 A: Some of the churches hold that.
- 146 Q: Some of the churches?
- 147 A: Yes .
- 148 Q: Do you have a church near you that you can get to okay?
- 149 A: Oh yeah.
- 150 Q: Are you a driver?
- 151 (A short discussion about a past driving problem.)
- 152 Let's see what do you think has been the most helpful for you to learn
- 153 about diabetes?
- 154 A: Medication has done one thing.
- 155 Q:Okay
- 156 A: Micro.. or what ever they give you. That's been good.
- 157 Q: Did you get any teaching about your Micronase?
- 158 A: No.
- 159 Q: No?
- 160 A: No, no instruction what so ever. We were just told for me to take
- 161 it.And I've been taking it with no sweat. And then when they told me,
- 162 the doctors told me to knock it off I just knocked it off.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 7 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

- 163 Q: So that worked?
- 164 A: (affirmative nodding)
- 165 Q: Has anything created any problems for you?
- 166 A: No.
- 167 Q: You haven't gotten any bad teaching?
- 168 A: No. Not so far.
- 169 Q: Nothing that was confusing or upsetting or anything?
- 170 A: No. I would say it was very helpful, I would say.
- 171 Q: What else do you think I should be asking? What else do you have to
- 172 do to stay healthy?
- 173 A: Well.. Like I say some people over do a bit. Some over do on the
- 174 drinking, some of the them, stress. They worry, that's stress. And that
- 175 has a lot to do with it.
- 176 Q: What helps you when you get worried or stressed out?
- 177 A: Stressed out (pointing to self) Nah, Call up a friend and talk to him
- 178 (laughing).
- 179 Q: That's not bad advise.
- 180 A: Call up a friend and say, "Hey what are you doing?" Bull throw with
- 181 him, You know? Sure.
- 182 Q: Some "buddy support"?
- 183 A: That's right you have some "buddy support". Or a sister-in -law
- 184 or..somebody like that
- 185 Q: Some family support?
- 186 A: Yeah , that's right. Cause they have problems too and they might
- 187 want to talk to you too.
- 188 Q: So sometimes it helps to help a friend or a family member?
- 189 A: That's right. That's correct, correct.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 8 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

- 190 Q: Sounds like pretty good advice.
- 191 A: Oh yeah.
- 192 Q: Some of the folks that I talk to say that sometimes their family tries to
- 193 help but they mess up, they nag. Have you..
- 194 A: Oh yeah, they nag. But my family isn't that way , They don't help but
- 195 they don't nag. They are all with you. Do you understand?
- 196 Q: (Affirmative nod.)
- 197 A: My daughter, my son, my in-laws everybody. They are with me.
- 198 Q: So is there anything else I should be asking about?
- 199 A: Let's see what could you be asking about?
- 200 Q: Do you do anything special for your feet?
- 201 A: I go to a doctor's
- 202 Q: A podiatrist?
- 203 A: Yes that's what put me in here.
- 204 Q: He's the one that caught this thing. I went to 2 of them and 2 of
- 205 them messed it up.
- 206 Q: Oh my.
- 207 A: Two of them messed it up, Dr. (Name) and Dr. (Name). And this
- 208 man(Name) really saw what was running and put me right in the hospital.
- 209 Q: So that helped?
- 210 A: So that got a ..
- 211 Q: It really matters to have a doctor who knows what he is doing.
- 212 A: Right. (laughter) Some of these guys are only in for the Medicare. You
- 213 get everything.?
- 214 Q: Ummhmm.
- 215 A: Just like this Dr. (Name) he got \$55 a throw for doing nothing
- 216 Q: Oh dear.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 9 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

217 A: and Dr. (Name) \$90 a throw. Doing nothing for you. Just put his
218 hands on this and saying , "Go ahead I'll see you next week." Well I was
219 still in pain.

220 Q: And is it better now?

221 A: It's getting better.

222 Q: How about your eyes, anything special for that?

223 A: I'm getting a bit of a cataract on this one here.

224 Q: Do you see anybody about that?

225 A: No, no . I'm not messing with that until...

226 Q: Are you waiting until it is "Ripe"?

227 (Conversation interrupted by staff's discussion of schedule.)

228 Q: So you see your family doctor every 3 months for that. How about
229 any dental problems?

230 A: (Laughter) I fixed that years ago, I had then all out.

231 (Conversation concerning families non-diabetes related illness and health
232 history) And I have a brother who died from cancer on Memorial Day.

233 Q: I'm sorry to here that.

234 A: He had cancer and they couldn't help him but what can you do?

235 Cancer of the esophagus. Well he smoked it was his own fault. He never
236 quit. There's no question.

237 Q: So you think what a person does has some influence on their
238 illnesses?

239 A: Yeah, it helps. It straightened me out. Fifteen years.

240 Q: That's terrific.

241 (Conversation from others in room.)

242 Q: Thank you very much for your time.

243 A: Well I hope I was able to help you out, You are welcome I'm sure.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 10 of 10

Patient Number: 15 Interview Number: 1 Interview Date: 11-26-93

-
- 244 Q: I think you were, I think the thing that will be the most helpful will be
245 the buddy support.
246 A: Oh yes, "buddy support" has a lot to do with it, friends. They're
247 friends.
248 Q: Thank you.
249 A: Thank you, very much I'm grateful.

-
- 1 Q: Today is December 8. Got the red light on so were in good shape.
- 2 Um, I think that's the end of it.
- 3 A: I see that, yeah. Um, that's right there, okay?
- 4 Q: Over here, oh. [Pause.]
- 5 Q: Does that help a little? [Pause.]
- 6 A: She's 80 years old, but still going strong.
- 7 Q: Oh, you know what? I'm sorry.
- 8 A: unintelligible.
- 9 Q: I apologize, I've labeled it, I've labeled it wrong.
- 10 A: (Laughs)
- 11 Q: There you go.
- 12 A: Okay, now it's better.
- 13 Q: Let's start that one, there now. Does that look familiar?
- 14 A: Yeah.
- 15 Q: Okay.
- 16 A: Okay, that's good.
- 17 A: unintelligible.
- 18 Q: I'm sorry, the questions are the same.
- 19 A: Well, how? (Laughs) Uh huh.
- 20 Q: We wouldn't have found the buddy therapy.
- 21 A: Yes, that's good. [Pause.]
- 22 Q: Yeah, you got it, you got it, we got it, we got it.
- 23 A: A long report.
- 24 Q: Um hmm.
- 25 A: We did all right, you know? I hope this helps me out.
- 26 Q: It does.
- 27 A: I hope so.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 2 of 3

Patient Number: 15 Interview Number: 2 Interview Date: 12-8-93

- 28 Q: I think, one of your suggestions for ah, calling a friend. The other
29 thing that I noticed that was very useful, it sounded like you were saying
30 it's important to give back to others, to take care of your family.
31 A: Oh yeah.
32 Q: They need you too. And that's a good way to feel good about
33 yourself.
34 A: Oh yeah.
35 Q: Nobody else said that.
36 A: How about that...unintelligible...(crying)
37 Q: Is it hard to read about that? I think your family loves you very
38 much. [Pause.]
39 A: (Laughs)
40 Q: I see you nodding, which part are you nodding about?
41 A: The doctors.
42 Q: Ah, the doctors. You need a good doctor that knows what their
43 doing.
44 A: Right...true, true...good.
45 Q: Did I get it right?
46 A: Good report. Yeah, good, very good.
47 Q: Thank you, is there any?
48 A: unintelligible.
49 Q: anythi...?
50 A: unintelligible.
51 Q: It has already, is there anything else you can think of that should be
52 on here?
53 A: (Laughs) I think we have it pretty well...you know, organized here.
54 Let me get a tissue.

Mary K. Schoen Transcript of Patient Interview Diabetes Instruction Page 3 of 3

Patient Number: 15

Interview Number: 2

Interview Date: 12-8-93

-
- 55 Q: Can I get that for you? Would you like a copy of this?
- 56 A: Yeah, sure.
- 57 Q: Okay, I will make that tomorrow morning cause I've got to run off
- 58 and teach a class.
- 59 A: Oh, okay.
- 60 Q: And would like a summary of the study when it's finished?
- 61 A: Alright, sure.
- 62 Q: Okay, I have your home address and I'll send it to you.
- 63 A: Okay, good Mary, very good.
- 64 Q: Thank you, thank you.
- 65 A: Bye now.

Mary K. Schoen

Analysis of Patient Interview

Page 1 of 5

Patient Number:15

Interview Number:15A

File:MEMO15A.WPW

1	Line 10	This gentleman believes the most important thing a
2		person needs to learn about is diet.
3		
4	Line 17-19	The specific characteristics of this are:
5		
6		What to eat.
7		
8		What to drink.
9		
10	Line 21	On questioning, he agreed the amounts were also
11		important.
12		
13	Line 23	Overdoing the amount, especially with alcohol, is a
14		barrier to adherence.
15		
16	Line 27	He feels that his excess consumption of alcohol has
17		caused his hypertension.
18		
19	Line 31	He learned he has DM while being hospitalized for a
20		fractured leg.
21		
22	Line 32	He feels his DM has been corrected with the use of
23		micronase (an OHA).
24		
25		
26		
27		

Mary K. Schoen

Analysis of Patient Interview

Page 2 of 5

Patient Number:15

Interview Number:15A

File:MEMO15A.WPW

28	Line 33	The steps he followed were :
29		
30		Surprise diagnosis,
31		
32		Medication,
33		
34		Getting busy with the diet.
35		
36	Line 41	His result is "doing good."
37		
38	Line 46	Doing good is when a professional/health care provider
39		says, "Your count is low."
40		
41	Line 55	He judges his progress by the change in color on the
42		chem strips when he checks his urine. Only his
43		physician does any monitoring of his capillary or venous
44		blood sugars. He does not know the numerical
45		equivalent to these color changes.
46		
47	Line 82	His physician has made the decision for him to do urine
48		as opposed to blood testing. He does not feel the
49		change in methodology would be a problem if his
50		physician asked him to do so.
51		
52		
53		
54		

Mary K. Schoen

Analysis of Patient Interview

Page 3 of 5

Patient Number:15

Interview Number:15A

File:MEMO15A.WPW

55	Line 92	Families should know everything the person with DM
56		has to know.
57		
58		This includes diet,
59		
60		Contacting the physician when you don't feel well.
61		
62	Line 105	He believes the over-use of alcohol caused his DM.
63		
64	Line 108	Cigarettes are also bad for you.
65		
66	Line 110	He was enabled to do this when his children said to
67		him, "Hey Dad, we want you around. Mommy's gone."
68		
69	Line 119	His resources for learning about DM were a dietician at
70		a local hospital and this rehabilitation facility.
71		
72	Line 131	His physician also taught him.
73		
74	Line 134	Seminars/DM classes are also helpful.
75		
76	Line 140	Seminars/classes on related topics are also useful.
77		
78		
79		
80		
81		

Mary K. Schoen

Analysis of Patient Interview

Page 4 of 5

Patient Number:15

Interview Number:15A

File:MEMO15A.WPW

82	Line 146	Churches will sometimes hold programs like this.
83		
84	Line 160	This participant reports his only instruction for taking
85		his medication was, "Just take it."
86		
87	Line 174	Stress is a barrier to good blood sugar control.
88		
89	Line 177-190	Strategy for dealing with stress:
90		
91		Call a buddy or supportive family member.
92		
93	Line 192-197	His family's support is important to him and he feels
94		they do not nag.
95		
96	Line 201	Going to a good podiatrist is important.
97		Avoid care givers who are in it "just for the money."
98		
99	Line 204	A good physician will know when you need to be in the
100		hospital.
101		
102	Line 223	Having a cataract and having to wait until it is ready for
103		surgery are two problems for this gentleman.
104		
105		
106		
107		
108		

Mary K. Schoen

Analysis of Patient Interview

Page 5 of 5

Patient Number:15

Interview Number:15A

File:MEMO15A.WPW

109	Line 230	He feels he cannot have oral problems because he no
110		longer has any teeth.
111		
112	Line 235-239	This gentleman believes his late brother caused his
113		esophageal cancer by his own smoking. Based upon
114		this, he believes a person and his/her choices affect
115		his/her health. This is also a reason for him to stop
116		smoking.
117		
118		
119		
120		
121		
122		
123		
124		
125		
126		
127		
128		
129		
130		
131		
132		
133		

Mary K. Schoen

Analysis of Patient Interview

Page 1 of 1

Patient Number:15

Interview Number:15B

File:MEMO15B.WPW

1	Line 7-13	This participant has been accidentally handed the copy of another participant's interview. He is re-handed the correct transcript.
2		
3		
4		
5	Line 22	The participant states the transcript is as he remembers the interview.
6		
7		It is important for this gentleman to take care of his family as well as to be taken care of by them.
8	Line 30	
9		
10		Rest of interview: thanking him for his participation, making arrangements for copies and saying goodbye.
11	Line 55	
12		
13		
14		
15		
16		
17		
18		
19		
20		
21		
22		
23		
24		
25		
26		
27		

2
VITA

Mary Kosik Schoen

Candidate for the Degree of

Doctor of Education

Thesis: A CLIENT AUTHORED CURRICULUM FOR DIABETES MELLITUS
USING THE APPROACH OF PAULO FREIRE

Major Field: Curriculum and Instruction

Biographical:

Personal Data: Born in Port Chester, New York, May 12, 1948, the daughter
of Mary Brochard Kosik and John Kosik, Jr.

Education: Graduated from Rippowam High School, Stamford, Connecticut, in
June of 1966; received the Bachelor of Science Degree in Nursing from
the University of Connecticut in May, 1970; received the Master of
Science Degree in Education from Western Connecticut State University
in May, 1977; completed requirements for the Doctor of Education degree
at Oklahoma State University in July, 1996.

Professional experience: Staff Nurse, Windham Memorial Hospital, Willimantic,
CT, 1970-1971; Staff Nurse, Windham Visiting Nurse Association,
Willimantic, CT, 1971-1972; Staff Nurse, Visiting Nurse Service of
Summit County, Akron, OH, 1972; Liaison Nurse, D.N.A. of Ridgefield,
Ridgefield, CT, 1973; Staff Supervisor, Lawrence General Hospital,
Lawrence, MA, 1974; Staff Nurse, Homemakers Upjohn, Hauppauge, NY,
1975-1977; Clinical Instructor, Fairfield Hills Hospital, Newtown, CT,
1978-1979; Supervisor Administrator, Washington-Warren V.N.A.,
Washington, CT, 1980; Rehabilitation Specialist, Cigna, Herndon, VA,
1980; Health Educator, Dhahran Medical Center, Dhahran, Kingdom of
Saudi. Arabia, 1982-1985; Graduate Assistant, Oklahoma State
University, Stillwater, Stillwater, OK, 1987; Rehabilitation Consultant,
The Travelers Insurance Company, Oklahoma City, OK, 1988-1989;

Clinical Resource Nurse, St. Lawrence Rehabilitation Center,
Lawrenceville, NJ, 1990-1993; Case Manager/Staff
Supervisor, Diabetes Treatment Center, Somerville, NJ, 1994-1995.